Understanding Consumers' Preferences for Health Service Change:

Measures to inform the development of patient-centred interventions in chronic disease ambulatory clinics

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Declarations

Statement of originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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Acknowledgement of authorship

I hereby certify that this thesis is in the form of a series of published papers of which I am a joint author. I have included as part of the thesis a written statement from each co-author, endorsed by the Faculty Assistant Dean (Research Training), attesting to contribution to the joint publication.

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Elizabeth Alexandra Fradgley

Date

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List of papers included as part of this thesis

Paper 1

Fradgley EA, Paul CL, Bryant J. A systematic review of barriers to optimal outpatient specialist services for individuals with prevalent chronic diseases: what are the unique and common barriers experienced by patients in high income countries? International Journal for Equity in Health. 2015;14:52.

Paper 2

Fradgley EA, Paul CL, Bryant J, Roos IA, Henskens FA, Paul DJ. Consumer Participation in Quality Improvements for Chronic Disease Care: Development and Evaluation of an Interactive Patient-Centered Survey to Identify Preferred Service Initiatives. Journal of Medical Internet Research. 2014;16(12).

Paper 3

Fradgley EA, Paul CL, Bryant J, Oldmeadow C. Getting right to the point: identifying Australian outpatients' priorities and preferences for patient-centered quality improvement in chronic disease care. Accepted at the International Journal for Quality in Health Care (acceptance date: March 30th, 2016).

Paper 4

Fradgley EA, Paul CL, Bryant J, Zucca A, Oldmeadow C. System-wide versus person-specific: a cross-sectional study identifying demographic and clinical characteristics associated with patient preferences for health service change in specialist outpatient care. Under editorial review at BioMed Central Health Service Research (submission date: September 17, 2015).

Paper 5

Fradgley EA, Bryant J, Paul CL, Hall A, Sanson Fisher R, Oldmeadow C. Cross-sectional data that explore the relationship between outpatients' quality of life and preferences for quality improvement in oncology settings. Journal of Oncology Practice. 2016; 12(5).

Paper 6

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Identifying and comparing stakeholder preferences for patient-centred quality improvement: a cross-sectional survey of the types and numbers of quality initiatives selected by outpatients and health professionals. Accepted at Evaluation and the Health Professions (acceptance date: June 10th, 2016).

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ReCAP: Research Contributions Abbreviated for Print (Journal of Oncology Practice requirement)

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Henskens FA., Paul DJ, Wallis M., Bryant J, Carey M<u>, Fradgley EA</u>, Koller CE, Paul CL, Sanson-Fisher RW, Zucca A. Web-based Support for Population-based Medical Research -Presenting the QuON Survey System. Proceedings of Conference on Health Informatics, pp. 196-204, DOI: 10.5220/0004738301960204, 2014.

Tzelepis F, Sanson-Fisher RW, Zucca AC, <u>Fradgley EA</u>. Measuring the quality of patientcentered care: why patient-reported measures are critical to reliable assessment. Patient Prefer Adherence. 2015;9: 831-5.

<u>Fradgley EA</u>, Paul CL, Rose S, Gedye C, Trebble S, Pockney S, Ackland S. A narrative overview of the cancer patient-journey: minimising delay and improving access to an ideal cancer care system. Under editorial review at J Cancer Policy.

Appendix C: Conference abstracts

<u>Fradgley EA</u>, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Advancing collaborative quality improvement in tertiary settings: Do chronic disease outpatients and health professionals identify similar types and numbers of quality initiatives? 2015 Hunter Cancer Research Symposium, 27 November 2015, Newcastle, Australia.

<u>Fradgley EA</u>, Paul CL, Bryant J, Zucca A, Oldmeadow C. Aiming For The Right Quality Improvement Target: Cross-Sectional Data Exploring Outpatients' Priorities And Preferences For Quality Improvement In Tertiary Clinics. 2015 Hunter Cancer Research Symposium, 27 November 2015, Newcastle, Australia.

<u>Fradgley EA</u>, Paul CL, Bryant J, Roos IA. A data collection tool to enable consumer participation in quality improvements for oncology care: Development and evaluation of an interactive survey to identify preferred service initiatives. IPOS 16th World Congress of Psycho-Oncology and Psychosocial Academy, 20 – 24 October 2014, Lisbon, Portugal.

<u>Fradgley EA</u>, Paul CL, Bryant J, Zucca A. A multi-site study to explore patient-identified and prioritized health service initiatives to improve oncology outpatient care: Are we aiming for the right targets? IPOS 16th World Congress of Psycho-Oncology and Psychosocial Academy, 20 – 24 October 2014, Lisbon, Portugal.

<u>Fradgley EA</u>, Bryant J, Paul CL, Sanson Fisher R. Making It Real: Operationalising Medical Oncology Outpatients' Preferences For Health Service Change In Hunter New England Clinics. 11th Behavioural Research in Cancer Control Conference, 8-10 May 2013, Adelaide, Australia. <u>Fradgley EA</u>, Bryant J, Paul CL, Sanson Fisher R. Assessing health service intervention preferences among chronic disease outpatients. Australasian Society of Behavioural Health and Medicine 10th Annual Scientific Conference, February 6-8 2013, Newcastle, Australia

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Acronyms

CHF: Chronic heart failure

CINAHL: Cumulative Index to Nursing and Allied Health Literature

CAHPS: Consumer Assessment of Healthcare Providers and Systems

CHEERIES: Checklist for Reporting Results of Internet E-Surveys

CI: Confidence interval

Consumer-PS: Consumer Preferences Survey

COPD: Chronic obstructive pulmonary disorder

EBCD: Experience-based codesign

EORTC OUTPATSAT35: European Organisation for Research and Treatment of Cancer Outpatient Satisfaction with Care survey

FACT-G: Functional Assessment of Cancer Therapy-General

HRQoL: Health-related quality of life

HUNT-3: Nord-Tondelag Health Survey

IOM: Institute of Medicine

IQR: Interquartile range

ISPOR: International Society for Pharmacoeconomics and Outcomes Research

MDD: Major depressive disorder

MeSH: Medical Subject Heading

OECD: Organization for Economic Co-operation and Development

OR: Odds ratio

PASQOC: Patient Satisfaction and Quality in Oncological Care survey

PCC: Patient-centred care

PCQ-PD: Patient Centered Questionnaire for Parkinson's Disease

PCEHR: Personally Controlled Electronic Health Record

PICO: Population, Intervention, Comparison (or control), and Outcome framework

PRECEDE: Predisposing, Reinforcing, and Enabling Constructs in Educational Diagnosis and Evaluation (part of the PRECEDE-PROCEED model)

PRISMA: The Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROCEED: Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development (part of the PRECEDE-PROCEED model).

Professional-PS: Professional Preferences Survey

RE-AIM: Reach Effectiveness Adoption Implementation Maintenance

STROBE: Strengthening the Reporting of Observational Studies in Epidemiology statement

WHO: World Health Organization

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Thesis abstract

The economic and personal burden associated with chronic diseases is substantial for patients and health services. Patient-centred care is a promising and ethically important approach for improving patient experiences, outcomes, and health service efficiency. Data from patientexperience surveys suggests that health services struggle to consistently deliver patient-centred care. Improving this aspect of care is challenging, particularly as patient-experience data may not be sufficiently specific and detailed to guide the design of quality improvement initiatives. This thesis by publication reports the development and administration of a Web-based survey designed specifically for patient-centred quality improvement purposes. The thesis introduction provides an overview of the definition and benefits of patient-centred care along with evidence on existing gaps in the delivery and measurement of patient-centred care.

A systematic literature review and 5 papers with original data comprise the thesis, which has the following overarching objectives:

- To summarize the barriers to patient-centred care experienced by a range of chronic disease outpatients in order to generate a comprehensive list of potential quality improvement initiatives (Paper 1).
- To systematically construct and evaluate a Web-based tool, the Consumer Preferences
 Survey, that enables outpatients to generate comprehensive, personalised, and
 prioritised lists of quality improvement initiatives (Paper 2).
- (3) To report the high-priority initiatives that are commonly selected across a large sample of chronic disease outpatients (Paper 3).
- (4) Identify a set of generic initiatives that are equally valued across a range of health services users along with a set of targeted initiatives selected by specific patient demographic and clinical groups (Papers 4 and 5).
- (5) Compare patients' and health professionals' preferences for quality improvement using the adapted Professional Preferences Survey (Paper 6).

Cross-sectional survey data was provided by 939 individuals (124 health professionals and 815 outpatients) who were recruited from 9 Australian hospital-based services specializing in cardiology, neurology, or medical oncology care. The thesis discussion synthesizes the key findings from the 6 papers and reflects on the evidence informing patient-centred quality improvement in chronic disease care. Recommendations are provided to assist health services to design initiatives that align closely with patients' preferences for change and improve the delivery of patient-centred care.

Brief explanatory overview

Patient-centred care is 1 of 6 key dimensions of high-quality healthcare proposed by the Institute of Medicine and is defined as care which is respectful and responsive to patients' needs and preferences [1]. A growing body of evidence suggests patient-centred care is associated with a variety of improved patient outcomes, including increased overall satisfaction with care, greater perceived quality of care, and improved well-being [2-15]. The benefits of patient-centred care extend to health services and professionals with numerous studies reporting increased job retention and satisfaction among health professionals, improved service efficiency, and decreased services costs [16-20]. Patient-centred care is part of a growing consumer movement within health care and is endorsed by several health organisations, such as the World Health Organization, The Commonwealth Fund, and the Organisation for Economic Co-operation and Development [21-23].

This thesis by publication makes a significant contribution to describing individuals' preferences and priorities for patient-centred quality improvement within outpatient hospital services. These services provide complex care for prevalent and costly chronic diseases such cancers, stroke, and ischaemic heart disease, which are also considered to be health priority areas in many high-income countries [24-27]. Australian health policy recently identified hospital-based services as a key area of improvement and recommended reviewing the patient-centredness of these services [28].

This thesis comprises an introduction, 6 papers formatted as journal articles, and a discussion providing detailed recommendations for health services seeking to strategically implement patient-centred quality improvement initiatives. A systematic literature review is included along with 5 data-based papers which report the findings from cross-sectional surveys conducted in outpatient cardiology, neurology and medical oncology centres located in New South Wales, Australia. **Papers 1, 2, and 5** have been published [29-31]. **Papers 3** and **6** were accepted for publication by International Journal for Quality in Health Care and Evaluation and

the Health Professions on March 30th and June 10th 2016, respectively. **Paper 4** is currently under editorial review (submitted to BioMed Central Health Services Research on September 17, 2015).

The thesis **Introduction** explores the existing gaps in the quality of patient-centred care reported in international and national patient-experience surveys, such as The Commonwealth Fund Health Policy Surveys [32-38]. The survey results suggest health services struggle to consistently deliver patient-centred care. Furthermore, qualitative and quantitative evidence reports quality improvement based on similar patient-experience surveys is difficult and may not be sufficiently detailed to inform quality improvement activities [39-48]. The **Introduction** argues additional evidence is needed to bridge the gap between describing patient experiences and designing quality improvement initiatives. The first 2 papers focus on developing a patient-report tool capable of providing this evidence; the last 4 papers describe administration of the tool to report and compare the findings across chronic disease outpatients attending publicly and privately funded oncology, cardiology, and neurology services.

Paper 1 is a systematic review of the scope and commonality of barriers experienced by chronic disease outpatients when accessing and receiving patient-centred care in 31 high-income countries. This review was undertaken to provide a synthesised and comprehensive list of possible health service initiatives to improve the equitable delivery of patient-centred care across a range of chronic diseases. A total of 74 quantitative articles were reviewed and barriers were classified according to a previously validated model of access and defined in more detail using 33 Medical Subject Headings. Overall, the review highlights the need for more comprehensive and detailed (i.e. sufficiently covering the full scope and depth of patient-centred care) evidence on patient-centred quality improvement relevant to multiple chronic disease types – this finding is foundational to the rationale of **Papers 2** through **5**. **Paper 1** was published in the *International Journal for Equity in Health* [29].

Paper 2 describes 2 phases required for the systematic development and evaluation of an interactive Web-based tool capable of providing comprehensive and actionable information suitable for designing patient-centred service initiatives for chronic disease care. Within the development phase, the survey content was generated and refined in three stages: (1) a structured

literature review of 336 articles, (2) iterative feedback from 2 stakeholder groups of 47 health professionals and outpatients, and (3) adaptation into a Web based survey platform. The final Consumer Preference Survey allows chronic disease outpatients to directly identify up to 23 general initiatives that would improve their experiences within a health service. The survey software includes complex adaptive branching patterns and interactive item types. These features allow participants to select an additional 110 detailed initiatives, if relevant based on previous responses, and easily complete a modified relative prioritization exercise to indicate the relative importance of chosen initiatives.

The second phase included testing within 4 hospital-based outpatient clinics and evaluated the (1) test–retest reliability, (2) patient-perceived acceptability of the survey content and delivery mode, and (3) average completion time, completion rates, and Flesch-Kincaid reading score. A total of 529 outpatients participated, with 39 individuals completing the test–retest component. Substantial or moderate reliability was reported and the majority of participants indicated the Web-based survey, including the relative prioritization exercise, was easy to complete and would be willing to complete a similar survey again. **Paper 2** was published in the *Journal of Medical Internet Research* [30].

Paper 3 presents the results from a cross-sectional study in which the Consumer Preferences Survey was administered in 4 hospital-based clinics specialising in oncology, neurology, and cardiology outpatient care. A total of 541 outpatients participated and included a subgroup of individuals attending a privately funded facility. To provide a comprehensive and specific list of quality improvement initiatives in order of patient priority, the following findings were reported: (1) the proportion of individuals selecting each general quality improvement initiative, (2) the proportion of individuals selecting each detailed quality improvement initiative corresponding to commonly-selected general initiatives, and (3) the relative priority of commonly selected initiatives. Briefly, initiatives targeting service accessibility and information provision, such as parking and up-to-date information on patient prognoses and progress, were commonlyselected and perceived to be of relatively greater priority. This paper has been accepted at the *International Journal for Quality in Health Care* (accepted on March 30, 2016).

To identify initiatives equally valued across a range of health services users along with a set of targeted initiatives, **Paper 4** reports and compares the relative odds of selecting quality improvement initiatives according to specific patient demographic and clinical groups. This information can provide further guidance on how to strategically introduce quality improvement initiatives according to patient characteristics such as age, gender, chronic disease type, and appointment frequency or type. A total of 475 individuals participated and includes only those attending 3 publicly funded hospital-based clinics. Information-based initiatives were selected equally across demographic subgroups and therefore may warrant system-wide implementation. However, the odds of selecting a few initiatives was associated with characteristics such as age, gender, insurance coverage, chronic disease type, and appointment type– for example, additional emotional support is particularly relevant for neurology outpatients. This paper is currently under review at *BioMed Central Health Services Research* (submitted on September 17, 2015).

Paper 5 reports the quality improvement initiatives commonly selected by 263 oncology outpatients. These data were collected as part of an intervention study evaluating the effectiveness of a consumer driven breakthrough action model in reducing unmet supportive care needs and improving overall quality of life. This larger trial is listed on the Australian New Zealand Clinical Trials register (ID: ACTRN12614000702617). This ongoing trial administered the Consumer Preferences Survey as a baseline measure and implemented the recruitment procedures developed and trialled within Papers 2 through 4. Within the framework of this thesis, Paper 5 provides further information on how quality improvement preferences may differ by patient factors, in particular individuals' health-related quality of life (as measured by the Functional Assessment of Cancer Therapy-General). Similar to the rationale applied within Paper 4, implementing those quality improvement initiatives of greatest importance to individuals with reduced functional status may be an efficient strategy to maximise the value and benefit of service change. While the adjusted odds of selecting 5 specific initiatives were greater for those individuals reporting lower

levels of quality of life scores, the association was weak and did not meet adjusted significance levels in 4 of the 5 logistic regression models. This finding suggests a wider spectrum of patient characteristics must be considered when targeting quality improvement to patient subgroups. This paper is published in the *Journal of Oncology Practice* [31].

Paper 6 outlines a cross-sectional survey study comparing the number and types of quality improvement initiatives selected by 2 stakeholder groups, 541 outpatients and 124 health professionals, in chronic disease hospital-based services. Quantifying patient and professional views can highlight the ways in which stakeholder perspectives may vary and, therefore, identify potential obstacles to collaborative service improvement. Distinguishing and negotiating different stakeholder priorities is an essential step within collaborative improvement models, such as the consumer driven breakthrough action model proposed in Paper 5. Using the Consumer Preferences Survey and the adapted Professional Preferences Survey, the number and types of initiatives selected by each group are compared using summary statistics and chi-square tests. To provide another point of comparison, the 10 most-frequently selected initiatives are listed for each group. On average, outpatients selected 2.4 initiatives whereas professionals selected 10.7 initiatives. Outpatients demonstrated a strong preference for improvements to clinic organization, such as appointment scheduling and clinic contact; professionals selected initiatives related to communication with patients and other professionals, including coordinating multidisciplinary care. Improvements to information provision were commonly selected by both groups and offer a strategic opportunity to address patients' and professionals' preferences. This paper has been accepted at the Evaluation and the Health Professions (acceptance date: June 10th, 2016).

The thesis **Discussion** synthesizes the key thesis findings in order to assist health services to design initiatives which accord with patients' preferences and priorities for change. This section also includes reflections on the current evidence and practices used to inform collaborative patient-centred quality improvement. Recommendations are briefly summarized in the following section – **Thesis recommendations for patient-centred quality improvement.** Examples of these recommendations include: adopting personalized approaches to information provision through use of Web-based information packages and community-based health organizations; evaluating and improving emotional support for individuals with neurological conditions; and supplementing traditional consumer engagement strategies, such as consumer advocates, to represent the diversity of patient experiences and priorities in the decision making process.

Collectively, a key strength of this thesis is the development of a novel survey tool that engages patients to identify potential areas requiring quality improvement. Furthermore, by using innovative survey software, the main contribution of the Consumer Preferences Survey to the broader quality improvement literature is the ability to hone-in on very specific targets for health service change [46, 47]. However, there are a few methodological limitations to the survey approach and the cross-sectional data. The limitations include low completion rates as a result of the active recruitment approach within health services and the lack of recognised psychometric techniques for fully testing the validity and reliability of a Web-based interactive survey which does not have a traditional survey structure. Furthermore, it is important to acknowledge that describing and delineating specific types of health service changes is necessary but does not guarantee that change will occur. Longitudinal data exploring the use of this tool in quality improvement models, such as experience-based codesign and consumer driven breakthrough action models, will provide additional information on how patients' preferences for health service change can be used to strategically improve the delivery of patient-centred care.

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Thesis recommendations for patient-centred quality improvement

The following overarching recommendations are based on the results reported within **Papers 1** through **6**. The recommendations are developed in depth within the **Thesis Discussion**.

- To inform patient-centred quality improvement, highly detailed evidence on individuals' preferences is needed, ideally from studies with a sufficient number of patients across 2 or more chronic disease types.
- 2. To improve the methodological approach and interpretation of similar interactive surveys with relative prioritisation exercises, recommended refinements include: (i) limiting the number of initiatives included in prioritisation exercises to 3; and, (ii) providing an opt-out option to reduce embedding bias. Studies that examine the advantages of different relative prioritisation methods in a head-to-head comparison, along with additional qualitative work exploring individuals' reasons for attributing value, are also needed.
- 3. To align with patients' preferences for tailored and timely information provision, an initiative commonly selected and perceived to be a high priority by outpatients, more personalised approaches to information provision could be implement through increased use and awareness of augmented Web-based information packages. Based on outpatients' selection of increasingly-detailed initiatives, these information packages should include detailed information on possible prognoses, have the ability to store and access personalised health information, and directly notify an individual when new information is added to their record.
- 4. To address patients' preferences for additional information outside of clinic settings, health services could strengthen collaboration with community-based organisations through established referral pathways and external services should be continually promoted as part of comprehensive care plans.
- 5. To improve service accessibility, health services should be aware of patient-centred organisation models, such as the Advanced Access Model, which can accommodate patient preferences in scheduling systems. Furthermore, patients should be informed of estimated wait times upon arrival. Improved accessibility also includes evaluating current parking

arrangements, specifically the ability to provide patient-dedicated parking areas. The importance of organisational change and the accessibility of health services in relation to patient experiences must be emphasized to engage clinical stakeholders in these non-clinical areas of improvement.

6. To account for the constellation of patient factors which influence individuals' preferences for change, multiple consumer engagement strategies should be used including consumer advocates and detailed scoping assessments of the characteristics and preferences of health service users. Introduction

What are the essential components of high-quality health care?

Substantial deficits in the quality and safety of health care have been identified as a global concern [1]. The benefits of advances in medical knowledge have not been consistently and rapidly translated into improved practice [1-3]. The causes for these deficits are related, in part, to the increased complexity of medical treatment and the growing prevalence of chronic conditions [3]. Current health care systems are not adequately designed for this shift toward complex and chronic disease care [3]. For example, a 2003 landmark study found approximately 56% of American adults received the recommended care for a chronic condition in the previous 2 years [4].

Building upon the report "To Err is Human: Building a Safer Health System" [1] in which the shortfalls of existing health systems were outlined, the Institute of Medicine released the 2001 seminal report, "Crossing the Quality Chasm: A New Health System for the 21st Century" [3]. This report provided an agenda for redesigning health systems and proposed 6 essential components for highquality care. Firstly, care must be safe and adverse events should be avoided at all costs. This closely aligns with one of the basic ethos of the Hippocratic Oath: to do no harm. Secondly, health care must be effective and evidence-based. This can reduce misuse or overuse of valuable health resources, unnecessary adverse events from ineffective treatments, and inequitable variation in the care delivered by services and individual health professionals. Thirdly, care must be timely with minimal delay in diagnosis and treatment of disease. This has the potential to reduce long-term costs and further physical deterioration and morbidity. Fourthly, services must be efficient and avoid wasting resources, including both monetary and workforce capacity. Fifthly, the quality of care must be equitable with easily accessible services. Equitable provision of care must be relative to individuals' needs and not vary according to individual characteristics, such as age, ethnicity, or socioeconomic status. Finally, care must be patient-centred. The Institute of Medicine defines patient-centred care as care that is respectful and responsive to patient needs and preferences [3]. Other terminology interchangeable with patient-centred care includes consumer-, people-, family-, or person-centred care; patientfocused care; personalised care; and responsive care [5].

What is patient-centred care?

Within the United States, the Picker Institute coined the term "patient-centred care" in the late 1980s. The work, conducted as part of the Picker-Commonwealth Program for Patient-Centered Care and along with the seminal book "*Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*"[6], specified 7 patient-centred care dimensions [7-9]. These dimensions were developed following a rigorous assessment of patients' perceptions of patient-centred care; an eighth dimension, access to care and services, was added later.

National survey programs have been modelled on the Picker dimensions with notable examples including the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys created by the Agency for Healthcare Research and Quality [10]. Table 1 lists the Picker dimensions of patient-centred care and provides examples from publicly available Picker Surveys, such as the Hospital-CAHPS Expanded Picker Plus survey for admitted adult inpatients [11, 12].

Dimension [6]	Examples of survey items [11, 12]
Respect for patients' preferences, values, and needs	 Did doctors talk in front of you as if you weren't there? Did you want to be more involved in decisions made about your care and treatment?
Clear information and education	 During this hospital stay, how often did doctors explain things in a way you could understand? If you had to wait to go to your room, did someone from the hospital explain the reason for the delay?
Coordination and integration of care and services	 Sometimes in a hospital, one doctor or nurse will say one thing and another will say something quite different. Did this happen to you? Were you checked into the emergency room and evaluated in a timely manner?
Emotional support	 During this hospital stay, how often did you have confidence and trust in the nurses treating you? If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you?
Physical comfort	 During this hospital stay, how often did the hospital staff do everything they could to help you with your pain? During this hospital stay, how often was the area around your room quiet at night?
Involvement of family and close others	 During this hospital stay, how often did the hospital staff include your family or someone close to you in discussions about your care? Did the doctors or nurses give your family or someone close to you all the information they needed to help you recover?
Continuity and transition from hospital to home	 During this hospital stay, did doctors, nurses, or other hospital staff talk with you about whether you would have the help you needed when you left the hospital? Did someone tell you about the danger signals regarding your illness or treatment to watch for after you went home?
Access to care and services	How would you rate the availability of our doctors?While you were in hospital, were you able to get all the services you needed?

Table 1: The Picker Institute's dimensions of patient-centred care and survey item examples.

The Institute for Patient- and Family-Centered Care and the Planetree models propose similar dimensions but include additional holistic elements [13, 14]. For example, the 10 components of the Planetree Model are human interaction, architectural and interior design, food and nutrition, patient and family education, family involvement, spirituality, human touch, healing art, complementary and alternative therapy, and health communication [14]. Planetree is a notfor-profit organisation that seeks to develop a network of health care services that endorse, promote, and sustain this model of patient-centred care as a core operating value [15].

Other patient-centred models and frameworks are available in the academic literature, such as that provided by Mead and Bower [16]. In reviewing empirical evidence, 5 patient-centred concepts emerged: taking a biopsychosocial perspective, viewing the patient as a unique individual with diverse needs and illness experiences (e.g. 'patient-as a person'), sharing power and responsibility, promoting a therapeutical relationship with the patient, and recognising the physician as a person with subjective influences. The Mead and Bower framework notably emphasises health professionals' roles in providing patient-centred care [16].

Although these different models and frameworks suggest there are multiple approaches to defining 'patient-centred', there are few recurrent concepts, such as informed participation in health care decisions and self-management [17, 18]. In this way, the patient is viewed as an active consumer of health services and part of a therapeutic alliance with health professionals [6, 19]. This is a fundamental tenant to patient-centred care and challenges previous approaches, such as medical paternalism and professional autonomy in treatment decisions. Furthermore, health services are required to anticipate and respect patients' unique needs and individualise care accordingly [3]. The International Alliance of Patients' Organizations reports personalised care is a common element in patient-centred care definitions and represents a paradigm shift away from traditional biomedical models whereby the patient's illness experience is reduced to a set of symptoms and disease processes [16, 18].

Patient-centred care is part of a growing consumer movement within health care and is endorsed by several health organisations, such as the World Health Organization, The Commonwealth Fund, and the Organisation for Economic Co-operation and Development [2022]. Table 2 provides examples of country-specific guidelines and suggests there are common policy strategies to enhance the delivery of patient-centred care, such as emphasis on access, patient choice, and flexibility of health services to respond to individual needs [23-26].

Guideline (year)	Organization (country)	Examples of patient-centred strategies
Improving Quality: A Systems Approach for the New Zealand Health and Disability Sector (2003)	Ministry of Health (New Zealand)	 Care is customised based on patient needs and values, including local indigenous groups Services are easily accessible, timely, and provided in the most appropriate place for patient needs Services are integrated across care continuum
National Health Services Improvement Plan: Putting People at the Heart of Public Services (2004)	National Health Service (United Kingdom)	 Provide flexible access to health care based on patient needs and preferences Provide greater choice and shared decision making in treatment and care, with access to information and support needed to exercise choice
National Safety and Quality Framework (2010)	Australian Commission on Safety and Quality in Health Care (Australia)	 Improve access to health care Increase health literacy Involve patients in care decisions and self-management Provide care that is culturally safe Enhance continuity of care
National Strategy for Quality Improvement in Healthcare (2011)	Department of Health and Human Services (United States)	 Create a delivery system that is less fragmented and more coordinated Provide patients and professionals with the information needed to optimise care partnerships Build a system that has the capacity to capture and act on patient-reported information, including preferences and care experiences

Table 2: Examples of country-specific patient-centred policy and strategies.
What are the benefits of a patient-centred approach?

The available data suggest patient-centred care is associated with a variety of improved patient outcomes, including increased overall satisfaction with care, greater perceived quality of care, and improved well-being [19, 27-38]. This evidence base includes systematic and meta-analytic reviews in which an overall positive relationship between patient-centred care and a comprehensive set of patient outcomes is reported [30, 32, 33, 39]. For example, Coulter and Ellins [39] synthesised the results from 129 systematic reviews of patient-focused interventions and found most interventions related to the Picker dimensions (e.g., health literacy, clinical decision making, and self-management) were effective in improving patients' knowledge, experience, and health status while decreasing service use. It is important to note that the provision of patient-centred care is itself an important outcome because it aligns with principles such as patients' democratic rights to empathetic and respectful care.

Figure 1 describes 5 randomised or multiple baseline trials to show the wide range of outcomes associated with patient-centred health service interventions [40-44]. The Population, Intervention, Control, and Outcome (PICO) framework is used to provide a quick study summary along with the targeted Picker dimension(s). Studies were selected to represent a variety of patient populations and health care settings, including outpatient care for diabetic individuals, inpatient care for the elderly or individuals with chronic heart failure, and primary care for individuals diagnosed with depressive disorders [40-43]. Figure 1 also demonstrates how patient-centred care principles such as personalised care and patient involvement can be 'packaged' into various health interventions, such as decision boards, self-management plans, and goal-setting forms [40, 42-44]. Overall, these interventions were associated with a diverse set of improved patient outcomes, ranging from increased uptake of preventative health care for diabetic patients to increased depth of physician–patient relationships [40, 44].



Figure 1: Examples of trials evaluating the outcomes of patient-centred health service interventions using the PICO framework.

The following sections present additional examples from program evaluation studies and observational studies that did not employ a controlled or randomised study design, such as cross-sectional surveys. Evaluation studies were selected to represent the previously mentioned patient-centred models, such as the Institute for Patient- and Family-Centered Care and the Planetree models. The presented evidence further confirms the value of patient-centred care in real-world settings and provides additional information on the associated benefits for health professionals and services.

Improved patient satisfaction: Following implementation of the Planetree model in a rehabilitation centre and hospital units, patient satisfaction increased across patient-centred dimensions [45, 46]. Although these increases were admittedly small (1.07% mean difference) within the rehabilitation centre, the improvement was significant when compared to similar institutions' performance [45]. Similarly, a tertiary hospital implementing the Patient- and Family-Centered Care Methodology and Practice model (which emphasises directly observing patient experiences, collecting narratives, and collaborative quality improvement design) found patient satisfaction scores increased across 5 units; one unit reported satisfaction scores in the 99th percentile, higher than the national averages reported by Hospital Consumer Assessment of Healthcare Providers and Systems surveys [47].

Improved patient well-being: Studies demonstrate patient-centred care is also associated with improved short- and long-term physical outcomes for patients with chronic diseases, including overall health status; symptom adjustment, duration, and burden; and clinical indicators such as reduced systolic blood pressure and stabilised glycaemic control [30, 48-50]. For example, higher scores on a patient-centred care index (based on a modified version of an inpatient Picker survey) were significantly associated with lower mortality 1 year after discharge in a sample of 1 858 individuals hospitalised for acute myocardial infarction [50]. Further analysis revealed single dimensions scores for 4 Picker dimensions (access to services, respect for patient preferences, care coordination, and physical comfort) were independently predictive of survival at 6 and 12

months [50]. Based on mortality hazard reduction calculations, the study authors suggested patient-centred care confers a protective effect after controlling for covariates such as age and previous medical history.

Improved health services efficiency and professional satisfaction: Comparative data from 2 hospital units found integration of the Planetree model decreased length of stay and lowered the cost per patient [46]. Similarly, the Patient- and Family-Centered Care Methodology and Practice model resulted in lower infection rates, decreased length of hospital stays, and mortality rates compared to the national averages [47]. Evaluation of a discharge program (Project RED) incorporating patient-centred components, such as patient education, care coordination and continuity, information to facilitate safe transitions to community settings, and access to services, reported greater patient knowledge, reduced emergency department use, and lower rehospitalisation rate [51].

The benefits of a patient-centred approach extend beyond hospital settings. For example, primary care physicians who explored patients' illness experiences, personal circumstances, and engaged patients in decisions and care plans completed fewer diagnostic tests and referrals [52]. Furthermore, study participants who perceived that their visit was patient-centred also reported improved health status despite the lower levels of investigation. Although this study focuses on patient-centred communication, other studies conclude care continuity and coordination is equally important to health service efficiency [48, 53]. For example, physicians who report little prior interaction with a specific patient are 10 times more likely to order diagnostic tests and are more likely to receive a referral [48, 53].

Health care settings implementing patient-centred models of care have also found positive associations with increased job retention and satisfaction among health professionals [45, 47]. For example, a cost-benefit analysis of the Planetree model found a significant improvement in staff retention (97.8%) and a reduction in the number of workforce grievances (by 67%) over a 5-year data collection period [45]. There is also evidence suggesting patient-centred care may reduce medical malpractice claims [28, 29, 54]. Kavalier and Spiedel [55] suggest several of the leading

causes of medical litigation can be directly attributed to poor patient-centred care and communication; in particular, deserting the patient, devaluing the patient's views, delivering information inadequately, and failing to consider the patient perspective

These findings address initial concerns that a patient-centred approach would result in an inefficient system with increased health care expenditure to respond to an overwhelming amount of patient-identified needs or preferences. Furthermore, because health services that consistently deliver high-levels of patient-centred care also perform well in the more technical and clinical aspects of medical care, accommodating patients' preferences does not necessarily compromise other quality dimensions [33, 56, 57].

What are the high-priority targets for patient-centred quality improvement?

The Institute of Medicine suggests health care redesign must begin with the common chronic diseases that affect large segments of the population [3]. Chronic diseases are characterised by multiple causality, genetic or lifestyle risk factors, long latency periods, and prolonged periods of illness (of at least 3 months) with some level of functional impairment or disability [58, 59]. With increased cancer survivorship rates, most cancer types are now considered chronic diseases [60]. Table 3 provides a few examples of prevalent chronic diseases. These conditions are considered to be health priority areas in Australia and other high-income countries in Pan America and Europe [61-64]. The World Health Organization's *International Classification of Diseases, Tenth Revision* are used to describe these conditions [65].

Chronic disease	International Classification of Disease description	Synonyms and related conditions
Essential hypertension	A disorder characterised by a pathological increase in blood pressure.	• High blood pressure
Ischaemic heart diseases	A range of disorders characterised by reduced blood supply to the heart caused by disease of the blood vessels.	 Coronary artery disease Coronary heart disease Atherosclerotic heart disease Coronary vessels disease
Malignant and metastatic neoplasms	A number of major histological groups of neoplasms exist: carcinomas including squamous (cell) and adenocarcinomas, sarcomas, other soft tissue tumours including mesotheliomas, lymphomas (Hodgkin and non-Hodgkin), leukaemia, other specified and site-specific types, and unspecified cancers.	• Cancer
Cerebrovascular diseases	A range of disorders related to the blood vessels supplying the brain in which cerebral function is altered.	Stroke (ischaemic or haemorrhagic)Transient ischaemic attackCerebral aneurysm or infarction

 Table 3: Descriptions of chronic diseases considered to be health priority areas in high-income countries.

The global incidence and mortality associated with chronic disease is substantial: The Global Burden of Disease Injuries and Risk Factors Study is a joint surveillance project initiated by the World Health Organization and The World Bank [66]. Since 1990, this study has provided exhaustive data on disease incidence, prevalence, and survivor rates across 187 countries.

The most recent Global Burden of Disease results (from 2013) indicate chronic diseases were leading causes of years of life lost in high-income countries. This includes the conditions listed in Table 3 (ischaemic heart disease, some forms of cancer, stroke) along with Alzheimer disease and other dementias, cirrhosis, depressive disorders, and chronic obstructive pulmonary disease [67]. For example, in 2010, ischaemic heart disease was the leading cause of death worldwide; the mean number of years of life lost ranged from 419 557 to 8 135 515 years in highincome regions [68].

Along with ischaemic heart disease, cancer and stroke are leading causes of death. In 2013, the age-standardised cancer incidence rate in developed countries was approximately 327.9 with an age-standardised death rate of 147.9 (per 100 000 people) [69]. In 2010, the age-standardised incidence rate of stroke was 257.96 with an age-standardised death rate of 88.41 (per 100 000 people) [70]. The disability-adjusted life-years lost due to stroke was approximately 102 232 304 years.

The incidence rates and associated burden of many chronic diseases will likely increase in the coming years due to ageing populations and increased prevalence of risk factors such as alcohol consumption, tobacco use, and obesity [71]. For example, incident cancer rates increased by 11.1% between 1990 and 2013 even after accounting for changing age structures [69]. Coupled with improved incidence to mortality rates, the volume of patients with chronic disease will continue to rise and strain communities and health systems.

The personal burden of chronic disease is high: By definition, individuals with chronic disease will experience prolonged periods of illness with some level of decreased functioning. Health-related quality of life assesses individuals' perceptions of how their disease influences their physical, psychological, social functioning, and general well-being. Compared to the general

public, individuals with chronic conditions, such as stroke, cancer, or cardiovascular disease, report relatively poorer health-related quality of life as reported by measures such as the Medical Outcomes Study 36-item Short-Form Health Survey, Functional Assessment of Cancer Therapy–General, and Assessment of Quality of Life instrument [72-74]. For example, an Australian population-based study reported individuals with cardiovascular disease scored relatively worse compared to healthy individuals (0.78 and 0.87, respectively) on the Assessment of Quality of Life instrument for which a score of 1.0 represents full health [74]. Individuals with comorbid major depressive disorder and cardiovascular disease reported an even lower mean score (0.57) in this study.

The chronic disease burden can also be understood by exploring specific illness experiences, such as managing symptoms or treatment side-effects, coping with changes to daily routines and social relationships, and altering expectations to align with decreased capacity, including loss of employment and potential income [73]. Table 4 presents a range of common symptoms and illness experiences for cancers, ischaemic heart disease, and cerebrovascular diseases, and provides a snapshot of the difficulties individuals with chronic diseases may encounter. These symptoms and experiences were drawn from practice guidelines, reported in systematic reviews, cohort studies, and management programs, or by registries including the National Cancer Data Base and the Surveillance, Epidemiology, and End Results; United Kingdom General Practice Database; and Cancer Care Outcomes and Research and Surveillance [75-87].

Chronic disease	Examples of symptom and treatment side effect		
	Physical	Other	
Ischaemic heart diseases	 Chest pain (angina) Physical discomfort Shortness of breath Lack of appetite Fatigue or drowsiness 	 Depression or poor mood, including inability to enjoy life Disturbed sleep Interference with general activities of daily living Reduced physical ability 	
Cancers Breast	 Lymphoma Premature menopause Osteoporosis Impaired fertility Pain Cognitive impairment Fatigue or drowsiness Hair loss Lack of appetite Dry mouth 	 Depression or poor mood, including inability to enjoy life Changes in relations Interference with work 	
Colorectal	 Abdominal pain Abdominal pain Rectal bleeding Fatigue or drowsiness Nausea Bowel impairment, including diarrhoea Rash Increased risk for secondary cancer 	 Interference with general activities of daily living Depression or poor mood, including inability to enjoy life Interference with work Changes in relations and limited social interaction Reduced physical ability 	
Lung	 Haemoptysis (blood in sputum) Cough Shortness of breath 	• Feelings of shame and stigmatisation	
Prostate	 Incontinence Bowel impairment Loss of libido and sexual function Irritability Osteoporosis Increased risk of diabetes, cardiovascular disease, obesity Fatigue or drowsiness Pain 	 Depression or poor mood, including inability to enjoy life Disturbed sleep Difficulty with concentration and memory Loss of libido 	
Cerebrovascular diseases	 Pain, including neuropathic and shoulder Tension-types headaches Spasticity, including pain Fatigue or drowsiness Incontinence Seizures Loss of sexual function Face drooping 	 Depression or poor mood, including inability to enjoy life Anxiety and emotionalism Loss of libido Disturbed sleep 	

Table 4: Common symptoms and side-effects associated with chronic diseases [75-87].

At time of diagnosis and throughout the disease trajectory, patients may have heightened anxiety due to uncertain prognoses, complex treatment decisions, and adjustments to lifestyles [88]. Given this, it is unsurprising that individuals with chronic diseases are at greater risk for suffering from depression and anxiety as compared to the general public [89, 90]. For example, the 2005 Canadian Health Community Survey reported the highest prevalence rates of comorbid mood disorders was recorded for individuals recently suffering from stroke (15.5%), cancer (10.1%), and heart disease (9.8%) in a community-based sample [90]. Similarly, a recent metaanalysis reported 40% of cancer patients had a diagnosable mood disorder [91]. Although some physical side-effects and symptoms will abate over time, a high proportion of patients will report ongoing emotional concerns, such as fear of recurrence or further deterioration [85].

Chronic disease accounts for a large portion of health care spending: Individuals with chronic diseases are frequent users of health care services [92, 93]. This may be due to the tendency for multiple comorbidities and the need to visit multiple health services; results from the 2009 Medical Expenditure Panel Survey suggest 25.3% of American adults were treated for multiple chronic diseases with the average number of health services used and prescriptions increasing with number of chronic diseases [94].

Due to the ongoing need for multiple forms of complex care, chronic diseases consume a large proportion of health care resources. This includes direct medical costs and indirect costs associated with loss productivity and unpaid caregiving from patients' relatives or friends [95]. Within the United States, Medical Expenditure Panel Survey data reported cardiovascular disease and cancer were in the top 5 most costly conditions for 2012; cardiovascular disease accounted for the greatest proportion of spending with the direct medical costs estimated at approximately US \$101 billion [96, 97]. In the first European systematic cost-of-illness study exploring the indirect and direct costs of cardiovascular disease, the economic burden was estimated to be \in 168 billion [98]. Similar data from the Australian Institute of Health and Welfare and Health Canada also suggests cardiovascular disease consumes the greatest proportion of health care expenditures [99, 100].

In 2009, the economic burden of cancer across the 27 European Union countries was estimated to be approximately \notin 126 billion – averaging 1.07% of the gross domestic product [95]. Indirect costs were upwards of \notin 23 billion with a staggering 3 billion hours of informal caregiving provided [95]. Similar expenditures have been reported within the United States (US \$124 billion, 5% total health care expenditure); United Kingdom (£5.9 billion, 5.6% total health expenditure); and Australia (A \$4.5 billion, 6.5% total health expenditure) [101, 102].

How is patient-centred care assessed?

Patient-centred care is one approach to minimise the financial and personal burden associated with chronic diseases and, since proposed as a measure of quality in 2001, it has become a prominent part of health policy and a major research priority in chronic disease management [103, 104]. The Institute of Medicine clearly stated ongoing evaluation of patientcentred care is essential and further suggested quality must be framed and evaluated according to patient experiences [105]. Although the concept of patient-centred care continues to be iteratively refined across health disciplines and settings, experts suggest there is a considerable amount of work to be done in developing and applying a rigorous methodology to evaluate patient-centred outcomes and experiences [29, 34-38, 106-110].

Operationalizing patient-centred care is conceptually difficult given the multidimensional nature of patient experiences and the need to standardise subjective care preferences, needs, and values [111]. Current ways of assessing patient experiences include direct observation of clinical encounters, reviews of medical records including registry-based reviews, clinician report, or patient report including survey tools [29, 112, 113]. However, there is no gold-standard measurement approach to assess and evaluate levels of patient-centred care and there are limitations to each of these measurement approaches [114].

Medical record reviews underestimate several aspects of clinician behaviour, do not capture the more interpersonal domains of patient-centred care, and may be inconsistent or unstandardised across health professionals. Furthermore, the reliability and validity of physician reports are unclear due to the heterogeneity of studies and previous research suggests physicians are not always accurate in their assessment of patients' needs [36, 115]. For example, although patients often desire information on treatment and available health services, physicians believe patients expect management of physical symptoms [116]. Direct observation of clinical encounters may only provide a snapshot of a few behaviours of interest and is a time-consuming and expensive approach [113, 117].

It is unlikely that patient-centred care will be achieved without a foundational understanding of the needs directly identified and prioritised by the patient [118, 119]. Qualitative methods can deconstruct complex patient experiences and highlight the value individuals attach to interpersonal aspects of care, such as trust in health professionals and feeling as if they were treated with respect and dignity [120]. However, this approach is also time-consuming, may not be representative of all health service user experiences, and may not allow for comparisons across patients, services, or time [121].

Although patient-report measures are subject to recall bias which increases with time and social desirability biases, real-time surveys have several benefits [[122]. A large patient sample can provide details on their experience and this can be repeated to monitor changes in service performance over time. Surveys can also be applied across multiple patient groups and provide valuable data to compare performance between health services and over time while potentially identifying specific patient groups who may be experiencing considerable gaps in the quality of care. As such, patient-administered questionnaires are thought to be a valuable approach to evaluate and summarise the quality of patient-centred care [29, 110, 119]. However, patient-report experience data are seldom collected as part of a systematic evaluation process or integrated into existing medical record or hospital databases [114].

Patient surveys are frequently used to assess patient-centred care: Accurate and

standardised tools that enable patients to directly evaluate the quality of patient-centred care are essential. Patient-experience and satisfaction surveys are commonly applied to evaluate patient-centred care and it is important to note that the concept and measurement of satisfaction and experience is complex and can overlap [121, 123]. Table 5 provides examples of survey item

stems, response scales, and measures to highlight both the similarities and differences in these patient-report tools [6, 124-129].

Although Table 5 presents the 2 approaches, satisfaction- or experience-based items, as mutually exclusive, some surveys include a number of experience-based questions along with global satisfaction questions. Examples of such hybrid surveys are the Canadian Community Health Survey and The Commonwealth Fund Health survey programs [130, 131]. The strengths and limitations of each of these approaches are discussed in the subsequent section.

Survey type	Example of survey measure	Example of survey item stems	Example of response scales
Satisfaction	Press Ganey Satisfaction Survey [124]	Amount of time the care provider spent with you	Very poor; poor; fair; good; very good
	European Organisation for Research in the Treatment of Cancer (Inpatient Cancer Care) [125]	How satisfied were you with the clarity of information given by doctors?	Unsatisfied; somewhat satisfied; rather satisfied; quite satisfied; very satisfied
	Friends and Family Test [126]	How likely are you to recommend the clinic to family or friends?	Extremely likely; likely; neither likely nor unlikely; unlikely; extremely unlikely (and don't know)
Experience	Picker Patient Experience Questionnaire [6]	If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you?	Yes, completely; yes, to some extent; no, I didn't have anxieties or fears
	General Practice Patient Survey [127]	Generally, how easy is it to get through to someone at your GP surgery on the phone	Very easy; fairly easy; not very easy; not at all easy; haven't tried
	Supportive Care Needs Survey [128]	In the last month, what was your level of need for help with not being able to do the things you used to do?	No need, not applicable; no need, satisfied; some need, low need; some need, moderate need; some need, high need
	Camberwell Assessment of Needs Short Appraisal Schedule [129]	Have you been given clear information about your medication?	No need; met need; unmet need

Table 5: Examples of survey item stems, response scales, and measures used to assess satisfaction and experiences with patient-centred care.

Patient satisfaction surveys: Patient satisfaction is a broad concept and individuals' levels of satisfaction with health care services is dependent on a complex interplay between their preferences, expectations, and experiences of care [123]. Early work in satisfaction research by Penchansky and Thomas [132], Aday and Andersen [133], and Ware and Snyder [134] provided a number of long-standing multifaceted models in which satisfaction is an outcome of availability, accessibility, accommodation, affordability, and acceptability of services; patient predisposing characteristics; and professional characteristics and conduct. Given this, the simplicity of many satisfaction surveys has led many researchers to question the validity of the results [121, 135]. Furthermore, it is difficult to identify specific gaps in the quality of patient-centred care using this more global approach. For example, reporting the proportion of respondents who would be likely to recommend the service to family or friends does not readily identify how experiences could be improved. Finally, patient satisfaction surveys are often subject to a well-documented ceiling effect and respondents may be influenced by social desirability bias [121, 135].

It is important to note that the simplicity of satisfaction surveys may also be an advantage in certain circumstances. These questions are often relatively quick for patients to complete and do not pose a large cognitive burden. The simple structure of these surveys and the subsequent results can also readily facilitate benchmarking practices and are easily interpretable when comparing or monitoring change [121].

Patient-experience surveys: Using this approach, respondents reflect on a recent interaction with the health service or professional and report if this interaction was ideal and met expectations for care. This approach was developed in part to address the limitations of satisfaction surveys. Asking respondents if the actual interaction met their expectations for ideal care is a more direct approach than satisfaction surveys and identifies the specific aspects of care that patients felt were not adequate [121, 123]. Furthermore, when evaluating specific components of this experience, participants may be more likely to recall both positive and negative experiences. This more-factual approach may reduce the potential for ceiling effects [121].

The experience-based approach to measure patient-centred care within chronic disease services is gaining popularity in national health reform; within the United Kingdom, France and the United States, government policy encourages health services to routinely collect and disseminate patient-experience data.[136, 137] These data are also often linked to pay-for-performance programs that provide financial incentives for those services that perform well on these measures, although the success and appropriateness of pay-for-performance programs are contentious [136, 137].

Need assessment tools are a specific type of patient-experience measure [138]. Although the definition of need differs according to theoretic approach, unmet needs are commonly defined as the differences between the services perceived by the patient to be necessary to manage a health condition and the services actually received [128, 139]. This is conceptually similar to ideal-versus-actual care surveys in that patients specify the extent to which actual services met their needs (i.e., ideals) for care. Those areas in which patients identify a gap between their needs and the services received are classed as "unmet needs" and can be grouped into a variety of patient-centred care domains, including (1) physical, (2) psychological, (3) health system and information, (4) patient care, (5) activities of daily living, and (6) psychosocial [115]. Need assessment tools are commonly administered within cancer research and has contributed to the emergence of supportive cancer care and psycho-oncology [36, 115].

Although there are limitations to each approach, patient-experience and satisfaction tools have represented a major advancement in patient-centred care and can be used (1) as a screening or communication tool in patient–physician interactions; (2) to estimate prevalence of unmet need or dissatisfaction within specific chronic condition groups as an indicator of health service performance; (3) to guide patient-centred interventions to those care areas or patient groups with reporting relatively worse experiences, levels of unmet need, or dissatisfaction; and (4) as a benchmarking tool or to monitor changes in health service delivery over time [29, 116, 128, 138, 140-145]. With such a multitude of applications, widespread use of patient-experience data in routine practice has been reported with approximately 93% of physician group leaders (medical directors, administrators, and managers within an American managed care plan) recall having seen at least one patient-experience report annually [146].

What are the gaps in patient-centred care as reported by individuals with chronic disease?

For the growing number of individuals with chronic disease, ensuring care is patient-centred may help to improve experiences and outcomes. Furthermore, implementing patient-centred care may improve cost-efficiency and care processes for health services and professionals. However, patient-experience surveys, such as The Commonwealth Fund International Health Policy Surveys, conclude patients frequently experience gaps in the quality of patient-centred care across several of the Picker dimensions [59, 131, 147-151].

The following sections provide examples of patients' experiences of poor patient-centred care for several Picker dimensions of patient-centred care as reported by The Commonwealth Fund Health Policy Surveys [59, 131, 147-151]. This is an ongoing survey program involving large patient samples across multiple high-income Commonwealth countries. Systematic evaluations of survey measures conducted by Tzelepis et al. [106], Levesque et al. [152], and Hudon et al.[29], report that few tools address all patient-centred dimensions. Although The Commonwealth Fund Health Policy Surveys provide detailed summaries of patients' perspectives on access, coordination, and communication with health professionals, there is limited information on patients' perceptions of emotional support, physical comfort, and specific aspects of health service accessibility. For these particular sections, evidence from the Picker Institute Europe, specifically collected for the United Kingdom's National Health Service, is provided [153-155]. Box 1 briefly describes the Commonwealth Fund and National Health Service survey programs.

Box <u>1</u>: Survey programs reporting gaps in patient-centred care.

The Commonwealth Fund Health Policy Surveys [59, 131, 147-151]

Purpose: To report perceptions of access, cost, quality, and satisfaction with services, and to compare these experiences across high-income countries.

Survey methods: Computer-assisted telephone interviews with random sampling of national phone directories.

Survey samples: Respondents were (1) adults aged 18 years or older who self-reported (i) in poor or fair health, (ii) received medical care for serious chronic illness, injury, or disability in the prior year, (iii) had surgery in the prior 2 years, or (iv) had been hospitalised in the prior 2 years; or (2) adults aged 55 years or older.

Participating countries and sample size, by year:

	2014*	2013	2011	2010	2008
Australia	1 670	2 200	1 500	3 552	750
Canada	3 147	5 412	3 958	3 302	2 6 3 5
France	860	1 406	1 001	1 302	1 202
Germany	547	1 125	1 200	1 005	1 201
The Netherlands	582	1 000	1 000	1 001	1 000
New Zealand	379	1 000	750	1 000	751
Norway	651	1 000	753	1 058	
Sweden	5 000	2 400	4 804	2 100	
Switzerland	1 084	1 500	1 500	1 306	
United Kingdom	581	1 000	1 001	1 511	1 200
United States	1 116	2 002	1 200	2 501	1 205

National Health Service (Care Quality Commission), Picker Institute Europe [153-155] Purpose: To ensure patients receive effective, safe and compassionate care in a timely manner and to monitor service performance over time and participating sites.

Survey methods: Postal survey coordinated by participating services including samples of consecutive patients within a specific time period.

Participating adult-only services:

	Most recent survey	Sample size
Inpatient	2014	59 000
Emergency services	2008	50 000
Outpatient	2005	84 280
Condition-specific		
Stroke	2006	1 700
Cancer	2000	65 000
Coronary heart disease	2004	3 784
Diabetes	2006	68 501
Community mental health	2015	13 500
Primary care (including trusts)	2008	69 000

* 2014 Commonwealth Fund survey included adults aged 55 years or older

Respect for patients' preferences, values, and expressed needs: The 2008 Commonwealth Fund Health Policy Survey found a considerable proportion of respondents across the 8 participating countries reported they were sometimes, rarely, or never encouraged to ask questions by their regular physician (24% to 38%) or felt informed about treatment options and participated in treatment decisions (12% to 31%) [59]. The 2011 Commonwealth survey reported similar proportions across 11 participating countries, with only 31% (Norway) to 77% (United Kingdom and Switzerland) of respondents reporting their health professional always or often encouraged questions and explained things clearly [148]. Although 80% of respondents from Switzerland reported shared decision making with specialists, this was reported by only 37% of respondents from France and 40% from Norway.

Clear and evidence-based information, education, and communication: Failure to provide adequate and clear information is a common source of patient dissatisfaction. For example, less than one-third (31%) of 2008 Commonwealth survey respondents (Germany) received a written plan or instructions to self-manage their condition at home [59]. With the exception of the United States (66%), all participating countries reported proportions below 50% on this aspect of patient-centred care [59].

Although information provision is critical for patients at time of diagnosis and when transitioning from hospital to community settings, information needs are ongoing and can change as chronic diseases and treatments progress [156]. However, only 54% of 2011 Commonwealth respondents (France) felt they could easily contact their health care professional for advice or additional questions [148]. Further compounding poor information provision is the potential to receive conflicting advice from multiple physicians — for example, up to 22% of 2007 Commonwealth respondents from the United States reported often or sometimes receiving different and inconsistent information from health professionals [147].

Coordination and integration of care and services: Individuals with chronic disease will often be required to access multiple health services and transition between primary and specialist care. For example, the typical cancer patient in the United Kingdom will access a total of 28 services [157]. As

such, coordination and integration of care is particularly relevant and health service navigation may pose several challenges for patients.

Across the 8 Commonwealth countries participating in the 2008 survey, up to 46% of respondents from the United States believed care was inefficient or wasteful due to poor coordination [59]. Although the United Kingdom reported the best performance on this item with only 28% of respondents reporting inefficient or wasteful care, overall this is a common source of patient dissatisfaction and may be a result of poor communication between health professionals. The 2011 Commonwealth survey reported similar results with 56% of respondents from Germany reporting a coordination gap; the United States showed a slight improvement (42%), whereas the United Kingdom continued to perform well and even improve on this aspect of care (20%) [148].

Exploring these coordination gaps in more detail, up to 27% of 2011 respondents from the United States reported test results or medical records were unavailable at the time of scheduled appointments and/or had completed duplicative tests [148]. Up to 37% of respondents from France reported their specialists did not have access to medical history or their regular physician did not seem informed and up-to-date about their specialist care [148]. Overall, 2008 data reported the proportion of respondents experiencing poorly coordinated care increased with the number of doctors seen [59].

Continuity and transition from hospital to home: Continuity of health professionals is essential to the ongoing management of chronic conditions. This is recognised by patients with 74% to 84% of 2007 Commonwealth respondents (the Netherlands and United Kingdom, respectively) reporting it was very important to have a usual source of care [147]. Although a high proportion of respondents from the participating 2011 Commonwealth countries reported having a regular physician or place of care (91% to 100%), patients frequently reported poor experiences when transitioning between health services and professionals [148]. In 2008, 38% (from United States) to 71% of respondents (from France) hospitalised in the last 2 years experienced at least one gap when transitioning to community-based care. These gaps included not receiving clear information on emergency symptoms when discharged from hospital (37%, France), being unsure about who to contact for further advice (17%, United Kingdom), and no arrangements for follow-up care (40%, France) [59].

Access to care and services: Access is defined as the ability to receive timely resources to manage personal health care needs to achieve the best possible outcomes [158]. The ability to access care is complex and 5 types of barriers have been proposed by Penchansky and Thomas [132, 159]: affordability, availability, accommodation, accessibility, and acceptability to patients.

Affordability: Affordability is defined as the relationship between the price of services and the patients' ability and willingness to pay for these services [132]. The 2010 and 2011 Commonwealth surveys included countries characterised by a diverse range of publicly funded and privately funded health systems. Even within publicly funded systems, respondents often reported the inability to afford medical services and treatments. For example, only 64% of Australians, 68% of Canadians, and 69% of Norwegians were confident they would be able to afford care if seriously ill [150]. Within the United States, although 58% of respondents were confident that they would be able to afford care, up to 33% forwent care or medications due to cost and 20% had serious difficulties or were unable to pay medical bills in the previous year [150]. It is important to note that within the 2011 Commonwealth survey, 36% of respondents from the United States reported an out-of-pocket expense of more than US \$1 000 in the previous year with similar proportions reported by respondents from Australia (39%) and Switzerland (39%) [150].

Availability: Availability is defined as the relationship between the volume or type of existing services and patient volume or type of needs [132]. Availability can be conceptualised as the difference between supply or type of medical services and the demand for these services; this supply–demand gap may result in lengthy wait times for services. In 2010, up to 33% of respondents (Canada) reported waiting at least 6 days to see a doctor with a greater proportion (41%) waiting for 2 or more months for a specialist appointment [150]. The lack of time spent with a physician was also a source of patient concern in the 2011 Commonwealth survey with only 70% of respondents (Sweden) reporting they felt their physician spent enough time with them [148]. This is an improvement from previous surveys [147].

Accommodation: Accommodation is defined as the relationship between the manner in which the supply resources are organised to accept patients and the patients' ability to accommodate to these factors [132]. Accommodating patients' preferences within clinic services can include flexible appointment scheduling, availability of out-of-hours care, and ability to easily and quickly contact professionals and services. In 2008, up to 62% of respondents (Australia) reported it was somewhat to very difficult to access care at night, weekends, or on holidays without accessing emergency services [59]. Furthermore, up to 17% of these respondents reported visiting emergency services for issues that could have been addressed by their usual physician [59]. Data from other countries, such as the United States (60%), Canada (56%), and France (56%), indicated the majority of respondents experienced difficulties accessing after-hours care. Similar to respondents from Australia, respondents from Canada (23%) and the United States (19%) also believed their reason for visiting emergency services could have been addressed by their usual physician [59].

<u>Accessibility and acceptability</u>: Accessibility is defined as the relationship between the location of health services and the location of the patients [132]. Acceptability is defined as the relationship between patients' attitudes to personal and practice characteristics of existing providers and, alternatively, provider perceptions of patients' characteristics [132]. The Commonwealth Survey series and Picker Institute Europe do not provide data on these specific barriers to access.

Emotional support: Qualitative work suggests patients perceive emotional support as encompassing empathy, informative communication, professionals being available and present, inspiration and hope, personalisation, supportive gestures, humour, and familiarity or a friendly environment [160]. The 2014 United Kingdom's National Health Service Inpatient Survey (Picker Institute Europe survey program) reported 81% of respondents felt they were always treated with dignity and respect [153]. A high proportion also reported confidence and trust in nursing staff (78%) and physicians (80%). However, 24% of these respondents indicated that doctors often or sometimes spoke in front of them as if they were not there; a slightly smaller proportion reported this for nursing staff (19%).

This component of patient-centred care also includes preparing patients for potentially distressing situations, side-effects, or symptoms. However, only 58% of British patients reported they were completely informed on how they could expect to feel after an operation or procedure, 28% felt informed to some extent, whereas 14% reported they were not informed [153].

Physical comfort: The 2014 United Kingdom's National Health Service Inpatient Survey also explored the physical environment of participating hospitals, specifically privacy, cleanliness, and noise [153]. Overall, the majority of participants reported the admission and emergency departments afforded at least some degree of privacy and were placed on a ward with members of the same sex. Respondents also reported hospital rooms and wards were very or fairly clean. However, up to 39% of respondents reported being bothered at night by noise created by other patients and hospital staff.

This specific dimension of patient-centred care includes professionals' response to physical issues. The 2014 National Health Service Inpatient Survey assessed the degree to which individuals felt hospital staff did everything they could to help control their pain and also the time taken for staff to respond to the call button [153]. Approximately one-third of respondents felt staff assisted with pain management to only some extent (24%) or not at all (6%); and close to one-fifth (19%) reported staff took more than 5 minutes to respond.

In 2006, the United Kingdom's National Health Service surveyed individuals who recently experienced a stroke and provided additional detail specifically on the unmet emotional needs of stroke survivors [155]. Respondents frequently reported that they did not receive enough support for emotional issues (44% and 58% depending on the type of ward); did not receive assistance to regain mobility while in hospital (approximately 8%), 4 months postdischarge (approximately 22%), and 1 year postdischarge (approximately 25%); and did not receive assistance for difficulties with speaking while in hospital (16%), 4 months postdischarge (31%), and 1 year postdischarge (26%).

Involvement of family and close others: Family and close others play a substantial role in caregiving for individuals with chronic diseases. For example, qualitative research suggests patients would like to have a family member or close other for emotional support when receiving a diagnosis

[120]. This role can also include coordinating and attending patient appointments, being responsible for household and financial responsibilities, and providing further emotional support as disease and treatments progress. However, the Picker Institute reports family and close others are frequently not involved in patients' care. For example, only 42% of British inpatients reported a family member or close other received the information needed to help them recover [154].

Is additional patient-experience data needed to facilitate quality improvement?

Overall, a considerable proportion of 2008 Commonwealth survey respondents believed fundamental changes (33% to 57%) or a complete "rebuild" (9% to 33%) to their nation's health system was needed [59]. Unfortunately, these proportions were similar to those reported by the 11 participating countries in 2011 (35% to 54% and 3% to 25%, respectively) [151]. Recognising these gaps in patient experiences and poor patient confidence in the health system, health organisations continue to invest considerable resources in evaluating patient-centred care through routine collection of patient-experience data.

Patient-experience measures can be used as screening tools or to facilitate communication:

Patient-experience tools, including need assessment surveys, provide valuable insight as (1) indicators of health service performance and comparative benchmarks across settings and providers, and (2) screening or communication tools in patient–physician interactions [116, 128, 138, 140-144]. Systematic reviews suggest the use of patient-reported outcome and experience tools are associated with significantly higher detection rates of psychological need or distress in routine practice [161, 162]. Moderate detection rates for functional problems have also been reported, whereas need assessment when used as a communication tool has showed moderate positive effects on detection rates [116, 162]. This evidence suggests use of patient-experience data as a screening or communication tool is highly valuable.

However, many patient-experience tools have not been designed specifically to inform health service change, and quality improvement has proven to be a difficult and slow process [121, 135, 162-

164]. This has led many researchers to suggest patient-experience reports may not be an ideal quality improvement mechanism [120, 135, 142, 146, 163, 165-168]. This uncertainty was echoed by the World Health Organization's Health Evidence Network in the report "How Can Hospital Performance be Measured and Monitored?" [169].

Thesis rationale

The following sections suggest 4 additional pieces of evidence are needed to bridge the gap between describing patient experiences and designing quality improvement initiatives. This includes (1) comprehensive and personalised information on patients' preferences for quality improvement; (2) information on the relative priority of quality improvement initiatives; (3) evidence comparing quality improvement preferences across patient groups; and, (4) information summarizing health professionals' preferences as key stakeholders in evaluating and implementing health service changes. The overarching purpose of this thesis was to develop a patient-report tool capable of providing this evidence and subsequently administer the tool and compare the findings across chronic disease outpatients, including individuals attending publicly and privately funded oncology, cardiology, and neurology services.

1. Quality improvement must be directly informed by patient preferences.

Many patient-experience tools do not directly request patients to identify their preferences for patient-centred health service interventions. Health services and professionals want to be able to clearly identify and act on the 'improvement message' within patient-experience data [146, 165, 167]. Without this clear and actionable improvement message, Boiko and colleagues [165] suggest it is unrealistic to expect patient-experience surveys to stimulate major health service change.

The difficulties in acting upon the quality improvement message may relate to the specificity and relevance of patient-experience data. Firstly, clinicians and researchers are required to interpret whether a reported unmet need or poor patient experience requires intervention within the health service. Drawing on need assessment literature, Richardson et al. [115] provide a poignant example to highlight this important distinction: "An elderly widow with cancer, for instance, may be very lonely and it may be useful for professionals to be aware of this fact, but this does not mean that she expects them to do anything about it." (pg.43). Furthermore, with increasing evidence on the value of multidisciplinary and community-based services, it is possible patient concerns can arise and be addressed in multiple health service settings [170, 171]. Echoing this need for specificity, 71.4% of health services selected a survey measure that was customised to their subunit and diagnostic group as opposed to a more generalised measure [172].

Given the scope of the Picker dimensions, there are many varied options for patient-centred quality improvement and provision of patient-centred care is admittedly complex. This ranges from improving physical symptom management by encouraging treatment adherence to improving care coordination by implementing complete and accessible electronic medical records. However, using current measurement tools, patients are typically unable to directly specify how unmet needs, poor experiences, or dissatisfaction should be addressed within care; it is unclear which interventions are beneficial from the perspective of the patient [166]. For example, none of the need assessment tools reported in a systematic literature review offered specific health service improvement targets [115]. As such, there is limited evidence on the specific actions needed to improve patient experiences and how patient-experience data has been used to directly effect change [135, 146, 164, 166, 168].

Comprehensive and personalised information on patients' preferences for quality

improvement is needed: Allowing patients to directly select from a range of comprehensive and varied actions for improvement may assist health services to introduce initiatives that directly align with patients' preferences for change.

2. Quality improvement should be implemented according to patient priorities.

Certain aspects of care experiences are relatively more important to patients and may be strategic targets for health service change. For example, the Picker Institute analysed National Health Service data from British outpatients (n=72 447) to identify which aspects of outpatients' experiences had the greatest effect on reported satisfaction [173]. Six domains were found to be the best predictors of overall satisfaction: (1) dealing with the reason why individuals presented to the outpatient department; (2) physician availability and communication; (3) cleanliness of the department; (4) communication and access to other professionals; (5) information about discharge; and (6) information about treatment. The study authors suggest these domains are of relatively greater priority for future quality improvement [173]. Qualitative work conducted by the National Health Service supports this finding by suggesting these specific aspects of care will have a greater impact on how patients perceive the quality of experienced care [120].

Being able to understand patients' priorities for specific quality improvement initiatives has practical benefits. Limited budgets and time is frequently cited as a barrier to quality improvement [164, 167]. Quality improvement programs also confer an opportunity cost whereby services choose to reallocate financial resources and workforce capacity that could have be used in other aspects of patient care. Understanding which initiatives may of greatest value to patients will allow health services to strategically dedicate resources. However, many existing patient-experience tools do not allow patient to directly identify and prioritise quality improvement initiatives [115, 135]. Without such information, health services face a difficult task in selecting which unmet need or patient concern should be addressed first from a potentially-extensive list [145].

Quality improvement should be implemented according to patients' priorities: Future quality improvement measures should include a method to prioritise patients' preferences for health service change.

3. Quality improvement can be targeted to specific patient groups.

Health care access and experiences are mediated by individual demographic and clinical characteristics [174-176]. For example, a national survey of 69 086 individuals diagnosed with cancer in the United Kingdom found women and ethnic minorities were significantly more likely to report poor experiences than their counterparts [174]. Similar findings were reported by Bleich and

colleagues [177] when analysing data from the World Health Survey (responsiveness module) conducted in 21 European Union countries.

The association between patient characteristics and experiences has led to increased attention on collecting detailed demographic information and implementing targeted interventions — defined as interventions customised to the specific sociodemographic or behavioural characteristics of a group [178, 179]. For example, lower rates of bowel cancer screening are associated with lower socioeconomic status, ethnic diversity, limited health literacy, male gender, increasing age, and poorer self-reported health [180-183]. A recent randomised controlled trial reported the efficacy of a computer-delivered tailored intervention to promote bowel cancer screening specifically among African-American participants [184]. Intervention participants received information on screening and cancer based on their age, gender, perceived cancer risk, perceived barriers to testing, and family history. Usual care participants received generic information. Compared to the usual care group, the tailored-intervention group reported greater changes in cancer screening knowledge, perceived cancer risk scores, screening barrier scores, and colonoscopy benefit scores.

Targeted and tailored interventions report greater effect sizes and failure to account for the characteristics of health services or its users is cited as a major barrier to successful adoption of quality improvement programs [184, 185]. In practice, targeting initiatives to only those patient groups reporting suboptimal patient-centred care may be an efficient use of limited quality improvement resources. Conversely, those initiatives valued and required by a large proportion of service users, independent of clinical or demographic characteristics, may be appropriate to implement on a generic, system-wide level.

It is important to note that patient-centred care research, including intervention studies, have seldom compared the differences in patients' perspectives, experiences, or preferences across chronic disease types [140]. This gap in the literature may be a result of the sampling and surveying approaches used. Large satisfaction and experience surveys, such as the Commonwealth survey series and Hospital Consumer Assessment of Healthcare Providers and Systems, are often conducted with very heterogeneous samples (e.g., all inpatients or individuals recently experiencing ill health) and may obscure the details of patient preferences or experiences within specific subgroups. On the other

side of the spectrum, several surveys have been developed to be disease specific and may include only a single patient group; this approach does not facilitate between-group statistical comparisons. Therefore, there is a need for studies which involve a sufficient number of patients across 2 or more chronic diseases with some commonality of experience (e.g., similar geographic location and publicly funded) and a standard survey tool. Evidence in which the gaps in the quality of care are compared and contrasted across chronic disease types may identify particular services that perform relatively better. These high-performing services may be used a model for subsequent quality improvement activities.

Information comparing quality improvement preferences across patient groups is needed.

Future quality improvement surveys should be applicable across a wide of range health service users, including different chronic disease types, and identify opportunities to target initiatives to specific patient groups.

4. Quality improvement must be seen as feasible and relevant by health services.

Overall, health professionals and services recognise the value of patient surveys [167, 168]. However, there is qualitative evidence suggesting health professionals question the credibility of survey methods, particularly to depict complex patient experiences [146, 165]. Furthermore, suboptimal proportions typically under 50% of surveyed health professionals report using patientexperience data to inform quality improvement or change patient management [162, 168, 186, 187].

It is possible that not all patient-experience data are recognised as relevant or potentially modifiable in the patient-professional interaction [115, 146, 165, 166, 188]. For example, a physician or nurse may recognise and adequately resolve an unmet informational need regarding symptom control during a clinical appointment, but be less familiar on how to address a scheduling concern, transportation issue, or need for information on financial assistance. This may also be perceived by patients as an inappropriate use of time in a clinical appointment. However, these nonclinical but salient issues affect the accessibility and accommodation of services; without health service

evaluation and change, these issues may pose major and unaddressed barriers to receiving patientcentred care.

Health professionals are also instrumental in the earlier stages of quality improvement design, particularly in providing an additional perspective on the quality of care. The need to involve professionals is recognised in multiple improvement and implementation frameworks and policies, such as the United Kingdom's Medical Research Council "Developing and Evaluating Complex Interventions: New Guidance" [185]. In addition, health professionals' support and leadership within quality improvement activities are identified as important enabling factors within the PRECEDE-PROCEED Model (Predisposing, Reinforcing, and Enabling Constructs in Educational Diagnosis and Evaluation and Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development) [145]. These frameworks, along with leading experts in quality improvement and implementation science, clearly state that engaging health professionals in quality improvement processes is essential to adoption and maintenance of health service change [189, 190].

Despite the increasing policy emphasis on collaborative quality improvement, there is emerging evidence that patients and health professionals have different priorities for care provision [108, 191-193]. Previous research suggests patients focus on interpersonal dimensions and the convenience of care (e.g., respect or empathy, and wait times). Conversely, professionals emphasise system processes, clinical indicators, and preventative aspects of care, such as care coordination, emergency department visits, and physical activity counselling [191]. This incongruence between the types of quality improvement valued by each group may act as a barrier to implementing policies and initiatives.

Multiple stakeholder preferences must be considered when designing quality improvement surveys and subsequent initiatives: A survey tool which focuses on modifiable aspects of care relevant to routine practice and allows for direct comparison of different stakeholder (patient versus health professional) preferences for quality improvement would provide actionable information and highlight where commonalities or differences exist between stakeholder preferences.

Summary of key points and relation to each thesis paper

In summary, the chronic disease burden in high-income countries is substantial for both patients and health services. Patient-centred care is a promising and ethically important approach for improving patient experiences, outcomes, and health service efficiency. However, health services struggle to consistently deliver patient-centred care. Quality improvement in this area has proven to be slow and difficult. This may be partly due to the challenges of using of patient-experience data as a quality improvement mechanism.

Four additional pieces of evidence are needed in order to provide comprehensive, personalised, and prioritised summaries of patients' preferences for quality improvement; these summaries should be compared across patient groups and health professionals to identify opportunities for targeted or system-wide intervention. **Papers 1** and **2** of this thesis describe the content and development process for a Web-based tool capable of generating these summaries; **Paper 3** reports cross-sectional survey results in which chronic disease outpatients' preferences and priorities for quality improvement in 4 tertiary centres were identified; **Papers 4** and **5** compare preferences across patient demographic and clinical characteristics, including health-related quality of life selfreported by a sample of medical oncology outpatients; and **Paper 6** contrasts health professionals' and patients' quality improvement preferences and identifies areas of agreement and disagreement.

Thesis objectives

The overall objectives of this thesis are to:

- I. Summarise the barriers to patient-centred care experienced by a range of chronic disease outpatients to generate a comprehensive list of potential quality improvement initiatives (Paper 1).
- II. Systematically construct and evaluate a Web-based tool that enables outpatients to easily generate comprehensive, personalised, and prioritised lists of quality improvement initiatives (Paper 2).
- III. Report the high-priority initiatives that are commonly selected across a large sample of chronic disease outpatients recruited from 4 tertiary specialist clinics (Paper 3).
- IV. Identify a set of generic initiatives that are equally valued across a range of health services users along with a set of targeted initiatives selected by specific patient demographic and clinical groups (Papers 4 and 5).
- V. Compare health professionals' and patients' preferences for quality improvement using the adapted Professional Preferences Survey (Paper 6).

The 6 papers are formatted as articles and are either published or are currently under editorial review at peer-reviewed scholarly journals.

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Paper 1

A systematic review of barriers to optimal outpatient specialist services for individuals with prevalent chronic diseases: what are the unique and common barriers experienced by patients in high income countries?

Overview

Paper 1 provides an overarching summary of the barriers experienced by patients with chronic diseases when accessing outpatient specialist services. There is emerging quantitative evidence suggesting the value of patient-centred care may differ according to chronic disease type [1]. However, there has been no overarching review to distinguish the experiences or concerns which are common across groups compared to those which are unique to particular disease groups. From a policy perspective, understanding the unique barriers to patient-centred care experienced by subsects of health service users may help to develop quality initiatives to target specific accessibility issues. Alternatively, those barriers which are commonly experienced by all health service users should be prioritised and managed on a system-level. Furthermore, approaches which have successfully addressed the barriers to patient-centred care for a particular patient group may provide an adaptable model for similar concerns reported in other groups.

This systematic literature review was conducted according to The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and draws upon a previouslyvalidated model of access [2, 3]. A total of 74 quantitative studies were reviewed and the study results represent a diverse set of high-income nations with a variety of health system structures (i.e. payment and cost-sharing schemes). To further refine the specificity of results, the reviewed studies included at least 1 of the following prevalent chronic diseases: Type 2 diabetes, arthritis, osteoporosis, ischaemic heart disease, stroke, depression, asthma, non-melanoma cancers, and chronic obstructive pulmonary diseases. As quality improvement must be directly informed by patient preferences, this review was foundational to the larger thesis in highlighting barriers to optimal care from the patient perspective which could be mitigated by quality improvement within hospital-based outpatient settings. *Citation*: Fradgley EA, Paul CL, Bryant J. A systematic review of barriers to optimal outpatient specialist services for individuals with prevalent chronic diseases: what are the unique and common barriers experienced by patients in high income countries? Int J Equity Health. 2015;14:52.

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Abstract

Health utilization and need assessment data suggest there is considerable variation in access to outpatient specialist care. However, it is unclear if the types of barriers experienced are specific to chronic disease groups or experienced universally. This systematic review provides a detailed summary of common and unique barriers experienced by chronic disease groups when accessing and receiving care, and a synthesized list of possible health service initiatives to improve equitable delivery of optimal care in high-income countries.

Quantitative articles describing barriers to specialist outpatient services were retrieved from CINAHL, MEDLINE, Embase, and PyscINFO. To be eligible for review, studies: were published from 2002 to May 2014; included samples with cancer, diabetes mellitus, osteoporosis, arthritis, ischaemic heart disease, stroke, asthma, chronic pulmonary disorder (COPD) or depression; and, were conducted in high-income countries. Using a previously validated model of access (Penchansky and Thomas' model of fit), barriers were grouped according to five overarching domains and defined in more detail using 33 medical subject headings. Results from reviewed articles, including the scope and frequency of reported barriers, are conceptualized using thematic analysis and framed as possible health service initiatives.

A total of 3181 unique records were screened for eligibility, of which 74 studies were included in final analysis. The largest proportion of studies reported acceptability barriers (75.7 %), of which demographic disparities (44.6 %) were reported across all diseases. Other frequently reported barriers included inadequate need assessment (25.7 %), information provision (32.4 %), or health communication (20 %). Unique barriers were identified for oncology, mental health, and COPD samples. Based on the scope, frequency and measurement of reported barriers, eight key themes with associated implications for health services are presented. Examples include: common accommodation and accessibility barriers caused on service organization or physical structure, such as parking and appointment scheduling; common barriers created by poor coordination of care within the healthcare team; and unique barriers resulting from inadequate need assessment and referral practices. Consideration of barriers, across and within chronic diseases, suggests a number of specific initiatives are likely to improve the delivery of patient-centered care and increase equity in access to high-quality health services.

Keywords

Health services, Outpatient, Cancer, Depression, Diabetes mellitus, Heart diseases, Joint diseases,

Stroke, Systematic review, Accessibility

Introduction

In the last decade, chronic diseases such as cancer, heart disease and diabetes have become the leading cause of death worldwide and are associated with 59 % of deaths and 46 % of the global disease burden [1]. Chronic diseases are characterised by multiple causality, genetic and lifestyle risk factors, long latency periods, and prolonged periods of illness with some level of functional impairment or disability [2]. Individuals diagnosed with a chronic disease often suffer from reduced quality of life and report poor physical functioning and emotional wellbeing [3].

Individuals with chronic diseases are frequent users of complex and costly healthcare services [4]. Chronic disease care usually requires comprehensive and personalised services involving multidisciplinary teams. This care is often delivered at outpatient clinics, which are defined as services providing diagnostic or therapeutic care not requiring an overnight stay in a medical institution [5]. Currently, non-emergency outpatient services for chronic diseases account for a large proportion of health expenditures within high-income countries [6]. In 2011, the Organization for Economic Cooperation and Development (OECD) estimated high income countries allocate, on average, approximately 33 % of their total healthcare budgets to outpatient services [6]. However, several countries dedicate an even larger proportion to these services including a variety of private and public-based systems.

With the associated high healthcare expenditure and disease burden, effective management of chronic diseases have been targeted in policy and research initiatives. Within high-income countries, emphasis has been placed on improving the efficiency and ability of health systems to respond to chronic disease patients' evolving healthcare needs in an equitable manner. Several performance indicators relating to chronic care are incorporated into quality frameworks proposed by organizations such as the Institute of Medicine [7], the Australian National Health Performance Committee [8], the United Kingdom's National Institute of Health [9], and the World Health Organization [10]. Suggested performance domains focus on equity, effectiveness, safety, responsiveness, continuity of care, efficiency and accessibility. Beyond these domains, patient-centered care is also considered to be

essential to high quality healthcare and requires patients' preferences and values to be considered in healthcare provision [11].

Accessibility is defined as the ability to receive timely resources to manage personal healthcare needs in order to achieve the best possible outcomes [12]. Several theoretical frameworks have been proposed in order to differentiate and operationalize the factors that can act as potential barriers to receiving care [13]. Roy Penchansky and William Thomas suggested a model of fit where access is conceptualized as the degree of fit between patient need and the service's ability to respond to and meet those needs [14]. Poor 'fit' will result in an access barrier. Five distinct forms of barriers have been proposed and validated within this model (Table 1). Metrics used to describe these potential barriers to service access have included: 1) equitable patterns of service utilization according to demographic, clinical, or health insurance characteristics; 2) having a usual source of care; 3) patient need assessment, for example levels of unmet medical, supportive care, or prescription needs; and 4) patient satisfaction surveys [12, 15–17].

Form of barrier	Definitions [107]
Availability	The relationship between the volume or type of existing services and patient volume or type of needs.
Accessibility	The relationship between the location of health services and the location of the patients.
Accommodation	The relationship between the manner in which the supply resources are organized to accept patients and the patients' ability to accommodate to these factors.
Affordability	The relationship between prices of services and the patients' ability and willingness to pay for these services.
Acceptability	The relationship between patients' attitudes to personal and practice characteristics of existing providers and alternatively, provider perceptions of patients' characteristics.

 Table 1 Definition of barriers within the model of fit

There is considerable inequity in access to high quality outpatient services. Health service utilization data has consistently demonstrated an association between patient characteristics and access barriers for individuals with chronic diseases. For example, ethnic minorities within the United States have been found to be significantly less likely to access outpatient services for asthma, hypertension, diabetes mellitus or congestive heart failure as compared to Caucasians [18]. This trend has also been identified in access to oncology services [19]. The proportion of unmet needs reported by patients is significantly higher for those with chronic diseases and increases with comorbidities [20]. Results from the Canadian Community Health Survey and national hospitalisation data report that unmet needs in samples of people with chronic diseases remain disproportionally high even after controlling for socio-demographic characteristics [20]. Research also suggests individuals with chronic diseases (lasting at least 6 months with restrictions in activities of daily living) were three times more likely to report an unmet need than individuals without a chronic disease [4]. Overall, health service utilization and need assessment survey data suggest individuals with chronic diseases struggle to access required health services; while these health services struggle to meet patients' ongoing needs.

Health service planning and policy would benefit from detailed information on the scope of common and unique (i.e., disease-specific) barriers to optimal care. Currently, there is a lack of research comparing the barriers to care experienced across groups with chronic diseases [21]. While there are some trends in the types of barriers experienced by these groups, there has been no overarching review to distinguish experiences or concerns which are common across chronic disease groups compared to those which are unique to particular groups or diseases. Understanding the unique barriers to care experienced by particular groups may help to guide health service research to develop quality initiatives to target specific accessibility issue; conversely, those barriers that are common across groups should be prioritised and managed on a system-level.

This systematic literature review will examine the common and unique barriers experienced by nine chronic disease groups when accessing specialist outpatient care. For the purposes of this review, the definition of barrier proposed within the model of fit will be used - any factor which impedes or reduces the availability, accessibility, affordability, accommodation or amenability of outpatient care [14]. Additional factors that influence patient unmet needs, utilization patterns, and satisfaction that are not adequately captured by the model of fit will also be recorded. This includes patient-centered care domains, such as support for self-management or care coordination within multidisciplinary teams, that have recently become corner-stones of healthcare quality initiatives [22, 11]. The results will be highly applicable to a range of chronic disease health services and will be the preliminary step to understanding how limited access and unmet needs can be appropriately addressed by quality improvement initiatives within specialized outpatient settings.

Objectives

This systematic review of quantitative studies was conducted to describe:

- The scope and frequency of barriers reported by chronic disease patients when accessing outpatient specialist services;
- 2. The common and unique barriers that are reported across or within chronic diseases.

Beyond providing a quantitative description of the scope, frequency, and commonality of barriers experienced when accessing services, recurrent themes within the reviewed studies were summarized and framed within the context of health service interventions. This synthesis of study results provides a preliminary understanding of those approaches capable of improving the equitable delivery of chronic disease outpatient care within high-income countries.

Methods

A systematic literature review of quantitative studies was conducted according to The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [23].

Search strategy: Search terms were generated iteratively by the research team and reviewed by an experienced medical librarian. Search terms used in various combinations included: chronic disease; neoplasm; outpatient or ambulatory services. The following search limits were applied: English language; all adults defined as over the age of eighteen years; and publication date between 2002 and 2014. This year range was applied to capture articles published in response to several seminal articles released in 2001 that proposed accessibility as a quality indicator. This includes the Institute of Medicine's Crossing the Quality Chasm [7]. An example of the electronic search strategy is available in the Supplementary Material (Additional file 1).

Information sources: The search was conducted in: the Cumulative Index to Nursing and Allied Health Literature (CINAHL); Embase; MEDLINE; and PsychINFO. The final search was completed May 2014.

Eligibility criteria: Quantitative or mixed methods studies which report barriers to receiving optimal specialist outpatient care were eligible for review. Six inclusion and eight exclusion criteria were applied to retrieved articles (Table 2). To ensure articles were relevant within high-income countries, only research conducted in 31 high-income Organization for Economic Co-operation and Development (OECD) countries were eligible for review [24]. A total of nine prevalent chronic diseases were included: Type 2 diabetes, arthritis, osteoporosis, ischaemic heart disease (coronary heart disease), stroke, depression, asthma, non-melanoma cancers, and chronic obstructive pulmonary disorders. These diseases were selected as they have been proposed as health priority areas within Australia [25], the Pan-Americas [26], Europe [27], and are included in major WHO reports relating to chronic diseases [28].

Paediatric research was excluded. Research involving childhood cancer survivors was included if the majority (>50 %) of participants were eighteen years of age or older. Several studies explored barriers across specialist, primary care, and inpatient services – these studies were only included if the majority of participants (>50 %) accessed outpatient services or a sub-group analysis was performed. Eligibility criteria were independently pilot tested by two members of the research team with a random sample of titles and abstracts (10 %).

Study selection process: Using the eligibility criteria, a research team member reviewed all titles and abstracts. A random 10 % of these were reviewed by an independent secondary reviewer. A Cohen's kappa value was recorded to assess inter-rater reliability. Discrepancies between the two reviewers were discussed, and if unresolved, a third reviewer was included to reach consensus. The study selection process was facilitated by Synthesis, a literature review software package [29].

Data collection process: Study characteristics and data describing the barriers to receiving optimal outpatient care were extracted from full-text articles using a structured electronic form. All eligible full-text articles were coded by one reviewer, with a random 10 % of articles coded by a second independent reviewer. Coded results from the two reviewers were compared to ensure the process was systematic and comprehensive.

Inclusion criteria	Exclusion criteria
1. Quantitative or mixed methods study design	1. Qualitative study design, editorial letters, opinion articles or teaching documents
2. Adult patient, health service professionals or support persons are sampled	2. Paediatric samples (less than 18 years of age)
3. Study setting is an outpatient specialist service	3a. Participants are recruited from outpatient settings, but barriers to other care settings are assessed
	3b. Palliative, emergency or in-patient services only
	3c. Non specialist services only (such as primary care practices)
4. Study must clearly specify one or more of diseases of interest are included in the study sample.	4. Acute or other chronic diseases not listed as diseases of interest
5. A barrier to optimal outpatient care is measured	5. No barrier is measured (eg. treatment efficacy, diagnostic protocol, symptom or disease prevalence)
6. High income OECD countries ^a	6. All middle or low income non-OECD countries
7. Full text articles published in English	7. Conference proceedings, unavailable full text articles or article not published in English

Table 2: Eligibility criteria for all retrieved articles

^a Defined by the World Bank based on 2011 Gross National Income per capita [24]

Data items: Data items were extracted to address the following study objectives:

<u>Objective 1</u>: To describe the scope and frequency of barriers experienced when accessing specialist outpatient services, the following was recorded: 1) if a barrier relating to one of five domains within the model of fit - availability, accessibility, affordability, accommodation or acceptability (defined in Table 1)- was assessed; 2) the disease(s) of interest; and 3) the service(s) of interest. To describe any additional variables focusing on any barriers to optimal outpatient care that were not adequately captured within the model of fit, patient-centered care domains including information provision, selfmanagement, need assessment, coordination of care, and medical errors were also recorded. For each of the five domains defined in the model of fit and for additional barriers to optimal care, key terms were used to describe barriers in more detail. Where possible, Medical Subject Headings (MeSH) were chosen. For example, a general affordability barrier could be described as inadequate insurance coverage (MeSH: health insurance) or inability to pay for initial services or ongoing care (MeSH: medical fees).

<u>Objective 2</u>: To describe the common and unique barriers reported by chronic diseases, the number of disease groups reporting the barrier was recorded. A barrier was considered common if reported in relation to three or more diseases. Alternatively, a barrier was considered unique if reported in relation to one or two diseases. This range was selected as the high volume of oncology studies masked potential unique barriers experienced by only one other chronic disease, such as depression.

Finally, in order to frame these results within the context of health service interventions, the research team summarized emerging concepts using a thematic analysis approach [30]. To determine those concepts which were of most significance and relevance to outpatient service, raw study data were recorded and recurrent themes were summarized by the research team. This is considered as a data-driven thematic approach [30].

Summary measures: If reported, the proportion or odds ratio of participants indicating a barrier was recorded as raw data. Due to the heterogeneity of study designs and outcome measures, meta-analysis could not be conducted.

Results and discussion

Study selection: A total of 3263 records were identified using the electronic search strategy, of which 3181 were unique records (Fig. 1). The eligibility screening process excluded 2767 abstracts. The initial kappa value reported for agreement between the two raters when reviewing the first 10 % of abstracts (selected using a statistical software random number generator) was 0.72, indicating substantial inter-rater reliability [31]. After discussion, all eligibility disagreements were resolved.



Figure 1 Study selection and screening process

A total of 414 full text articles were screened for eligibility. The initial kappa value reported for agreement between the two raters when reviewing the first 10 % of full text articles (selected using a statistical software random number generator) was 1.0, indicating perfect agreement [31]. The eligibility screening process excluded 340 full text articles. The most common reasons for exclusion were not including a specialist outpatient setting (28.2 %), not measuring any barriers (38.8 %), or conference proceedings (15.3 %). One paper was excluded as the authors did not respond to a request for additional clarification on the applied study measure. A total of 74 articles met eligibility criteria and were included in the review (Fig. 1).

Study characteristics: The majority of studies employed a descriptive cross-sectional survey design (50 of 74 studies, 67.6 %) [32–81] and all chronic diseases of interest were reported in at least one article. However, the volume of articles differed between chronic diseases: 59 articles (79.7 %) included oncology samples [32–40, 42–45, 19, 82, 46, 47, 50–52, 83, 53–55, 84, 57, 85, 86, 58–60, 87, 61–63, 88, 65, 66, 89, 67–69, 90, 70, 91–93, 71, 72, 94, 95, 74, 76–78, 96, 79–81]; 12 articles (16.2 %) included depression [32, 33, 41, 83, 97, 62, 98, 64, 93, 99, 100, 75]; 10 articles (13.5 %) included diabetes [32, 33, 48, 83, 56, 18, 102, 64, 74, 75]; 7 articles (9.5 %) included COPD [32, 33, 49,

56, 102, 74, 75]; 7 articles (9.5 %) included asthma [32, 33, 83, 18, 64, 74, 75]; 6 articles (8.1 %) included arthritis [32, 33, 83, 73–75]; and 3 articles (4.1 %) included osteoporosis [73–75]. A total of 12 studies (16.2 %) included more than one disease of interest [32, 33, 83, 56, 18, 62, 102, 64, 93, 73–75]. As such, excepting oncology, diseases of interest were predominately analysed as part of a cluster.

Objective 1: The scope and frequency of accessibility barriers

On average, studies examined 1.67 (SD = 1.11) of the five overarching barriers to specialist care outlined in the model of fit. No study examined all five overarching barriers. The scope and frequency of barriers reported for each domain is provided in Table 3.

Barrier to outpatient services	Percentage of studies	References
Availability	28 4 (21)	References
Delays	68(5)	[32 34 37 30 40
Provider availability	8.1 (6)	52-54, 57, 59, 40, 52 55 58 61-63
Consultation time	6.8 (5)	89, 67, 68, 93, 71,
Service availability	6.8 (5)	95, 76, 77, 79]
Referral	11.0 (8)	
Accessibility	14.9 (11)	
Environment, parking	9.4 (7)	[36 33 37 54 60
Transport	5.4 (4)	61, 65, 67, 69, 77,
Professional practice location	2.7 (2)	79]
Lodgings	1.4 (1)	
Affordability	23.0 (17)	
Medical fees	5.4 (4)	[32, 36, 39, 19, 47,
Health insurance	10.8 (8)	49, 83, 55, 57, 87,
Prescription fees	4.1 (3)	61, 98, 103, 69, 74,
Cost of illness, economic	4.1 (3)	75, 96]
Affordability, general	5.4 (4)	
Accommodation	25.7 (19)	
Appointments and scheduling	4.1 (3)	
Wait times	9.5 (7)	[32-34, 37, 52, 59, 60, 97, 101, 62, 64]
Out of hours care	6.8 (5)	60, 87, 101, 63, 64, 80, 00, 70, 02, 71
Continuity of care	10.8 (8)	75 77 801
Provider contact	4.1 (3)	75, 77, 60]
Accommodation, general	2.7 (2)	
Acceptability	75.7 (56)	[32, 34, 36–40, 42,
Healthcare disparity, demographic	44.6 (33)	45, 19, 47, 50–52,
Decisional involvement	16.2 (12)	54, 97, 55, 84, 56,
Health communication	27.0 (20)	57, 85, 86, 59, 60,
Professional-patient relations (interpersonal skills)	17.6 (13)	67, 18, 01, 02, 101, 63, 102, 64, 88, 65
Choice of professional	2.7 (2)	89, 67, 68, 103, 90,
Clinical competence (technical skills)	8.2 (6)	70, 91–93, 71, 99,
Patient motivation or willingness to accept care	5.4 (4)	100, 94, 73–78, 96, 79, 80]
Other barriers to optimal outpatient services	51.4 (38)	[79-81, 76, 77, 73
Need assessment, undetected or untreated issues	25.7 (19)	72, 93, 71, 69, 65,
Service amenities	12.2 (9)	66, 89, 67, 63, 61,
Consumer information	32.4 (24)	58-60, 55, 84, 56,
Patient care team, coordination and medical record	9.5 (7)	53, 52, 50, 82, 46-
Self care	5.4 (4)	48, 43–45, 41, 35–
Medical errors	2.7 (2)	37, 32, 33]

Table 3 Percentage of reviewed studies reporting each overarching and specific barrier to specialist outpatient care (n = 74)

A total of 56 studies measured an acceptability barrier (75.7 %) and this was the most common barrier assessed. Within this domain, a total of 33 studies (44.6 %) reported patient demographics as a potential acceptability barrier to outpatient specialist care. It is important to note that demographic characteristics also served as moderator variables for other barriers. For example, male gender and lower income were associated with decreasing continuity of specialist care [101]. A total of 38 studies (51.4 %) examined other barriers (i.e., outside the model of fit) to optimal specialist care, including undetected or untreated physical or emotional issues and significant levels of unmet needs.

Objective 2: Common and unique barriers experienced by patients with chronic diseases

Twenty three specific barriers were considered to be common across chronic diseases (Table 4) and ten were considered unique (Table 5). It is important to consider the number of studies reporting each of these barriers, particularly as the volume of articles differed between oncology and other chronic diseases. For example, sixteen oncology-specific studies reported communication with health professionals as an acceptability barrier [34, 36, 37, 40, 42, 51, 86, 59, 60, 91, 92, 71, 94, 76, 77, 80], whereas only four studies reported a similar barrier within any of the other eight diseases of interest [32, 56, 64, 93].

Common barriers

Within each domain, several barriers were common across chronic diseases (Table 4). As the most frequently described barrier to outpatient care, difference in service use, levels of need, or satisfaction according to demographic characteristics were reported across all diseases of interest [34, 38, 41, 45, 19, 47, 51, 52, 54, 97, 55, 84, 57, 85, 87, 18, 61, 101, 102, 64, 88, 65, 89, 68, 103, 91, 92, 99, 100, 74, 75, 96, 79]. Additional barriers resulting from sub-optimal interactions with healthcare teams or non-patient focussed health service organization were commonly reported. Common barriers resulting from health service organization or physical structure included: waitlists and appointments delays [32, 33]; poor service availability [33, 52, 55, 58, 63]; difficulties with parking [33, 36, 37, 60, 65, 77, 79]; poor transport options [33, 36, 61, 69]; distance to the outpatient

clinic [33, 54, 67]; inability to meet medical fees [32, 47, 49, 61] or prescription costs [32, 49, 83]; inadequate health insurance coverage [39, 19, 47, 83, 55, 87, 98, 75]; and poor service amenities [33, 37, 46, 60, 65, 89, 71, 77, 79].

Common barriers resulting from sub-optimal interactions with healthcare teams included: decisional involvement [32, 40, 50, 51, 56, 59, 60, 64, 67, 92, 71, 80]; communication with health professionals [32, 34, 36, 37, 40, 42, 51, 56, 86, 59, 60, 64, 91–93, 71, 94, 76, 77, 80]; relations with health professionals [37, 38, 40, 42, 51, 59, 60, 64, 65, 89, 71, 77, 80]; inadequate information provision [32, 33, 36, 37, 45, 82, 46, 47, 50, 52, 53, 55, 56, 59–61, 63, 65, 89, 67, 69, 71, 77, 81]; poor coordination of care and information within the care team [32, 33, 43, 48, 60, 77, 80]; limited support for self-care practices [32, 82, 59, 76]; and medical errors [32, 77].

corresponding studies	Reported in relation to:		Number of stue	dies
Barrier	STR OST ART COP ISC DIA DEP AST CAN	Total #	Oncology only (n = 53)	Other disease (n = 21)
Acceptability				
Decisional involvement	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	9	3
Healthcare disparity by patient demographics	<i>」 」 」 」 」 」 」 」 」</i>	9	22	11
Health communication	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	16	4
Professional-patient relations	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	5	12	1
Accessibility				
Parking	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	6	1
Professional practice location	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	2	1
Transport	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	3	1
Accommodation				
Appointments and scheduling	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	2	1
Continuity of care	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	8	4	3
Out of hours care	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	2	3
Provider contact	\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark	7	1	2
Wait times	\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark	7	6	1
Affordability				
General affordability	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	8	2	2
Health insurance	/ / / / / / / / /	8	5	3
Medical fees	/ / / / / / / /	7	2	2
Prescription fees	\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark	7	0	3
Availability				
Delays	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	3	2
Service availability	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	4	1
Optimal care				
Consumer information	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	21	3
Medical errors	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	1	1
Patient care team, coordination	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	4	3
Self care	$\checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark \checkmark$	7	3	1
Service amenities	<i>\ \ \ \ \ \ \ \ \</i>	7	8	1

Table 4 Common barriers to specialist outpatient care by chronic condition and number of corresponding studies

Abbreviations: *CAN* Cancer, *AST* Asthma, *DEP* Depression, *DIA* Diabetes, *ISC* Ischaemic heart disease, *COP* Chronic obstructive pulmonary disorder, *ART* Arthritis, *OST* Osteoporosis, *STR* Stroke

Unique barriers

Ten barriers were considered unique and were predominately reported in oncology and depression samples (Table 5). Unique barriers to oncology care included access to or information on accommodation for those who were required to travel for treatment [69]; inadequate consultation time [34, 37, 40, 76, 79]; poor provider availability [37, 39, 55, 89, 95, 79]; professionals' technical skills or clinical competence [37, 40, 42, 89, 76, 79]; and option to choose their healthcare professional [39, 63]. Cost of illness was reported as a barrier by both oncology and COPD patients [49, 36, 69]. Studies examining oncology, depression or the comorbid relationship between these diseases also reported: poor referral practice [52, 61, 67, 71, 95, 76, 62, 93]; inadequate need assessment [35, 43–45, 47, 50, 52, 53, 84, 59, 65–67, 93, 72, 76, 80, 81, 41]; and patient factors, such as motivation and willingness to accept care, as barriers to outpatient care [39, 62, 63, 76]. For example, patients' level of perceived need was significantly associated with outpatient mental health service use [62]. Similarly, adult cancer survivors did not seek care if they felt they were in good health [63] or did not perceive the services were relevant to those in remission [39].

	Repo	orted i	in rela	ation	to:	<u>unci n</u>		<u>, , , , , , , , , , , , , , , , , , , </u>	<u>, .</u>	respondi	Number of studies	
Barrier	CAN	AST	DEP	DIA	ISC	COP	ART	OST	STR	Total #	Oncology only (n = 53)	Other disease $(n = 21)$
Acceptability												
Choice of professional	✓									1	2	0
Clinical competence (technical skills)	\checkmark									1	6	0
Patient factor	\checkmark		✓							2	3	1
Accessibility												
Lodgings	\checkmark									1	1	0
Accommodation												
General	✓									1	2	0
Affordability												
Cost of illness, economic	✓					✓				2	2	1
Availability												
Consultation time	\checkmark									1	5	0
Provider availability	✓									1	6	0
Referral	✓		✓							2	6	1
Optimal care												
Inadequate need assessment	1		1							2	17	2

Table 5 Unique barriers to specialist outpatient care by chronic condition and number of corresponding studies

Abbreviations: CAN Cancer, AST Asthma, DEP Depression, DIA Diabetes, ISC Ischaemic heart disease, COP Chronic obstructive pulmonary disorder, ART Arthritis, OST Osteoporosis, STR Stroke

Key themes and implications for health services

Results from this review suggest there are a wide range of barriers experienced by chronic disease outpatients. Following thematic analysis and synthesizing the results of the 74 reviewed studies, eight key themes according to the scope, frequency and commonality of barriers were found and are summarized below. Themes 1 through 6 are based on recurrent findings across individual studies. Themes 7 and 8 are reflections on the overall state of the evidence relating to barriers to specialist outpatient care. Health service or research implications for each of these themes can be found in Table 6 and provides a set of possible approaches for improving equity to high-quality specialist services.

Summarized themes	Relation to study objective	Health service or research implications				
Demographic characteristics create or exacerbate barriers	Frequent barrier	Improve breadth of patient participation and health literacy to reduce disparities				
		Assess the degree to which services are culturally competent				
		Target disadvantaged groups with additional supportive services				
Availability barriers exist at first point of contact	t Common barrier	Provide explanations for and estimates of delays				
Service structures create accommodation and accessibility barriers	Common barrier	Improve appointment scheduling systems: - record individual preferences for date and time - coordinate all required appointments at the facility on one day -convenient rescheduling process				
		Decrease wait-times				
		Incorporate notification system for estimated wait-times				
Continuity and coordination of care poses barriers	Common barrier	Improve content and access to medical records: -systematic data collection for accuracy and completeness ability to record additional patient concerns -notification or alerts when test results are available -centralized progress summaries for multiple service providers				
Decisional involvement and	Common barrier	Provide personalized information to patients				
acceptability of care		Provide ongoing opportunities to review progress and concerns				
		Provide access to additional information sources				
		Provide communication training for providers				
		Consider and discuss individual patient preferences for decisional involvement				
Need assessment and referral processes for cancer and/or depression	Unique barrier	Conduct systematic, comprehensive and routine screening of patients' needs				
can be improved		Refer automatically to support services				
		Inform health professionals of additional services available				
Barriers can be described in additional detail	l Scope of barrier	Deconstruct barriers to design more targeted initiatives for improving access				
Evidence on barriers to non-oncology services is limited	Volume of articles	Barriers reported within clusters of conditions mask differences across groups				
		Conduct more studies in non-oncology patient groups				

Table 6 Summary of key themes and implications for health services and research

Theme 1: Patient demographic characteristics frequently create or exacerbate barriers

Of the reviewed articles, the most frequently reported barrier to care examined was acceptability. This was primarily due to the focus on patients' demographic characteristics as both a barrier to receiving optimal care and as a critical factor in mediating the magnitude of barriers experienced. Examples include examining disparities according to race [19, 18, 102, 91]; education [71, 61]; age [89, 65, 71, 92]; gender [51, 65, 52]; presence of comorbidities, disease severity or reduced health status [89, 92, 103]; and socioeconomic groupings [101, 74, 96]. For example, using the population-based Nord-Tondelag Health Survey (HUNT-3), Vikum et al. explored the differential use of healthcare according to patients' education levels and household income [74]. The large sample (n = 44,755) included patients who self-reported suffering from one or more of 18 chronic diseases including: cancer; diabetes; respiratory illness, such as COPD and asthma; musculoskeletal disorders, such as arthritis and osteoporosis; and stroke. Overall, the need for all services was greatest for those in lower income groups and a positive significant relationship exists between both income and education levels and the use of outpatient specialist services, with the exception of males aged 20–39 years.

Socioeconomic status was a common demographic variable of interest and, as one would expect, was related to an individual's ability and willingness to pay for services. Approximately 17 articles explored a barrier resulting from the cost of healthcare [32, 36, 39, 19, 47, 49, 83, 55, 57, 87, 61, 98, 103, 69, 74, 75, 96]. These articles were conducted in a variety of healthcare systems, including those with publically-funded healthcare schemes designed to encourage universal access to services. This suggests that patients still must contend with several other sources of financial strain resulting from the need to access healthcare, such as lost-income or out-of-pocket spending. While this review cannot describe the differences in the barriers experienced according to the funding structures of different OECD countries, results suggest that the affordability of healthcare and the disparities that result are still a source of considerable patient concern. This is supported by previous research [32].

Theme 2: Common availability barriers exist at first point of contact with health services

A range of availability barriers, such as delays to treatment, are considerable concerns for patients when first accessing services. Across chronic disease groups, barriers exist at first point of contact with a particular service and include delays to receiving care and limited provider availability. Delays to receiving care were reported across multiple chronic diseases and were frequently experienced within several high-income countries. Within Canada, Australia, New Zealand and the United Kingdom, the majority of patients who experienced recent ill health did not receive specialist care within 4 weeks [32]. Acceptable wait periods to receive treatment or surgical interventions have been established within national guidelines, mainly to optimize patient outcomes [68]. However, wait times also pose a significant concern from a patient perspective. Paul et al. report approximately 52 % of Australian radiotherapy outpatients experienced some level of concern regarding delays in treatment [68]. Patients expect that care, particularly for recently-diagnosed prevalent chronic disease (e.g., diabetes), should be received in a timely manner and ideally within 14 days from receiving a referral [33].

<u>Theme 3: Health service structure and organization create common accommodation and</u> <u>accessibility barriers</u>

Synthesized results suggest patients continue to experience barriers over the course of their interaction with health services and patients' preferences are not accommodated within health service organization. These barriers include non-clinical aspects of the service's physical structure, such as difficulties with parking. For patients who must access services for treatment, such as intravenous chemotherapy, parking remains a major issue [79, 33, 36, 37, 60, 65, 77]. For example, within a study of cancer patients in the United Kingdom, parking was rated as the least met need despite being rated as a highly salient [65]. Non-clinical accommodation barriers were also experienced as a result of the service organizational structure. This was predominately reported by patients' dissatisfaction with appointment scheduling [71], appointment wait times, inability to contact the clinic or professionals [64], or limited availability of out of hours care [59].

Up to 60 % of oncology outpatients reported that waiting times of more than 15 min contributed to poor experiences within health services [59] and lengthy wait times accounted for a third of all patient-reported experiences of poor care [77]. This represents a potential area of improvement as wait times are highly salient to patient experiences [70] and patients who experienced lengthy wait times were more likely to report significantly lower levels of satisfaction and perceive shorter consultation times [34]. Inadequate consultation times were also reported as a barrier to oncology outpatient care. Studies using the EORTC OUTPATSAT35 report both physician punctuality and the amount of physician time devoted to the patient were the worst performing subscales and received scores below 70 [79, 89]. Patients identified sufficient time to review all questions regarding disease and treatment and having their physician's complete attention as being very important when receiving a diagnosis [40].

Theme 4: Common patient barriers are reported as a result of poor coordination of care

In 2008, the Commonwealth Fund International Health Policy Survey of Sicker Adults reported a considerable proportion of patients believed their medical care was inefficient or wasteful (rates range from 27-46 %) [32]. This negative perception of care may be a result of poor clinical competence of health professionals, lack of continuity of care, poor coordination of the patient care team, and medical errors.

Continuity and coordination has been associated with improved patient care and is frequently assessed according to patients' access to a usual source of care. For example, having a usual care provider was associated with improved screening and use of outpatient services for diabetic patients [101] and treatment of depression for patients with comorbid diseases [75]. Advanced lung cancer patients identified as having experienced poor continuity of care were more likely to have unmet supportive care needs across domains such as health information and psychological needs [80]. In addition to improved patient care and outcomes, studies consistently identify continuity of care as essential to patients' experiences of care. In a study of elderly patients' priorities for health service delivery, patients rated continuity as the most important aspect of care with approximately 94 % indicating it was extremely important to see the same physician at every appointment [33]. Similarly,
three studies of young adults found the majority of patients prefer follow-up care to be delivered by their treating physician and service [63, 34, 52].

In a study of patients' perceptions of outpatient care in eight Commonwealth countries, poor continuity or availability of information within the healthcare team was reported [32]. This included: non-availability of medical records or test results at time of scheduled appointment; unnecessary duplication of tests; and poor information exchange between general practitioners and specialists. Discrepancies in medical records were also reported by reviewed studies. For example, a review of oncology medical records revealed only 49 % of symptoms were documented and patient-identified issues, such as difficulties with mobility or maintaining activities of daily life, were frequently omitted [43]. Similar discrepancies between patient-identified symptoms and documentation have been reported for patients with chronic heart disease [48].

<u>Theme 5: Aspects of the patient-physician relationship can negatively impact the acceptability</u> <u>of care</u>

Barriers in the patient-physician interaction arose when examining decisional involvement, communication, and information provision. Approximately 70 % of oncology patients reported there was a difference between the ideal and actual physician relationships [51]. Of this, approximately 32 % of patients reported poor decisional involvement and 28.5 % did not feel encouraged by their physician. Across the 13 domains of the PASQOC survey, co-management and shared decision making had the second highest problem frequency (30 %) with a large proportion of oncology patients indicating they did not make the treatment decision (47 %) and were not effectively informed on the probability or management of side-effects (49 % and 38 %, respectively) and changes to daily life (37 %) [59]. Furthermore, 34 % did not feel as if they were treated as an expert on their body. Across multiple diseases, considerable gaps in patient-provider communication were reported and included: patient preferences and goals for treatment are not discussed (26-50 %); patients are rarely or only sometimes encouraged to ask questions (24-38 %); and are rarely or only sometimes told about treatment options and involved in decisions (12-31 %) [32]. Within COPD and chronic heart

failure (CHF) outpatients, only within 5.9 % of COPD group and 3.9 % of CHF group did both patient and physician report discussing preferences for life-sustaining treatment [56].

Information on the impact of treatment and potential trade-offs between quality and prolongation of life is typically communicated by treating physicians. Within study results, patients identify information content as the most important aspect of a clinical appointment [40]. Patients attribute high importance to being informed on the best treatment options and being aware of all treatment options [40]. Additionally, patients would like to be aware of prognoses, treatment results and be provided with information on their personal situation [71]. Within oncology outpatients, patients identified a lack of information on changes in relationships, sexual activity, or emotions was an area of improvement [67]. Poor communication and information provision for family and close others was also reported within the review as an area of relatively lower quality [51, 71].

<u>Theme 6: Inadequate need assessment and referral practices are unique barriers experienced in</u> <u>relation to few chronic diseases</u>

Patients with cancer and/or depression diagnoses report unmet needs and referral processes as a barrier to optimal outpatient care. For patients diagnosed with depression and/or cancer, synthesized study results suggest that health professionals do not consistently identify psychological or physical symptoms. For example, within outpatient oncology clinics only 49 % of patients with major depressive disorder (MDD) reported speaking to a health care professional about feeling depressed (albeit this study did not distinguish between a primary care provider or oncologist for this stage of screening); 36 % reported receiving any subsequent treatment or a referral to a specialist mental health service; and in total authors estimated up to 85 % of patients did not receive appropriate specialised treatment for MDD [93]. Slightly higher rates of treatment for moderate to severe symptoms of depression (61.9 %) and anxiety (60.6 %) were reported in a sample of several outpatient clinics specializing in cancer and chronic disease care, but this remained sub-optimal [62]. Referral processes was also reported by patients as a critical gap in the provision of outpatient care. Automatic referral to a social worker for financial, emotional, and organizational concerns was rated as important by young adults currently receiving or having completed oncology treatment [52]. Only

one in two patients are referred to a social workers due to resource limitations [95]. Referral to and availability of services such as nutritional counselling, physical therapy, support groups and rehabilitation were also reported by cancer outpatients as highly important to optimal outpatient care [61]. Only one in two patients reported using such supportive services and patients' lack of knowledge of these services (22.4 %) or lack of physician referral (23 %) was reported as the main reasons for underuse. Referral was the strongest predictor of recent mental health treatment (OR = 7.91) as compared to variables such as appointment frequency, perceived need, and prior use [62].

<u>Theme 7: To provide more practice-ready evidence, barriers to outpatient specialist care should</u> <u>be described in additional detail</u>

A total of 30 distinct barriers were reported within the reviewed papers. Consideration of the scope of these barriers using MeSH terms suggests that it is important to go beyond the overarching barriers such as the volume or affordability of available services. For example, affordability was explored in 17 papers and described four distinct forms of affordability barriers experienced by chronic disease outpatients: inadequate health insurance coverage; inability to meet the costs of medical services; inability to afford prescriptions; and the cost of illness, such as lost income for those who are unable to work. Each of these barriers requires a different type of solution suggesting it is important to have detail about the barrier in order to take appropriate action.

Theme 8: This review found little evidence on barriers to non-oncology services

There is a wealth of information on the barriers to outpatient oncology care, but barriers experienced by other chronic illnesses are less understood. A total of 59 articles described a barrier to oncology services. Comparatively, few studies (15 of 74) focused on other chronic illnesses and typically analysed barriers within a heterogeneous sample of diseases. However, it is important to note that this review may not have captured the barriers experienced by some chronic disease groups, such as people with osteoporosis, because of the limited focus on specialist services. It is possible that these groups are adequately managed within primary care settings and do not frequently require access to specialist care.

Limitations

It is possible that publication bias affected the results of this systematic review, whereby articles with significant results are more likely to be accepted in peer-review journals. By accessing only peer-reviewed studies it is possible study results over-estimates the barriers experienced by chronic disease outpatients. Grey literature or qualitative articles may have provided additional or alternative views of access to care. Additionally, most studies employed a cross-sectional survey design which may not have provided a longitudinal view of patients' ongoing experience with care. However, given the large number of articles reviewed with a range of patient samples, results are inclusive of several areas of care such as diagnosis, treatment decisions, and ongoing patient needs.

Barriers were classified according to Medical Subject Headings and grouped according to definitions proposed within Penchansky and Thomas' model of fit [14]. This required some subjectivity on behalf of the research team and the team generated a sixth barrier relating to dimensions of patient-centered care. While coding processes and data extraction was pilot-tested and agreement verified, several assumptions regarding these classifications were made. For example, specific barriers such as health communication and professional-patient relations are intertwined concepts necessary for a patient-centered approach to care. There are additional access frameworks, such as that proposed by Donabedian [104], and Andersen and Aday [105], which could have been applied within this review. Debate on the value of each framework is presented elsewhere [12], and research to evaluate the degree to which these models are inclusive of emerging quality of care dimensions would be valuable.

Subjective judgements were required when reviewing the results in order to generate thematic concepts. While this is an inherent limitation of an interpretive review, this allowed authors to provide a more concise summary of the recurrent barriers reported by a large volume of articles employing a range of measurement approaches in markedly different patient groups. Themes were generated according to well-established qualitative methods [106].

Conclusions

Overall, patients with prevalent chronic diseases experience thirty-three specific barriers to outpatient care across six accessibility domains. This includes additional patient-centered care dimensions such as self-care, consumer information provision, and need assessment. By focusing on prevalent chronic diseases within outpatient specialist settings, this systematic review describes the scope and frequency of common and unique barriers to care and synthesizes this into a concise list of potential quality improvement initiatives.

Results from this review suggest that in order to design targeted initiatives, it is important characterize barriers in detail and to explore possible barriers in the delivery of patient-centered care. In examining the common barriers, four themes were recurrent across chronic disease groups. First, at initial contact with a health care service, individuals experience delays to first appointment or treatment and causes considerable patient concern. Second, patients report health services are not organized or sufficiently flexible to accommodate scheduling preferences, and the physical structure of the clinic limits accessibility. Third, poor continuity of care and information transfer in the healthcare team was perceived to negatively impact the quality of care received. Fourth, inadequate information provision and a lack of involvement in treatment decisions were reported by multiple chronic disease groups. Given these themes were recurrent across chronic disease groups, system-wide initiatives targeting these gaps in the quality of care are appropriate and should be prioritized. Health services may consider improvements in: appointment scheduling systems; content of and access to medical records across health professionals; and timely provision of personalized information with multiple opportunities to review patient concerns.

In examining the unique barriers experienced by only a few chronic disease groups, need assessment practices and referral processes were seen as sub-optimal by individuals diagnosed with cancer and/or depression. Health services may consider evaluating current screening practices to ensure need assessments are: routinely and systematically conducted; sufficiently flexible to document salient needs that may be outside the scope of physical or emotional concerns, such as psychosocial or spirituality needs; and provide instruction and a process to address a detected need, such as an automatic referral pathway. Results from this study suggest these initiatives may best targeted within oncology or mental health services.

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Paper 2

Consumer Participation in Quality Improvements for Chronic Disease Care: Development and Evaluation of an Interactive Patient-Centered Survey to Identify Preferred Service Initiatives

Overview

The Institute of Medicine states continual evaluation of patient-centred care is essential and suggests quality must be evaluated according to patient perspectives [1]. Patient perspectives are frequently collected using cross-sectional surveys such as the Supportive Care Need Survey [2], the National Health Services Friends and Family Test [3], and the Consumer Assessment of Healthcare Providers and Systems [4]. Although this measurement approach provides overarching summaries of the existing gaps in care, these surveys were not designed to deliver comprehensive, practice-ready, and influential data specifically for the purposes of quality improvement design [5-7].

Paper 2 outlines reports the development and evaluation process for a Web-based tool, the Consumer Preferences Survey. This included 2 phases of: 1) survey development with 3 embedded steps – i. structured literature, ii. iterative feedback from relevant stakeholders, and iii. adaptation for web-based administration (completed February 2013); and, 2) a pilot study within 4 outpatient oncology, cardiology, and neurology clinics to evaluating the reliability, feasibility, and acceptability of the survey (completed December 2013).

The rationale for a novel survey approach relevant to multiple chronic disease groups and capable of providing detailed information on outpatients' quality improvement preferences was derived from the results of the literature review described in **Paper 1**. With advances in survey software, it is now possible to create dynamic Web-based surveys with complex adaptive branching and interactive survey items. These branching patterns allow participants to hone-in and provide additional detail on only those quality improvement initiatives relevant to their personal experiences. Compared to static patient-experience surveys, this approach can provide highly-detailed and comprehensive information while minimizing participant burden. To our knowledge, this survey approach has not been applied to inform patient-centred quality improvement in chronic disease outpatient settings.

A copy of the Consumer Preferences Survey is available in the Supplementary Material. To view survey navigation and interactive features, an online version is also available at: 'https://hbrg.newcastle.edu.au/quon/public/Demo_CPS'. Appendix B includes co-authored publications relating the software development and the need to consider patients as an expert information source when evaluating the quality of healthcare. Appendix D includes additional information regarding the survey development process which could not be included in **Paper 2** due to journal word limitations.

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Abstract

Background: With increasing attention given to the quality of chronic disease care, a measurement approach that empowers consumers to participate in improving quality of care and enables health services to systematically introduce patient-centered initiatives is needed. A Web-based survey with complex adaptive questioning and interactive survey items would allow consumers to easily identify and prioritize detailed service initiatives.

Objectives: The aim was to develop and test a Web-based survey capable of identifying and prioritizing patient-centered initiatives in chronic disease outpatient services. Testing included (1) test-retest reliability, (2) patient-perceived acceptability of the survey content and delivery mode, and (3) average completion time, completion rates, and Flesch-Kincaid reading score.

Methods: In Phase I, the Web-based Consumer Preferences Survey was developed based on a structured literature review and iterative feedback from expert groups of service providers and consumers. The touchscreen survey contained 23 general initiatives, 110 specific initiatives available through adaptive questioning, and a relative prioritization exercise. In Phase II, a pilot study was conducted within 4 outpatient clinics to evaluate the reliability properties, patient-perceived acceptability, and feasibility of the survey. Eligible participants were approached to complete the survey while waiting for an appointment or receiving intravenous therapy. The age and gender of nonconsenters was estimated to ascertain consent bias. Participants with a subsequent appointment within 14 days were asked to complete the survey for a second time.

Results: A total of 741 of 1042 individuals consented to participate (71.1% consent), 529 of 741 completed all survey content (78.9% completion), and 39 of 68 completed the test-retest component. Substantial or moderate reliability (Cohen's kappa>0.4) was reported for 16 of 20 general initiatives with observed percentage agreement ranging from 82.1%-100.0%. The majority of participants indicated the Web-based survey was easy to complete (97.9%, 531/543) and comprehensive (93.1%, 505/543). Participants also reported the interactive relative prioritization exercise was easy to

complete (97.0%, 189/195) and helped them to decide which initiatives were of most importance (84.6%, 165/195). Average completion time was 8.54 minutes (SD 3.91) and the Flesch-Kincaid reading level was 6.8. Overall, 84.6% (447/529) of participants indicated a willingness to complete a similar survey again.

Conclusions: The Web-based Consumer Preferences Survey is sufficiently reliable and highly acceptable to patients. Based on completion times and reading level, this tool could be integrated in routine clinical practice and allows consumers to easily participate in quality evaluation. Results provide a comprehensive list of patient-prioritized initiatives for patients with major chronic conditions and delivers practice-ready evidence to guide improvements in patient-centered care.

Keywords: Ambulatory care; Health care surveys; Patient-centered care; Consumer participation; Medical oncology; Chronic disease; Cardiology; Neurology

Introduction

In the past decade, chronic diseases have become the leading cause of death worldwide and are associated with 59% of deaths and 46% of the global disease burden [1]. Prevalent chronic diseases include hypertension, diabetes mellitus, arthritis, asthma, chronic obstructive pulmonary disease, nonmelanoma cancers, and depression [2,3]. Care for chronic diseases usually requires comprehensive, personalized, and long-term services involving multidisciplinary teams. This complex care is often delivered by outpatient clinics, which are defined as services providing diagnostic or therapeutic care not requiring an overnight stay in a medical institution [4].

Within most developed countries, hospital-based outpatient clinics provide a substantial proportion of health care services and require considerable resources. For example, within Australia, hospital outpatient costs in 2011 represented approximately 61% of all health care spending [5]. The National Hospital Ambulatory Medical Care Survey reported 96.1 million outpatient department visits within the United States in 2009 alone [6]. Therefore, quality assurance initiatives targeting hospital-based outpatient services have the potential to deliver substantial benefits from both a patient perspective and a health service efficiency perspective.

A patient-centered framework is a critical component to improving chronic disease care. Patient-centered care recognizes the values, preferences, and involvement of patients and their loved ones and establishes patients as an expert information source for assessing health care quality [7]. This quality indicator has been adopted into both evaluation practice and national policies including the Australian National Health Performance Framework [8]; the United Kingdom's National Standards, Local Action, Health and Social Care Standards and Planning Framework [9]; and the Canadian Institute for Health Information's Health Indicators [10].

Appropriate measurement of patient-centered care is essential to quality evaluation practices. Patient satisfaction surveys and unmet need measures, such as the Supportive Care Need Survey [11] and the Camberwell Assessment of Needs [12], elicit participants' evaluations of outpatient care and are traditionally administered in pen-and-paper format [13]. These tools allow consumers to identify existing gaps in care and summarize perceptions of health services. For example, studies of cancer patients indicated although most were satisfied with their overall care [14], improvement was needed regarding information, relationship, and patient care needs [15-17]. Outpatients with mental disorders reported unmet needs in psychological, relationship, and activities of daily living domains [18]. Other groups, such as patients with cardiovascular disease, reported unmet information and psychological needs [19]. Overall, such literature suggests that health care services struggle to address the needs of patients who require frequent care and have greater disease severity [20]. Results from intervention studies also suggest that attempts to translate results from needs assessment tools into practice has limited or inconsistent effects on care, outcomes, and satisfaction [13,21,22].

Practice-Ready Evidence and Consumer Engagement in Designing Health Service Initiatives

The gap in translating unmet needs to improved patient-centered care may be related to difficulties in operationalizing the results of needs assessment tools. To operationalize these data and influence practice, it is important to gather additional evidence to identify patients' preferences for changes within their health care services, strategically introduce initiatives according to patients' priorities, provide clear and feasible service-level targets for initiatives, and provide sufficient detail to design initiatives that align closely with patients' preferences and priorities. Static needs assessment tools are generally not designed to deliver such comprehensive, practice-ready, and influential data across multiple chronic conditions.

First, needs assessment tools do not enable patients to be highly specific about which unmet needs should be addressed within outpatient clinics. For example, although existing tools may facilitate patients' identification of loneliness as an unmet need, patients may not expect health professionals to provide support for this issue [13]. For unmet needs that patients do want addressed within outpatient clinics, the level of detail provided by current needs assessment tools is unlikely to be adequate. For example, parking is a frequently identified unmet need but is reported without specificity regarding what could be changed—spaces for clinic patients only or drop-off zones for caregivers? Without a tool capable of identifying which specific action is most likely to improve patients' experiences, health services may fail to resolve the issue. A Web-based tool with adaptive questioning would allow participants to provide information that is more detailed and personally relevant and would eliminate the time and effort required to navigate inapplicable content.

Second, an accurate method of identifying initiatives in order of priority is needed to direct limited health resources to those of greatest importance to patients. In a recent literature review of needs assessment tools frequently used in oncology care, no tool included a priority setting exercise capable of generating a comprehensive yet concise list of specific service initiatives [23]. Efforts that generate such information, such as willingness to pay or contingent valuation, are complex tasks for participants to complete using the traditional pen-and-paper format [24]. A Web-based tool with interactive survey content can be used to efficiently examine consumers' priorities.

Third, to elicit change, tools must produce results in a form that can be readily used by health service providers and managers. Items identified by patients must be modifiable on a service level and recognized as relevant by the service providers who receive the information [25].

Finally, previous research suggests that to integrate patient reported surveys into routine clinic practice, tools should be psychometrically robust, acceptable to patients with structured and comprehensive content, and feasible to administer in health care settings as measured by completion times and ease of administration [13]. Web-based survey software can be used to ensure these criteria are met. For example, research indicates use of this technology allows for improved readability and comprehension with simplified question formats, convenient data entry, reduction of missing data, complete timing statistics recorded by the software, and reduced administration times as compared to pen-and-paper versions [13,26,27].

Need for a Comprehensive Tool to Inform Health Service Initiatives Based on Consumers' Preferences

This study reports the development and evaluation process for an interactive Web-based tool capable of providing practice-ready, influential information suitable for designing patient-centered service initiatives for chronic disease care. This information-generating tool, the Consumer Preferences Survey, includes a set of general initiatives. Using adaptive questioning and interactive survey content, the survey also contains a comprehensive list of initiatives that are more detailed and a priority setting exercise. This will offer an alternative and efficient data collection method for identifying and introducing strategic changes to outpatient services.

This study aimed to:

- Systematically construct a tool that (1) includes a comprehensive set of patientcentered initiatives that can be introduced at a service level, (2) allows participants to easily generate a customized list of initiatives that would improve their experiences as an outpatient, and (3) generates practice-ready and actionable evidence in the form of a list of patient-prioritized initiatives (Phase 1).
- Establish the following in relation to the this tool: (1) test-retest reliability, (2) patient-perceived acceptability of the survey content and delivery mode, and (3) average completion time, completion rates, and Flesch-Kincaid reading score (Phase 2).

Methods

Phase 1: Systematic Development and Pretesting of the Consumer Preferences Survey

Structured Literature and Stakeholder Review

Given the extensive qualitative work underpinning measures of need and satisfaction with patient-centered care [23,28], a literature-based approach was used to generate a comprehensive pool of item content (overarching domains and health service initiatives), preference eliciting techniques (item stems and response scales), and possible prioritization exercises.

A total of 336 articles were reviewed for item content and techniques. A total of 179 unique items and 6 unique domains were identified. Approximately 5 unique item stems were identified which incorporated concepts such as satisfaction with care, impact or value of an initiative, and perceived importance of an initiative. Four relative prioritization exercises were developed and included: ranking processes, modified willingness-to-pay questions, visual apportioning of a pie chart to

respective health service initiatives, and a visual analog scale in which participants were asked to place initiatives according to importance.

Items and techniques generated by the structured literature review were circulated to 2 expert committees using an iterative process. The first committee included chronic disease physicians, health service managers from hospital-based specialist services, community-based chronic disease experts, and health behavior researchers including an academic biostatistician and a health economist (n=20). The second committee included consumer advocates and health service users within cancer, neurology, and cardiology fields (n=27).

Final Survey Content

After 2 rounds of feedback from each expert group, a total of 23 general service initiatives were generated from the item pool (Table 1). These initiatives were organized as 4 steps in the process of care: (1) scheduling an appointment, (2) arriving at an appointment, (3) during a clinical appointment, and (4) managing a chronic illness at home. Both expert committees preferred this approach. By allowing participants to sequentially consider each way in which care was experienced and could be improved, recall bias and cognitive burden may be reduced. However, these areas are not considered latent variables or constructs.

specific initiatives.	
Area of care and general initiatives	Specific initiatives (n)
1. Making an appointment	
Schedule convenient times	7
Easy contact with clinic staff	2
Transportation to appointment	3
2. Arriving at an appointment	
Car parking	7
Comfortable wait rooms	10
Reduced time in wait rooms	3
Having friends or family with you	_
3. During clinical appointment	
Provide more information	4
Ensure all your concerns are addressed	4
Involve you more in treatment decisions	3
Keep you up-to-date on the progress of your treatment and condition	3
Ensure good interactions and relationships with all clinic staff	5
Provide comfortable and pleasant treatment rooms	10
Provide good quality hospital catering	_
Better coordination of your care and information	7
Minimize pain or discomfort when you receive treatment	4
4. Managing at home	
Help with physical symptoms	6
Help with emotional health or relationships	4
Help with daily activities and healthy lifestyles	6
Help with employment, finances, or insurance	5
Information on your condition and treatment	8
Support and involvement of family and friends	5
Knowledge on how to handle a medical emergency	4

Table 1. Consumer Preferences Survey content by area of care, including number of possible specific initiatives.

Participants selected initiatives that would greatly improve their experience within the outpatient clinic from lists presented on the touchscreen computer. This is considered a dichotomous response scale. Selected initiatives were recorded as a 1 and unselected initiatives were coded as a 0. If a general initiative was selected, the survey displayed a subsequent list of specific health service initiatives using adaptive questioning: "On the last screen, you indicated that [general health service initiative] could improve your experience. What specifically could the clinic change to help you? [list of possible specific health services initiatives displayed]." A total 110 specific health service initiatives were available, including having emergency appointments available within a week (making an appointment), being informed of estimated wait times on arrival (arriving at an appointment), an action plan is created to address your concerns (during an appointment), and knowing which symptoms require emergency attention (self-management at home). Only those participants who selected all 23 broad health service initiatives would view all 110 detailed health service initiatives. Complete survey content is available in Multimedia Appendix 1..

Once the 4 steps were completed, participants who selected more than 5 general initiatives were presented with an autopopulated list of their previous selections and were asked to choose the 5 initiatives that were of greatest importance to them. These participants and those individuals who selected at least 2 but less than 5 initiatives were directed to a modified relative prioritization exercise. Participants were asked to allocate 100 points across their desired initiatives to indicate the relative perceived importance of each.

Final Web-Based Format

To facilitate adaptive questioning and the branching patterns required to navigate the survey, a novel software program using touchscreen technology was developed in collaboration with health behavior researchers and information technology experts [29]. To confirm the technical functionality and usability of the survey software, a total of 75 participants pretested the final format without error. To commence the survey, a research assistant first registered the user with a unique username before handing the touchscreen device to the participant. This registration step allowed participants to pause and restart the survey without losing previously entered information by re-entering their username. The unique username was stored with each result set, and removed before analysis, to allow detection of nonunique participants. If a duplicate was discovered, the entry with complete data only was used for analysis.

Once a username was created, participants were able to progress through the survey using a clearly presented "Next" button located at the bottom of every survey page. Participants were also able to navigate to previous responses using the "Back" button. All participants received 4 instruction screens and 4 screens listing the 23 general initiatives. In the unlikely scenario a participant selected all general initiatives, based on adaptive questioning they would receive an additional 7 screens listing 110 specific initiatives. The prioritization exercise included 2 instruction screens and 2 exercise screens. The maximum number of survey items presented on a screen was 4 and participants may have been required to page scroll to view all items.

Phase 2: Test-Retest Reliability and Patient Acceptability of the Consumer Preferences Survey

<u>Clinic Settings</u>

High-volume tertiary outpatient medical oncology, cardiology, and neurology clinics were included to ensure the pilot sample reflected a range of prevalent chronic illnesses. Pilot sites included a public tertiary outpatient clinic specializing in both cardiology and neurology care, a public tertiary outpatient clinic specializing in oncology care, and a private tertiary outpatient clinic specializing in intravenous chemotherapy only.

Participant Eligibility

Eligible participants were able to read English, 18 years of age or older, and had attended the clinic at least once prior to recruitment. A subsample of participants completed the survey again within 14 days to assess test-retest reliability. Eligibility for the test-retest component of the study required written consent and a second appointment scheduled within 10-14 days. Given this narrow timeframe, only medical oncology patients with an ongoing treatment schedule were approached to participate in the test-retest component of the study.

Recruitment and Survey Administration

Trained research assistants approached patients in the outpatient clinic waiting rooms or intravenous chemotherapy treatment spaces. Eligible participants were invited to complete the survey at the time of recruitment only and individuals were not provided the website address to access the survey outside of the clinic setting. The survey was voluntary, not advertised, and no incentives to participate were offered. The age and gender of nonconsenters was estimated to ascertain consent bias.

Measures

The touchscreen survey consisted of the Consumer Preferences Survey and the following:

Demographic information: age, gender, marital status, education, private health insurance, concessional card, Aboriginal or Torres Strait Islander origin, and appointment frequency within the past 3 months were collected. Participants also reported the reason for attending the clinic with response options of a routine exam for a diagnosed condition, discussion of symptoms for a diagnosed or nondiagnosed condition, or to receive tests or treatments.

Acceptability items: a total of 6 questions assessed the acceptability of the Consumer Preferences Survey: (1) Do you think the directions given for filling out the survey were adequate?, (2) Overall, how would you rate the length of the survey? with response options "it was too short," "it was just right," or "it was too long," (3) Did the survey miss any changes that could improve your experience in this outpatient clinic?, (4) Did you find filling in the survey confusing or difficult?, (5) Would you be willing to complete a similar survey in the future?, and (6) Do you believe the survey will provide an accurate summary of initiatives which could improve your experience within the outpatient clinic? Only those participants who reported difficulty completing the survey were asked additional questions assessing the ease of navigation, layout or functioning of iPad screens, adequacy of directions, and whether some changes would be helpful. Participants who selected at least 2 general initiatives and were instructed to complete the relative prioritization exercise received 3 additional questions, including (1) Do you think the directions given for this exercise were adequate?, (2) Did this exercise help you to decide which changes to the clinic are most important to you?, and (3) Did you find this exercise difficult?

Data Analysis

To examine test-retest reliability, nonweighted Cohen's kappa coefficients and percent agreements were calculated to report differences between responses at participants' first completion of the survey and second completion of the survey. Items with a kappa value equal to or greater than 0.60 were considered to have substantial test-retest reliability [30]. Those items reporting a kappa value from 0.40 to 0.59 were considered to have moderate test-retest reliability.

Acceptability items were examined using proportions and 95% confidence intervals. Differences in estimated age, gender, or clinic characteristics of consenters or nonconsenters were examined using chi-square statistics. A P value of <.05 was considered statistically significant.

Ease of integration of the Consumer Preferences Survey was assessed by examining Flesch-Kincaid reading level [31], average time to complete, and survey completion rates. The survey software recorded timing statistics and survey completion rates. The average time to complete, including standard deviations, each portion of the survey is reported.

Institutional Review Board Approval and Data Protection

Ethics approval was provided by Hunter New England Human Research Ethics Committee and the University of Newcastle Human Research Ethics Committee. Consent was implied if an individual chose to begin the survey. All personal information was immediately uploaded via an encrypted channel and stored on secure university servers with password-protected access granted to study researchers only.

Results

A total of 1042 chronic disease outpatients were approached to participate over a 10-month period from March to December 2013. A total of 741 individuals agreed to participate—a 71.11% consent rate (Table 2). Of the 301 individuals who declined to participate, clinic site was documented and age and gender estimated for 291 individuals (96.7%). Of the 741 consenting participants, age, gender, and clinic sites were recorded for 674 individuals (91.0%). There were no significant differences between consenters and nonconsenters by gender (P=.85). Age category was significantly related to consent (P=.007). Consent rates were also significantly higher within the privately funded

intravenous chemotherapy clinic compared with both the publically funded oncology clinic and

publically funded cardiology and neurology clinic (P=.001).

Demographic characteristic	Nonconsenters, n (%)	Consenters, n (%)	$\chi^2 (df)$	Р
	(n=291)	(n=674)		
Male (n=438)	134 (46.2)	304 (45.1)	0.04 (1)	.85
Clinic site			14.7 (2)	.001
Public oncology (n=476)	148 (31.1)	328 (68.9)		
Public cardiology and	135 (32.5)	280 (67.5)		
neurology (n=415)				
Private oncology (n=74)	8 (10.8)	66 (89.2)		
Age category			14.1 (4)	.007
18-25 (n=38)	5 (2.7)	33 (4.6)		
26-40 (n=155)	49 (16.8)	106 (16.1)		
41-55 (n=262)	80 (27.9)	182 (25.4)		
56-70 (n=354)	95 (31.9)	259 (35.8)		
≥71 (n=156)	62 (20.8)	94 (18.2)		

Table 2. Demographic characteristics by consent status for Consumer Preferences Survey pilot (N=965).

A total of 143 of 184 medical oncology participants (consent rate 78.1%) were willing to participate in the test-retest component. Only 68 of these 143 had a scheduled appointment within 14 days (48.9% eligibility). Due to rescheduled appointments and participants' physical well-being at the second appointment, 39 participants were included in the final test-retest sample.

Sample Demographic Characteristics

A total sample of 674 participants completed the demographic module and included 394 medical oncology patients (58.5%) and 280 (41.5%) cardiology or neurology patients (Table 3). Females were slightly overrepresented (54.9%, 370/674) in the sample and the average age was approximately 59.7 years (SD 15.5 years). Participants were most likely to have attained a high school equivalent of year 10 or lower (49.2%, 332/674) and to be married or living with a partner (66.3%, 447/674). The most common reported reasons for attending the clinic were related to a diagnosed condition, with 41.9% (282/674) of participants attending for a routine exam and 30.5% (206/674) attending to receive tests or treatment.

Sample characteristics	Participants
Age (years), mean (SD)	59.7 (15.5)
Male, n (%)	304(45.1)
Highest level of education attained, n (%)	
High school equivalent of year 10 or lower	332 (49.2)
High school completion	93 (13.8)
Diploma or trade certificate	140 (20.8)
Bachelor's degree	63 (9.4)
Not specified	46 (6.8)
Marital status, n (%)	
Married or living with partner	447 (66.3)
Single	84 (12.5)
Widowed	84 (12.5)
Not specified	59 (8.7)
Aboriginal and/or Torres Strait Islander origin, n (%)	28 (4.2)
No private insurance coverage, n (%)	361 (53.6)
Concessional card, n (%)	448 (66.5)
Chronic condition group, n (%)	
Cardiology or neurology	280 (41.5)
Medical oncology	394 (58.5)
Medical oncology private facility, n (%)	66 (9.8)
Reason for attending, n (%)	
To discuss symptoms, treatments or tests for diagnosed condition	121 (17.9)
To discuss symptoms or tests for undiagnosed condition	49 (7.3)
To receive tests or treatments for diagnosed condition	206 (30.5)
For a routine exam for a diagnosed condition	282 (41.9)
Not specified	16 (2.4)
Number of appointments in last 3 months, n (%)	
1 in last 6 months	328 (48.7)
2-3	145 (21.5)
4-5	92 (13.6)
6	31 (4.6)
≥7	73 (10.8)
Not specified	3 (0.8)

Table 3. Sample demographic characteristics of Consumer Preferences Survey pilot test (N=674).

Reliability Statistics

A total of 39 oncology patients participated in the test-retest component (Table 4). Substantial test-retest reliability was reported for 9 general initiative items (Cohen's kappa>0.6) and moderate test-retest reliability was reported for 7 general initiatives (Cohen's kappa=0.40-0.59). Four initiatives reported a value below a 0.4 threshold, indicating poor reliability. However, observed agreement for these items ranged from 94.9%-97.4%. There were an insufficient number of observations to calculate

a test statistic for 3 initiatives. Across all initiatives, the average observed agreement was 93.7% with

moderate test-retest reliability (Cohen's kappa=0.53).

Table 4. Cohen's kappa values and observed percentage agreement for general initiative
(n=39).

General initiatives selected by area of care	Observed	Cohen's ĸ
	agreement (%)	(95 % CI)
1. Area of care: making an appointment	0 (/	
Provide more convenient appointment times	89.7	0.44 (-0.01, 0.09)
Make it easier to contact the clinic	94.9	0.64 (0.18, 1.00)
Help to arrange transport to and from the clinic	94.9	0.47 (0.15, 1.00)
None selected	89.7	0.69 (0.40, 0.97)
Total number selected	87.2	0.62 (0.46, 0.68)
2. Area of care: arriving at an appointment		
Improve car parking	89.7	0.79 (0.59, 0.98)
Provide a comfortable and pleasant waiting room ^a		_
Reduce waiting times	94.9	0.47 (-0.15, 1.00)
Ensure family and friends are comfortable within waiting rooms	97.4	0.66 (0.03, 1.00)
None selected	82.1	0.64 (0.40, 0.88)
Total number selected	84.6	0.71 (0.52, 0.95)
3. Area of care: arriving at an appointment		
Provide more information about treatment and condition	97.4	0
Ensure your concerns are discussed with health care	97.4	0.79 (0.38, 1.00)
professionals		
Involve you in treatment decisions	100.0	1.00 (1.00, 1.00)
Keep you up-to-date on your treatment and condition progress	92.3	0.53 (0.06, 0.99)
Ensure good interactions with all clinic staff	97.4	0
Provide a comfortable and pleasant treatment room ^a	_	_
Provide good hospital catering	89.7	0.55 (0.18, 0.92)
Better coordination of your care	97.4	0.66 (0.03, 1.00)
Minimize pain or discomfort during treatment ^a	-	_
None selected	84.6	0.60 (0.32, 0.88)
Total number selected	79.5	0.50 (0.33, 0.80)
4. Area of care: managing your condition at home		
Access to help or information to manage physical symptoms	97.4	0.66 (0.03, 1.00)
Access to help or information to manage emotional symptoms	94.9	-0.03 (-0.09, 0.04)
Access to help in order to maintain activities of daily living	94.9	-0.03 (-0.09, 0.04)
Access to help or information related to finance, work, insurance	97.4	0.84 (0.54, 1.00)
Access to information to review at home	94.9	0.48 (-0.12, 1.00)
Access to help or information for family support	94.9	0.48 (-0.12, 1.00)
Information on how to manage medical emergencies	94.9	0.64 (0.19, 1.00)
None selected	89.7	0.72 (0.46, 0.97)
Total number selected	84.6	0.60 (0.29, 0.63)

^a Insufficient number of observations to calculate a test statistic.

Acceptability Statistics

A total of 543 of 674individuals (80.6%) completed the acceptability items related to selecting and navigating general initiatives and 529 (78.9%) completed items related to the perceived value of survey results (Table 5). This noncompletion rate was observed for those participants who were called into their appointment before completing the survey. Of the 543 participants, most found the Consumer Preferences Survey easy to complete (97.9%, 531/543), comprehensive (93.1%, 506/543), an appropriate length (95.5%, 519/543), and thought adequate directions were provided (98.3%, 534/543). Of the 195 participants who received the relative prioritization exercise, the majority indicated it was easy to complete (97.0%, 189/195) and that directions were clear (94.6%, 184/195).

Table 5. Reported acceptability of the Consumer Preferences Survey, including relative prioritization exercise.

Acceptability	Participants, % (95% CI)
Selecting and navigating general initiatives (n=543)	
The directions provided were adequate	98.3 (97.2-99.6)
The length of the survey was appropriate	95.5 (93.5-97.5)
The survey was comprehensive of all initiatives	93.1 (90.7-95.6)
The survey was clear and easy to complete	97.9 (96.4-99.3)
Completing the relative prioritization exercise ^a (n=195)	
The directions for the points exercise was adequate	94.6 (92.2-97.0)
The point exercise helped to decide what was important	84.6 (80.4-88.8)
The point exercise was clear and easy to complete	97.0(95.2-98.8)
Overall value of survey(n=529)	
The survey is an accurate summary of the initiatives desired	80.7 (77.0-84.5)
Willing to complete a similar survey in the future	84.6 (81.0-88.2)

^a Completed by only those participants with 2 or more general initiatives selected

A small minority of participants indicated they were unsure if the results were an accurate summary of the initiatives desired (17.4%, 92/529) or were unsure if they would be willing to complete a similar survey in future (9.9%, 52/529). However, the majority of participants (80.7%, 427/529) believed the survey results were an accurate summary of initiatives which could improve their experience within the outpatient clinic, whereas 84.6% (165/195) reported the relative prioritization exercise helped them to decide which general initiatives were of greatest importance. Overall, 84.6% (448/529) of participants were willing to complete a similar survey in the future. The

Flesch-Kincaid reading level was grade 6.8, indicating that those who completed 7 years of formal education would be able to easily comprehend the survey content.

Completion Rates and Timing Statistics

Approximately 78.4% (529/674) of participants completed the Consumer Preferences Survey and all acceptability questions. Completion was significantly related to clinic site (data not shown; *P* <.001), with completion rates significantly higher within the privately funded intravenous chemotherapy clinic (98.5%, 65/66) compared to the publically funded oncology clinic (82.3%, 325/394). Both oncology clinics reported significantly higher completion than publically funded cardiology and neurology clinic (69.3%, 194/280).

Approximately 5 minutes (mean 5.02, SD 3.07 minutes) was required to navigate and select initiatives and to complete the relative prioritization exercise. The total time to complete all pilot survey content, excluding acceptability questions, was approximately 8.54 (SD 3.91) minutes.

Discussion

Principal Results

The development of the Consumer Preferences Survey was successful in providing a novel tool capable of generating a customized and concise list of health service initiatives relevant to patients' experiences of outpatient care, identifying a comprehensive set of targets that are modifiable on a service level, and generating a list of prioritized initiatives to ensure service-level change is introduced strategically. The interactive survey software also allows participants to select up to 110 specific initiatives and indicate the relative importance of chosen initiatives in improving their care experience.

Results from our pilot study suggest the tool is sufficiently reliable and acceptable to patients. The test-retest reliability of each general initiative was moderate to substantial and observed percentage agreement was above 80%, indicating that this tool provides a stable summary of patients' preferences for health service change. Participants reported the Consumer Preferences Survey was easy to complete, comprehensive, and of an appropriate length. Based on average completion times and reading level, this tool can also be integrated into routine clinic practice and allows consumers to quickly participate in a quality evaluation exercise. Time to complete is approximately 9 minutes and is comparable to, or shorter than, other patient-report tools, such as the Cancer Care Monitor (12 minutes), Supportive Care Needs Survey (15-20 minutes), and Camberwell Assessment of Need (16 minutes) [12,13]. The Flesch-Kincaid reading level of the survey was assessed at 6.8. This requires participants to have completed a level of formal education well below the level of education recommended by the Australian National Health Medical Research Council for presenting information to health consumers [32].

Electronic touchscreen surveys are becoming a popular mode of survey administration within health research [33]. The Consumer Preferences Survey uses innovative Web-based software capable of complex adaptive questioning and interactive item types. The branching patterns allow participants to easily navigate through all general initiatives and only receive subsequent questions focusing on specific initiatives when appropriate. The survey content, particularly the way in which participants receive questions and the relative prioritization exercise, is a novel approach to summarizing and prioritizing patients' perceptions of the quality of care. As such, it is promising that approximately 85% of individuals indicated they would be willing to complete a similar survey in the future and only 2% believed the survey did not provide an accurate summary of desired health service initiatives. The relative prioritization exercise was perceived to be a helpful and easy exercise that could be completed in a relatively short amount of time. Similar Web-based exercises have been successfully used to explore consumers' research priorities and decision preferences [24, 34]. With limited health care resources available, simplified willingness-to-pay exercises may be an appropriate data collection approach to strategically determine funding priorities according to consumers' preferences.

Value and Application of the Consumer Preferences Survey

The involvement of consumers in shaping health policy and services is widely recognized as important for promoting patient-centered care in chronic diseases. Firstly, it is seen as an ethical and democratic right [35]. This can be an empowering experience for consumers who have been traditionally passive receivers of care with little opportunity to discuss their experiences. Secondly, consumers also offer a different but equally important perspective on the quality of health care than those of health service providers, researchers, and policy makers [35]. As research funding organizations and government health policies continue to mandate consumer involvement, a process to systematically collect and measure consumers' perspectives of care is needed.

The Consumer Preferences Survey allows consumers to participate in a quality evaluation exercise and provides valuable information on how health services can be restructured. This is an information-generating tool and can be used to determine consumers' preferences and priorities for health service initiatives. The data collection process is systematic, meaningful to consumers and health services, and sufficiently detailed and concise to translate into meaningful patient-centered health initiatives. The touchscreen survey covers a wide range of issues relatively quickly to minimize participant burden and maximize the feasibility of administering the tool in a range of health care settings.

Limitations of the Consumer Preference Survey

Unlike tools such as the Patient Generated Index [36], the Consumer Preferences Survey does not allow participants to nominate other aspects of their care they would like changed. However, these tools are not amenable to touchscreen mode of administration and cannot incorporate benefits such as an interactive action-prioritization exercise. Furthermore, a format allowing participants to generate new (and potentially highly personalized) items introduces challenges in relation to the prioritization of initiatives across chronic condition groups and users. As part of the evaluation process, the pilot test allowed participants to suggest additional initiatives that had not been covered by the survey. Only 5% of individuals suggested an additional initiative. Suggested initiatives were often specific initiatives that had been eliminated by expert review as they were deemed nonmodifiable or relevant to only a very small portion of service users.

The Consumer Preferences Survey has not been tested for validity following some traditional psychometric methods, such as factor analysis, given the lack of common denominator for items due to use of a sophisticated branching pattern. Furthermore, the organization structure of the survey into 4 distinct chronological areas of care eliminates the possibility of item randomization. These areas of
care serve only as an organization structure and do not infer latent variables or construct dimensions. However, given that the Consumer Preference Survey was not designed to measure a psychological construct or diagnose a disease state, but rather as a tool for identifying and prioritizing subjective changes to hospital-based outpatient care, reliability is likely to be the most appropriate and important psychometric characteristic to establish. To further establish the credibility of survey results, additional research replicating the reliability portion of this pilot study with a greater sample size is required.

Although this pilot study included a range of settings and a large number of participants, there are several methodological limitations that may introduce bias. Firstly, age and gender were not recorded for all consenting individuals (9% missing data). As described, participants were recruited in clinic waiting rooms before their appointment or in treatment rooms while receiving intravenous therapy. All participants recruited within the privately funded clinic completed the survey while receiving intravenous treatment and did not experience time constraints. Missing data are observed for those participants called into their appointment before survey completion; this predominately occurred within the publically funded clinics. This difference in recruitment location explains the significant difference between clinic site and completion rates. There are a number of benefits that justify applying an active recruitment method within the health service settings. Firstly, participants can use the touchscreen device and survey software specifically designed for this study instead of more laborious methods, such as a postal survey or arranging a telephone interview. Secondly, participation rates are much higher with face-to-face interaction and may mitigate any response bias [37]. This can result in a more equitable representation of patients' preferred initiatives. Although it could be argued that this approach introduces social desirability bias, this may be mitigated by the touchscreen technology which prior research suggests is a very private and acceptable data collection method [38].

Within the pilot, age was significantly related to consent. Individuals aged 71 years of age or older were more likely to decline participation than any other age group. There is evidence suggesting that age is generally not a barrier to using touchscreen technology within ambulatory settings [33]; within the study, the second oldest age group (50-69 years) reported a slightly higher than average consent rate (73%). This may suggest this result is isolated or an additional explanatory variable, such

as increasing illness severity within the older age group. A recent literature review indicates illness severity is a common barrier to research participation across multiple conditions and study designs. However, this cannot be confirmed within the existing dataset and requires further evaluation.

Conclusions

Results from the Consumer Preferences Survey can be used to guide patient-centered care initiatives within health services and will provide a list of patient-prioritized targets across several chronic conditions. This will offer an alternative and reliable method to introduce strategic initiatives to chronic disease outpatient services with the objective of empowering consumers to participate in quality improvement activities.

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Paper 3

Getting right to the point: identifying Australian outpatients' priorities and preferences for patient-centered quality improvement in chronic disease care

Overview

Paper 3 provides the first snapshot of the type and depth of information generated by the Consumer Preferences Survey, including the relative prioritization exercise described in **Paper 2**. Previous research suggests health services and professionals want to be able to clearly identify and act on the improvement message within patient survey data and prefer customizable surveys [1-4]. For example, while it may be important to record the proportion of patients who would recommend the service or were dissatisfied for benchmarking and monitoring purposes, it is difficult to enact specific types of change based on such data. This cross-sectional study adds to existing evidence by providing a highly-specific and refined list of quality improvement initiatives in order of patient priority. This information can assist health services to strategically introduce quality improvement initiatives and deconstructs patient-centred care into more manageable and strategic initiatives, such as access to information at home and improved appointment scheduling systems.

This study was conducted according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [5]. Analyses of the demographic differences according to consent and completation statuses are available in Supplementary Material, along with a copy of the Consumer Preferences Survey (also available at 'https://hbrg.newcastle.edu.au/quon/ public/Demo_CPS'). This paper is accepted at the International Journal for Quality in Health Care.

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Abstract

Objectives: To identify specific actions for patient-centered quality improvement in chronic disease outpatient settings, this study identified patients' general and specific preferences among a comprehensive suite of initiatives for change.

Design and setting: A cross-sectional survey was conducted in three hospital-based clinics specializing in oncology, neurology and cardiology care located in New South Wales, Australia.

Participants and measures: Adult English-speaking outpatients completed the touch-screen Consumer Preferences Survey in waiting rooms or treatment areas. Participants selected up to 23 general initiatives that would improve their experience. Using adaptive branching participants could select an additional 110 detailed initiatives and complete a relative prioritization exercise.

Results: A total of 541 individuals completed the survey (71.1% consent, 73.1% completion). Commonly selected general initiatives, in order of decreasing priority, included: improved parking (60.3%); up-to-date information provision (15.0%); ease of clinic contact (12.9%); access to information at home (12.8%); convenient appointment scheduling (14.2%); reduced wait-times (19.8%); and information on medical emergencies (11.1%). To address these general initiatives, 40 detailed initiatives were selected by respondents.

Conclusions: Initiatives targeting service accessibility and information provision, such as parking and up-to-date information on patient prognoses and progress, were commonly-selected and perceived to be of relatively greater priority. Specific preferences included the need for clinics to provide patient-designated parking in close proximity to the clinic, information on treatment progress and test results (potentially in the form of designated brief appointments or via telehealth); and comprehensive and trustworthy lists of information sources to access at home.

Key words: Hospital care, Chronic disease; Cancer; Quality improvement; Consumer participation;

Patient-centred care; Surveys

Introduction

Health services are increasingly required to deliver efficient, equitable and patient-centered care [1]. Patient-centered care (PCC) is defined as that which is respectful of and responsive to individual values and needs, and advocates for patient education and involvement in clinical decisions [2]. PCC is further classified into eight fundamental dimensions: 1) respect for patients' preferences, values and expressed needs; 2) information, education and communication; 3) coordination and integration of care and services; 4) emotional support; 5) physical comfort; 6) involvement of family and close others; 7) continuity and transition from hospital to home; and 8) access to care and services [2]. Since the Institute of Medicine proposed PCC as a component of healthcare quality, it has become part of international and government policy and a major research priority [3-5].

Overall, PCC has been associated with improved patient outcomes, treatment adherence and satisfaction across a range of chronic conditions [6-10]. From a health system perspective, PCC can reduce costs, malpractice claims, and medical errors, with higher overall job satisfaction and staff retention [6, 10, 11]. Despite these benefits, many health services struggle to deliver consistent and comprehensive PCC [12, 13]. For example, a survey of the quality of PCC provided in eleven high-income countries reported considerable proportions of respondents did not believe their doctor spent enough time with them, encouraged them to ask questions, or provided clear information; furthermore, respondents did not feel involved in treatment decisions [13]. Earlier work by the same authors found approximately 48% to 60% of respondents who had recently experienced poor health believed their country's health system required fundamental changes [14].

Government health policy and quality assurance policy increasingly mandates collecting patients' perspectives on service experiences in order to identify the existing gaps in care and subsequently improve the quality of care [15-17]. One of the potential reasons why services may struggle to deliver consistent and comprehensive PCC may be the challenges in identifying and acting upon the feedback collected from such patient-experience or outcome surveys [18-21]. Patient-experience measures are seldom designed to directly inform the design of quality improvement initiatives and there is limited guidance about how this data should be used to promote PCC in health services [22-25]. For quality improvement purposes, these surveys do not allow patients to directly

specify whether unmet needs or sources of dissatisfaction should be addressed within clinics and if so, which actions are beneficial from the patient perspective [24]. For example, although parking is a well-documented and common source of patient dissatisfaction and relates to health service accessibility (a key PCC dimension), there is little evidence on which aspect of parking should be improved – is it proximity, cost, availability? Similarly, while these measures may identify a global need to address information needs, should health services focus on providing personalized, written information during a clinic visits, improving access to community-based information services, or both? Increasingly detailed information on patient-preferred quality improvement initiatives may ensure preferences can be easily actioned by health services.

Inadequate budgets and work-force capacity are also cited as common quality improvement barriers and services may have insufficient resources to address all areas of unmet need or dissatisfaction [26]. Therefore, there is a need for measurement approaches which allow patients to assign relative priorities to quality improvement initiatives. Such data would assist health services to strategically allocate finite resources to those changes which are of greatest value to patients.

Using novel survey software, this study provides additional detail on patients' preferences and priorities for quality improvement.

Web-based surveys with adaptive questioning provide large item pools in which participants can 'hone-in' and provide additional detail on only those initiatives relevant to their personal experiences. Furthermore, relative prioritization exercises may be simpler to complete using survey software with auto-populated lists and calculator functions. To our knowledge, this survey approach has not been applied to inform patient-centered quality improvement in chronic disease outpatient settings where patients' needs may be intensified.

The web-based Consumer Preference Survey (Consumer-PS) provides additional evidence on patients' preferences for quality improvement initiatives which: i) is sufficiently detailed and directed to inform service change; and, ii) aligns with patient priorities for care. The survey development and evaluation process is described in more detail elsewhere [27]. The content was systematically developed in three phases: i) content development by a structured review of 336 articles drawn from

patient-centered literature including need assessment, patient experience, and satisfaction measures; ii) item refinement by two expert committees; and, iii) survey programming and pretesting in a final web-based format [27]. The Consumer-PS contains three interactive exercises to provide detailed summaries of patient-identified and prioritized quality improvement initiatives (Box 1; complete

survey available in Supplementary Material). Previous research found the touch-screen survey is highly acceptable to participants and has moderate to substantial test-retest reliability [27].

Using a novel survey and survey software, this study adds to existing work by providing a more specific and refined list of quality improvement initiatives in order of patient priority. This information will assist health services to strategically introduce quality improvement initiatives and **Box 1: Navigating the Consumer Preferences Survey** *1. Select up to 23 general service initiatives:* Participants select general service initiatives that would improve their experience within the outpatient clinic.

2. Select up to 110 specific service initiatives: If a general initiative is selected, the survey displays a subsequent list of increasingly specific initiatives.

3.a. Select general initiatives that are of most importance: Participants receive an auto-populated list of previously selected general initiative and are asked to select up to five initiatives that would improve their experience the most. Those who select only one general initiative do not receive this exercise.

3.b. Prioritize general service initiatives:

Participants who select at least two general service initiatives in the previous step are directed to a relative prioritization exercise. Participants allocate 100 points across a maximum of five general initiatives in order to indicate the relative priority of each.

deconstructs PCC, a multifaceted and complex concept, into more manageable and strategic initiatives [28].

Objectives

A cross-sectional patient survey was conducted to:

- 1. Report the proportion of individuals selecting each general quality improvement initiative;
- 2. Provide a list of detailed quality improvement initiatives corresponding to commonly-

selected general initiatives (defined as initiatives selected by more than 10% of participants);

and,

3. Report those commonly-selected initiatives in order of relative priority.

Based on this information, a detailed set of recommendations for Australian health services wishing to implement commonly-selected and high-priority quality improvement initiatives to enhance the delivery of patient-centered care are provided.

Methods

Study design

A cross-sectional patient survey was conducted according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [29]. Data reported here is one component of a larger evaluation study exploring patients' preferences for quality improvement and research involvement [27, 30]. Data was collected over a 16-month period ending in January 2014. The Hunter New England Health and the University of Newcastle Human Research Ethics Committees provided ethical approval.

Settings

Three hospital-based outpatient clinics located in New South Wales, Australia, participated in the study: 1) a publically-funded medical oncology centre; 2) a smaller privately-funded medical oncology centre; and 3) a publically-funded centre specializing in both cardiology and neurology care. Both publically-funded centres are affiliated with large teaching institutions and report a minimum of 550 outpatient visits daily (includes all non-admitted services). The smaller privately-funded oncology centre reports an average of 75 daily outpatient visits. All centres are based within the same region which has approximately 361 000 residents.

Participants

Research assistants approached individuals in waiting rooms or treatment spaces to complete the touchscreen survey. Eligible individuals were: 18 years of age or older; had attended the clinic at least once prior to recruitment; and English-speaking. The gender and estimated age range of nonconsenters was recorded.

Measurement

Outpatients completed the Consumer-PS and provided demographic information. This included: date of birth; gender; marital status; highest level of education achieved; if they were of Aboriginal and/or Torres Strait Islander origins; if they possessed an Australian concession card (a government-subsidy program which allows holders to access health services for free or at a reduced fee); and, if they had private health insurance. Participants also reported appointment frequency in the last six months and a reason for clinic attendance (response options: receive tests or treatment for a diagnosed condition; routine exam for a diagnosed condition; discuss symptoms or tests for an undiagnosed condition; discuss symptoms for a diagnosed condition; or unknown).

Statistical methods

Summary statistics report demographic characteristics and the proportion of participants selecting each general initiative. For those commonly-selected general initiatives (i.e. chosen by more than 10% of respondents), the sample proportions selecting the corresponding detailed quality improvement initiatives are reported. This provides a concise description of specific approaches to target only those initiatives relevant to a considerable proportion of health service users.

Reporting commonly-selected initiatives in order of relative priority: Participants allocated 100 points across at least two and at most five general initiatives in the relative prioritization exercise. Only those participants who selected at least two initiatives completed this exercise. An initiative allocated more points was considered to be of relatively greater priority to the participant. The average number of points allocated by participants is reported according to the number of initiatives in the exercise: two, three, four, or five initiatives. To easily compare assigned priorities, the average number of points allocated by participants for each of these four groups was summed. Participants who did not complete the survey were removed from analyses. All data analysis was completed using Stata 11(Statacorp, College Station, TX).

Results

Participants

A total of 1042 individuals were approached to participate, of which 741 consented to

complete the survey (71.11% consent). A total of 541 of 741(73.1%) consenting individuals

completed all survey content. Demographic information for these individuals is presented in Table 1.

Characteristics	Number of participants (%)
Years of age	average = 60.2 (SD=15.3)
Male	262 (48.4)
Highest level of education attained	
High school equivalent of year 10 or lower	270 (49.9)
High school completion	64 (11.8)
Diploma or trade certificate	119 (22.0)
Bachelor's or postgraduate degree	88 (16.3)
Marital status	
Married or living with partner	371 (68.6)
Single (never married, divorced or widowed)	170 (31.6)
Aboriginal and/or Torres Strait Islander origin	21 (3.9)
No private insurance coverage	282 (52.1)
Recruited from	
Cardiology or neurology, public facility	205 (37.8)
Medical oncology, public facility	271 (50.2)
Medical oncology, private facility	65 (12.0)
Reason for attending ¹	
To discuss symptoms/treatments/tests, diagnosed	90 (17.0)
To discuss symptoms/tests, undiagnosed	36 (6.8)
To receive tests or treatments, diagnosed	189 (35.6)
For a routine exam, diagnosed	216 (40.7)
Do not know	5 (0.9)
Number of appointments in last three months	
At least once in the last six months	259 (47.9)
2-3	112 (20.7)
4-5	78 (14.4)
6 or more	92 (17.0)

Table 1: Respondent demographic characteristics (n=541).

The difference in the characteristics of those who did not consent or complete the survey is available in Supplementary Material. Briefly, individuals over the age of 70 had lower consent rates (60.2%), and those attending the privately-funded clinic had higher consent rates (89.2%). Additionally, those with a high-school education reported significantly lower completion rates

(67.4%) with those attending for tests or treatments reporting greater completion rates (96.4%).

Commonly selected general initiatives

Of the 23 general initiatives available, seven initiatives were selected by at least 10% of respondents (Table 2). Improved parking was selected by the greatest proportion (60.3%), followed by reduced waiting times in the clinic (19.8%) and being kept up-to-date on treatment and condition progress (15.0%). Comfortable and pleasant wait or treatment rooms were selected by the smallest proportions (1.5% and 1.3%, respectively).

General initiatives	Number of participants
Improve car parking	326 (60 3)
Reduce waiting times in the clinic	107 (19.8)
Keep you up-to-date on your treatment and condition progress	81 (15.0)
Provide more convenient appointment times	77 (14.2)
Make it easier to contact the clinic	70 (12.9)
Access to information at home	69 (12.8)
Information on how to manage medical emergencies	60 (11.1)
Access to help in order to maintain activities of daily living	53 (9.8)
Provide good hospital catering	49 (9.1)
Access to help or information to manage physical symptoms	48 (8.9)
Access to help or information to manage emotional symptoms	48 (8.9)
Ensure your concerns are discussed with healthcare professionals	44 (8.1)
Help to arrange transport to and from the clinic	35 (6.5)
Ensure good interactions with all clinic staff	33 (6.1)
Involve you in treatment decisions	32 (5.9)
Better coordination of your care	28 (5.2)
Access to help or information for family support	28 (5.2)
Access to help or information relating to finance, work, insurance	28 (5.2)
Provide more information during appointment	26 (4.8)
Minimize pain or discomfort during treatment	17 (3.1)
Ensure family and friends are comfortable within waiting rooms	12 (2.2)
Provide a comfortable and pleasant waiting room	8 (1.5)
Provide a comfortable and pleasant treatment room	7 (1.3)

Table 2: Proportions of respondents selecting a general initiative (n=541).

Detailed initiatives corresponding to commonly-selected general initiatives

Table 3 reports the sample proportions who selected the detailed quality improvement

initiatives corresponding to commonly-selected general initiatives. Only individuals who selected the

corresponding general initiative were presented with the more detailed options, of which they were

able to select more than one option.

Specific quality improvement initiatives	Number of participants (%)
Improve car parking	
Spaces for clinic patients only	205 (62.9)
Parking options close to the clinic	180 (55.2)
Affordable options	87 (26.7)
Additional disabled parking spaces	64 (19.6)
Drop-off zones and short-term parking	53 (16.3)
Information on parking options	44 (13.5)
Easy to use parking machines	21 (6.4)
Provide up to date information	
Understand possible next steps in treatment	59 (72.8)
Know your current treatment and condition progress	55 (67.9)
Receive test results as soon as possible	47 (58.0)
Make it easier to contact the clinic	
Ensure a staff member is available when you call	62 (88.6)
Able to leave a message	21(30.0)
Access to information at home	
Information to review on long-term effects	48 (69.6)
Information to review on possible side-effects	36 (52.2)
Information to review on possible symptoms	35 (50.7)
Provide a list of trustworthy information sources	32 (46.4)
Information on remission and recurrence	24 (34.8)
Information on tests and why they are needed	23 (33.3)
Information on changes to activities of daily life	22 (31.9)
Information on patient rights and responsibilities	10 (14.5)
Access to help or information to maintain daily living activities	
Information about being active and having a healthy diet	30 (56.6)
Assistance with household chores, such as meals and yard work	24 (45.3)
Assistance with mobility inside or outside your home	15 (28.3)
Access to medical aids or devices, such as raised seats or hand rails	13 (24.5)
Assistance to reduce unhealthy activities, such as smoking	9 (17.0)
Assistance with personal hygiene, such as bathing or dressing	8 (15.1)
Convenient appointment scheduling	
Offer more choices in appointment times	45 (58.4)
Shorter waiting times for surgery or first treatment	16 (20.8)
Schedule all appointments at this clinic on one day	15 (19.5)
Offer evening or weekend appointments	14 (18.2)
Help to coordinate appointments with different services	14 (18.2)
Available appointment times for emergencies	13 (16.9)
Appointments available within a week	12 (15.6)
Information on how to handle a medical emergency	
Knowing which symptoms are an emergency	43 (71.7)
Providing information to family/caregivers	37 (61.7)
Knowing whom to contact first	34 (56.7)
Knowing what to do if the clinic is closed	31 (51.7)
Reduced time in the waiting room	
Be informed of estimated wait times upon arrival	87 (71.9)
Paging system so you can leave the waiting room	38 (35.5)
Only be required at the clinic 5 minutes before appointment	19 (17.8)

Table 3: Proportion of respondents selecting a specific quality improvement initiative, by commonly-selected general initiative

Commonly-selected initiatives in order of greatest priority to outpatients

Approximately 62.8% of the sample, 340 of 541, did not select more than one initiative. The remaining 201 participants (37.2%) completed the exercise, of which: 69 participants (34.3%) allocated points across two initiatives; 35 participants (17.4%) across three; 33 participants (16.4%) across four; and, 64 participants (31.8%) across five.

Figure 1 reports the average number of points allocated to the seven commonly-selected initiatives by the 201 study participants. Car parking and up-to-date information provision received a relatively greater number of points. Although selected by second greatest proportion of participants (21%), wait times received the second lowest average number of points within the relative prioritization exercise.



Figure 1: Average number of points allocated to commonly-selected general initiatives (n=210).

Discussion

This multi-site study provides a detailed set of initiatives perceived to be of greatest priority to patients. This evidence, collected using novel survey and software, will assist health service to action preferences and priorities into patient-centered quality improvement initiatives. Within the study, initiatives targeting non-clinical areas, such as parking and ease of contacting the clinic, were selected by more than 10% of respondents and were of relatively greater perceived priority. Additionally, two aspects relating to information provision, receiving up-to-date personalized information and ability to access information outside of the clinic setting, were also perceived to be of relatively greater priority. Interestingly, while wait-times were selected by second largest sample proportion (21%), this initiative was perceived as a lower priority relative to other commonly-selected initiatives. Specific approaches to addressing commonly selected and high-priority initiatives are explored in more detail below.

Up-to-date information provision is a commonly identified and a highly valued quality improvement initiative which requires a multicomponent intervention.

Up-to-date information provision was selected by 15% of study participants (81 of 541) and was allocated the second greatest average number of points. Participants selected at least two of three specific initiatives corresponding with this general initiative: understanding the next treatment steps (72.8%); knowing your treatment and condition is progressing (67.9%); and receiving test results as soon as possible (58.0%).

Collectively, these results imply a multi-component intervention focused on delivering timely and personalized information on a patient's progress and prognosis may be appropriate. This could take the form of brief 'update' appointments, whereby patients have the opportunity to ask questions and receive recent test results with a health professional present. Within Australia, several types of brief consults are billable under the Medicare Benefits Scheme [31]. Services wishing to address this area of improvement may consider incorporating brief consults into regular clinic operations as an information provision appointment only. Recent advances in telecommunications may also provide the opportunity for virtual appointments, and patients may prefer email or telephone communication as a more convenient and timely mode of contact for this information.

Accessing information at home is a common concern and quality improvement initiatives could focus on providing a list of trustworthy information sources.

Commonly selected specific initiatives included providing information to review on longterm effects (71.8%); symptoms or side-effects (50.7%); and remission, recurrence and spreading symptoms (36.6%). Overall, these results highlight several topics are relevant for patients. Close to half the sample (45.1%) identified access to a list of trust-worthy sources. Previous research suggests individuals have different information-seeking styles, with some patients accessing large volumes of information while others access less in order to avoid potentially distressing information [32]. By providing a comprehensive list of sources relating to each topic, patients are able to seek information according to their preferences. For health services, this may also be a more efficient 'blanket' approach as compared to providing information for each topic on a case by case basis. This list should also include detailed information on how to handle medical emergencies. This general initiative was selected by 11.1% of respondents with all four corresponding detailed initiatives selected by over half of respondents: information on symptoms requiring emergency care (71.7%); information for family and caregivers (61.7%); knowing who to contact first (56.7%); and knowing what to do if the clinic is closed (51.7%).

Initiatives to improve access and accommodating patients' preferences within the clinic are commonly identified and highly-valued by chronic disease outpatients.

Improved parking was selected by the greatest number of participants (346 of 573, 60.4%) and was perceived to be of greatest priority when compared to other initiatives. Parking is a common and well-documented patient concern [33-35]. Despite this, parking remains a source of dissatisfaction specifically within the study area where local patient advocacy groups have recently released highly-publicized reports calling upon health districts, outpatient treatment centres, and

health infrastructure planners to evaluate current parking arrangements [33, 36]. As respondents completed the touchscreen surveys within clinic settings, they may also have very recently experienced difficulties accessing parking.

For some health services, parking fees are a source of revenue and a recent editorial sparked debate on the feasibility of eliminating these costs [37]. In this study, when selecting specific initiatives relating to parking only one in four respondents chose providing more affordable parking options. Comparatively, one in two participants selected allocated spaces for clinic patients' use only (55.0%) or closer proximity to the clinic (47.6%) as specific strategies to improve parking. For services wishing to address this seemingly old problem, these two specific strategies may be the solutions that patients prefer.

Other commonly-selected initiatives included improving clinic contact, convenient appointment scheduling systems, and reducing time spent in the wait-room. These non-clinical initiatives are salient to patient experiences and study results suggest patients prefer relatively simple initiatives to address these areas of dissatisfaction: be informed of wait-times upon arrival (71.9%); be given a choice when scheduling appointment times (58.4%); and ensure a staff member is available when calling the clinic (88.6%).

Limitations

Results from this cross-sectional study must be considered in the context of a few limitations. A consent bias by age and completion bias by education level were observed. However, it is unclear how this may have impacted the sample representativeness as completion bias was the reverse of that usually encountered (higher completion for patients with a lower education level) and highest consent rates were observed in the second oldest age group (56-70 years of age). Consent and completion rates were high and comparable to previous studies using similar survey methodology in specialist outpatient settings [38].

Survey content relies upon patients' willingness and ability to identify and prioritize initiatives. While all study material emphasized the clinic supported and valued their involvement in

quality evaluation and data was collected via private hand-held tablet computers, study results may be influenced by social desirability bias. Individuals may perceive the desire for a quality improvement as making a complaint or being ungrateful. This may have resulted in a ceiling effect. However, these results suggest patients concentrate on specific and observable aspects of their experience, such as parking. Qualitative work exploring how patients conceptualize quality improvement is warranted.

Due to the low number of initiatives selected, only 37% (201 of 541) of the sample received the relative prioritization exercise. Results from this exercise should be therefore be cautiously interpreted. There are also different prioritization methods, such contingency valuations that would have provided additional evidence by producing one-to-one comparisons of initiatives. While this study provides an overarching summary of preferred initiatives across a range of chronic disease types and clinics, further work examining the differences according to patient demographic characteristics and by clinic site is planned. Although this study included three health services of varying sizes and payment structures, it is important to note that these results may only be appropriate for similar hospital-based settings within Australia only and replication in other settings would be valuable.

Conclusions

This cross-sectional study quantifies consumers' preferences and priorities for quality improvement and provides concise and detailed initiatives. In conclusion, to improve the quality of outpatient chronic disease care according to patients' preferences and priorities, results suggest health services should focus on providing patient-designated parking spaces in close proximity to the clinic, providing up-to-date information via new communication approaches or incorporating short information-provision appointments, and providing a comprehensive and trustworthy list of information sources to access at home.

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Paper 4

System-wide versus person-specific: a cross-sectional study identifying demographic and clinical characteristics associated with patient preferences for health service change in specialist outpatient care.

Overview

There is substantial evidence of an association between individuals' demographic and clinical characteristics and their use and experiences of care [1-4]. This association between patient characteristics and experiences has led to increased attention on collecting detailed demographic information and implementing targeted interventions — defined as interventions customised to the specific sociodemographic or behavioural characteristics of a group [5, 6]. From a policy perspective, targeted interventions have 2 key advantages. Firstly, targeted and tailored interventions report greater effect sizes and failure to account for the characteristics of health services or its users is cited as a major barrier to successful adoption of quality improvement programs [7, 8]. Secondly, targeting initiatives to only those patient groups reporting suboptimal patient-centred care may be an efficient use of limited quality improvement resources.

The role of demographic characteristics in mediating individuals' experiences is welldocumented in the literature and was a key finding in **Paper 1**. **Paper 4** expands upon this concept and seeks to understand if respondents' characteristics such as age, gender, education, insurance coverage, and appointment frequency, were associated with their preferences for health service change. This paper includes a subset of the data reported in **Paper 3**; only patients recruited from publicly funded services are included to ensure respondents received a similar suite of services. Analyses of the demographic differences according to consent and completation statuses are available in Supplementary Material, along with a copy of the Consumer Preferences Survey (also available at 'https://hbrg.newcastle.edu.au/quon/ public/Demo_CPS'). This paper is currently under editorial review at BioMed Central Health Services Research (submission date: September 17, 2015). *Citation*: Fradgley EA, Paul CL, Bryant J, Zucca A, Oldmeadow C. System-wide versus personspecific: a cross-sectional study identifying demographic and clinical characteristics associated with patient preferences for health service change in specialist outpatient care. Under editorial review at BMC Health Serv Res (submitted on September 17, 2015).

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Abstract

Background: Patient preferences for quality improvement may vary according to individual characteristics. However, few studies include large heterogeneous samples of chronic disease outpatients and do not directly elicit patients' preferences for quality improvement. Additional evidence is needed to understand how quality improvement can be targeted to patient characteristics and preferences. This information provides a strategic approach to best enhance the delivery of care for specific patient groups.

Objective: This cross-sectional study reports the (1) proportion of chronic disease outpatients selecting each quality improvement initiative, and (2) initiatives that are differentially selected between individuals according to demographic characteristics.

Methods: English-speaking adults completed surveys in three publically-funded specialist clinics. Participants selected up to 23 patient-centered improvement initiatives and completed nine characteristic items. Univariate Chi-Square or Fisher's Exact tests compared sample proportions selecting an initiative between characteristic subgroups. Due to the number of initiatives tested at the univariate level (n=23), a stringent Bonferroni threshold (0.002) was used to assess significance. For initiatives reaching this threshold, multivariable logistic regression reported the adjusted odds of selection according to demographic subgroups.

Results: A total of 475 individuals participated (62.8% consent; 78.1% completion). Commonlyselected initiatives included: reducing wait-times (22.3%); receiving up-to-date information (16.0%); and accessible information at home (14.1%). Information-based initiatives were selected equally across demographic subgroups. Women were more likely to select ease of clinic contact (OR=2.53; p=0.001) and discussing concerns with professionals (OR=3.05; p=0.003); undiagnosed outpatients were more likely to select additional information during appointments (OR=4.17; p=0.02); and, compared to oncology, neurology outpatients were more likely to select additional emotional support (OR=2.89; p=0.005). Compared to the youngest group (18-46.9 years), participants aged 60-66.9 years were less likely to select financial/insurance information (OR=0.13; p=0.01) and improved parking (OR=0.48;p=0.04); participants aged 67-74.9 years were less likely to select additional emotional support (OR=0.09; p=0.03) and improved catering (OR=0.30;p=0.05).

Conclusions: System-wide programs to enhance information provision are strategic approaches to improve experiences across clinic settings and patient characteristics. A few initiatives can be targeted to characteristics such as age, gender, insurance coverage, chronic disease type, and appointment type– for example, additional emotional support is particularly relevant for neurology outpatients.

Keywords: Health Services, Outpatient; Chronic disease; Cancer; Neoplasm; Quality improvement; Consumer participation

Introduction

Patient-centred care (PCC) is defined as care that is respectful of and responsive to individual patient values and needs [1]. In 2001, the Institute of Medicine (IOM) proposed PCC as one of six essential components of high quality healthcare [2]. Following the principles of PCC, patients are considered expert information sources. Consequently, healthcare quality must in part be defined and evaluated according to patient perspectives and expectations for health services [3].

Consumer involvement in evaluating health services is widely recognized as important for promoting PCC and is increasingly included in national guidelines [4-6]. There are several ways in which consumers can be engaged in evaluating the quality of PCC. These approaches range from individuals acting in advocacy roles to groups of health service users responding to cross-sectional surveys about their experiences [7]. This latter form of involvement is an inclusive approach to gaining multiple perspectives on the quality of care experienced and the resulting data is frequently incorporated into quality assurance programs.

Data from large-scale patient surveys indicate that health care experiences are mediated by individual demographic and clinical characteristics [8-10]. For example, a national survey of 69 086 individuals diagnosed with cancer in the United Kingdom found women and ethnic minorities were significantly more likely to report poor experiences than their counterparts [8]. While the relationship is admittedly complex, associations between experiences and a variety of patient characteristics have been reported in surveys of people with other chronic diseases including heart disease, diabetes, and hypertension [9, 10].

Efficient implementation of PCC for all patients requires an understanding of the common and system-wide areas of dissatisfaction as well as any potential person- or group-specific concerns. In practice, targeting initiatives according to patient characteristics may be an efficient use of limited quality improvement resources. For example, lower rates of bowel cancer screening are associated with lower socio-economic status; ethnic diversity; limited health literacy; male gender; increasing age; and, poorer self-reported health [11-14]. Previous work examining effective care models outline quality improvement strategies such as cultural awareness training, trained interpreters, and engaging members of the disadvantaged group in developing health service interventions [15]. While the targeted approach may address disparate use and outcomes, those initiatives valued and required by large proportion of service users independent of clinical or demographic characteristics may be appropriate to implement on a generic, system-wide level.

In order to identify and target group-specific versus service-wide areas of improvement, it is critical to understand how experiences may differ across groups according to demographic and clinical characteristics. Large satisfaction or unmet need surveys are often conducted with very heterogeneous samples and therefore may obscure the details of patient preferences or experiences of particular subgroups. Conversely, surveys including a single patient group do not facilitate between-group statistical comparisons. Therefore, there is a need for studies which involve a sufficient number of patients across two or more chronic diseases with some commonality of experience (e.g. similar geographic location and publically-funded) in order to advance our understanding of how patient characteristics may guide attempts to improve patient-centred care.

The touch-screen Consumer Preference Survey (Consumer-PS) was designed to directly inform quality improvement activities in chronic disease outpatient settings and allows for comparisons across a range of patient characteristics and chronic diseases (available in Supplementary Material). This is a novel approach to consumer engagement in quality improvement and expands upon existing patient-experience tools which do not allow respondents to directly select initiatives. The validity of these patient-experience tools as quality improvement mechanisms have been questioned [16].

The survey contains 23 general quality improvement initiatives drawn from need assessment, patient experience, and satisfaction measures and was reviewed iteratively by two expert committees of consumers and health professionals [17]. This ensured survey items were grounded within individuals' experiences as health service users, and provided realistic and modifiable targets for health service change. The survey development process and the final survey content is described in more detail elsewhere [17].

To inform targeted, person-specific or generic, system-wide quality improvement in chronic disease care, this cross sectional study reports the demographic factors associated with selecting particular quality improvement initiatives. This is some of the first work to provide a broadly-scoped view of initiatives across chronic disease groups in tertiary outpatient care. For health services and policy makers, this information provides a set of generic initiatives that are equally valued across a range of health services users along with a set of targeted initiatives selected by specific patient groups. A set of patient characteristics towards which quality improvement may be efficiently targeted is also identified.

Objectives

Using the Consumer-PS, this multisite study reports the:

- 1. Proportion of individuals selecting each initiative for service change; and,
- Initiatives that are differentially selected between individuals according to demographic and clinical characteristics.

Methods

Study design: A cross sectional survey of outpatients accessing chronic disease specialist services was conducted according to The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [18]. Data was collected over a 16-month period with recruitment ceasing in January 2014.

Setting: Outpatients were recruited from two publically-funded tertiary hospitals in New South Wales, Australia. This included a specialist clinic providing cardiology or neurology and a medical oncology centre providing physician consultation and intravenous chemotherapy treatment.

Participants: English-speaking adult outpatients were recruited from clinic waiting rooms or treatment areas by trained research assistants. To be eligible, participants must have attended the clinic at least once prior to recruitment. Assistance with the touch-screen device was provided as needed. Research assistants estimated the gender and age-range of non-consenters to ascertain possible consent bias.

Measurement: Participants completed the Consumer-PS (available in Supplementary Material) and a patient characteristic module. On average, the Consumer-PS takes approximately nine minutes to complete and requires a Flesch-Kincaid reading level of grade 6.8 [17]. The patient characteristic module included the following items:

<u>Demographic information</u>: Seven demographic characteristics were self-reported: date of birth; gender; marital status (response options: single or married/ de-facto partner); highest education level achieved (response options: high school equivalent of year 10 or lower, high school completion, diploma or trade certificate, Bachelor's or postgraduate degree); Aboriginal and or Torres Strait Islander origin; private insurance coverage; and if they possessed a concession card. Australian concession cards reduce healthcare costs and are restricted to pensioners, social security allowance recipients, and low-income earners.

<u>Clinical characteristics</u>: Two clinical characteristics were self-reported: reason for attending the clinic (response options: a routine exam for a diagnosed condition; discussion of symptoms for a diagnosed or non-diagnosed condition; to receive tests or treatments; unknown); and appointment frequency within the last six months. Oncology participants completed two additional questions, primary cancer site and time since receiving diagnosis, if known. The clinic in which participants were recruited from was recorded in the dataset.

Statistical methods: Descriptive statistics reported demographic and clinical variables and the proportion of individuals selecting each initiative. To identify initiatives that are differentially selected according to these variables, a two-step process was completed:

Univariate Chi Square or Fisher's Exact tests were used to compare the proportion selecting an initiative between subgroups of each patient characteristic. To reduce the number of spuriously reported associations due to the large number of initiatives tested (n=23), a stringent Bonferroni significance threshold of 0.002 was used [19]. Initiatives that reached this threshold for at least one demographic or clinical variables proceeded to the next stage.

Multivariable logistic regression was used to identify the characteristics associated with selecting initiatives. All demographic variables were included in the multivariable model, and variables were removed from the models if the Wald p-values were greater than 0.25 and removal from the model did not alter remaining coefficients by more than 15% [20]. Adjusted differences between subgroups in the probability of selecting an item are presented on the odds ratio scale. All data analysis was completed using Stata 11(Statacorp, College Station, TX).

Ethics, consent and permissions: Ethics approval was provided by Hunter New England Human Research Ethics Committee (HREC 12/08/15/4.04) and the University of Newcastle Human Research Ethics Committee (H-2013-0234). Following an introduction to the study and touchscreen device, participants were informed that consent was implied once the survey was started. No individual patient data is presented.

Results

Participants: A total of 968 individuals were approached to participate in the two clinics, of which 608 individuals consented to complete the touch screen survey (62.8% consent). A total of 475 (78.1%) participants completed the survey, of which 271 (57.1%) were oncology outpatients, 135 (28.7%) were neurology outpatients and 68 (14.4%) were cardiology outpatients. Sample demographic and clinic characteristics are available in Table 1. On average, participants were 60.3 years of age, married or living with partner (66.7%), did not have private health insurance coverage (59.2%), and had completed the high school equivalent of a year ten or lower level of education (52.6%). The sample had an equal ratio of men (50.2%) to women (49.8%).

Sample characteristics	Number of participants (%)
Average years of age	average =60.3 (SD 15.6)
Male	238 (50.1)
Highest level of education attained	
High school equivalent of year 10 or lower	250 (52.6)
High school completion	53 (11.2)
Diploma or trade certificate	104 (21.9)
Bachelor's or postgraduate degree	68 (14.3)
Marital status	
Married or living with partner	317 (66.7)
Single (never married, divorced or widowed)	158 (33.3)
Aboriginal and/or Torres Strait Islander origin	19 (4.0)
No private health insurance coverage	281 (59.2)
Concessional card	323 (68.0)
Recruited from	
Cardiology or neurology	204 (42.9)
Cardiology-specific	68 (33.5)
Neurology-specific	135 (66.5)
Medical oncology	271 (57.1)
Reason for attending	
To discuss symptoms, treatments or tests for diagnosed condition	90 (19.0)
To discuss symptoms or tests for undiagnosed condition	36 (7.6)
To receive tests or treatments for diagnosed condition	125 (26.3)
For a routine exam for a diagnosed condition	215 (45.3)
Do not know	9 (1.9)
Number of appointments in last three months	
At least once in the last six months	253 (53.3)
2-3	95 (20.0)
4-5	62 (13.1)
6+	65 (13.7)
Primary cancer site $(n=2/1)$	
Breast	60 (22.1)
Bowel	33 (12.2)
Blood	53 (19.6)
Prostate	19 (7.0)
Gynaecological	12(4.4)
Head and neck	12(4.4)
Lung	22 (8.1)
Melanoma	2(0.7)
Other	39 (14.4)
Do not know	/ (2.6)
Time since cancer diagnosis $(n=2/1)$	\mathcal{L}
Less than o months Detween 6.12 months	00 (24.0) 52 (10.2)
Detween 0-12 months	52 (19.2) 50 (21.8)
More then 2 years	27 (21.8) 81 (20.0)
Nore than 5 years	$\delta 1 (29.9)$
Do not know	13 (4.8)

 Table 1: Sample demographic and clinical characteristics (n=475)
Differences in the characteristics of those who consented versus those who declined to participate, as well as those who completed the survey versus those who did not are available in Supplementary Material. Briefly, individuals older than 71 years reported lower consent and completion rates (59.9% and 48.1%, respectively). Men, medical oncology outpatients and those attending for tests or treatment reported higher completion rates.

The proportion of individuals selecting each initiative: Across the 23 initiatives, improved parking was selected by the greatest proportion of respondents (67.2%), followed by reduced wait-times (22.3%) and up-to-date information provision (16.2%) (Table 2). Comfortable waiting rooms and comfortable treatment rooms were selected by a small proportion of participants (1.7% and 1.5% respectively).

Initiatives selected by statistically similar proportions across patient characteristics:

Sixteen initiatives were selected by statistically similar proportions (p-values>0.002) across all demographic and clinical characteristics (Table 2).

Initiatives selected by statistically different proportions across patient characteristics:

Seven initiatives were selected by varying proportions of participants (p-values=<0.002), according to demographic and or clinical characteristics (Table 2).

Table 2: Proportion of participants selecting each initiative and proportional differences according to patient characteristics identified (n=475)

Initiatives	Number of participants	According to patient characteristics, selected by:	
	(%)	Similar proportions ¹	Different proportions
1. Reduce waiting times	106 (22.3)	\checkmark	
2. Keep you up-to-date on treatment and condition progress	77 (16.2)	\checkmark	
3. Provide more convenient appointment times	76 (16.0)	\checkmark	
4. Access to information to review at home	67 (14.1)	\checkmark	
5. Information on how to manage medical emergencies	54 (11.4)	\checkmark	
6. Assistance or information to help maintain your activities of daily living	49 (10.3)	\checkmark	
7. Assistance or information to help you manage your physical symptoms	45 (9.5)	\checkmark	
8. Involve you in treatment decisions	32 (6.7)	\checkmark	
9. Help to arrange transport to and from the clinic	32 (6.7)	\checkmark	
10. Ensure good interactions with all clinic staff	31 (6.5)	\checkmark	
11. Better coordination of your care	27 (5.7)	\checkmark	
12. Access to assistance or information for family support	26 (5.5)	\checkmark	
13. Minimize your pain or discomfort during treatment	17 (3.6)	\checkmark	
14. Ensure your family/friends are comfortable in wait-rooms	9 (1.9)	\checkmark	
15. Provide a comfortable and pleasant waiting room	8 (1.7)	\checkmark	
16. Provide a comfortable and pleasant treatment room	7 (1.5)	\checkmark	
1. Improve car parking	319 (67.2)		\checkmark
2. Make it easier for you to contact the clinic	67 (14.1)		\checkmark
3. Assistance or information to help you manage your emotional symptoms	44 (9.3)		\checkmark
4. Ensure your concerns are discussed with health professionals	42 (8.8)		\checkmark
5. Improve hospital catering	41 (8.6)		\checkmark
6. Provide more information on your treatment or condition during your appointment	25 (5.3)		\checkmark
7. Assistance or information relating to your finances, work, insurance	24 (5.1)		\checkmark

1. Chi-Square or Fisher's Exact tests are not significant (p-values> 0.002).

Adjusted odds of selecting an initiative according to patient characteristics: Results from the multivariable logistic regression models used to compare demographic and clinical factors for the seven initiatives reporting significant differential proportions are given in Table 3 and summarized below:

Provide more information on your treatment or condition during your appointment:

Individuals who were attending the clinic to discuss an undiagnosed condition were more than four times (OR: 4.17, CI 95%: 1.21-14.4) more likely to select receiving additional information during an appointment then those attending to discuss a diagnosed condition.

Ensure your concerns are discussed with health professionals: Females (OR: 3.05, CI 95%:

1.46-6.37) and those with a high school education (OR: 2.72, CI 95%: 1.01-7.35) were approximately three times more likely to select this initiative.

Assistance or information to help you manage your emotional symptoms: Neurology

outpatients were more likely (OR: 2.89, CI 95% 1.37-6.10) to select assistance and information to manage emotional symptoms as compared to medical oncology outpatients. Those without private insurance (OR: 0.49, CI 95% 0.23-1.01) and, compared to individuals between the ages of 18 and 46.9 years, those between the ages of 60-66.9 years (OR: 0.09, CI 95% 0.01-0.78) were less likely to select this initiative.

Assistance or information relating to your finances, work, insurance: The odds of selecting this initiative were significantly associated with age- compared to individuals between 18 and 47 years of age, those between the ages of 60 and 66 years were less likely to select this initiative (OR:0.13, CI 95%: 0.30-0.63). No individuals 67 years of age and older selected this initiative.

Make it easier for you to contact the clinic: Women reported significantly greater odds (OR: 2.53, CI 95%: 1.44-4.46) of selecting this initiative compared to men.

Improve hospital catering: The odds of selecting improved catering were greater for individuals: with post-secondary educations (OR: 2.57; CI 95%: 0.99-6.67); attending for tests or treatments (OR: 4.83, CI 95%: 1.29-18.04); and who attended clinics more frequently in the past six months (OR: 1.41, CI 95%:1.00-1.99). Compared to individuals between 18 and 47 years of age, those between the ages of 67 and 74.9 years were less likely to select this initiative (OR:0.30, CI 95%: 0.09-1.00).

Improve hospital parking: Neurology and cardiology outpatients were less likely (OR: 0.25, CI 95%: 0.14-0.45; OR: 0.32, CI 95%: 0.17-0.64, respectively) to select improved parking as compared to oncology outpatients. Uninsured individuals (OR: 0.48, CI 95%: 0.30-0.77) and those between the ages of 60 and 66.9 years were less likely to select improved parking (OR: 0.47, CI 95%: 0.24-0.95).

Characteristics	Adjusted OR (95% CI)	p-value		
Provide more information on your treatment or condition during your appointment				
Highest level of education attained				
High school equivalent of year 10 or lower	Reference			
High school completion	1.99 (0.58-6.81)	0.27		
Diploma or trade certificate	1.23 (0.43-3.58)	0.69		
Bachelor's or postgraduate degree	0.77 (0.16-3.66)	0.74		
Reason for attending				
To discuss symptoms, treatments or tests for diagnosed condition	Reference			
To discuss symptoms or tests for undiagnosed condition	4.17 (1.21-14.40)	0.02		
To receive tests or treatments for diagnosed condition	0.46 (0.11-1.92)	0.29		
For a routine exam for a diagnosed condition	0.56 (0.17-1.84)	0.34		
Appointment frequency in the last 6 months (continuous)	1.21 (0.78-1.86)	0.40		
Ensure your concerns are discussed with health professionals				
Gender				
Male	Reference			
Female	3.05 (1.46 - 6.37)	0.003		
Highest level of education attained	· · · · ·			
High school equivalent of year 10 or lower	Reference			
High school completion	2.72 (1.01-7.35)	0.05		
Diploma or trade certificate	2.04 (0.87-4.77)	0.10		
Bachelor's or postgraduate degree	2.00 (0.7-5.30)	0.17		
Recruited from				
Medical oncology clinic	Reference			
Neurology clinic	0.53 (0.22-1.30)	0.16		
Cardiology clinic	0.68 (0.23-2.06)	0.50		
Reason for attending				
To discuss symptoms, treatments or tests for diagnosed condition	Reference			
To discuss symptoms or tests for undiagnosed condition	3.05 (0.91-10.27)	0.07		
To receive tests or treatments for diagnosed condition	0.74(0.23-2.39)	0.61		
For a routine exam for a diagnosed condition	0.89(0.33-2.42)	0.82		
Assistance or information to help you manage your emotional sympton	ns	0.02		
Age percentile (years)				
1-20(18-46.9)	Reference			
21-40(47-59.9)	1.72(0.72-4.13)	0.22		
41-60 (60-66 9)	0.51(0.16-1.57)	0.22		
61-80 (67-74 9)	0.09(0.01-0.78)	0.03		
80-100 (75+)	0.09(0.010.70) 0.54(0.18-1.63)	0.03		
Highest level of education attained	0.54 (0.10 1.05)	0.20		
High school equivalent of year 10 or lower	Reference			
High school completion	234(0.88-6.3)	0.09		
Diploma or trade certificate	2.34(0.00-0.3) 1 67 (0 72-3 91)	0.02		
Bachelor's or postgraduate degree	1.07(0.72 - 3.91) 1.13(0.33 - 3.20)	0.24		
Descripted from	1.15 (0.55-5.29)	0.01		
Medical opeology elipic	Pafaranaa			
Neurology chinic	$\frac{1}{2} \frac{1}{2} \frac{1}$	0.005		
Cardiology clinic	2.07 (1.37 - 0.10) 0.08 (0.27.2.62)	0.005		
Uselth insurance coverage	0.90 (0.27-3.02)	0.90		
Drivete health insurance	Defences			
Private health insurance	$\kappa e_{f}e_{f}e_{f}e_{f}e_{f}e_{f}e_{f}e_{f}$	0.05		
No private nearth insurance coverage	0.49 (0.23-1.01)	0.05		
Possesses an Australian concession card	D (
Yes	Keference			

Table 3: Adjusted odds of selecting an initiative according to patient characteristics, by multivariate logistic regression

Characteristics	Adjusted OR (95% CI)	p-value
No	0.99 (0.47-2.09)	0.97
Assistance or information relating to your finances, work, insurance		
Age percentile (years)		
1-20 (18-46.9)	Reference	
21-40 (47-59.9)	0.62 (0.24-1.60)	0.32
41-60 (60-66.9)	0.13 (0.03-0.63)	0.01
61-80 (67-74.9)	Omitted	
80-100 (75+)	Omitted	
Highest level of education attained	01111111	
High school equivalent of year 10 or lower	Reference	
High school completion	1 33 (0 32-5 55)	0.69
Diploma or trade certificate	2.02(0.32-5.33)	0.19
Bachelor's or nostoraduate degree	1.29(0.36-4.57)	0.71
Reason for attending	1.27 (0.30-4.37)	0.71
To discuss symptoms, treatments or tests for diagnosed condition	Deference	
To discuss symptoms, treatments of tests for undignosed condition	Omittad	
To discuss symptoms of tests for diagnosed condition	$1 \in I (0, 12 \in 22)$	0.47
To receive tests of treatments for diagnosed condition	1.04(0.43-0.32) 1.12(0.24,2.91)	0.47
For a routine exam for a diagnosed condition	1.13 (0.34-3.81)	0.84
Improve hospital catering		
Age percentile (years)	DC	
1-20 (18-46.9)	<i>Reference</i>	0.10
21-40 (47-59.9)	0.51 (0.18-1.39)	0.19
41-60 (60-66.9)	0.58 (0.20-1.64)	0.30
61-80 (6/-/4.9)	0.30 (0.09-1.00)	0.05
80-100 (75+)	0.33 (0.10-1.10)	0.73
Highest level of education attained	D (
High school equivalent of year 10 or lower	Reference	0.00
High school completion	1.15 (0.35-3.80)	0.82
Diploma or trade certificate	1.77 (0.74-4.25)	0.20
Bachelor's or postgraduate degree	2.57 (0.99-6.67)	0.05
Reason for attending ¹		
To discuss symptoms, treatments or tests for diagnosed condition	Reference	
To discuss symptoms or tests for undiagnosed condition	0.62 (0.06-6.47)	0.69
To receive tests or treatments for diagnosed condition	4.83 (1.29-18.04)	0.02
For a routine exam for a diagnosed condition	1.92 (0.52-7.05)	0.33
Appointment frequency in the last 6 months (continuous)	1.41 (1.00-1.99)	0.05
Health insurance coverage		
Private health insurance	Reference	
No private health insurance coverage	2.10 (0.96-4.60)	0.06
Make it easier for you to contact the clinic		
Gender		
Male	Reference	
Female	2.53 (1.44-4.46)	0.001
Highest level of education attained		
High school equivalent of year 10 or lower	Reference	
High school completion	2.06 (0.93-4.53)	0.07
Diploma or trade certificate	1.10 (0.53-2.28)	0.80
Bachelor's or postgraduate degree	2.01 (0.95-4.27)	0.07
Recruited from		
Medical oncology clinic	Reference	
Neurology clinic	1.84 (0.96-3.55)	0.07
Cardiology clinic	0.79 (0.31-2.04)	0.63
Reason for attending		

Characteristics	Adjusted OR (95% CI)	p-value
To discuss symptoms, treatments or tests for diagnosed condition	Reference	
To discuss symptoms or tests for undiagnosed condition	0.91 (0.32-2.53)	0.85
To receive tests or treatments for diagnosed condition	0.41 (0.16-1.09)	0.07
For a routine exam for a diagnosed condition	0.69 (0.35-1.36)	0.28
Improve hospital parking		
Age percentile (years)		
1-20 (18-46.9)	Reference	
21-40 (47-59.9)	0.70 (0.36-1.37)	0.30
41-60 (60-66.9)	0.48 (0.24-0.95)	0.04
61-80 (67-74.9)	0.74 (0.37-1.50)	0.41
80-100 (75+)	0.56 (0.28-1.12)	0.10
Highest level of education attained		
High school equivalent of year 10 or lower	Reference	
High school completion	0.83 (0.43-1.61)	0.59
Diploma or trade certificate	1.36 (0.78-2.37)	0.28
Bachelor's or postgraduate degree	0.60 (0.32-1.13)	0.11
Recruited from		
Medical oncology clinic	Reference	
Neurology clinic	0.25 (0.14-0.45)	< 0.001
Cardiology clinic	0.32 (0.17-0.64)	0.001
Reason for attending		
To discuss symptoms, treatments or tests for diagnosed condition	Reference	
To discuss symptoms or tests for undiagnosed condition	0.81 (0.34-1.92)	0.34
To receive tests or treatments for diagnosed condition	0.64 (0.30-1.36)	0.30
For a routine exam for a diagnosed condition	1.21 (0.69-2.10)	0.69
Appointment frequency in the last 6 months (continuous)	1.17 (0.93-1.48)	0.18
Health insurance coverage		
Private health insurance	Reference	
No private health insurance coverage	0.48 (0.30-0.77)	0.002

Discussion

This study provides a broadly scoped summary of potential areas of improvement commonly selected across a range of outpatients with chronic disease and identifies a concise list of potential initiatives for enhancing the delivery of PCC for specific patient groups.

Study results suggest that several commonalities exist in the types of initiatives identified by participants across demographic and clinical variables. In general, these initiatives related to improving information provision and the accessibility of care, and may warrant system-wide implementation. However, a few initiatives such as enhanced emotional support, may be more relevant to specific patient groups and could be strategically targeted to such groups within a clinic. With the shift towards providing specialized care in centralized and high-volume facilities, it is increasingly important to consider how a larger and therefore more-diverse group of patients may experience care [21, 22]. Clear targets for improvement may emerge only when exploring how specific patient groups may experience care.

A few information-based initiatives may warrant system-wide implementation: Commonly selected initiatives included being kept up-to-date on treatment and condition progress (16.2%), access to information at home (14.1%), information to manage emergencies (11.4%) and assistance and information to maintain activities of daily living (10.3%). Furthermore, the proportion of individuals selecting these initiatives did not differ significantly across demographic or clinical characteristics. Given the relatively high frequency at which these initiatives were selected by study participants, programs and policy to improve information provision are appropriate to implement on a system-wide level and are strategic approaches to improving patients' experiences across multiple clinic settings.

Quality improvement is not a one-size fits all approach and preferences are influenced by demographic factors: This study sought to identify the initiatives selected by different proportions of individuals and the adjusted odds of selecting these initiatives according to demographic and clinical characteristics. For those seven initiatives reporting a significant association with patient

characteristics, several key characteristics emerged in multivariate models including: age, gender, chronic condition, education, reason for attending, appointment frequency and health insurance coverage.

Increasing age and male gender was frequently associated with lower odds of selecting quality improvement initiatives. Within this study, women were three times more likely to select being able to discuss concerns with a health professional and 2.5 times more likely to select ease of contacting the clinic. Compared to the youngest age group, one of the older age groups reported decreased odds of selecting: access to information and assistance for financial, work or insurance concerns; improved catering; information to manage emotional symptoms; and improved parking. However, the trend between increased age and decreased odds of selection was not always linear.

Previous studies have reported differences in patient satisfaction according to both gender and age [8]. For example, results from the 2011/2012 English Cancer Patient Experience Survey, a national mail-out survey completed by 71 793 individuals, found individuals aged 65-74 years reported a more positive experience than any other age range [8]. Concordant with our results, women were also significantly more likely to report comparatively poorer experience and similarly reported poor experiences when attempting to contact a clinical nurse specialist or being able to discuss worries and fears with staff [8]. However, a few inconsistencies exist between the English Cancer Patient Experience Survey and our study. For example, the English Cancer Patient Experience Survey found those in the eldest group (85 years or more) reported worse experiences and younger patients reported positive experiences of being offered financial assistance [8]. Within our sample, increased age was associated with selecting fewer quality improvement initiatives and participants aged 18 to 47 years were most likely to select information and assistance with finances, work leave and insurance. However, less than 8% of our sample was within this advanced age range and. it is possible our survey item masked potential differences in the need for financial assistance versus assistance with work leave and insurance claims.

While it is beyond the quantitative results of this study, previous research reports elderly individuals are less likely to indicate poor perceptions of care due to greater experience with navigating health care services (known as the maturation explanation) and lower expectations based on generational values [23]. However, the relationship between age, gender, and satisfaction remains complex and may be moderated by variables such as health status and education levels.

Accessing information and support for emotional concerns is particularly relevant for

individuals attending for neurology services. As compared to medical oncology outpatients, neurology outpatients were significantly more likely to select emotional support (OR=2.89, p=0.005). High levels of unmet emotional needs have been previously reported by individuals with neurological conditions, such as stroke and multiple sclerosis [24, 25]. For example, a study of long-term needs in individuals up to five years post-stroke reported approximately 77% reported emotional problems with the majority indicating these needs went largely unmet [24]. A recent systematic review of individuals with multiple sclerosis highlighted the importance of individuals' emotional experiences of care, particularly at time of diagnosis, with poor information provision and limited access to supportive care services associated with increased patient distress [25].

Health services specializing in neurological care may consider improving supportive care by incorporating routine need assessment and distress screening into usual care, and ensuring appropriate psycho-social services are available. These approaches have been successfully associated with improved supportive oncology care [26]. The reported need for additional supportive care may also be of interest to not-for-profit organisations, as a substantial amount of patient advocacy, information, and care occurs in such settings.

Initiatives to improve the accessibility and accommodation of care were commonly

selected. Reduced wait-times (22.3 %) and convenient appointment scheduling systems (16.0%) were commonly selected by participants and were not associated with patient characteristics. While a large proportion of the sample selected improved car parking (67.2%), those with private health

insurance and oncology outpatients were significantly more likely to select this initiative as compared to individuals attending the neurology and cardiology clinic. It is important to note that initiatives targeting the comfort of the clinic spaces were infrequently selected by the study participants (1.7% and 1.5%, respectively) suggesting resources should be prioritised towards other aspect of health services.

While patient concerns regarding the accommodation and amenities of care are not clinical issues, health services should be aware of how such organizational factors may influence perceptions of care. In a recent literature of psycho-oncology need assessment tools, Richardson et al. suggest that health professionals may consider some patient concerns, relating to these more front-line areas, as outside their scope of practice [27]. However, initiatives to improve the accessibility of care mitigate practical barriers to care that may have long term patient and system implications and therefore should therefore be designed with the patient perspective in mind to support easy accessibility – particularly for patients who need to attend services regularly or frequently, such as oncology patients.

Limitations

It is possible that study results are influenced by a social desirability bias in that participants may have been unwilling to indicate discontent with health care service and results demonstrate a ceiling effect. However, these results follow a similar trend identified within satisfaction surveys [28].

This study followed a two-step statistical analysis to identify a concise list of patient characteristics towards which specific quality improvement initiatives may be efficiently targeted. Due to the large number of tests, a stringent Bonferroni threshold was used to determine statistical significance at the univariate level. While this reduced the potential of results being influenced by a Type II error, an association between a patient factor and quality improvement preference may have been missed.

This study included a limited set of variables to describe patient characteristics and clinical settings. Individuals were asked to report if they possessed an Australian concession card and this

provides a very rough estimate of individuals' socioeconomic status. While this variable could have been better recorded, the association between patient experiences and social disadvantage is welldocumented [29]. Capturing additional variables, such as staff volumes and available service amenities, would have been valuable to explore the association between clinic settings and preferred initiatives. A more complete description of participating clinics would also have been valuable for evaluating the degree to which these results are generalizable to other services. Due to consent and completion biases, replication in additional sites would strengthen the validity and representativeness of results.

Conclusion

In order to improve the quality of outpatient chronic disease care according to patients' preferences and priorities, health services should focus on implementing information-based initiatives on a system-wide level. However, a few targetable initiatives emerged such additional emotional support for neurology outpatients. Given the number of factors associated with patient preferences for quality improvement, this study emphasizes the need for detailed scoping analyses to inform any quality improvement and specific concerns need to be addressed using a more tailored approach.

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Paper 5

Cross-sectional data that explore the relationship between outpatients' quality of life and preferences for quality improvement in oncology settings

Overview

Quality improvement initiatives may confer an opportunity cost whereby services choose to reallocate resources that could have be used in other aspects of patient care. From an implementation perspective, identifying those initiatives which are clearly preferred by those individuals at risk for relatively-worse outcomes may justify the opportunity cost and be strategic targets to enhance the care for this vulnerable patient group. Poor health-related quality of life is an important clinical indicator and is associated with shorter length of survival, unmet supportive care needs, poor patient adherence to interventions, and lower patient satisfaction [1-6].

Expanding upon the rationale and findings of **Paper 4** regarding targeting of change toward particular patient groups, **Paper 5** focuses on establishing whether there is an association between patients' health-related quality of life and their quality improvement preferences. Two specific research questions were developed: how would oncology outpatients change health services in order to improve their experiences, and are these improvement preferences correlated with respondents' HRQoL? We anticipated that individuals with relatively-poorer health-related quality of life would be more likely to select quality improvement initiatives.

Paper 5 presents the baseline cross-sectional survey results (collected from July 2014 to January 2015) from an ongoing intervention study. This larger study aims to assess the effectiveness of a consumer driven breakthrough action model in improving aspects of cancer treatment systems, particularly the effectiveness in reducing unmet supportive care needs and improving overall quality of life (Australian New Zealand Clinical Trials ID: ACTRN12614000702617). Although previous research has used health-related quality of life scores as a means to stratify samples and improve trial efficiency, there is limited evidence that compares quality improvement preferences across this important and prognostic clinical indicator [2, 7]. This paper provides preliminary evidence to address this existing gap in the literature. Compared to **Papers 3** and **4**, this paper includes a more homogenous sample - only medical oncology patients attending publicly funded health services for intravenous chemotherapy treatment. Sample demographic characteristics and a journal-mandated summary are included in Supplementary Material.

Citation: Fradgley EA, Bryant J, Paul CL, Hall A, Sanson Fisher R, Oldmeadow C. Crosssectional data exploring the relationship between outpatients' quality of life and preferences for quality improvement in oncology settings. J Oncol Practice. 2016; 12(5).

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Abstract

Introduction: This cross-sectional study assessed the association between oncology outpatients' quality improvement preferences and health-related quality of life (HRQoL). Implementing specific initiatives preferred by patients with lower HRQoL may be a strategic approach to enhancing care for potentially vulnerable patients.

Methods: English-speaking adults were recruited from five outpatient chemotherapy clinics located in New South Wales, Australia. Using touchscreen devices, participants selected up to 25 initiatives that would improve care experiences and completed the Functional Assessment of Cancer Therapy-General (FACT-G) survey. The logistic odds of selecting an initiative according to FACT-G scores were calculated to determine if preferences were associated with HRQoL after controlling for potential confounders.

Results: Of the 411 eligible outpatients approached to participate, 263 (64%) consented and completed surveys. Commonly-selected initiatives included: up-to-date information on treatment and condition progress (19.8%); access or information on financial assistance (18.3%); and reduced clinic wait-times (17.5%). For those individuals with relatively lower FACT-G scores, the adjusted odds of selecting five initiatives illustrated an increasing trend: convenient appointment scheduling (+23%, p=0.002); reduced wait-times (+15%, p=0.01); information on medical emergencies (+14%, p=0.04); access to or information on finance assistance (+15%, p=0.009); and help to maintain daily living activities (+18%, p=0.007).

Conclusion: Two areas of improvement were commonly selected: (1) easily accessible health services, and (2) information and support for self-management. While results were suggestive of an association between a few quality improvement preferences and HRQoL, a wider spectrum of patient characteristics must be considered when targeting quality improvement to patient subgroups.

Keywords: Health Services, Outpatient; Chronic disease; Cancer or Neoplasm; Quality improvement; Consumer participation

Introduction

In 2013, the disability-adjusted life years associated with cancer in developed countries was approximately 61 million years [1]. Developed countries also allocated 5-7% of healthcare expenditures to cancer-related services [2, 3]. Given this high cost and burden, international organizations and national health policy are focused on evaluating and improving the quality of oncology services. The Institute of Medicine (IOM) proposed ten recommendations for improving cancer services which include receiving timely, evidence-based, and multidisciplinary care personalized to meet individuals' needs [4-6]. The emphasis on personalized care aligns closely with the patient-centered care movement [7, 8]. Patient-centered care is defined as care that is respectful and responsive to individual needs and preferences and is associated with: improved patient outcomes, higher levels of patient and health professional satisfaction, increased service efficiency, and decreased healthcare costs [9].

Following foundational principles of patient-centred care, healthcare quality must in part be evaluated according to patient perspectives [10, 11]. Collecting patients' perspectives is increasingly mandated by government policy and has resulted in growing numbers of patient-experience surveys [12, 13]. For example, a Massachusetts study found upwards of 93% of medical administrators recall having seen at least one patient-experience report annually [14]. However, many patient-experience surveys were not developed to directly inform quality improvement activities and previous research suggests health services and professionals find it challenging to act upon this type of feedback [15-17].

While the reasons for this translation gap are complex, existing surveys may not provide sufficient detail to design initiatives that align closely with patients' preferences for health service change [18]. For example, inadequate information provision is a well-documented unmet need but is reported without specificity regarding what could be changed from patients' perspectives: providing personalized and written information; question prompt sheets; or, access to community-based services such as peer-support groups or telephone helplines?[19] A tool capable of providing highly-detailed information on patients' preferences for health service change may be one approach to bridge the gap between describing and improving patient experiences.

The Consumer Preferences Survey (Consumer-PS) is an information-generating tool designed to provide clear quality improvement messages that are actionable by health services. Using webbased survey software, large patient samples can generate comprehensive lists of patient-centered quality improvement initiatives. This is a systematic approach to directly elicit and incorporate patients' perspectives in quality improvement activities. The Consumer-PS may also be used to identify how quality improvement preferences differ according to patient characteristics. Pragmatically, initiatives that are preferred by only specific patient subgroups, such as those with relatively-poor quality of life, could be introduced using a highly-targeted approach; whereas initiatives that are commonly-selected independent of patients' characteristics may warrant systemwide implementation.

Health-related quality of life (HRQoL) tools assess the impact of disease and treatment on individuals' physical, psychological, social functioning, and general well-being [20]. HRQoL measures, such as the Functional Assessment of Cancer Therapy-General (FACT-G) survey, provide a validated method to identify patient groups who are at increased risk for poor health outcomes [16, 20, 21]. Systematic reviews report a prognostic association between poor HRQoL and shorter length of survival after controlling for sociodemographic and clinical variables in large heterogeneous cancer samples [22, 23]. Other population-based cohort and cross-sectional studies correlate lower levels of HRQoL to unmet supportive care needs, poor patient adherence to interventions, and lower patient satisfaction [24-27].

Patients with relatively-poor HRQoL may warrant additional support from health services and targeting quality improvement to this group may be an efficient use of quality improvement resources. Previous research suggests using HRQoL as a means to stratify research samples and improve trial efficiency [23]. A systematic review evaluating the effects of psycho-oncology interventions on patients' emotional distress and quality of life found studies which preselected participants with increased distress reported greater effect sizes [28]. While this suggests individuals with reduced

HRQoL may receive additional benefit from service intervention, there is limited evidence that compares quality improvement preferences across levels of HRQoL.

A cross-sectional survey was administered in five oncology centres to address the following research questions: how would oncology outpatients change health services in order to improve their experiences, and are these improvement preferences correlated with respondents' HRQoL? We anticipated that the odds of selecting quality improvement initiatives and HRQoL would be inversely correlated, i.e. those with relatively-poorer HRQoL would be more likely to select quality improvement initiatives. For oncology services, quality initiatives favoured by respondents with relatively poorer HRQoL may be strategic opportunities to enhance care for this vulnerable patient group.

Methods

Study design: This article presents a subset of the baseline cross-sectional survey results from an ongoing intervention study. This larger study aims to assess the effectiveness of a consumer driven breakthrough action model in improving aspects of cancer treatment systems (Australian New Zealand Clinical Trials ID: ACTRN12614000702617).

Settings: Five oncology clinics located in New South Wales, Australia participated. These clinics provide outpatient intravenous chemotherapy and are based within publically-funded hospitals.

Participant recruitment: Individuals completed touchscreen surveys in clinic wait-rooms or treatment spaces with assistance provided by trained research volunteers. Eligible participants were: at least 18 years of age; attending to receive intravenous chemotherapy; English-speaking; and had attended the clinic at least once prior to recruitment. The number of individuals who declined to participate was recorded to report consent rates.

Measures: The survey included the following modules:

<u>i. Demographic and clinical information</u>. Individuals reported: sex; marital status; date of birth; highest level of education attained; private insurance coverage; and, income range. Self-reported clinical information included: treatment goal; reason for attending the clinic; and appointment frequency within the last three months.

<u>ii. Consumer-PS</u>. Participants selected up to 25 patient-centered initiatives that would enhance their personal experiences of outpatient oncology care. An evaluation study including 541 chronic disease outpatients reported that the 23-item Consumer-PS: has substantial to moderate test-retest reliability (82.1%-100.0% observed agreement); is highly acceptable to participants; and can be completed in an average of 9 minutes [29]. These evaluation results and survey development process are described in more detail elsewhere [29].

For the purposes of the larger study, the Consumer-PS was modified from the original 23item version. Two additional items were included: (i) reducing the wait-time from referral to first appointment; and (ii) providing preparatory information about oncology services and treatment. An item focused on family and friends comfort in wait rooms was removed; and the original item related to financial, work leave and insurance was split into two more detailed items: (i) provide information on financial assistance; and (ii) help with coordinating work leave or insurance claims. The survey is available upon request.

<u>iii. FACT-G survey.</u> The FACT-G is a 27-item HRQoL measure validated for use in oncology samples [30-32]. Individuals indicate their level of agreement with statements such as "I have a lack of energy" and "I get emotional support from my family" using a five-point scale. Respondents were able to select "Prefer not to answer" for an item exploring sexual relationships.

The FACT-G was scored according the Version 4 guidelines (see www.facit.org for scoring rules and information). The scores for each of the sub-scales were summed to derive a total score; a lower score represents poorer HRQoL. Scores from the social wellbeing subscale were pro-rated as individuals were able to skip the sexual relationship item. As specified in scoring guidelines, more

than 50% of the subscale items were answered and the overall item response rate was greater than 80%.

Statistical methods: Descriptive statistics reported the sample proportion selecting each Consumer-PS initiative and the total FACT-G score including: mean, standard deviation, and percentages at floor and ceiling.

To determine if quality improvement preferences differed according to outpatients' HRQoL, separate logistic regressions were undertaken to assess the relationship between frequently-selected initiatives and FACT-G scores. Frequently selected initiatives were selected by at least 10% of respondents; this cut-point ensured an adequate sample size was obtained for each analysis, while allowing us to focus on those improvements perceived as most relevant to a considerable proportion of patients and likely to be of most interest to health services.

The variable of interest in logistic regressions was the total FACT-G score, which was transformed into five-point increments. A five-point difference has been used in previous studies as a minimally important difference [30, 31]. Based on previous research reporting confounding relationships between HRQoL and patient characteristics, the following variables were included in adjusted models: sex; age; marital status; income; highest level of education completed; treatment goal; and, appointment frequency [25, 27, 31]. The site in which participants were recruited from was included in models to account for any clustering of preferences within specific clinics.

For each model the unadjusted and adjusted odds ratios (95% CIs) and associated p-values are presented for each 5 point decrease in FACT-G score, which can be interpreted as the change in the odds of initiative selection as HRQoL scores decrease. To account for the increase in risk of obtaining type I errors due to multiple analyses, the significance level was adjusted using the Bonferroni correction to $\alpha = 0.004$. Significance levels between 0.004 and 0.05 were interpreted as being suggestive of an association between HRQoL and quality improvement preferences. All data analysis was completed using Stata 11 (Statacorp, College Station, TX).

Ethical approval: Approval was provided by Hunter New England Human Research Ethics Committee (13/08/21/4.04) and the University of Newcastle Human Research Ethics Committee (H-2012-0099).

Results

This paper reports data collected from July 2014 to February 2015. A total of 411 eligible outpatients were approached to participate, of which 263 consented and completed all survey modules (63.9%).

Patient characteristics: On average, participants were 59 years of age (SD=17), female (56.6%), and married or in a de-facto relationship (65.0%). Just over half (51%) of respondents had obtained an education of year 10 or lower and over a quarter (28.9%) reported a weekly household income of AUD \$300-\$499. Relative to Australian census data, the sample reported lower education levels and weekly household income than the general population [33, 34]. Approximately 40% of respondents had more than six appointments within the previous three months and 51.7% reported the treatment goal was curative. Complete demographic characteristics are provided in Supplementary Material.

Quality improvement preferences: Of the 25 quality improvement initiatives included in the Consumer-PS, 13 initiatives were selected by at least 10% of respondents (Table 1).

General initiatives	Number of participants	
	(%)	
Improve car parking	135 (51.3)	
Keep you up-to-date on your treatment and condition progress	52 (19.8)	
Access to help or information relating to finance assistance	48 (18.3)	
Reduce waiting times in the clinic	46 (17.5)	
Provide good hospital catering	42 (16.0)	
Information on how to manage medical emergencies	39 (14.8)	
Access to help or information to manage physical symptoms	39 (14.8)	
Access to help or information for family support	39 (14.8)	
Access to help in order to maintain activities of daily living	37 (14.1)	
Provide more convenient appointment times	32 (12.2)	
Ensure good interactions with all clinic staff	32 (12.2)	
Access to information at home	31 (11.8)	
Access to help or information to manage emotional symptoms	29 (11.0)	

Table 1: The thirteen general initiatives selected by at least 10% of respondents (n=263).

FACT-G scores: The mean FACT-G score was 77.0 (SD=17.4) with a median score of 79. This is comparable to scores reported by similar studies in outpatient oncology settings (75.3, SD=16.9) and below the general population norms suggested for Australian samples (85.9, SD=15.1) [31, 35]. The lowest observed score was 23; one participant (0.4%) reported a score of 108, which is the highest possible FACT-G value.

Association between patients' quality of life and quality improvement preferences: Table 2

presents the odds ratios with associated p-values from the 13 logistic regression models conducted to assess the association between commonly-selected initiatives and respondents' FACT-G scores. The odds ratios represent the expected change in respondent odds of selecting the initiative for every 5 unit decrease in FACT-G scores (i.e. as participants report lower levels of HRQoL). An odds ratio greater than one indicates individuals were more likely to select the initiative with each five point decrease in FACT-G score.

	Unadjusted models		Adjusted for confounders*	
-	Odds ratio	Р	Odds ratio	Р
Initiative	(95% CI)		(95% CI)	
Improve car parking	0.98 (0.91, 1.05)	0.56	0.95 (0.87, 1.03)	0.22
Keep you up-to-date on your treatment and condition progress	1.04 (0.95, 1.13)	0.38	1.08 (0.96, 1.19)	0.20
Access to help or information relating to finance assistance	1.15 (1.05, 1.25)	0.003	1.15 (1.03, 1.28)	0.009
Reduce waiting times in the clinic	1.09 (0.99, 1.19)	0.07	1.15 (1.03, 1.30)	0.01
Provide good hospital catering	1.10 (1.00, 1.20)	0.05	1.02 (0.92, 1.15)	0.66
Information on how to manage medical emergencies	1.15 (1.04, 1.27)	0.005	1.14 (1.01, 1.28)	0.04
Access to help or information to manage physical symptoms	1.04 (0.95, 1.15)	0.38	1.04 (0.93, 1.16)	0.46
Access to help or information for family support	1.12 (1.02, 1.23)	0.02	1.10 (0.99, 1.23)	0.09
Access to help in order to maintain activities of daily living	1.20 (1.08, 1.33)	0.0003	1.18 (1.04, 1.33)	0.007
Provide more convenient appointment times	1.20 (1.08, 1.33)	0.0005	1.23 (1.08, 1.41)	0.002
Ensure good interactions with all clinic staff	0.94 (0.85, 1.05)	0.33	0.93 (0.82, 1.05)	0.28
Access to information at home	1.10 (0.99, 1.22)	0.08	1.11 (0.98, 1.27)	0.10
Access to help or information to manage emotional symptoms	1.12 (1.01, 1.25)	0.03	1.11 (0.98, 1.27)	0.10

Table 2: The association between total FACT-G score and the odds of selecting the 13 most frequently identified quality improvement initiatives.

* Confounders included: age; gender; income; education level; treatment goal; appointment frequency; marital status; and recruitment site.

After adjusting for confounders, the odds of selecting convenient appointment scheduling increased by 23% for each five-unit decrease in FACT-G score at the adjusted significance level (p< 0.004). The odds of selecting four other initiatives approached significance (p<0.05) and increased according to lower FACT-G scores: reduced wait-times (15% increase); information on how to manage medical emergencies (14% increase); access to help or information relating to finance assistance (15% increase); and access to help in order to maintain activities of daily living (18% increase).

Discussion

This study used a novel survey approach to answer two research questions: how would oncology outpatients change health services in order to improve the quality of patient-centered care, and are improvement preferences associated with respondents' health-related quality of life? Commonly-selected initiatives were related to service accessibility and information provision. There was trend for individuals with relatively-poor HRQoL to be more likely to select one of five quality improvement initiatives in the adjusted logistic models. However, only one model met the corrected significance level: provide more convenient appointment scheduling (OR: 1.23; p=0.002).

Easily accessible outpatient oncology services: Considerable proportions of study participants selected improved car parking (51.3%), convenient appointment scheduling systems (12.2%), reduced wait-times (17.5%) and improved hospital catering (16.0%). These 'front-line' areas of improvement have been identified as common concerns in a similar survey of Australian outpatients from tertiary cardiology, neurology and medical oncology clinics [36]. Other studies report participants recruited from two French outpatient oncology centres were least satisfied with waiting times (including obtaining an appointment and contacting clinic staff) and the physical environment (including access and comfort) [27]. Similarly, Spanish cancer patients undergoing active treatment were least satisfied with doctor punctuality, consultation time, and ease of access (including parking) [37].

These non-clinical areas are relevant to the patient experience and have been the focus of recent national health reforms. For example, the United Kingdoms' National Services and United States' Department of Health have identified quality improvement targets for hospital catering, physical environment, availability of staff, and timeliness of services [38, 39]. Within Australia, state-based Cancer Councils have initiated large evaluations of parking arrangements and rallied health districts, cancer service directors, and infrastructure planners to address this relevant patient concern [40].

Improved information provision and support for self-management: A second set of quality improvement initiatives was related to information provision and support to manage conditions: up-to-date information on treatment and condition progress (19.8%); and access to help or information on financial assistance (18.3%), medical emergencies (14.8%), physical (14.8%) and emotional (11.0%) symptoms, family support (14.8%), and activities of daily living (14.1%). These findings are comparable to reports of unmet information needs and low levels of satisfaction with information provision [41-44].

Leading institutions have endorsed information provision and support for self-management as essential components of patient-centered care [7, 9]. Information provision, particularly to encourage involvement in treatment decisions, strengthens patients' ability and confidence to self-manage conditions and is associated with improved treatment adherence [45, 46]. However, study results suggest there remains a considerable opportunity to improve information provision. Oncology services may consider completing an audit of the available information topics readily accessible to patients, and incorporate interventions evaluated by the Cochrane Collaboration such as decisional aids, question checklists, and patient coaching [47-51].

Targeted quality improvement based on health-related quality of life: Individuals with relatively worse HRQoL had higher odds of selecting the following initiatives: convenient appointment scheduling; reduced wait-times in the clinic; information on medical emergencies; access

to help or information relating to finance assistance; and access to help or information to maintain daily living activities. While improvements to wait-times and appointment scheduling would likely require system-wide intervention, additional help or information for medical emergencies, financial assistance, and activities of daily living, could be introduced using a more targeted approach.

Although it is promising that each of these associations were in the anticipated direction (the odds of selection increased as respondents' HRQoL decreased), four of five adjusted logistic models did not reach the corrected significance level. There are several possible reasons for the low number of significant associations found between individuals' HRQoL and improvement preferences within this study. Firstly, those with reduced HRQoL may not want health service change and those who are not suffering from reduced HRQoL may desire health service change. Several studies challenge the assumption that patients with relatively worse health will inherently desire additional or different forms of care [25, 52-54]. Studies reported only 18-50% of cancer patients experiencing distress express a need for assistance with symptoms or additional health services [52-54]. Conversely, 20% of cancer patients without psychological distress indicated a need for health services [53].

Secondly, the relationship between patient preferences for care and HRQoL is most probably a complex one, affected by multiple patient characteristics in addition to HRQoL [55, 56]. This complexity is highlighted by conflicting results that exist across studies within the field. For instance, in line with our findings, a previous study found a low correlation between quality of life and cancer patients' satisfaction with care [37]. Conversely, another study reported a significant proportion of variation in breast cancer patients' supportive care needs was explained by quality of life [25]. Due to these findings, we suggest quality improvement programs should be informed by a variety of patientreport measures and be supplemented by additional patient consultation, such as that suggested in collaborative experience-based codesign models.

Limitations

Due to ethical considerations, we were unable to record demographic details for individuals who declined to participate and therefore cannot confirm if the study sample is representative of the overall population. While consent (79.0%) and completion (80.9%) rates are comparable to other Australian studies administering touchscreen surveys in outpatient oncology settings, study results should be interpreted in the light of potential consent and completion biases [57].

The Consumer-PS was adapted for the purposes of the larger evaluation study by: adding two items related to preparatory information and referral wait-times, and distinguishing between financial assistance and assistance with work leave and insurance claims. While this may have improved the specificity of study results, it is unclear how this may have affected the psychometric properties of the tool.

The Consumer-PS was specifically developed as an information-generating tool. Principalclass analysis confirmed there are no latent structures or underlying groupings that may be used to reduce the number of initiatives tested (unpublished data). To correct for multiple tests (n=13) a Bonferroni threshold of 0.004 was used to determine statistical significance. While this threshold reduced the potential for spurious associations, it is also possible that a Type II error occurred – whereby an association between HRQoL and improvement preferences was not reported.

Conclusions

To address patients' preferences for quality improvement, health services should consider two overarching areas: (1) fast and easy access to health services with patients' preferences accommodated in clinic organization systems, and (2) information and support for self-care. The odds of selecting five initiatives increased as respondents' HRQoL decreased. This is suggestive of an association between a few select quality improvement preferences and individuals' wellbeing. However, additional research is needed to explore the complex relationship between patients' quality improvement preferences and a broader spectrum of characteristics.

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Paper 6

Collaborative patient-centered quality improvement: A cross-sectional survey comparing the types and numbers of quality initiatives selected by patients and health professionals.

Overview

Health professionals can provide an additional perspective on the quality of care, particularly on technical and system-wide aspects of care which may not be visible or well-understood by patients. As such, involving health professionals in the earlier stage of quality improvement design is recognised in multiple improvement and implementation frameworks and policies [1, 2]. Garnering professionals' support for organizational change is a key factor to adoption and maintenance of quality improvement [2]. However, incongruity between the types of quality improvement valued by patients and health professionals may act as a barrier to implementing policies and initiatives.

There is emerging evidence that patients and health professionals have different priorities for care provision [3-6]. This evidence has typically focused on primary care settings and has not taken a specific focus on patient-centred dimensions. This paper adds to existing work by specifically focusing on patient-centred quality improvement in outpatient tertiary settings and includes health professionals of varying experience and roles in providing outpatient care. By including a sample of outpatients within **Paper 3** and health professionals within **Paper 6**, results presented in this thesis can provide detailed and comparative information on both key stakeholders' perceptions of quality improvement and be used to inform the first steps within collaborative improvement models.

This cross-sectional study was conducted according to The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement and a comparably high response rate for the professional sample was achieved [7, 8]. Outpatient data was collected over a sixteen-month period ending in January 2014; health professional data was collected over a four-month period ending in December 2015. Copies of the Consumer Preferences Survey and Professional Preferences Survey are available in the Supplementary Material section and online at: 1) Consumer Preferences:
'https://hbrg.newcastle.edu.au/quon/public/Demo _CPS'; 2) Professional Preferences:

'https://hbrg.newcastle.edu.au/quon/public/Demo_PPS'.

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Abstract

Identification of patients' and health professionals' quality improvement preferences is an essential first step in collaborative improvement models. This includes experience-based codesign (EBCD), where service change is strategically introduced following stakeholder consultation. This study compared the number and types of improvement initiatives selected by outpatients and health professionals. Using electronic surveys designed to inform EBCD studies, 541 outpatients (71.1% consent) and 124 professionals (47.1% response) selected up to 23 general initiatives. On average, outpatients selected 2.4 (median=1, IQR=1-3) initiatives and professionals selected 10.7 (median=10; IQR=6-15) initiatives. Outpatients demonstrated a strong preference for improvements to clinic organization, such as appointment scheduling and clinic contact. Outpatients selected relatively fewer initiatives potentially reducing the complexity of service change and resources required to address preferences. Comparatively, professionals indicated a greater degree of change is needed and selected initiatives related to communication with patients and other professionals, including coordinating multidisciplinary care. Improvements to information provision were commonly selected by both groups and offer a strategic opportunity to address patients' and professionals' preferences. By quantifying the ways in which preferences differed, this study emphasizes the need for collaborative approaches to health service change and may be used to initiate an informed discussion on patients' and professionals' quality improvement preferences in tertiary care.

Introduction

Health policy and research is increasingly focused on improving the quality and efficiency of healthcare, in part due to the growing prevalence and costs of managing chronic medical conditions [1]. In 2001, the Institute of Medicine defined high quality care as being safe, effective, timely, efficient, equitable and patient-centered [2]. However, health service deficits in these six key dimensions remain a major concern [3-6]. With ongoing financial and intellectual investment in quality improvement, addressing the obstacles to high quality healthcare is increasingly important [7]. To overcome the barriers to high quality healthcare, quality improvement and implementation science focus on introducing change using a scientific approach with the overarching goal to optimize practice and health outcomes [8]. These fields emphasize the importance of collaborative stakeholder involvement to facilitate design and adoption of quality improvement initiatives and models such as experience-based design are increasingly applied [9]. Experience-based codesign is defined by Bate and Robert (2006) as a patient-focused design process with the goal of making patients' experiences accessible to health professionals or policy makers who are designing and driving health service change [10].

The benefits of a collaborative approach to quality evaluation and improvement are acknowledged by a marked increase in policy initiatives mandating consumer engagement in health policy and research [11-13]. This represents a paradigm shift from traditional improvement models where health service change is driven by health professional and researcher priorities towards a more patient-centered model. This model considers patients as an expert information source on the quality of care and recognizes patients' ability to identify potential areas of improvement based on their perceived needs and experiences [14]. Furthermore, patient-reported data can highlight and legitimize the need for specific types of change and the availability of patient information systems has been positively associated with quality improvement success [15-19].

With increasing evidence on the value of interdisciplinary teams and access to a variety of ancillary services, it is increasingly relevant to capture a range of health professionals' perspectives on the quality of care and preferences for health service change including nurses, physicians, laboratory

technicians, and allied health professionals [20, 21]. As the direct providers of care, they are in a unique position to identify technical and system-level issues which may negatively impact patient care. Professionals are also able to assess the degree to which it is feasible to implement quality improvement initiatives within healthcare settings. Previous research reports that health professionals can act as change champions with clinical leadership and supportive workplace culture associated with quality improvement success [18]; however, when the degree of change proposed is perceived as too burdensome or complex, professionals may be reluctant to participate especially with increasing workload and associated burn-out [17, 22]. Garnering professionals' support for organizational change is a key factor to adoption and maintenance of quality improvement.

Following collaborative models such as experience-based codesign, both patients' and healthcare professionals' perspectives should be integrated into quality improvement programs [10]. However, previous research suggests the two groups may have different priorities in the provision of care [9, 23-25]. For example, a study involving 83 patients and 89 health professionals in primary care settings found patients tended to focus on interpersonal dimensions and the convenience of care such as respect or empathy, and wait-times; professionals placed more emphasis on system processes, clinical indicators, and preventative aspects of care such as care coordination, emergency room visits, and physical activity counselling [23]. Professionals may believe these areas are more directly within the scope of practice in keeping with existing quality assurance programmes already maintained within many medical specialities [9, 26].

Few studies have directly compared different stakeholder (patient versus health professional) priorities for quality improvement and no study has done this in the context of tertiary care, where patients' needs may be intensified. This study uses a new tool designed to facilitate direct selection of general initiatives for change. The Consumer Preference Survey was specifically designed as a priority-setting exercise in order to capture and incorporate a large number of patients' perspectives of health service change. This provides a foundation on which to begin collaborative quality improvement and supplements other consumer involvement approaches such as consumer advocates which are equally valuable but may not represent the range of patient experiences and priorities in the decision making process [12].

Using the Consumer Preferences Survey and the Professional Preferences Survey, outpatients and a range of health professionals selected up to 23 general service initiatives [27]. These initiatives focus on patient-centered care dimensions such as: information provision; decisional involvement; physical or emotional needs; and accessibility and convenience of care [14]. The specificity of this approach makes it a useful tool for the purpose of quantifying patient and professional views which can assist policy makers to understand the ways in which stakeholder perspectives may vary and therefore, identify potential obstacles to collaborative service improvement. Areas of agreement may be strategic targets in which health policy can address both groups' preferences.

Results from this study address two research questions that can help to better understand the different points of view between patients and professionals regarding patient-centered quality improvement within tertiary settings. Firstly, do healthcare professionals and patients believe the same degree of change (i.e. few versus many changes) is needed to improve patient-centred care? Secondly, do healthcare professionals and patients identify the same opportunities for quality improvement?

Objectives

To compare health professionals' and patients' preferences for quality improvement, the Consumer Preferences Survey (Consumer-PS) and Professional Preferences Survey (Professional-PS) was administered to report the:

- 1. Average number of general quality improvement initiatives selected by each group; and,
- Similarities and differences between the two groups in the proportion selecting each general initiative.

Methods

This cross-sectional study was conducted according to The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [28]. The Hunter New England (HNEHREC:12/08/15/4.04) and University of Newcastle (H-2013-0169) Human Research Ethics Committees provided ethical approval.

Outpatient recruitment and eligibility: Outpatients were recruited from hospital-based clinics located in New South Wales, Australia: 1) a public-funded oncology centre; 2) a smaller private-funded oncology centre; and,3) a public-funded centre providing cardiology and neurology ambulatory care. The patient throughput at these centres ranged from approximately 75 to 530 daily outpatient visits. Research assistants approached patients in waiting rooms or treatment areas to complete the touch-screen Consumer-PS. In order to be eligible, outpatients were 18 years of age or older, English-speaking, and had attended the clinic at least once prior to recruitment. This latter exclusion criterion ensured participants were able to draw upon a previous experience with the specific health service. The number of non-consenters were recorded along with genders and estimated ages.

Health professional eligibility and recruitment: Professionals affiliated with participating clinics were recruited using one or more of the following strategies: i) email invitation with a web link to the survey using department lists; ii) face to face recruitment at department meetings with the opportunity to complete the touch-screen survey on-the-spot; and, iii) distribution of leaflets with a web link. To be eligible, professionals were actively involved in outpatient care. However, in order to capture a wide range of perspectives, eligibility did not rely on individuals' qualification or role in outpatient care. To report response rates, the total number of individuals approached using each method was summed and used as the denominator; this provides a conservative estimate as some individuals may have been approached via more than one method. The characteristics of non-consenters could not be collected.

Measures:

<u>Outpatient sample</u>: Demographic questions included: date of birth; gender; marital status; highest education level attained; Aboriginal and Torres Strait Islander origin; and if they possess a concession card. Australian concession cards are part of a government initiative to provide health service and pharmaceutical rebates to vulnerable groups, such as pensioners and low-paid workers [29]. Concession cards allow holders to access healthcare services for free or at a reduced fee. Participants reported their appointment frequency in the last six months and reason for attending the clinic (response options: routine exam for a diagnosed condition; discuss symptoms for a diagnosed or nondiagnosed condition; or receive tests or treatments).

<u>Health professional sample</u>: Demographic questions included: profession; health condition(s) of interest; gender; length of time providing outpatient care; and if they were affiliated with privately-funded facilities or rural facilities. Participants could select 'Prefer not to answer' for any demographic question.

Individuals completed the Consumer-PS or Professional-PS (available upon request) and were instructed to select as many of the 23 general initiatives as desired. The option to select 'None of the above' was provided on each screen. The confidentiality of survey responses was emphasized on survey start screens and participant information forms. Minor differences in the item wording were required to reflect the differing roles of patients and professionals in receiving or delivering the initiative (e.g. 'Keep you up-to-date on the progress of your treatment and condition' vs. "Ability to provide up-to-date information to patients on their treatment or condition progress"). The research team reviewed the Consumer-PS and Professional-PS to ensure the general initiatives were comparable.

The Consumer–PS has moderate to substantial test-retest reliability and has been evaluated to ensure it is comprehensive and relevant to patients' preferences for quality improvement. [27]. The Consumer-PS contains two additional exercises, selecting increasingly specific initiatives and a relative prioritization exercise, which are not presented here. *Statistical methods*: Summary statistics are provided for demographic information, the average number of initiatives selected, and the sample proportion who selected the initiative according to participant group (outpatient or professional). Chi-square and Fisher's Exact tests were conducted to identify statistically significant differences in the two group proportions. Due to multiple tests, a corrected Bonferroni value of 0.002 was used to assess statistical significance. To provide another point of comparison, the ten most-frequently selected initiatives are listed for each group and were ranked according the proportion selecting the initiative. Top-ten lists have been used previously in need assessment literature to highlight important areas of improvement and potential differences in stakeholder priorities for care [30, 31].

To ascertain any consent biases, Chi-square tests were conducted according to consent status and age, gender and recruiting clinic. Similarly, Chi-square tests were conducted to determine if those who did not complete the survey were significantly different according to age, gender, education, recruiting clinic and reason for clinic attendance. Participants who did not fully complete the survey were removed from analyses. Data analyses were completed using Stata 11 (Statacorp, College Station, TX).

Results

Outpatient sample: A total of 741 of 1042 (71.1%) individuals consented to participate in the study. Those over 70 years of age were less likely (60.3% consent, p=0.01) and those aged between 18 and 25 were more likely (86.8% consent, p=0.05) to participate. Additionally, oncology patients attending the private clinic were significantly more likely to participate (89.2% consent, p=0.001) than those attending the public clinic (68.8% consent).

The final sample includes 541 participants (73.1% completion). Of the 200 cases removed from analysis, 114 (57.0%) individuals were excluded as they did not complete the demographic module (presented first). The remaining 86 individuals did not fully complete the Consumer-PS; this

represents a small proportion of the total number of consenting individuals (11.6%; 86/741 individuals).

Participants completing the survey while receiving tests or treatment had higher completion rates than those waiting for a physician consultation (96.3% vs.76.9%, p-value =0.002). Those who had completed 12 years of formal education were also less likely to complete the survey than those who had completed only 10 years of formal education (80.1% vs. 67.4%, p-value = 0.003). Outpatient demographic characteristics are available in Table 1.

 Table 1: Outpatient sample demographic and clinical characteristics (n=541)

Outpatient characteristics	Number of participants (%)
Years of age	average = 60.2 (SD=15.3)
Male	262 (48.4)
Highest level of education attained	
High school equivalent of year 10 or lower	270 (49.9)
High school completion	64 (11.8)
Diploma or trade certificate	119 (22.0)
Bachelor's or postgraduate degree	88 (16.3)
Marital status	
Married or living with partner	371 (68.6)
Single (never married, divorced or widowed)	170 (31.6)
Aboriginal and/or Torres Strait Islander origin	21 (3.9)
No private insurance coverage	282 (52.1)
Concessional card	355 (65.6)
Recruited from	
Cardiology or neurology, public facility	205 (37.7)
Medical oncology, public facility	271 (50.2)
Medical oncology, private facility	65 (12.0)
Reason for attending	
To discuss symptoms/treatments/tests, diagnosed	90 (17.0)
To discuss symptoms/tests, undiagnosed	36 (6.8)
To receive tests or treatments, diagnosed	189 (35.6)
For a routine exam, diagnosed	216 (40.7)
Do not know	5 (0.9)
Number of appointments in last three months	
At least once in the last six months	259 (47.9)
2-3	112 (20.7)
4-5	78 (14.4)
6 or more	92 (17.0)

Professional sample: Approximately 272 individuals were invited to participate, of which 128 (47.1%) completed the Professional-PS. A range of professionals participated including: physicians (32.0% of participants); nurses and care coordinators (32.8%); allied health professionals, such as social workers (19.5%); and clinic support staff , such as clinic schedulers and receptionists (11.7%). Professional demographic characteristics are available in Table 2.

Professional characteristics	Number of participants (%)
Role in outpatient care	
Physician, trainee or medical officer	41 (32.0)
Nurse and/or care coordinator	42 (32.8)
Allied healthcare professional	25 (19.5)
Clinic support staff	15 (11.7)
Other	5 (4.9)
Related chronic condition*	
Medical oncology and/or haematology	48 (37.5)
Radiation therapy	19 (14.8)
Surgery associated with a chronic condition (e.g. cancer)	20 (15.6)
Psychiatry	5 (13.3)
Neurology	17 (13.3)
Cardiology	42 (32.8)
General practice	8 (6.3)
Years providing outpatient chronic disease care	
Less than 6 months	7 (5.5)
6-12 months	7 (5.5)
1 to 2 years	10 (7.8)
3-4 years	16 (12.5)
5-10 years	38 (29.7)
More than 10 years	46 (35.9)
Prefer not to answer	4 (3.1)
Type of healthcare facility	
Public-funded only	95(74.2)
Private-funded only	1 (0.8)
Both public- and private-funded	30 (23.4)
Prefer not to answer or not applicable	2 (1.6)
Location of healthcare facility	
Urban	105 (82.0)
Rural	22 (17.2)
Prefer not to answer or not applicable	1 (0.8)
Female	80 (62.5)

Table 2: Professional sample demographic characteristics (n=128)

*Respondents were able to select more than one option.

The number of quality improvement initiatives identified by outpatients and professionals:

On average, outpatients selected 2.4 (median= 1, SD=2.6) and professionals selected 10.7 (median=10; SD=5.4) initiatives (Figure 1). The distribution patterns of the number of initiatives selected by each group differed: the interquartile range of the outpatient sample was smaller than that of the professional sample and had a right skew; while that of the professional sample had a very slight left skew. Approximately, 30.3% of outpatients selected only one initiative.



Figure 1: Box-plot distributions of the number of initiatives selected by each participant group, with marked median (x).

Similarities and differences between the two groups in the proportion who selected each

initiative: For each initiative, the proportion of the professional group selecting the initiative was significantly higher (p values of >0.001) than the outpatient group (Table 3).

Initiatives are ranked according to the sample proportion and presented according to whether: (1) the initiative is within the ten mostly frequently selected by participant groups (8 initiatives), the outpatient group only (4 initiatives), the professional group only (3 initiatives), or (2) the initiative is within neither groups' ten most frequently selected (8 initiatives). While eight initiatives were included within both groups' ten most frequently-selected, seven initiatives were included in only one group's top ten. Up-to-date information provision, the convenience of clinic scheduling, ease of clinic contact, and improved hospital catering was ranked higher for the outpatient group. Comparatively, care coordination, patient communication, and transportation were ranked higher for professionals only.

Initiatives	Ranking by proportion		Participant group, n (%)		Test statistic	
	Outpatient	Professional	Outpatient	Professional	χ2 (df=1)	Р
Selected in top ten by both outpatients and professionals						
Improve car parking	1	1	326 (60.3)	112 (87.5)	34.0	
Reduce waiting times	2	3	107 (19.8)	85 (66.4)	110.0	
Access to information at home	6	4/5	69 (12.8)	78 (60.9)	140.2	
Information to manage medical emergencies	7	6	60 (11.1)	76 (59.4)	149.0	< 0.001
Assistance/information to maintain activities of daily living	8	4/5	53 (9.8)	78 (60.9)	171.9	
Assistance/information to manage physical symptoms	10/11	2	48 (8.9)	86 (67.2)	219.8	
Assistance/information to manage emotional symptoms	10/11	8	48 (8.9)	64 (50.0)	125.6	
Selected in top ten by outpatients only						
Up-to-date information on treatment or condition progress	3	11	81 (15.0)	60 (46.9)	63.4	
Convenient appointment scheduling	4	14/15	77 (14.2)	55 (43.0)	54.0	
Ease of clinic contact	5	18	70 (12.9)	42 (32.8)	29.3	< 0.001
Improve hospital catering	9	22	49 (9.1)	31 (24.2)	22.6	
Selected in top ten by professionals only						
Arrange transport to and from the clinic	13	7	35 (6.5)	72 (56.3)	190.9	
Patient concerns are discussed with health professionals	12	9/10	44 (8.1)	62 (48.4)	126.1	< 0.001
Improved coordination of care	15/16/17	9/10	28 (5.2)	62 (48.4)	166.4	

Table 3: Group proportions selecting each initiative with goodness of fit test-statistics (n=669)

Discussion

This cross-sectional study compared outpatients' and professionals' preferences for patient-centered quality improvement in terms of number and type of initiatives selected. Professionals, on average, selected an additional eight initiatives as compared to patients and a greater proportion of health professionals selected each initiative. While several initiatives were included in both groups' top ten most frequently selected initiatives, a few areas of disagreement in the groups' preferred initiatives were reported.

Health professionals and outpatients identified a few different areas of improvement:

The ten most-frequently selected initiatives reported by each participant group highlighted several areas of agreement. These initiatives may be strategic approaches to satisfying both groups' preferences for change and may be more readily adopted into practice. For both groups, improved parking was selected by the largest proportion of participants. Previous research suggests these more 'front-line' areas are relatively amenable to change compared to more interpersonal (and potentially complex) dimensions of care such as decisional involvement [32].

Moving beyond the well-documented concern of parking [33], six initiatives relating to information provision were frequently selected by both groups. This finding is supported by previous research reporting information provision as a common unmet need in multiple chronic disease groups, including several primary cancer types, stroke, and cardiovascular conditions [34-36]. Initiatives to improve the efficiency and quality of information provision are urgently needed and are strategic policy targets which address both groups' preferences.

Two areas of disagreement between the outpatient and health professional groups were identified and may pose a barrier to implementation. Convenient appointment scheduling, ability to easily contact the clinic, and catering, were only included in the outpatient group's ten most frequently selected initiatives. While ability to contact the clinic and catering might not be considered clinical issues, previous research indicates poor accessibility and accommodation can impact patient outcomes and are frequently identified as salient components of patients' experiences [37, 38]. For example, appointment convenience may impact patients' ability and willingness to attend a clinic and thus adherence to long-term care. In this way, policies which mitigate practical barriers to care may have long term patient and system implications.

Initiatives included only in the health professionals' top ten most frequently selected were generally focused on improved professional-patient communication and coordination of multidisciplinary care. This finding is supported by qualitative research in which health professionals frequently equated ability to provide patient-centered care with communication skills [25]. The emphasis on coordinated care may reflect the increasing evidence on the value of a multidisciplinary team in providing complex and comprehensive chronic disease care [20, 21]. However, this strategy is relatively recent and further evaluation of barriers to adopting and maintaining this specific approach is needed.

Health professionals and outpatients did not identify a similar degree of change: There

are a few possible explanations for the finding that professionals identify more quality improvement initiatives relative to patients. Health professionals are able to draw upon more global experiences across patient groups and consider the varying needs of all their patients. This incorporates professionals' knowledge and expectations of which services should be provided by an institution to the totality of their patient population. This accords with the patient data in that all initiatives were selected by at least one patient (data not shown).

Health professionals are aware of the need to deliver consistent, high quality care while striving for continual improvement [39]. As such, they may be more critical and reflective of the gaps in all aspects of patient care. Previous studies also suggest the definition and provision of patient-centered care differs across health professionals [25, 40]. This lack of clarity and consensus may have lead professionals to 'err on the side of caution' by selecting a wider range of initiatives. Additional qualitative research exploring how professionals evaluate and define the quality of care, specifically patient-centeredness, would be valuable.

Patients' selection of relatively few items accords with the findings of need assessment studies which report patients identify small mean or median numbers of unmet needs [41, 42]. All

participants had attended the clinic at least once prior to completing the Consumer-PS and the majority (52.1%) of respondents had attended the clinic on at least a monthly basis. While this suggests patients were able to draw upon numerous experiences with the service and provide a comprehensive assessment, it is unclear if the number of initiatives selected would change as individuals continue to experience care potentially exposing areas of improvement. However, previous work by the study authors found no significant associations between outpatients' appointment frequency and the adjusted odds of selecting initiatives (unpublished data).

From a policy perspective, outpatients identified a few concise targets for health service improvements. This targeted approach may address common barriers to quality improvement, such as the complexity of service change and resources required [17]. This is an encouraging message for services and professionals who have previously reported patient-centered care cannot be improved given limited resources [25]. However, this finding should be cautiously interpreted as it may be the result of a ceiling effect found in similar survey tools [43].

Limitations

Although the Consumer-PS takes approximately 9 minutes to complete, approximately 25% of the sample did not provide complete data as a result of the active recruitment approach in the health care setting [27]. A completion bias was also observed according to education level but was the reverse of that usually encountered (higher for patients with a lower education level). Furthermore, the acceptability of the Consumer-PS has been evaluated with results suggesting outpatients find the survey easy to complete with a Flesch-Kincaid reading level below the recommended level for health information [27]. While the reliability and acceptability of the consumer version of the survey has been established, the Professional-PS has yet to be evaluated and is important to note there were minor wording differences between the two versions that may have impacted upon responses.

The response rate for the professional sample was 47.1%. This compares favourably to a recent systematic review of survey studies with health professionals which reported a lower

average response rate (38%) for online surveys [44]. This high response rate suggests a potentially representative professional sample despite use of convenience recruitment techniques. It is possible the two participant groups were not completely correspondent, i.e. professionals who did not provide care to at least one of our participating outpatients may have completed a survey. While the general demographic characteristics of the two groups suggests we achieved a reasonably high degree of correspondence, for confidentiality reasons we are unable to identify where this may have occurred. Furthermore, it is important to note that only a small proportion of each sample was associated with a private-funded clinic (24.2% of health professionals and 12% of outpatients) and the study results may not be generalizable to private-funded services.

Future research applications

This study provides a summary of preferred initiatives and identifies areas of disagreement in both the types and number of initiatives selected. These results suggest there is a need to negotiate differing stakeholder priorities and engage in collaborative quality improvement. A recent cluster randomised control trial in primary care settings compared a professional-only approach to setting priorities for quality improvement with a process involving both patient and professional perspectives at baseline [23]. The types of initiatives selected by the intervention and control sites were significantly different at follow-up with intervention sites reporting greater agreement rates between patients and professionals in the final improvement initiatives selected. This is a promising approach and is similar to other collaborative models such as experience-based codesign [10, 45]. We recognize that describing and achieving consensus on the types of initiatives needed is only one component of a comprehensive strategy to implement and sustain quality improvement programmes [19]. An intervention study is currently underway to assess the effectiveness of a collaborative quality improvement strategy, informed by the intervention participants' use of the Consumer-PS, in improving aspects of tertiary cancer services (Australian New Zealand Clinical Trials ID: ACTRN12614000702617).

Conclusions

This report provides a summary of the number and types of patient-centered quality improvements identified by two stakeholder groups in a range of tertiary outpatient settings. From a policy perspective, it is important to be aware that while there are many commonalities across stakeholders, there is a likelihood that health professionals may emphasise aspects which relate to their daily practise (patient-provider interaction), while patients may emphasise factors which relate to their daily lives (accessibility). The differing perspectives in the number and types of initiatives selected emphasize the importance of including patients and health professionals in a collaborative approach to develop health policy. The results presented here can be used to initiate an informed discussion on the value and feasibility of policy and service changes to improve this dimension of care.

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Discussion

Overview

Patient-centred care can improve patient outcomes, health service efficiency, and health professionals' level of workplace satisfaction. Yet high-income countries struggle to deliver consistent patient-centred care and quality improvement in this specific area is proving difficult and slow. Although patient experience data can legitimise the need for action, it is difficult to identify and act upon the quality improvement message within the survey responses. For example, while it may be important for comparative purposes to monitor the proportion of individuals who are dissatisfied or would not recommend the service, this information does not readily delineate the types of changes needed to improve experiences.

The overarching goals of this thesis were twofold: firstly, to provide a systematic survey approach for generating comprehensive, customised, and prioritised summaries of patients' preferences for quality improvement (**Paper 1** and **2**); and secondly, to describe and compare these summaries across patient groups (as defined by demographic and clinical characteristics) and alongside the views of health professionals (**Papers 3-6**). The comparisons identified several opportunities for targeted intervention according to chronic disease types and demographic characteristics. Collectively, this evidence may overcome some of the barriers associated with using patient experience data to inform change within outpatient settings. The specific objectives of this thesis, along with the corresponding paper numbers, are listed in Table 1.

Objective	Paper
Summarise the barriers to patient-centred care experienced by a range of chronic disease outpatients to generate a comprehensive list of potential quality improvement initiatives.	1
Systematically construct and evaluate a Web-based tool that enables outpatients to easily generate a comprehensive, personalised, and prioritised list of quality improvement initiatives.	2
Identify high-priority initiatives that are commonly selected across a large sample of chronic disease outpatients recruited from four tertiary specialist clinics.	3
Identify a set of generic initiatives that are equally valued across a range of health services users along with a set of targeted initiatives selected by specific patient demographic and clinical groups.	4,5
Compare health professionals' and patients' preferences for quality improvement.	6

Table 1: Overall thesis objectives with corresponding papers.

Papers 2 to 6 analysed data collected within Australian hospital-based specialist services. These services are a foundational part of the Australian health care system with more than 20 million outpatient visits recorded in 2012 [1]. The Australian Government identified hospitalbased services as a key area of improvement in the 2009 report "A Healthier Future for All Australians" and recommended reviewing the patient-centredness of these services [2]. The following sections synthesize the key findings that were recurrent across the 6 papers. The synthesis process included reviewing the textual descriptions and reported quantitative data within each paper to identify similarities or differences in the findings; drawing upon thematic analysis techniques, the key findings emerged in an iterative and inductive manner. Practice and research implications are provided for key findings to assist health services to design initiatives in accordance with patients' preferences and priorities for change. All recommendations are summarised at the end of each section.

Summary of key findings and recommendations

Key finding 1: Comprehensive and detailed evidence relevant to multiple chronic disease types is needed to inform patient-centred quality improvement in health services

Paper 1 described the scope and frequency of barriers experienced by individuals with chronic diseases when accessing patient-centred outpatient services. This systematic literature review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement [3]. Overall, using a data-driven thematic approach and drawing upon Penchansky and Thomas' validated model of fit [4], the literature review provided eight recommendations for enhancing patient-centred care in high-income countries. One finding from the systematic review was considered to be foundational for **Papers 2** to **5**: the need for more comprehensive and detailed (i.e., sufficiently covering the full scope and depth of patient-centred care) evidence on patient-centred quality improvement relevant to multiple chronic disease types. This finding is briefly summarised in relation to the overall thesis objectives subsequently. As this finding is a more general reflection on the current evidence informing patient-centred quality improvement in chronic disease care, a recommendation for health services is not provided for this first key finding.

Across the 74 quantitative articles reviewed in **Paper 1**, no study examined all 5 factors: availability, accessibility, accommodation, affordability, and acceptability. On average, approximately two overarching barriers were described per study. This finding is consistent with previous reviews of patient-centred studies and survey measures [5-8]. For example, a recent review found only 9 of 40 included studies examined the linkages between patient-centred processes and patient outcomes for all 8 Picker dimensions of patient-centred care [7]. Similarly, the Tzelepsis et al. [6] evaluation of patient-reported outcome measures in oncology settings found only 1 tool (the Indicators, Non-small Cell Lung Cancer [9]) of 21 unique tools assessed covered all six of the studied Picker dimensions. Along with finding limited scope in the barriers studied, **Paper 1** identified a need to describe barriers in greater depth. A total of 30 unique barriers were reported using Medical Subject Headings (MeSH) terms. This is comparable to a recent review of 88 069 patient complaints across 59 studies in which 29 subcategories emerged [10]. These findings suggest that to deliver patient-centred care it is critical to move beyond general descriptions of patient experiences, sources of dissatisfaction, or barriers. From a policy and implementation perspective, a detailed understanding of each concern can assist with identifying the specific type of health service action required. For example, **Paper 1** reported that the overall objective to improve the accommodation of health services could be achieved through a wide range of more detailed actions such as modifying appointment scheduling systems, decreasing appointment wait times, providing access to out-of-hours care, and/or improving ease of clinic contact.

Paper 1 also highlighted a deficit in the number of studies focusing on patient-centred specialist care for specific chronic disease groups. In all, 59 of 74 studies (80%) focused on the quality of oncology care whereas there was relatively little evidence on the barriers experienced by people with prevalent and high-priority conditions other than cancer. For example, only 3 studies focused on osteoporosis, a condition that effects 1 in 5 Australian women older than 65 years [11]. Only 1 study included individuals who had experienced a stroke. Furthermore, **Paper 1** reported that 6 of 7 diseases of interest (except cancer) were predominantly analysed as part of heterogeneous cluster.

Surveying heterogeneous groups can increase sample sizes and, thus, overall study power [12]. However, if there are a small number of participants from any single subgroup of the sample, this approach may mask the differences in the experiences and preferences of those specific subgroups and may not provide the information necessary to tailor and target quality improvement accordingly. A recent cross-sectional study compared the importance of specific dimensions of patient-centred care relative to other aspects of care, such as disease monitoring, and the relative importance across 5 patient groups with different acute and chronic health problems [13]. Although all groups reported patient-centred care was of relatively greater

importance, congestive heart failure patients attributed an even higher degree of importance to patient-centred care. This suggests that the value of a patient-centred approach may be dependent on disease type.

Key finding 2: Web-based surveys can be used to generate comprehensive evidence on quality improvement preferences across diverse patient groups and settings

Patient surveys are a valuable methodological tool for capturing the patient perspective and can be used to empower a large number of individuals to participate in quality evaluation activities. Although there is a need for comprehensive and detailed information on patients' preferences for patient-centred care (**Paper 1**), survey content must carefully balance the participant burden resulting from the number and complexity of survey items or mode of administration and the need for rich data. The length of a survey also has methodological implications. Longer surveys may result in lower response or completion rates, whereas shorter surveys may have reduced discriminatory power, reliability, and internal consistency [14].

The balance between survey length and data richness may be achieved by electronic survey approaches in which adaptive questioning and branching patterns are used to draw out relevant questions from a larger item bank. Using the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [15], **Paper 2** described the development and evaluation of a Web-based survey designed to provide comprehensive and detailed summaries of patients' quality improvement preferences. This approach moves beyond traditional pen-and-paper modes of administration; the associated benefits, along with limitations, are subsequently described. Coauthored articles on the software development are provided in Appendix B.

Adaptive questioning and customisable surveys are recognised as a valuable supplement or alternative to static generic testing, and touchscreen devices have been used successfully in chronic disease outpatient services [16, 17]. The practical benefits of this approach cannot be underestimated and include shorter completion times, immediate data entry and availability, and features to minimise participant burden, such as adjustable font size and predictive typing [18, 19]. Briefly, **Paper 2** found an overwhelming majority of study participants felt the Consumer Preferences Survey was clear and easy to complete (97.9%; 531 of 541 participants) and indicated that they would be willing to complete a similar electronic survey in the future (84.6%; 447 of 529 participants).

Beyond these practical considerations, the touchscreen survey with adaptive questioning provides a greater level of detail to health services and policy-makers when deciding upon the many varied options for patient-centred quality improvement. The ability to "hone-in" on very specific quality improvement initiatives is the main strength of the Consumer Preferences Survey and represents a valuable contribution to quality improvement research [16, 20]. All participants completing the Consumer Preferences Survey viewed a total of 23 general service initiatives, with subsequent screens presenting up to 110 detailed initiatives based on their previous responses. Survey completion including a basic demographic module took a mean of 9 minutes (standard deviation= 4). This time is considerably shorter than most need-assessment tools (with a mean completion time of 38 minutes); the survey also has fewer mandatory items than the Hospital Consumer Assessment of Healthcare Providers and Systems survey [14, 21].

Overall, **Paper 2** suggests the Consumer Preferences Survey was successful in achieving a balance between the levels of participant burden and collating comprehensive detailed information: up to 98.3% of participants reported the survey was an appropriate length and 93.1% reported the survey was comprehensive of the health service changes they believed would improve their experience.

Although some informal qualitative feedback was gained in the survey development phases through patient stakeholder consultation and a pretest with 75 participants, additional qualitative work would confirm participants' views on the suitability of the Web-based branching approach and may also identify opportunities to improve the survey. A free-text box was provided for those respondents who indicated the survey was not comprehensive of desired initiatives. Approximately 5% of participants within **Paper 2** entered information; however, the responses received were frequently initiatives that were not modifiable within the service or had been discussed and removed by stakeholders during the consultation process. A few individuals also

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took this opportunity to provide positive feedback on a specific experience of care or a health professional. These individuals may have felt the need to acknowledge the positives (rather than just what they want to change) in order to fully summarise their views.

It is important to note that a qualitative study found individuals responsible for the National Health Service Patient Experience Survey Programme perceived patients' written comments or complaints as a valuable tool to motivate health professionals and humanise a problem [22]. Hospital-based health professionals also reported that this form of qualitative feedback could be used to supplement survey data and would provide another contextual snapshot of experiences using patients' own words [23]. This concept of viewing the quality of care from the eyes of the patient, mainly through observation (i.e. shadowing) and story-telling, is also contained within The Patient- and Family-Centered Care Methodology and Practice guide to change [24]. For the purpose of this thesis, the standardised survey approach with close-ended questions allowed for comparisons across patient characteristics (**Papers 4** and **5**) and between health professionals and patients (**Paper 6**). Although the free-text box may not provide an overall and comparative summary of respondents' preferences, it may provide future opportunities to frame a few findings using patient narratives.

The relative prioritisation exercise: The Consumer Preferences Survey concludes with an interactive prioritisation exercise in which participants allocate 100 points across the general initiatives selected on previous screens. This information provides an indication of the relative priority of potential quality improvement initiatives. With a few notable exceptions of studies exploring individuals' preferences for research funding allocation or hospital redesign, this type of information has not been collected by existing patient experience surveys, including need-assessment surveys [21, 25-27]. The strengths and limitations of the relative prioritisation exercise are described subsequently.

Participants were provided the following information: "You can give points equally or give more points to those choices that are more important to you. The more points you give to a

change, the more important it is to you." This concept is underpinned by the principle of utility maximisation, whereby respondents will demonstrate the strongest preference for those heath service changes they believe will best meet their own personal needs [28]. Although this is a conceptually difficult task, **Paper 2** reported participants felt the directions provided were adequate (94.6%; 184 of 195 individuals) and the exercise was easy to complete (97.0%; 189 of 195). Approximately 85% (165 of 195 respondents) felt this exercise helped them to decide what was most important to them. Clinton-McHarg et al. [26] administered a similar point-based allocation exercise using touchscreen devices to determine research priorities for young people with haematological cancers and reported comparable levels of participant acceptability. For example, of the 80 participants who completed the exercise, 83% felt the exercise was easy to understand and 88% agreed that they were able to prioritise the areas of research they valued the most. Smaller proportions reported that the exercise was an appropriate method to determine priorities (63%) and would recommend the process (58%).

Reflecting upon the results from this exercise reported in **Paper 3**, there are several opportunities to improve the relative prioritisation exercise and a few inherent biases that warrant discussion.

Firstly, as reported in **Paper 3**, the mean number of initiatives selected by participants was approximately 2. However, approximately 62.8% of the study sample did not select 2 or more initiatives and, thus, did not receive the prioritisation exercise. The remaining participants (37.2%) allocated points across 2 to 5 initiatives. The varying number of initiatives included in the exercise posed a challenge for interpreting the relative importance of initiatives; for example, allocating 75 points to 1 initiative in a 2-initiative exercise indicates a relatively weaker preference compared to allocating 75 points to 1 initiatives included in this exercise, **Paper 3** reports the mean number of points allocated to each initiative according to the total number of items included in the exercise.

Secondly, the exercise relies upon individuals being able to consider the relative advantages of a particular initiative compared to another. It is difficult to evaluate a public good, such as a quality improvement initiative, without being aware of the potential personal benefits [29]. There may also be a sense of "moral outrage" (although this was not expressed by any participant) in asking individuals to place a value on a "good" that is unusual to consider in monetary terms, such as health information or empathetic and respectful communication [30]. Given the complexity of this cognitive task, previous research suggests some participants may attribute similar proportions across all items as a way to "opt out" of completing the task [30]. This response pattern is known as *embedding* [30]. This specific response pattern was not reported in **Paper 3** (due to journal word limit) and a small proportion of the sample (16.9%, 34/201) allocated equal proportions across all initiatives: 23 individuals allocated points equally across 2 initiatives, 1 individual allocated equally across 3 initiatives, 8 individuals allocated equally across 4 initiatives, and 2 individuals allocated equally across 5 initiatives.

Although the stakeholder committees in **Paper 2** clearly preferred this type of allocation exercise, there are other relative prioritisation formats. Exercises such as discrete-choice analysis could provide an alternative in which only two initiatives are compared at one time as part of a series of exercises [27, 29]. However, these series are often time-consuming for participants and can result in confusion or participants feeling overwhelmed by the number of choices available [31]. There is little consensus on which prioritisation method is preferable and there are few studies that examine the advantages of different methods in a head-to-head comparison [32]. It is also important to note that qualitative work exploring individuals' reasons for attributing value is limited, particularly for health areas, and requires further research [30].

<u>Recommendations</u>: The Consumer Preferences Survey is a novel approach to directly elicit outpatients' preferences and priorities for health service change; however, the methodological approach and interpretation requires further iteration. These refinements may provide valuable information for those researchers developing a similar survey and include limiting the number of initiatives included in the relative prioritisation exercise to three and providing an opt-out option such as "I can't choose" or "I am indifferent to the options." This latter option is suggested by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Good Research Practices for Conjoint Analysis Task Force [33]. Furthermore, given previous research suggests individuals select few items, increased sample sizes may be needed to ensure there are a sufficient number of individuals who will select enough items to complete the exercise [34, 35]. There are also a few gaps in our current knowledge and application of prioritization exercises which need to be addressed by completing head to head comparative studies along with qualitative research exploring individuals' thought-process in attributing value to less-tangible items such as improvements to healthcare experiences.

Key finding 3: Patient-centred strategies to provide personalised and timely information in both clinic and community settings are needed

The Consumer Preferences Survey includes 23 items spanning nonclinical and clinical quality improvement initiatives. The results presented in **Papers 3** and **5** demonstrate that chronic disease outpatients have a strong preference for quality improvement initiatives related to information provision. This finding, along with the practice and policy implications, is discussed subsequently. For convenient referencing, a summary table listing the proportions by paper is provided in Appendix D.

Personalised and timely information provision: Chronic disease outpatients commonly selected being kept up to date with their treatment and condition progress as a quality improvement initiative. For patient participant groups, this initiative was within the top 10 most frequently selected: 15.0% of chronic disease outpatients (Paper 3), 19.8% of medical oncology outpatients (Paper 5), and approximately half (46.9%) of health professionals selected this initiative (Paper 6). This recurrent result suggests that the provision of up-to-date information during the clinic appointment is highly important to chronic disease outpatients and health professionals.
Furthermore, the odds of selecting this initiative were not significantly associated with patient characteristics such as age, gender, marital status, education, reason for attending the clinic,

appointment frequency, clinic site or chronic disease type, and quality of life (**Papers 4** and **5**). Therefore, quality improvement initiatives regarding information provision should be implemented on a system-wide basis.

Although this is some of the first work to directly elicit patients' quality improvement preferences and compare these across chronic disease types, several disease-specific studies report poor experiences within this important area of patient-centred care [36-42]. For example, a crosssectional study of elderly individuals (aged 65 years or older) actively receiving outpatient chemotherapy found approximately 82% of respondents felt it was important to receive treatmentrelated information and 68% felt prognostic information was important [40]. Patients were generally satisfied with treatment-related information, but 91.4% felt prognostic information was lacking and 63.9% were not satisfied with the degree to which information was tailored to meet their needs. Neurology outpatients also indicated information provision was frequently inadequate but highly salient with the lack of timely information associated with increased anxiety and distress [41, 42]. Up to 71% of respondents recruited from 20 National Parkinson Foundation's Centers of Excellence (North America) indicated a poor experience with information provision when completing the Patient Centered Questionnaire for Parkinson's disease (PCQ-PD) [41]. Because participating sites were recognised as leaders in Parkinson's care, the study authors suggest the proportion of individuals experiencing poor information provision is likely to be higher in other centres. The PCQ-PD also provides a quality improvement score whereby higher scores represent areas of care that are frequent source of dissatisfaction and are highly-salient to patients; higher scores represent critical areas of improvement from the patient perspective. Along with collaborative care, information provision reported the highest quality improvement scores as compared with other aspects of care, such as accessibility, involvement, empathy, and emotional support [41].

A personalized approach is a common tenet of patient-centred care and interventions [43, 44]. Recognizing the complexity of information provision, researchers have applied the adage 'right patient, right time, right place' to information provision [41]. This concept aligns closely

with the responses from patients in this research, whereby outpatients valued personalized and timely information on their condition and treatment progress. However, in practice, tailored information provision remains limited with a recent study reporting only 3.2% of taped consultations between elderly cancer patients and nurses were adapted to patients' circumstances with only 5.8% of consultations including some discussion on how the specific individual could cope with the cancer diagnosis [40].

A recent Cochrane review of information provision for stroke survivors and caregivers reported passive information provision strategies, such as generic written booklets, were not found to be an effective strategy to improve health behaviour, knowledge and outcomes [45]. However, active and personalized strategies such as interactive workbooks and ongoing telephone communication with health professionals were associated with significantly decreased anxiety and depression (when reported as a continuous variable).

Augmented Web-based information packages to promote personalised information

provision: Electronic approaches to information provision may be a valuable resource to empower patients to access up-to-date information, a commonly-selected and high-priority quality improvement initiative in **Papers 3** and **5**. The Cochrane Collaboration has published multiple reviews on the efficacy of information and communication technology in improving patient outcomes and health behaviours [46-49]. These electronic information provision strategies are defined as an individual's interaction with or through an electronic device or communication technology to access or transmit health information or receive guidance and support on a healthrelated issue [47]. Reviewed interventions included Web-based decision aids, email communication, electronic (telephone or mobile text message) prompts, and online patientaccessible records with centralised storage of treatment plans, referral letters, and test results. There was limited or inconclusive evidence supporting the use of electronic prompting or email communication [46, 48]. However, interactive Web-based information packages augmented with at least one additional service, such as peer support, decision aids, or behaviour change support, were associated with improved patient knowledge, greater social support, self-efficacy, and behavioural outcomes including participation in health care [47]. There is further evidence that interactive Web-based packages with decisional aids are associated with increased knowledge, lower decisional conflict, and feeling clear about personal values and preferences [49].

An augmented interactive Web-based information package may help to encourage a personalised approach to patient-centred information provision by providing individuals with direct control over when and how frequently they access information; where they access information, including in the comfort of their own home; and the amount and type of information desired [41, 47, 50]. This approach may also mitigate the practical barriers to supportive services experienced by considerable proportion of Australians who reside in remote and regional areas [51]. A systematic review of interventions to promote integrated cancer care reported patient-directed information packages were relatively simple to implement and generally demonstrated positive effects on intervention outcomes [52].

An interactive Web-based package may also be designed to directly align with the participants' preferences reported in **Paper 3**: understand the potential next steps in your treatment (72.8%), ensure you are aware of your condition status (67.9%), and receive your test results as soon as possible (58.0%). Based upon these preferences, a Web-based information package should include a patient-held record with at least the following three key features: (1) detailed information on possible patient prognoses and outcomes; (2) ability to store and access personalised health records, such as shared health summaries, prescription records, and referral letters; and (3) direct-to-patient notifications when new information is added to their record, such as test results. Because patients view health professionals as an important and trusted source of information, any electronic-based approach should be considered as only one source of information and work in tandem with health professionals [53]. However, with **Paper 6** and other cross-sectional studies reporting incongruence between the types of information valued by patients and health professionals, a patient-directed electronic tool may allow individuals to fill-in the potential gaps in the information provided by health professionals [37, 40, 50].
The Personally Controlled Electronic Health Record (PCEHR) system contains some of the preceding key features and seeks to strengthen information provision and communication between a patient and their multitude of health professionals [54]. With an allocated budget of approximately AU\$485 million in 2015, this opt-in system is a notable example of the Australian government's commitment to implement eHealth tools to promote patient-centred care [54]. Similar programs exist within the United States (Medicare/Medicaid Electronic Health Record Incentive Program) [55]. However, studies suggest that consumers are generally unaware of the system or are unclear on the personal benefits of using such a package and there is evidence of limited uptake [56-60]. Once thoroughly evaluated, the successes and—perhaps more importantly—the challenges of implementing the PCEHR program may provide valuable information for equitable design and adoption of similar Web-based packages to engage individuals diagnosed with chronic diseases. It is also important to acknowledge that not all patients will be suited to this technology-drive approach; alternative forms of support such as community-based information services will be needed to ensure all individuals can access needed information according to their preferences and ability.

<u>Access to information outside of the clinical setting</u>: Access to information at home was also identified as an important area of improvement by health professionals (60.9%) and outpatients (12.8% and 11.8%; **Papers 3** and **5**, respectively).

Paper 3 reported the proportion of individuals who selected 1 of 8 corresponding detailed initiatives. The most commonly selected initiatives included information on possible long-term effects (69.6%), side effects (52.2%), symptoms (50.7%), and a list of trustworthy information sources (46.7%). A similar initiative related to self-management in community settings, information on how to manage medical emergencies, was also commonly selected by study participants. Within **Paper 6**, both initiatives (access to information at home and information on medical emergencies) were included in health professionals' top ten most frequently selected initiatives.

A relatively smaller proportion (4.8% versus 12.8%) of study participants in **Paper 3** identified additional information during clinic consultations as a needed quality improvement; furthermore, the initiative was also not included in outpatients' or health professionals' top 10 most frequently selected initiatives in **Paper 6**. Due to a number of reports detailing high levels of unmet information needs, it is likely that health professionals are aware of the demand for improved information provision [36-42, 61]. However, in-line with our findings, emerging evidence suggests it is not merely the volume of information that is important and often patients will differ in their preferred amount of information, known as either monitoring (desiring higher amounts of information) or blunting (preferring less detail) information preference styles [62].

Patient-centred information provision is complex and the ideal timing, content, and framing of health information will be dependent on individuals' varying preferences [63]. Focus groups conducted to determine the priority research areas within psycho-oncology reported participants felt additional evidence was needed to determine the ideal timing of information provision [64]. Similarly, Bensing et al. [65] note that communication training programs seldom emphasise how to differentiate patients' preferences for communication and tailoring information to patients' needs. This remains a major challenge to patient-centred care; although health professionals may recognise the demand for information, they may not perceive themselves as able to fully address the diversity of expectations for information, particularly within short consultation times.

The interesting comparison between the need for additional information within a clinical consultation versus access to additional information at home adds further credence to adopting a "right patient, right time, right place" approach to personalised information provision. Therefore, there is a need to delineate and maximise opportunities to meet patients' individual information needs not only within the clinical setting, but through use of community-based organisations and innovative Web-based information packages to access information and potentially clinical advice from home.

<u>Community-based health organisations to promote continual access to trustworthy</u>

information: Community-based health organisations play a pivotal role in providing trustworthy information in a structured manner with further access to supportive services such as peer support groups. Recognising the importance of these services, the Australian government has initiated large programs, such as headspace, a National Youth Mental Health Foundation initiative providing school-based support and online counselling services for adolescents experiencing mental health problems [66], and healthdirect Australia, which links individuals to nurse- and general practitioner-led telephone helplines, the National Health Services Directory, and the online Symptom Checker [67]. The New South Wales Cancer Information Strategy (2011-2015) also includes four system-level objectives, of which identifying and responding to patients' information needs is a key objective and will be achieved by engaging with community-based organisations such as Cancer Voices New South Wales and Cancer Council New South Wales [48]. With cross-sectional data reporting the majority of oncology services in New South Wales are capable of providing only limited to very limited routine psycho-oncology services, these community-based health organizations may represent a tremendous opportunity to fill a critical gap in the provision of patient-centred care [51]. Qualitative work in a similar sample of Australian health professionals also reported health professionals' desire to adopt a more flexible and collaborative approach to delivering psychosocial support in a range of settings [64].

A systematic review of qualitative evidence suggests individuals with chronic diseases prefer community-based services in some instances because hospital services are perceived as poorly individualised or an indication that their condition has worsened [68]. Community-based information services are also perceived to provide continuous access to knowledgeable health professionals, encourage self-management and therapeutic alliances with health professionals, and improve social support via access to programs such as peer support groups and rehabilitation programs. However, individuals with chronic diseases may be unaware or underutilise these services [69, 70]. For example, only 65.1 % of individuals caring for a family member with dementia reported using at least one community service [70]; perceived lack of need (despite reportedly high levels of caregiver overload and resentment) and lack of knowledge on the service were common reasons for nonuse.

To increase awareness and uptake of community-based services, health services may consider establishing formal referral pathways to community-based organisations [71]. A lack of referral to supportive services and hesitation to ask health professionals about these services has been previously identified by oncology patients as a barrier to use [72]. Information on or links to these services can also be incorporated in Web-based information packages. Furthermore, because evidence suggests patients may not recall receiving information on these services, it is important to provide multiple prompts for patients to consider these services as part of a comprehensive care plan [73].

<u>Recommendations</u>: In conclusion, **Papers 3** to **6** found chronic disease outpatients identify personalised and timely information provision in both clinic and community settings as a critical area of improvement. Web-based information packages and community-based organisations can encourage a more personalised approach to information provision and are associated with improved patient outcomes and satisfaction. Health services may consider facilitating access to and use of Web-based information packages and strengthening collaboration with communitybased organisations.

Both of these recommendations focus on providing additional opportunities for information provision outside of the clinical setting, which aligned closely with our finding that neither patients nor health professionals felt the volume of information provided during an appointment was an important area of improvement. Collaboratively, each different information source (Web-based, health professional, and community-based services) can play an essential role in addressing this long-standing patient concern and should be seen as complementary and reinforcing strategies. **Papers 4** and **5** suggest these information-related initiatives are equally valued by respondents regardless of demographic or clinical characteristics. Therefore, the uptake of Web-based information packages and use of community-based organisations will need to be carefully monitored to ensure the potential benefits are equitably accessible across a diverse range of health service users.

Key finding 4: Chronic disease outpatients commonly identify service accessibility, such as appointment scheduling, wait times, and parking, as critical areas of improvement

Accessibility is one of the eight Picker Institute dimensions of patient-centred care and is frequently included in patient-centred survey tools, such as the Supportive Care Needs Survey and Patient Satisfaction and Quality in Oncology Care [74, 75]. Within **Paper 1**, accessibility was broadly defined as the ability to receive timely resources to manage individuals' needs to achieve the best possible outcomes. This definition is drawn from Penchansky and Thomas' model of fit [4] in which an individual's ability to access services is influenced by 5 factors: (1) the available type and volume of services (availability), (2) the location of health services (accessibility), (3) the ability and organisation of the health service to accommodate the patient (accommodation), (4) the price of services (affordability), and (5) the individual's willingness to seek services (acceptability) [4]. **Paper 1** reported each factor can pose a barrier to receiving patient-centred chronic disease care.

Papers 3 to **6** found outpatients commonly identify quality improvement initiatives related to the accessibility and accommodation of health services are needed, such as reduced wait times, convenient appointment scheduling, and improved car parking. These initiatives, along with organisational strategies and policies to accommodate patients' preferences in clinic settings, are discussed subsequently. For convenient reference, a summary table listing the proportions by paper is provided in Appendix D.

<u>Informing patients of potential wait times</u>: Approximately one in five participants selected reduced waiting times in **Papers 3** (19.8%) and **5** (17.5%). **Paper 1** also reported a number of quantitative studies in which appointment wait times posed a barrier to patient-centred care for 6 of 7 chronic disease types examined (cancer, asthma, depression, diabetes, ischaemic heart disease, chronic obstructive pulmonary disease, and arthritis). These findings align with previous

studies in which lengthy wait times were associated with significantly lower levels of satisfaction and resulted in negative perceptions of the quality of care received [61, 76-81]. For example, up to 60% of oncology outpatients reported wait times of more than 15 minutes contributed to a poor experience with health services [61]. Furthermore, patients who reported lengthy wait times also believed they had received shorter consultation time [81]. A survey of elderly individuals and patients diagnosed with a chronic disease found 74% of respondents believed it was extremely important to wait less than 15 minutes when attending an outpatient hospital-based service [27].

The Consumer Preferences Survey provides additional information by establishing the relative importance of reducing wait times along with more detailed health service actions to improve this area of care. **Paper 3** reported a considerable proportion of individuals (71.9%) who identified reduced wait times as an area of improvement would like to be informed of estimated wait times upon arrival. This may be a relatively simple solution as opposed to altering staff to patient ratios. In accordance with this finding, O'Brien et al. [82] also suggested health services should provide patients with an indication of the expected delay and reasons for this delay when receiving oncology outpatient treatment. When informed of the reasons behind lengthy wait times, patients are also more accurate in gauging the actual time spent in clinic waiting rooms [77]. A version of the Consumer Assessment of Healthcare Providers and Systems survey has been modified for the sole purpose of quality improvement and now includes items related to this topic; for example: "In the last 6 months, after you checked in for your appointment, were you kept informed about how long you would need to wait for your appointment to start" [83].

The data described in **Paper 3** suggests that reduced wait times was of relatively lower importance to outpatients despite being selected by the second largest proportion of respondents (19.8%). The relatively low priority of wait times was also reported by a discrete-choice study in which patients' choice of health services was not influenced by wait times [27]. With these findings in mind, a less resource-intensive initiative, such as consistently informing and updating patients of the estimated wait times, may be an appropriate first step.

It is important to note that this initiative focused specifically on reducing the time spent waiting for an appointment in the clinic settings as opposed to the time between referral and the first appointment. This latter initiative was included as part of the larger study in regional medical oncology centres described in **Paper 5** and was selected by 1 in 10 (9.9%) respondents. We recognise the delay between referral and appointment is a common source of patient concern [84].

A narrative overview exploring patients' experiences with delays and barriers to receiving patient-centred care across the cancer trajectory is included in Appendix B. Briefly, this review took a more global look at the potential barriers to timely cancer care across three phases: (1) the prediagnostic phase with delay attributed to patients' ability to recognise cancer symptoms, complete cancer screening, and delay in seeking subsequent care; (2) appraisal in primary care settings with the poor positive predictive value of cancer symptoms suggested as a major cause of delay; and (3) diagnosis and treatment in secondary care settings with inequitable or delayed access associated with workforce capacity, geographic distribution of services, physician knowledge, and need for additional diagnostic imaging. Similar to the previous recommendations, this review suggested technology-based approaches, such as telephone consultations, electronic-based monitoring and prompting, and online information support, may offer real and promising opportunities to overcoming many barriers to care.

Convenient appointment scheduling: Approximately 14% and 12% of respondents selected convenient appointment scheduling in **Papers 3** and **5**, respectively. The Advanced Access Model is the gold-standard appointment model and is based upon a service being able to offer patients an appointment in a timely fashion, ideally within 2 days [76, 85]. There are a number of variations of the model, but at the centre of the Advanced Access Model is the patient's preference for when and with whom appointments will be conducted [76, 85, 86]. Of the seven detailed initiatives available, being offered a choice in appointment times was selected by the greatest proportion (58.4%) of respondents in **Paper 3**. This finding aligns closely with the emphasis on patient preferences within the Advanced Access Model and is echoed in recent qualitative research [87].

The Advanced Access Model has been adopted for use within the United Kingdom and United States [88-91]. However, there is conflicting evidence on the benefits of the model [86]. A recent systematic review reported limited or inconsistent effects in reducing no-show rates and improving cost efficiency, patient satisfaction, continuity of care, and utilisation of care [92]. Study authors also note that the current evidence base lacks rigour with a high overall risk of bias (as measured by an adapted version of the Cochrane Effective Practice and Organisation of Care Group Risk of Bias). Furthermore, approximately 34 of 64 articles exploring advanced access implementation were written in a narrative form (i.e., without a full methodology description or statistical analysis) and only one study employed a randomised controlled trial design.

There is little evidence on the implementation and evaluation of this model in Australian contexts [93, 94]. Recognising this gap, the Australian government initiated the Australian Primary Care Collaborative Program. Preliminary evidence from 2 regional primary care clinics suggests the model reduced no-show rates, improved staff morale, and increased practice income by 8% to 18% [94]. An automatized appointment system has also been designed by Hu et al. [88] specifically to support implementation of this model in Australian primary care settings. Understanding how this patient-centred model could be adapted for use specifically within hospital-based services that are based upon a referral process may also provide a valuable opportunity to improve patient experiences [95]. Of note, none of the participating health services in **Papers 3** and **5** operated with a form of the Advanced Access Model.

Improved parking: Improved parking was the initiative selected by the greatest proportion of respondents in **Papers 3** (51.3%) and **5** (67.2%). Furthermore, 87.5% of health professionals in **Paper 6** also selected this initiative. Similar to these results, the Cancer Council New South Wales and the Leukaemia Foundation of Queensland suggest parking is a major unmet need for chronic disease outpatients [96, 97]. For example, car parking was the most frequently identified unmet practical need when completing the Supportive Care Needs Survey [97].

Hospital physical environments have been long-associated with patients' wellbeing with previous research suggesting the hospital can act as a "healing landscape" or cause additional distress for patients and their loved ones [98, 99]. The role of the hospital environment is also acknowledged in the Planetree Model of Patient-Centered Care [100, 101]. Although this body of evidence is centred upon inpatient experiences of care, parking has been proposed as a key indicator of patient-friendly health services and is likely to be more relevant to outpatient settings [98, 99].

Patient complaints about parking have been well-documented since the early 1970s and remain a major and common source of patient dissatisfaction [39, 72, 96, 97, 102]. Patient advocacy organisations, such as Cancer Council New South Wales, recently released reports calling upon local health districts, cancer treatment centres, and health infrastructure planners to evaluate current parking arrangements [97]. Specific recommendations for health services included providing dedicated parking areas for patients' use only with a permit system, drop-off zones for carers, shuttle services and links to community-based transport options, and written information for staff and patients regarding parking options and procedures. Of these suggestions, respondents within **Paper 3** demonstrated an overwhelming preference for dedicated parking areas for patients only (62.9%) and ideally within close proximity to the clinic as opposed to more affordable parking options (26.7%), drop-off zones (16.3%), and information on parking (13.5%). For some health services, parking fees are a source of revenue. Furthermore, the feasibility of reducing these costs is debatable particularly in settings where parking is contracted to privately owned and for-profit organisations [96, 103]. Fortunately, the survey results suggest reducing the cost of parking is only one of a few options available to health services when considering how to improve this aspect of care.

It is important to note that the strong preference for improved parking may relate to the timing of survey administration. Respondents completed touchscreen surveys within clinic settings and may have very recently experienced difficulties with accessing parking at the health service. Compared to complex concepts, such as shared decision making and empathetic communication, parking is highly visible and conceptually straightforward and, therefore, may draw a response more readily from survey participants. Furthermore, selecting parking as an area of improvement does not impart any judgement on health professionals—a group that patients may be reluctant to criticise [104].

Health professionals' preferences for accommodation and accessibility initiatives: Collectively, accommodation and accessibility initiatives were commonly selected by chronic disease outpatients in **Papers 3** and **5**; this included improved parking, appointment scheduling, ease of contacting clinic, and catering, along with reduced wait times. However, within **Paper 6** only improved car parking and reduced wait times were included in health professionals' top 10 most frequently selected initiatives.

Implementation research suggests garnering health professionals' support is a critical factor to the successful adoption of quality improvement initiatives [105, 106]. The lack of congruity between some types of initiatives selected by patients and health professionals in Paper **6** may signal a potential barrier to improving the accessibility and accommodation of health services. Professionals may not believe such issues are within their scope of practice with previous research suggesting professionals focus on system processes, clinical indicators, and preventative aspects of care, such as care coordination, emergency room visits, and physical activity counselling [107]. Furthermore, a systematic review of patient-reported issues found little primary research extolling the importance of the more practical aspects of care, such as accessibility, was available [108]. However, there were numerous non-peer-reviewed government documents and reports, referred to as "tertiary sources" by the study authors, highlighting the salience of practical barriers from patient perspectives. It is also important to note that hospital auditing processes rarely include collecting and evaluating patient-reported data on perceived quality and accessibility of the care environment [109]. Without robust data on the value of improved accessibility and accommodation, it may be difficult to rationalise the cost and time spent on improving these nonclinical aspects of care. However, it is important to recognise

accommodating patient preferences and needs for care is a fundamental tenet of patient-centred care and, therefore, a necessary component to high-quality health care.

<u>Recommendations</u>: Results from the Consumer Preferences Survey emphasised the importance of quality improvement initiatives related to reduced wait times, convenient appointment scheduling, and improved car parking. This finding aligns closely with multiple studies conducted in chronic disease outpatient settings [39, 61, 78-81, 96, 97, 110, 111]. To accommodate patients' preferences into a clinic organisational structure, health services should consider adapting and evaluating the Advanced Access Model, informing patients of estimated wait times upon arrival, and providing dedicated parking for patients' use only. To garner health professionals' support particularly for organisational change, it may be appropriate to establish and reinforce the relevance and importance of the accessibility initiatives in relation to patients' overall experiences with the services [112].

Key Finding 5: Quality improvement preferences are associated with numerous patient factors, including disease type, but are not associated with health-related quality of life

Paper 1 found a considerable body of evidence (33 of 74 included studies) in which individuals' predisposing demographic characteristics, such as gender and education, were reported as both a barrier to receiving patient-centred care and a critical factor in mediating the magnitude of the barrier experienced. This finding is in-line with the narrative overview (Appendix B) and data from international and national experience-based and satisfaction surveys, including the English Cancer Patient Experience Survey, the 2003 World Health Survey (data available from 21 European Union countries), and the Ambulatory Care Quality Improvement Project (United States) [113-116].

The established association between specific patient characteristics and disparate experiences has led to increased attention to targeted and tailored interventions [113]. These interventions are typically designed for those patient groups reporting greatest need and may be customised according to patients' sociodemographic or behavioural characteristics [43, 109, 117]. The Consumer Preferences Survey is a novel approach, which very clearly identifies those initiatives that may be of comparatively greater importance to specific subgroups of health service users and, thus, may be appropriate for a more targeted approach.

Papers 4 and **5** reported the odds of selecting quality improvement initiatives according to individuals' demographic and clinical characteristics. It is important to note that **Paper 4** included only patients recruited from publicly funded facilities, with the analyses omitting individuals recruited from the privately funded medical oncology clinic included in **Paper 3**. Patients within this privately funded service differed substantially from other participants in that they selected significantly fewer initiatives and were considered as outliers by the study biostatistician (data included in Appendix D). Due to potential differences between the characteristics of the study sites, the analyses completed in **Papers 4** and **5** included recruiting site as a variable within logistic models to account for any clustering of preferences within specific clinics.

Previous research within primary care settings has found statistically significant differences in patients' experiences of care with clinic and physician factors accounting for a considerable proportion of the variation [118]. This evidence, along with the reported differences between the participating clinics, continues to emphasise the need to consider context in quality improvement science. However, a recent bibliometric review found no publications examining the role of treatment centre variables on psychosocial morbidity in oncology samples and suggests additional research exploring variation between treatment centres is needed [119]. Exploring additional variables, such as staff volumes and available service amenities, may have provided another layer of detail in which to explore the association between clinic settings and preferred initiatives.

Overall, **Papers 4** and **5** found several commonalities exist in the types of initiatives identified by participants across clinical and demographic characteristics. However, **Paper 4** found the adjusted odds of selecting a few initiatives were significantly associated with

participant gender, age range, education level, reason for attending the appointment, appointment frequency in the previous 6 months, and chronic disease type. These findings are reviewed in length in each paper. However, there are two noteworthy findings that warrant additional discussion here: (1) the need for additional emotional support for neurology outpatients as reported in **Paper 4** and (2) the weak association between quality improvement preferences and health-related quality-of-life scores reported by medical oncology outpatients in **Paper 5**.

Additional emotional support for neurology outpatients: Compared to medical oncology outpatients, neurology outpatients were almost three times (OR2.89; P=.005) more likely to select additional emotional support as a valuable quality improvement initiative in **Paper 4**. A recent systematic review of qualitative evidence found individuals with neurological conditions, such as multiple sclerosis, frequently experienced prolonged investigation processes, negative experiences when receiving a diagnosis, and dissatisfaction with subsequent care [42]. These experiences were associated with ongoing feelings of distress, uncertainty, and anxiety. Unfortunately, this review also reported that physical needs were often emphasised by health professionals at the expense of patients' emotional needs. This imbalance was also reported in **Paper 6**, whereby health professionals more frequently selected assistance to manage physical symptoms (67.2%) than emotional symptoms (50.0%).

In accordance with **Paper 1**, multiple systematic reviews have also reported little quantitative evidence describing the experiences of individuals with neurological disorders, such as stroke and multiple sclerosis, with the notable exception of the 2006 Healthcare Commission's (United Kingdom) follow-up survey of 1 700 individuals who had recently experienced a stroke [42, 45, 120, 121]. A rapid synthesis of individuals' experiences with patient-centred care, specifically self-management, was published by the National Institute for Health Research and similarly noted a paucity of evidence for stroke, epilepsy, and progressive neurologic disorders [120]. Of the qualitative evidence reviewed, major psychological needs were an emergent theme for stroke patients and were demonstrated to increase over the course of a patient's recovery. A 2012 Cochrane Review of the effectiveness of information provision for stroke patients similarly reflected on the lack of research progress in supportive neurology care [45]; only four new studies were published in this area since the previous review was completed in 2009.

Paper 4 suggests there is an opportunity to improve the emotional support provided to individuals with neurological diagnoses. The National Research Corporation suggests improving the emotional support provided by health services may be essential to influencing overall patient satisfaction; previous research in this area demonstrated strong links between emotional support and improved patient outcomes and satisfaction [122]. When asked to define a set of practices that would consistently ensure an optimal patient experience (referred to as "always events" by the study authors), interviews with primary care patients suggest emotional support, respect, and kindness are extremely important [87]. Qualitative interviews conducted with inpatients from general medical wards suggest patients perceive emotional support as consisting of empathetic interactions; informative and interactive communication on treatments, outcomes, and expectations; attentive and available health professionals; being given a sense of hope; personalised care whereby patients felt like an individual as opposed to a "case"; supportive gestures; humour; and friendly environments [122]. Health professionals have also expressed frustration with their ability to provide supportive and comprehensive care for neurology outpatients and indicated that training did not provide adequate skills in communicating distressing information [123].

Internationally, considerable work has been carried out in supportive cancer care to ensure patients' emotional needs are met and encouraged to actively self-manage their condition [52, 71, 124-127]. The needs of cancer and neurology patients will differ in some ways and there remain considerable gaps in the quality of patient-centred cancer care [51]. However, some of the successes in supportive outpatient oncology care may be translatable to similar neurology settings. These successes include the formulation of guidelines with psychosocial components, evaluating and improving emotional and information support structures, and implementing routine distress screening [128]. The success of this work is reflected in a number of standards

and national reports, such as the Institute of Medicine's "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs" report [129], the National Comprehensive Cancer Network's support of and guidelines for routine distress screening [130], the European Union's Council decision on reducing the burden of cancer [131], and the Pan-Canadian clinical practice guideline "Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient" [132]. Within Australia, numerous guidelines are available to inform the provision of supportive cancer care such as the National Breast Cancer Centre and National Cancer Control Initiative's "Clinical guidance for responding to suffering in adults with cancer" [133]. Within New South Wales, there have also been substantial investments in the form of additional workforce capacity in order to improve the provision of psycho-oncology services [51].

We acknowledge there is an emerging body of evidence to support the growing numbers of individuals and their loved ones who will suffer from dementia or Alzheimer within community settings; furthermore, as suggested by pioneers in patient-centred dementia care and the Alzheimer Society of Canada, supportive neurology care is still within its infancy and additional guidelines are needed to promote a patient-centred approach [134-136]. However, to the best of our knowledge, there is no evidence on the adaptability of the advances in supportive cancer care to other chronic illness groups. For those health services wishing to improve emotional support for neurology outpatients, Dilworth et al. [72] summarised the potential cultural, organisational, and professional barriers that impede implementation of supportive services in oncology services. These barriers may be applicable to similar interventions introduced in neurological services. The main barrier was patients' perceptions that psychosocial care was not needed followed by a lack of time, limited knowledge about services, and a lack of confidence in the benefit such care could provide. The concept that patients may not recognise the value of additional support, or health service changes, aligns closely with other cross-sectional survey data and is also reported in **Paper 5** [51]. This concept is discussed in more detail in the subsequent section.

Association between quality improvement preferences and health-related quality of life: **Paper 5** reported the quality improvement initiatives commonly selected by 263 medical oncology outpatients with the overall objective to identify if quality improvement preferences differed by individuals' health-related quality of life. Targeting quality improvement initiatives to specific patient subgroups, such as those who are at risk for poor health outcomes, may be an efficient strategy to maximise the value and benefit of service change [109, 137, 138]. This approach is reflected to some degree within existing health service policy and structure. For example, the Australian Community Sector Survey reported up to 62% of social service organisations in New South Wales adopted a more targeted approach to delivering services with emphasis on people with greatest need or in immediate distress [139]. The concept of targeted quality improvement is also included within **Paper 4**, but focused solely upon patients' demographic and service use variables.

Overall, **Paper 5** found few associations between respondents' quality improvement preferences and health-related quality of life. Of the 13 initiatives studied, 5 initiatives demonstrated an association using a significance value that did not correct for multiple tests (P=.05). Although odds of selecting any of these 5 initiatives demonstrated a trend in the expected direction (i.e., increased odds of selection for individuals with relatively poorer quality of life), only one initiative met the adjusted Bonferroni threshold (P=.002). Due to the weak association between an individual's quality of life and improvement preferences reported in **Paper 5**, it was not possible to provide any strong recommendations on the type of initiatives that could be targeted towards this potentially vulnerable subgroup.

The weak association reported between individuals' health status and preferences for quality improvement is inconsistent with need assessment and satisfaction evidence [36, 110, 116]. For example, a cross-sectional study of breast cancer patients' supportive care needs, satisfaction, and quality of life reported a moderate proportion of variance in specific types of supportive care needs were attributable to the corresponding quality of life dimensions, primarily psychological, physical, and daily living items [36]. A longitudinal analysis also found improved global health status was significantly associated with improved overall satisfaction during cancer treatment; at 3 months posttreatment, deterioration in global health status was also associated with decreased satisfaction with doctors' technical skills, interpersonal skills, and provision of information [110]. However, all the studied covariates were only associated with approximately 10% of the variation in satisfaction. This last finding may be a reflection on our limited understanding of the constellation of variables that influence patients' expectations for and experiences with health services.

There are a few conceptual explanations for the weak relationship found between individuals' health status and quality improvement preferences in **Paper 5**. The Consumer Preferences Survey is based upon the idea that participants desire a change in the way their care is delivered and received. However, there is some evidence suggesting patients do not desire any changes in the "status quo" [140]. A discrete-choice experiment was conducted to determine patients' preferences for a new hypothetical bowel screening test compared to the existing test; respondents preferred the existing test [140]. This is termed as an "endowment effect" whereby individuals demonstrate a preference for the goods or services they have had previous experience with (also referred to as the "veil of experience" by Salkfeld et al. [140]). In relation to the endowment effect, **Paper 4** reported high appointment frequency was a confounding variable in three of seven logistic models exploring the relationship between quality improvement preferences and patient characteristics. The endowment effect may also be an attributing factor to the relatively low number of initiatives selected in **Paper 3**.

<u>Recommendations</u>: Individuals' quality improvement preferences differed according to patient demographic and clinical characteristics. To target quality improvement initiatives to those patient groups at risk of relatively worse outcomes, it may be essential to consider a larger constellation of patient factors in addition to a single quality of life measure. Traditional consumer engagement approaches, such as individual advocates, should be supplemented with a detailed scoping assessment of the characteristics and potential preferences of a more representative sample of health service users. This additional data can be used to represent the diversity of patient experiences and priorities in the decision-making process [141]. Furthermore, due to endowment effects, it may also be important to provide patients with detailed information on how a specific health intervention or service change is preferable to current practices.

Compared to medical oncology outpatients, individuals with a neurological condition were more likely to indicate additional emotional support as an area of improvement. Supportive cancer care strategies, such as established psychosocial guidelines and distress screening, may provide a model for neurology services to enhance this specific aspect of patient-centred care.

Table 2 provides summarises all key findings and corresponding recommendations.

Table 2: Key findings and recommendations.

Key finding	Recommendations	Supporting data in:
1. Comprehensive and detailed evidence relevant to multiple chronic disease types is needed to inform patient-centred quality improvement.	Highly detailed information on individuals' preferences for patient-centred quality improvement is needed.	Papers 1 and 4
	Conduct studies with a sufficient number of patients across two or more chronic disease types.	
2. Web-based surveys can be used to easily generate comprehensive and prioritised lists of quality improvement initiatives.	The methodological approach and interpretation of the Consumer Preferences Survey, including the relative prioritisation exercise, requires further refinement. Refinements that are applicable to designing similar Web-based surveys include:	Papers 2 and 3
	Limiting the number of initiatives included in relative prioritisation exercises to three.	
	Providing an opt-out option, such as "I can't choose" or "I am indifferent to the options," to reduce embedding bias.	
	Studies that examine the advantages of different relative prioritisation methods in a head-to-head comparison are needed.	
	Additional qualitative work exploring individuals' reasons for attributing value is needed.	
3. Patient-centred strategies to provide personalised and timely information in both clinic and community settings are needed.	Adopt more personalised approaches to information provision by:	Papers 3, 5, and 6
	Promoting use and awareness of augmented Web- based information packages with three key features:	
	Detailed information on possible prognoses; Ability to store and access personalised health information; and Direct-to-patient notifications when new information is added. Strengthening collaboration with community- based organisations through:	
	Established referral pathways; and	
	Continual promotion of available services to patients as part of a comprehensive care plan.	
4. Chronic disease outpatients commonly identify service accessibility, such as appointment	Evaluate and adapt patient-centred organisation models, such as the Advanced Access Model, to accommodate patient preferences in scheduling systems.	Papers 1, 3, 5, and 6

scheduling, wait times, and parking, as critical areas of improvement.	Inform patients of estimated wait times upon arrival. Evaluate current parking arrangements, specifically the ability to provide patient-dedicated parking areas. Emphasise the importance of organisational change and the accessibility of health services in relation to patient experiences.	
5. Quality improvement preferences are associated with numerous patient factors, including disease type, but are not associated with health-related quality of life.	Supplement traditional consumer engagement strategies, such as consumer advocates, with detailed scoping assessments of the characteristics and preferences of health service users. Supportive cancer care strategies may provide a model for neurology services to enhance patient- identified areas of improvement: Formulating guidelines with psychosocial components;	Papers 1, 4, and 5
	 Evaluating existing emotional/information support structures; and Implementing routine distress screening. To target quality improvement initiatives, it may be essential to consider a larger constellation of patient factors. Due to endowment effects, patients may need detailed information on how interventions may be 	
	prototuoto to current practices.	

Limitations of the survey methodology and study results

A few conceptual limitations of this thesis have been previously discussed. These include the embedding response pattern within the relative prioritisation exercise (**Paper 3**), the minor emphasis on qualitative study components (**Paper 2**), and a possible endowment effect (**Papers 3** to **5**). Each paper includes a discussion of the study-specific limitations. However, the following sections describe the limitations of the Consumer Preferences Survey and recruitment approaches that should be considered when interpreting the overall thesis results. This includes nonmeasurement errors, such as consent and completion rates, and measurement errors associated with the psychometric properties of the Consumer Preferences Survey. These methodological considerations are discussed in more detail subsequently.

The impact of active recruitment in health services on nonmeasurement bias

The Consumer Preferences Survey was completed by English-speaking adults within clinic treatment areas or waiting areas before their appointment. This recruitment approach was applied in **Papers 3** and **5** and is similar to flow sampling, a survey technique used by some National Health Services (United Kingdom) whereby individuals are only eligible to participate in a survey by entrance to or exit from a particular service [20]. Alternative techniques, including postal surveys based on patient databases or practice registration lists, have been criticised previously because participants may not have recently accessed the health service or be able to accurately recall the particular health service of interest [20, 142].

<u>Consent and completion rates</u>: In **Paper 3**, the consent and completion rates were approximately 71% and 73%, respectively. Slightly higher consent and completion rates were reported in **Paper 5**: 79 % and 81%, respectively. These rates are comparable to similar touchscreen surveys completed in Australian outpatient settings, particularly for those studies recruiting patients within clinic waiting rooms [84, 143, 144].

Due to ethical considerations, the demographic characteristics of individuals who declined to participate were only collected in **Paper 3**. Consent rates differed significantly according to clinic site (P=.001) with individuals recruited from the privately funded medical

oncology service reporting the highest consent rates (89.2%). There was also a significant association (P=.007) between individuals' estimated age range and consent status; the highest consent rates were observed for those individuals aged between 18 and 25 years (86.8%), whereas the lowest consent rates were observed for individuals estimated to be 71 years or older (60.2%). It is possible that this selection bias may have been a result of the mode of administration. Elderly individuals may be less familiar with touchscreen devices and, thus, be hesitant to complete such surveys. However, previous research suggests elderly individuals do not demonstrate a preference for pen-and-paper versus electronic survey formats [145]. Trained research assistants were also available to assist and encourage participants to use the touchscreen technology. The consent bias according to older age may also be partially attributed to inaccuracies in estimating nonconsenting individuals' age range. The age of consenting individuals was extracted from survey responses; however, age ranges of nonconsenting individuals were estimated by research assistants.

Paper 3 also provides data on the demographic differences between individuals who completed the survey and those who did not. Significant differences (P<.05) in completion status were observed, with the following characteristics associated with lower completion rates: an age of 71 years or older, female gender, and a high school education (equivalent to 12 years of formal education). As expected, those who completed the surveys while receiving tests or treatments, including those attending the privately funded medical oncology clinic, also reported higher completion rates. However, the overall completion rates for both **Papers 3** (73.1%) and **5** (80.9%) are considerably higher than those reported within cross-sectional postal surveys (completion rates ranged from 29% to 56%) [39].

Study results should be interpreted in light of the possible consent and completion bias. This is acknowledged in each paper. However, the age and gender of the recruited samples were comparable to the characteristics of health service users reported in the Australian National Public Hospital Establishments Database and the National Non-Admitted Patient Care Database: females were slightly overrepresented (56%) in outpatient service encounters and 30% of encounters were with individuals aged 65 years and older [1]. These similarities suggest the samples may be reasonably generalizable to the larger population of health service users.

Measurement error in the Consumer Preferences Survey

The Consumer Preferences Survey was designed specifically for quality improvement purposes only. During the design process, we were aware that traditional psychometric testing may not be feasible for two critical reasons: (1) the lack of common denominator due to the branching patterns and (2) the organisation of the survey structure to follow the chronological experience of care. This structure was selected to assist participants to recall a complete experience with services: from making and arriving at the appointment to the clinical appointment itself and subsequently self-managing conditions within the community based on support and information provided by the service. These areas were not developed to act as underlying constructs. Similar to satisfaction surveys, the Consumer Preference Survey items are not considered to be psychological constructs suitable to be considered as construct variables. Rather, the items represent practical features of the patient experience organised chronologically. Principal component analysis has since been completed within a homogenous sample of 247 medical oncology outpatients to confirm there were no latent variables. The results of this analysis are available in Appendix D.

Following consultation with a biostatistician, **Paper 2** included a test–retest component to establish the reliability of the survey results. Given the Consumer Preferences Survey was not designed to measure a psychological construct or assess health statuses, but rather to identify and prioritise subjective preferences for quality improvements, reliability is likely to be an appropriate psychometric characteristic to establish. A total of 39 medical oncology outpatients completed two surveys within a 14-day period. The retest reliability of each general initiative was greater than 80%, indicating the Consumer Preferences Survey provided a stable summary of patients' preferences for health service change. However, because the sample was limited in size and to one patient group, additional research evaluating this specific aspect of the survey is warranted.

There is a substantial body of evidence exploring the factors that encourage uptake and adoption of need assessment and other experience-based surveys into routine practice that may be applicable to the Consumer Preferences Survey [21, 22, 142, 146-148]. For example, a scoping review of the United Kingdom's National Health Services' oncology departments found needassessment tools were adopted in varying degrees by health service professionals [21]. Reasons cited for selecting one tool relative to another included ease of administration, content, acceptability to patients, validity, compatibility with other applied measures, and historical precedence [21]. Major practical limitations for adopting need assessment into routine practice include the inability to apply tools across chronic condition groups, poor generalizability across the disease trajectory, and unknown or high associated costs [21, 149]. Other behavioural barriers to adoption include scepticism about the validity of measures, preference for more informal methods to obtain patient information, fears about compromising patient confidentiality when using electronic or paper-based surveys, and concerns that the data might be used to compare doctor performance [21]. The inability to apply traditional psychometric testing is an acknowledged limitation of the Consumer Preferences Survey, but may be offset by a few key features discussed in Paper 2: convenient administration method, secure server and privacy settings, a known one-time cost of a touchscreen device, relevance across multiple patient groups, and high levels of patient acceptability.

Strengths and applications of the Consumer Preferences Survey

The main contribution of the Consumer Preferences Survey to the broader quality improvement literature is the ability to hone-in on specific targets for health service change [16, 20]. Unlike most need-assessment tools, the Consumer Preferences Survey cannot be used within patient–physician interactions to address an individual's preferences for health service change and is intended for quality improvement at the service-level only.

It is important to acknowledge that describing and delineating specific types of health service change is necessary, but does not guarantee that change will occur. In analysing the possible reasons for why quality improvement within the United States remains a challenge, Chassin [150] suggests there has been insufficient attention on creating and reinforcing support for organisational change. However, **Paper 6** emphasises health professionals are aware of gaps in the quality of patient-centred chronic disease care; health professionals selected, on average, eight more quality improvement initiatives than outpatients with every quality improvement initiative selected by a significantly (P<.001) greater proportion of health professionals than patients. Because involving health professionals in quality improvement is essential to successful implementation, it is a promising message that health professionals believe there are considerable opportunities to enhance the delivery of patient-centred care. Interviews with health professionals in high- and low-performing Veteran Health Services (classified based on responses to a modified Picker survey) found established professional training programs for patient-centred care along with structured feedback and strong clinical leadership were associated with high-performing services [147].

Limitations of a survey-based approach to collaborative quality improvement

The Consumer Preferences Survey is currently being administered to inform an experience-based codesign intervention study briefly described in **Paper 5** (Australian New Zealand Clinical Trials ID: ACTRN12614000702617). Experience-based codesign is defined by Bate and Robert [106] as a patient-focused design process with the goal of making patients' experiences accessible to health professionals or policy-makers who are designing and driving health service change. **Papers 4** and **6** emphasise the importance of such a collaborative approach to quality improvement because there will be different priorities for change both within patient groups and between health professionals and patients. As part of the ongoing intervention work alluded to in Paper 5, there have been organisational changes made to regional oncology services (e.g., parking arrangements and additional information provision strategies).

Although the initiatives included within the Consumer Preferences Survey were adapted from patient-centred measures (**Paper 2**), it is important to note that these initiatives may not be associated with improved patient outcomes. Based on the PROCEED-PRECEDE and RE-AIM (Reach Effectiveness Adoption Implementation Maintenance) models which provide structured approaches to implement and evaluate interventions, health services will need to complete process evaluations to determine the effectiveness and efficiency of quality improvements in achieving the desired outcomes (e.g. increased satisfaction, reduced unmet information needs, or increased uptake of support services) [151, 152]. The longitudinal data collected within the larger intervention study will provide a better indication of how initiatives preferred by patients, health professionals, and health services in an experience-based codesign model will improve patient outcomes, including health-related quality of life and unmet supportive care needs.

While this thesis focuses on a survey-based approach to inform quality improvement design, there are other approaches to collating information on outpatients' preferences for change, including consumer representation on quality assurance committees and one-off patient focus groups [100, 141]. Consumer advocacy approaches are considered to be a more direct form of involvement as a consumer representative is typically present during the actual decision making process; data from survey participants are considered to be indirect involvement as the extent to which the information is used in the decision-making process is largely dependent on the participating health services and professionals [141]. A recent Cochrane review reported only 6 randomised controlled trials have assessed the impact of consumer involvement in developing health policy or research, clinical practice guidelines, and patient information materials [153]. This review, updated in 2013 with no changes to the conclusions, reported there was little evidence to suggest that different degrees of consumer involvement resulted in additional benefits or adverse effects such as increased costs or time to implement a health service change. The study authors conclude the lack of robust evidence on how to implement consumer involvement strategies and what benefits can be expected from such investments represents a major gap in our knowledge [153].

It is important to note that indirect and direct involvement strategies are not mutually exclusive and it is possible to design a quality improvement initiative based on multicomponent, triangulated information. Triangulated data may overcome the barriers associated with both indirect and direct consumer involvement strategies. For example, survey-based approaches can suffer from ceiling effects, social desirability biases, low response rates, and are necessarily dated due to lengthy data collection and analyses periods. Ultimately, survey data will require further interpretation by the end-users involved in the decision-making process and this interpretation can be hampered by the aforementioned limitations. Conversely, consumer representatives may be an advocate for only those patients with similar experiences. The degree to which they are able to influence decisions will also be dependent on their personal attributes and ability to assume a leadership role within a group dynamic and there is the possibility their involvement can be reduced to tokenism. The Patient- and Family-Centered Care Methodology and Practice is an example of a multicomponent quality improvement program which emphasises: directly observing patient experiences (termed as patient shadowing); collecting patient and family narratives; and establishing collaborative Improvement Teams [154, 155]. While this program has not yet been evaluated within a randomised controlled trial, it has been shown to improve patient satisfaction scores and did not result in higher service costs [154, 155].

A triangulated approach is currently being implemented in the larger trial described within **Paper 5**, with the Consumer Preferences Survey results provided to Consumer Action Groups consisting of consumer and health service representatives. While the Consumer Action Groups review summary reports of commonly-selected and high-priority quality improvement initiatives, the Consumer Preferences Survey is considered to be an information-generating tool only. Group training manuals specify that the results are meant to start informed and collaborative discussions on the areas of care that may require improvement. Furthermore, as the survey results do not outline implementation strategies specific to each health service's unique context, the ways in which this data is used by Consumer Action Group will inevitably vary.

The Consumer Preferences Survey can provide 4 additional pieces of evidence required for quality improvement: (1) comprehensive and personalised information on patients' preferences for quality improvement; (2) information on the relative priority of these quality improvement initiatives; (3) evidence comparing quality improvement preferences across patient groups; and, (4) information summarizing health professionals' preferences as key stakeholders in evaluating and implementing health service changes. While this information may help to bridge the gap between describing patients' experiences and implementing effective quality improvement initiatives, surveys are only one tool to encourage collaborative quality improvement and should be supplemented by other forms of consumer engagement.

Conclusion

This thesis focused on providing clear quality improvement messages for hospital-based services wishing to enhance the delivery of patient-centred care, 1 of the 6 key dimensions of high-quality health care proposed by the Institute of Medicine. Health services struggle to consistently deliver patient-centred care and improvement in this area has proven to be slow and difficult.

Within this thesis, a novel Web-based survey was developed in the hopes of overcoming some the challenges previously associated with using patient experience data as a quality improvement mechanism. The Consumer Preferences Survey assists patients to generate comprehensive, customised, and prioritised summaries of their preferences for health service change. Furthermore, the ability to hone-in on those specific areas of improvement which are considered to be valuable from the patients' perspectives is an important contribution to the larger evidence-base informing patient-centred quality improvement in tertiary settings.

Following cross-sectional surveys in multiple chronic disease outpatient settings, key areas of improvement emerged: (1) personalised and timely information in both clinic and community settings, and (2) service accessibility, such as appointment scheduling, wait times, and parking. Although these initiatives were equally selected across patient demographic and clinical groups, a few initiatives were selected by patient subgroups and represent strategic opportunities to target initiatives to those in greatest need. Although this descriptive work is only the first step in improving the quality of care delivered within Australian hospital-based services, it is envisaged that the data presented here will provide the foundation for an informed discussion on patients' and health professionals' preferences and priorities for change.

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Supplementary Materials

Paper 1: Supplementary Material

Information	Search terms and associated Boolean	Limits
source	operator	
Medline	1. Neoplasms or Chronic Disease (subject	1. All adults (19 plus years)
	headings),	2. Humans
	AND	3. English language
	2. Ambulatory Care Facilities or	4. Year = 2002 to Current
	Ambulatory Care or Outpatient (subject	(April 15 th 2012 or May 16 th
	headings),	2014)
	NOT	
	3. Assisted Living Facilities or Homes for	
	the Aged or Housing for the Elderly or	
	Palliative Care or Terminal Care or Urgent	
	Care or Emergency Medical Services	
	(subject headings),	
	NOT	
	4. Child* or Infant or Adolescent or	
	Paediatric (all fields)	

Additional file 1: Example of the electronic search strategy, including Medline database search terms and limits

Paper 2: Supplementary Material

Screenshots of the Consumer Preferences Survey

*Please note an online link to the Consumer Preferences Survey is available at: https://hbrg.newcastle.edu.au/quon/public/Demo_CPS

INSTRUCTION SCREEN

We would like your views about what can be done to improve or enhance the care you receive:



In each of these areas, we will present you with a list of possible improvements.

We really want to know which ones matter to you. Please choose the ones you think would improve or enhance the care you recieve. You can select as many changes as you want.

GENERAL INITIATIVES: Making an appointment



What could the clinic change to help you make an appointment?

- ✓ Schedule convenient appointment times
- Make it easy to contact someone at the clinic
- Make it easy to get to and from your appointments
- None of the above

SPECIFIC INITIATIVES: Making an appointment



On the last screen, you indicated that help **scheduling your appointment** could improve your experience. What specifically could the clinic change to **help you**?

- \square Offer more choices in appointment times
- \square Schedule all appointments at this clinic on one day

 \Box Offer evening (after 5 pm) or weekend appointments

- □ Have emergency appointments available
- Have appointments available within a week
- \square Shorter waiting times for surgery or first treatment
- \square Help to coordinate appointments with different clinic or services

SPECIFIC INITIATIVES: Making an appointment

On the last screen, you indicated that help **contacting the clinic** could improve your experience. What specifically could the clinic change to **help you**?

 \square Let you leave a message if the line is busy or the clinic is closed

Be able to speak to a staff member when you call



On the last screen, you indicated that help getting to and from the clinic could improve your experience. What specifically could the clinic change to help you?

□ Help arrange transport

 \square Offer more affordable transport options

Less waiting for pick-ups and drop-offs

GENERAL INITIATIVES: Arriving at an appointment



What could the clinic change to help you before your appointment?

- Car parking
- Comfortable or pleasant waiting room
- Reduced time in the waiting room
- Having family or friends with you in the waiting room
- None of the above

SPE CIFIC INITIATIVES: Arriving an appointment



On the last screen you indicated that help with **parking** could improve your experience.

What specifically could the clinic change to help you?

- □ Affordable options for parking
- \square Easy to use parking machines
- □ Spaces for cliric patients only
- \square Available parking close to the clinic
- \square More disabled only parking
- Patient drop-off zones or short stay parking for caregivers
- \square Providing information to patients about parking options

SPE CIFIC INITIATIVES: Arriving an appointment



On the last screen you indicated that the clinic could improve wait times. What specifically could the clinic change to help you?

 \square Paging system so you can leave the waiting room, but be paged to return

 \square Only be required at the clinic 5 minutes before scheduled appointment

Be informed of wait times upon arrival

SPECIFIC INITIATIVES: Arriving an appointment



On the last screen you indicated the clinic could **improve the waiting room**. What specifically could the clinic change to **help you**?

- Paint or decorate the walls
- □ Improve maintenance and cleaning
- □ Add comfortable furniture
- Provide enough furniture for patients and family
- C Reduce noise
- \square Better reading material, or television to occupy your time
- □ Wireless internet access
- C Visible clock
- \square Privacy from people walking by (e.g. frosted glass)
- \square Ability to make hot or cold refreshments

GENERAL INITIATIVES: During an appointment



What could the clinic change to help you during your appointment?

- Provide more information
- Ensure all your concerns are addressed
- ☑ Involve you more in treatment decisions
- Keep you up-to-date on the progress of your treatment and condition
- Ensure good interactions and relationships with all clinic staff
- Provide comfortable and pleasant treatment rooms
- Provide good quality hospital catering
- Better coordination of your care and information
- Minimise pain or discomfort when you receive treatment
- None of the above

SPECIFICINITIATIVES: During an appointment

On the last screen you indicated that help **getting information** could improve your experience. What specifically could the clinic change to help you?

Provide clear explanations of your treatment and condition

 \Box Provide written information or a list of available resources to take home

 \square Ask at the end of each appointment if you have any questions or need additional information

 \square Provide personalized written information to take home



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On the last screen you indicated that having all your concerns addressed would improve your experience. What specifically could the clinic change to help you?

 \square Ensure there is enough time to ask questions and raise concerns

 \square Ensure a plan is made to address your concerns

 \square Ask at the end of each appointment if you have any other concerns

 \square Have a handout with common concerns or questions to review or complete with your doctor

SPECIFIC INITIATIVES: During an appointment

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On the last screen you indicated that being more **involved in treatment decisions** could improve your experience. What specifically could the clinic change to help you?

 \square Provide more information on treatment options before you decide

 \square Provide more time to consider your options

 \square Your preferences and lifestyle are discussed and considered when making a decision



On the last screen you indicated that being kept up to date on your treatment progress and condition could improve your experience. What specifically could the clinic change to help you?

- Ensure you receive test results as soon as possible
- Ensure you know the status of your condition
- Ensure you are aware of the next steps in your treatment

SPECIFIC INITIATIVES: During an appointment

On the last screen you indicated that the clinic could improve the treatment rooms.

What specifically could the clinic change to help you?

 \square Paint or decorate the walls

Improve maintenance and cleaning

 \square Add comfortable furniture

Provide enough furniture for patients and family

C Reduce noise

 \square Better reading material, or television to occupy your time

□ Wireless internet access

C Visible clock

□ Privacy from people walking by (e.g. frosted glass)

 \square Ability to make hot or cold refreshments

SPECIFIC INITIATIVES: During an appointment

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On the last screen you indicated that hetter interactions and relations with clinic staff could improve your experience. What specifically could the clinic change to help you?

 \square Quick and sensitive response to your needs

- Being given bad news respectfully
- □ Be reassured by staff how you feel is normal
- Encourage a friendly, caring environment

□ Honest discussions with healthcare providers

SPECIFIC INITIATIVES: During an appointment

On the last screen you indicated that help coordinating your care and information could improve your experience. What specifically could the clinic change to help you?

 \square All clinic staff have your up-to-date information and medical history

 \square Healthcare providers communicate with each other

 \square Seeing the same healthcare providers at each appointment

 \square Short wait times for referrals to other healthcare providers

 \square Consistent information and advice from health care providers

 \square Having one healthcare provider to coordinate your care

 \square Knowing who to contact for a specific issue

SPECIFIC INITIATIVES: During an appointment



Don the last screen you indicated that minimizing pain and discomfort during treatment could improve your experience. What specifically could the clinic change to help you?

 \square Check you are warm and comfortable while receiving treatment

 \square Ensure all healthcare providers are skilful at giving needles or IV lines

Ensure immediate treatment side effects are managed

 \square Ensure healthcare providers monitor how you are feeling during treatment

GENERAL INITIATIVES: Self-management at home



What could the clinic change to assist you with your condition when at home?

- Help with physical symptoms
- Help with emotional health or relationships
- Help with daily activities and healthy lifestyles
- ${\ensuremath{\overline{\mathrm{M}}}}$ Help with employment, finances or insurance
- Information on your condition and treatment
- Support and involvement of family and friends
- Knowledge on how to handle a medical emergency
- None of the above

SPECIFIC INITIATIVES: At home



On that last screen you indicated that help with physical symptoms at home could improve your experience. What specifically could the clinic change to help you?

Help with lack of energy or feeling generally unwell

Help with pain, nausea or vomiting

Advice on the medication you need to take at home

Ensure prescription refills are available quickly

🗖 Help you manage any weight loss or gain

🗆 Help you cope with hair loss

On the last screen you indicated that help with emotions and relationships at home could improve your experience. What specifically could the clinic change to help you?

Ensure you know about a range of available support services

Provide better information about possible treatment outcomes

Provide better information on changing or distressing emotions

 \square Provide support services near the clinic

SPECIFIC INITIATIVES: At home A

On the last screen you indicated that help with daily activities and lifestyles could improve your experience.

What specifically could the clinic change to help you?

Services to help with household chores (like yard work, cleaning or cooking)

 \square Services to help with showering, bathing or dressing

Medical aids or devices (like raised seats or hand rails)

 \Box Mobility inside or outside your home

 \square Information about being active and having a healthy diet

 \square Help to reduce unhealthy activities (like smoking or drinking)



On the last screen you indicated that help with work, finances or insurance could improve your experience. What specifically could the clinic change to help you?

 \square Help with completing your sick leave forms

 \square Providing information about how long you may be away from work

 \square Advice and support about returning to work

 \square Help with coordinating insurance claims

 \square Finding information on available financial support

SPECIFIC INITIATIVES: At home

On the last screen you indicated that help getting information at home could improve your experience. What specifically could the clinic change to help you?

 \square Provide trustworthy information sources

 \square Knowing the long-term impacts of your condition or treatment

 \square Information about the changes to your daily life

 \square Being aware of possible symptoms

 \square Being aware of possible treatment side effects

 \square Knowing why specific tests are needed

 \square Knowing patient rights and responsibilities

 \square Information on remission, recurrence or spreading symptoms

SPECIFIC INITIATIVES: Athome



On the last screen you indicated that help involving family and friends could improve your experience. What specifically could the clinic change to help you?

Available professional counselors

Help to discuss your condition and treatment with family and friends

 \square Family and friends being made comfortable within the clinic

□ Involving family and friends in discussions and decisions

 \square Family and friends are able to contact the clinic on your behalf

SPECIFIC INITIATIVES: At home



On the last screen you indicated that help with medical emergencies could improve your experience. What specifically could the clinic change to help you?

□ Knowing which symptoms are an emergency

 \square Providing information to family or caregivers on how to handle an emergency

□ Knowing what to do if the clinic is closed

Knowing whom to contact first

Prioritization: Pick 5

We would also like to know which changes would most improve your experience.

This screen is based on your previous answers.

Please select the 5 changes that would improve your experience the most:

- Schedule convenient appointment times
- Make it easy to contact someone at the clinic
- Make it easy to get to and from your appointments
- Car parking
- ☑ Comfortable or pleasant waiting room
- \square Reduced time in the waiting room
- Having family or friends with you in the waiting room
- Provide more information
- Ensure all your concerns are addressed

Prioritization: Instructions for relative prioritization exercise

Now we would like you to prioritise your top changes. You have a total of <u>100 points</u> to distribute across your top changes.



You can give points equally or give more points to those choices which are more important to you. The more points you give to a change, the more important it is to you.

Touch where you would like to enter the points and the number pad will pop up on the screen.

You can see how many points you have left to distribute at the bottom of the screen in red.

Keep allocating points until you have 0 points left.

Prioritization: Point allocation

You have 100 points to distribute. How many points would you like to give to:

Schedule convenient appointment times

50

Make it easy to contact someone at the clinic

10

Make it easy to get to and from your appointments

10

Car parking

25

Comfortable or pleasant waiting room

5

Total: 100

Paper 3: Supplementary Material

Tuble 5. Demographic characteristics by consent status, with goodness of fit statistics					
Characteristic	Non-consenters (%)	Consenters (%)	Test statist	tics	
	$(n=291)^1$	$(n=674)^2$	χ^2 (df)	Р	
Male (n=438)	134 (46.2)	304 (45.1)	0.04 (1)	0.85	
Clinic site			14.7 (2)	.001	
Public oncology (n=476)	148 (31.1)	328 (68.9)			
Public cardiology and neurology (n=415)	135 (32.5)	280 (67.5)			
Private oncology (n=74)	8 (10.8)	66 (89.2)			
Age category			14.1 (4)	.007	
18-25 (n=38)	5 (13.2)	33 (86.8)			
26-40 (n=155)	49 (31.6)	106 (68.4)			
41-55 (n=262)	80 (30.5)	182 (69.5)			
56-70 (n=354)	95 (26.8)	259 (73.2)			
≥71 (n=156)	62 (39.2)	94 (60.2)			

Table 3: Demographic characteristics by consent status, with goodness of fit statistics

1. Data missing for 10 of 301 (3.3%) non-consenting individuals; 2. Data missing for 67 of 741 (9.0%) consenting individuals.

Table 4: Demographic characteristics by completion status, with goodness of fit
statistics

Characteristic	Incomplete (%)	Complete (%)	Test statistics	
	(n=200)	(n=541)	χ^2 (df)	Р
Age category			44.5(4)	< 0.001
18-25 (n=34)	11 (32.4)	23 (67.7)		
26-40 (n=118)	37 (31.4)	81 (68.7)		
41-55 (n=185)	35 (18.9)	150 (81.1)		
56-70 (n=263)	49 (18.6)	214 (81.4)		
≥71 (n=137)	64 (46.7)	73 (53.3)		
Gender ¹			6.2(1)	0.01
Male (n=320)	58 (18.1)	262 (81.9)		
Female (n=377)	98 (26.0)	279 (74.0)		
Highest education level ²			12.9(3)	0.005
High school equivalent of year 10 or less (n=337)	67 (19.9)	270 (80.1)		
High school completion (n=95)	31 (32.6)	64 (67.4)		
Diploma or trade certificate (n=145)	26 (17.9)	119 (82.1)		
Bachelor's or postgraduate degree (n=101)	13 (12.9)	88 (87.1)		
Recruited from ³			29.1 (2)	< 0.001
Cardiology/neurology, public facility (n=283)	79 (27.9)	205 (72.1)		
Medical oncology, public facility (n=322)	51 (15.8)	271 (84.2)		
Medical oncology, private facility (n=66)	1 (1.5)	65 (98.5)		
Reason for attending the clinic ⁴			Fisher's exact	t = 0.000
Discuss symptoms/treatments/tests, diagnosed	27 (23.1)	90 (76.9)		
Discuss symptoms/tests, undiagnosed	13 (26.5)	36 (73.5)		
Receive tests or treatments, diagnosed	7 (3.6)	189 (96.4)		
Routine exam, diagnosed	63 (22.6)	216 (77.4)		
Do not know	4 (44.4)	5 (55.6)		

1. Data missing for 44 respondents; 2. Data missing for 63 respondents; 3. Data missing for 70 respondents;

4. Data missing for 91 participants.

Paper 4: Supplementary Material

Characteristic	Non-consenters	Consenters (%)	Test statistics	
	(%)	$(n=608)^1$	$\chi^2 (df)$	Р
Male (n=410)	129 (45.6)	281 (46.5)	0.07 (1)	0.79
Clinic site			0.21 (2)	0.65
Medical oncology (n=476)	148 (52.3)	328 (54.0)		
Cardiology/neurology	135 (47.7)	280 (46.1)		
Age category			12.8 (4)	.01
18-25 (n=37)	5 (1.8)	32 (5.3)		
26-40 (n=144)	48 (17.0)	96 (15.8)		
41-55 (n=239)	79 (27.9)	160 (26.3)		
56-70 (n=319)	90 (31.8)	229 (37.6)		
≥71 (n=152)	61 (21.5)	91 (15.0)		

Table 5: Demographic characteristics by consent status, with goodness of fit statistics (n=891)

1. Data missing for 77 (7.9%) individuals

Characteristic	Incomplete (%) Compl	Complete (%)	Test statistics	
	n=195	n=475	χ^2 (df)	Р
Male (n=296)	58 (37.2)	238 (50.1)	7.55 (1)	0.006
Clinic site			13.0(1)	< 0.001
Cardiology/neurology, public facility (n=283)	79 (60.7)	204 (43.0)		
Medical oncology, public facility (n=322)	51 (39.2)	271 (57.1)		
Age category			37.7 (4)	< 0.001
18-25 (n=33)	11 (5.6)	22 (4.6)		
26-40 (n=108)	37 (19.0)	71 (15.0)		
41-55 (n=163)	34 (17.4)	129 (27.2)		
56-70 (n=233)	49 (25.1)	184 (38.8)		
≥71 (n=133)	64 (32.8)	69 (14.5)		
Highest education level			12.9(3)	0.005
High school equivalent of year 10 or lower (n=316)	66 (48.5)	250 (53.6)		
High school completion (n=84)	31 (22.8)	53 (11.2)		
Diploma or trade certificate (n=130)	26 (19.1)	104 (21.9)		
Bachelor's or postgraduate degree (n=81)	13 (9.6)	68 (14.3)		
Reason for attending the clinic			Fisher exact <	< 0.001
To discuss symptoms/treatments/tests, diagnosed (n=117)	27 (23.91)	90 (19.2)		
To discuss symptoms/tests, undiagnosed (n=49)	13 (11.5)	36 (7.7)		
To receive tests or treatments, diagnosed (n=131)	6 (5.3)	125 (26.6)		
For a routine exam, diagnosed (n=278)	63 (55.8)	215 (45.7)		

Table 6: Demographic characteristics by completion status, with goodness of fit statistics

Table 1: Sample demographic characteristics (n=263).				
Sample characteristics	Number of participants (%)			
Average years of age	Average = 59 (SD=17)			
Gender				
Male	114 (43.4)			
Female	149 (56.6)			
Highest level of education attained				
High school equivalent of year 10 or lower	134 (51.0)			
High school completion	39 (14.8)			
Diploma or trade certificate	50 (19.0)			
Bachelor's or postgraduate degree	40 (15.2)			
Marital status				
Married or in a de-facto relationship	171 (65.0)			
Single (never married, divorced or widowed)	92 (35.0)			
Weekly household income (before taxes, AUD)				
Less than \$300	23 (8.7)			
Between \$300-\$499	76 (28.9)			
Between \$500-\$799	40 (15.2)			
Between \$800-\$1000	31 (11.8)			
More than \$1000	32 (12.1)			
Prefer not to answer	61 (23.2)			
Treatment goal				
Curative intent	136 (51.7)			
To slow the cancer progression	110 (41.8)			
Do not know	17 (6.5)			
Number of appointments in last three months				
One	8 (3.0)			
Two	22 (8.4)			
Three	33 (12.5)			
Four	35 (13.3)			
Five	37 (14.1)			
Six	23 (8.7)			
More than six	105 (40.0)			

Paper 5: Supplementary Material

ReCAP (Research Contributions Abbreviated for Print)

<u>Questions asked</u>: What would individuals undergoing outpatient chemotherapy treatment change about their tertiary cancer services in order to improve personal experiences, and are these quality improvement preferences associated with respondents' health-related quality of life (HRQoL)?

<u>Summary answer</u>: Oncology outpatients frequently selected initiatives focused on service accessibility and information provision. There was trend for individuals with relatively-poor HRQoL to be more likely to select one of five quality improvement initiatives after adjusting for potential sociodemographic and clinical confounders.

<u>Methods</u>: Cross-sectional surveys were administered in one of five tertiary cancer centres located in New South Wales, Australia. Using touchscreen devices, individuals selected up to 25 patient-centered initiatives that would enhance their experiences and completed a validated HRQoL measure, the Functional Assessment of Cancer Therapy-General (FACT-G) survey. The proportion of individuals selecting each initiative and the average FACT-G scores are reported. Logistic regressions assessed the relationship between respondents' odds of selecting an initiative as FACT-G scores decreased. Due to multiple tests, the significance level was adjusted using the Bonferroni correction to $\alpha = 0.004$.

<u>Main results</u>: Commonly-selected initiatives included: improved parking (51.3%); up-to-date information on treatment and condition progress (19.8%); reduced wait-times (17.5%); and information on financial assistance (18.3%), medical emergencies (14.8%), and physical symptoms or side-effects (14.8%). After adjusting for confounders, the logistic odds of selecting convenient appointment scheduling increased by 23% with lower FACT-G scores (p < 0.004). The odds of selecting four other initiatives approached significance (p < 0.05) and increased according to lower FACT-G scores: reduced wait-times (+15%); information on manage medical emergencies (+14%); access to help or information relating to finance assistance (+15%); and access to help in order to maintain activities of daily living (+18%).

<u>Bias, confounding factors, drawbacks</u>: The Consumer-PS was specifically developed as an information-generating tool and there are no latent structures that may be used to reduce the number of initiatives tested. To correct for multiple tests, a Bonferroni threshold of 0.004 was used to determine statistical significance. While this threshold reduced the potential for spurious associations, it is also possible that a Type II error occurred – whereby an association between HRQoL and improvement preferences was not reported.

<u>Real-life implications</u>: To address patients' preferences for quality improvement, health services should consider two overarching areas: (1) fast and easy access to health services with patients' preferences accommodated in clinic organization systems, and (2) information and support for self-care. The odds of selecting five initiatives increased as respondents' HRQoL decreased. This is suggestive of an association between a few select quality improvement preferences and individuals' wellbeing. However, additional research is needed to explore the complex relationship between patients' quality improvement preferences and a broader spectrum of characteristics.

Appendix A

Author contribution statements

I, Associate Professor Christine Paul, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J. A systematic review of barriers to optimal outpatient specialist services for individuals with prevalent chronic diseases: what are the unique and common barriers experienced by patients in high income countries? International Journal for Equity in Health. 2015;14:52. doi:10.1186/s12939-015-0179-6.

Fradgley EA, Paul CL, Bryant J, Roos IA, Henskens FA, Paul DJ. Consumer Participation in Quality Improvements for Chronic Disease Care: Development and Evaluation of an Interactive Patient-Centered Survey to Identify Preferred Service Initiatives. Journal of Medical Internet Research. 2014;16(12). doi: 10.2196/jmir.3545.

Fradgley EA, Paul CL, Bryant J, Oldmeadow C. Getting right to the point: identifying outpatients' priorities and preferences for patient-centered quality improvement in chronic disease care. Under editorial review.

Fradgley EA, Paul CL, Bryant J, Zucca A, Oldmeadow C. System-wide versus person-specific: a cross-sectional study identifying demographic and clinical characteristics associated with patient preferences for health service change in specialist outpatient care. Under editorial review.

Fradgley EA, Bryant J, Paul CL, Hall AE, Sanson Fisher R, Oldmeadow C. Cross-sectional data exploring the correlation between outpatients' quality of life and preferences for quality improvement in oncology settings. Under editorial review.

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Identifying and comparing stakeholder preferences for patient-centred quality improvement: A cross-sectional survey of the types and numbers of quality initiatives selected by outpatients and health professionals. Under editorial review.

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I, Dr Jamie Bryant, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J. A systematic review of barriers to optimal outpatient specialist services for individuals with prevalent chronic diseases: what are the unique and common barriers experienced by patients in high income countries? International Journal for Equity in Health. 2015;14:52. doi:10.1186/s12939-015-0179-6.

Fradgley EA, Paul CL, Bryant J, Roos IA, Henskens FA, Paul DJ. Consumer Participation in Quality Improvements for Chronic Disease Care: Development and Evaluation of an Interactive Patient-Centered Survey to Identify Preferred Service Initiatives. Journal of Medical Internet Research. 2014;16(12). doi: 10.2196/jmir.3545.

Fradgley EA, Paul CL, Bryant J, Oldmeadow C. Getting right to the point: identifying outpatients' priorities and preferences for patient-centered quality improvement in chronic disease care. Under editorial review.

Fradgley EA, Paul CL, Bryant J, Zucca A, Oldmeadow C. System-wide versus person-specific: a cross-sectional study identifying demographic and clinical characteristics associated with patient preferences for health service change in specialist outpatient care. Under editorial review.

Fradgley EA, Bryant J, Paul CL, Hall AE, Sanson Fisher R, Oldmeadow C. Cross-sectional data exploring the correlation between outpatients' quality of life and preferences for quality improvement in oncology settings. Under editorial review.

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Identifying and comparing stakeholder preferences for patient-centred quality improvement: A cross-sectional survey of the types and numbers of quality initiatives selected by outpatients and health professionals. Under editorial review.

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Dr Ian Roos is since deceased. As per the International Committee of Medical Journal Editors, Dr Ian Roos approved the final manuscript which clearly states Ms Fradgley contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following:

Fradgley EA, Paul CL, Bryant J, Roos IA, Heńskens FA, Paul DJ. Consumer Participation in Quality Improvements for Chronic Disease Care: Development and Evaluation of an Interactive Patient-Centered Survey to Identify Preferred Service Initiatives. Journal of Medical Internet Research. 2014;16(12). doi: 10.2196/jmir.3545.

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I, Dr David Paul, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Roos IA, Henskens FA, Paul DJ. Consumer Participation in Quality Improvements for Chronic Disease Care: Development and Evaluation of an Interactive Patient-Centered Survey to Identify Preferred Service Initiatives. Journal of Medical Internet Research. 2014;16(12). doi: 10.2196/jmir.3545.

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I, Professor Frans Henskens, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Roos IA, Henskens FA, Paul DJ. Consumer Participation in Quality Improvements for Chronic Disease Care: Development and Evaluation of an Interactive Patient-Centered Survey to Identify Preferred Service Initiatives. Journal of Medical Internet Research. 2014;16(12). doi: 10.2196/jmir.3545.

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I, Dr Christopher Oldmeadow, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Oldmeadow C. Getting right to the point: identifying outpatients' priorities and preferences for patient-centered quality improvement in chronic disease care. Under editorial review.

Fradgley EA, Paul CL, Bryant J, Zucca A, Oldmeadow C. System-wide versus person-specific: a cross-sectional study identifying demographic and clinical characteristics associated with patient preferences for health service change in specialist outpatient care. Under editorial review.

Fradgley EA, Bryant J, Paul CL, Hall AE, Sanson Fisher R, Oldmeadow C. Cross-sectional data exploring the correlation between outpatients' quality of life and preferences for quality improvement in oncology settings. Under editorial review.

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I, Ms Alison Zucca, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Zucca A, Oldmeadow C. System-wide versus person-specific: a cross-sectional study identifying demographic and clinical characteristics associated with patient preferences for health service change in specialist outpatient care. Under editorial review.

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I, Laureate Professor Robert Sanson-Fisher, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Bryant J, Paul CL, Hall AE, Sanson-Fisher R, Oldmeadow C. Cross-sectional data exploring the correlation between outpatients' quality of life and preferences for quality improvement in oncology settings. Under editorial review.

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I, Dr Alix Hall, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Bryant J, Paul CL, Hall AE, Sanson Fisher R, Oldmeadow C. Cross-sectional data exploring the correlation between outpatients' quality of life and preferences for quality improvement in oncology settings. Under editorial review.

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I, Professor Stephen Ackland, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Identifying and comparing stakeholder preferences for patient-centred quality improvement: A cross-sectional survey of the types and numbers of quality initiatives selected by outpatients and health professionals. Under editorial review.

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I, Professor Christopher Levi, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Identifying and comparing stakeholder preferences for patient-centred quality improvement: A cross-sectional survey of the types and numbers of quality initiatives selected by outpatients and health professionals. Under editorial review.

Professor Christopher Levi (Co-author)

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21 December, 2015

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I, Mr Douglas Bellamy, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Identifying and comparing stakeholder preferences for patient-centred quality improvement: A cross-sectional survey of the types and numbers of quality initiatives selected by outpatients and health professionals. Under editorial review.

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I, Dr Nicolas Collins, attest that the Research Higher Degree candidate, Ms Elizabeth Fradgley, contributed to the manuscript conceptualisation, study design, data collection, data analysis and interpretation, and final manuscript preparation for the following manuscript:

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C. Identifying and comparing stakeholder preferences for patient-centred quality improvement: A cross-sectional survey of the types and numbers of quality initiatives selected by outpatients and health professionals. Under editorial review.

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Appendix B Related publications

How do health researchers benefit from web- based survey systems?

Henskens, F.A^{1,2}, Paul, D.J^{1,2}, Wallis, M¹, Bryant, J², Carey, M², Fradgley, E², Koller, C.E^{1,2}, Paul, C.L², Sanson-Fisher, R.W² and Zucca, A²

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Proceedings of e-Health 2014 (2014) [E1]

ABSTRACT

This paper discusses the needs of researchers working in areas of medical research in which the collection and analysis of people's opinions is central to the research activity. Until quite recently, collection of survey data has been either paperbased, or achieved using computer software that largely duplicates paper-based processes with limited additional functionality. The authors, who have developed and used many Web-based surveys in their health-related research, discuss the needs of health researchers who use surveys and similar tools to collect research data, and propose a set of functionalities that efficiently satisfies those needs. A Web-based software architecture that delivers on researchers' identified needs is presented, and an example implementation that has demonstrated its capabilities in recent research projects is introduced.

KEYWORDS

Survey Software, Web-based Surveys, Research Support, eResearch.

INTRODUCTION

Surveys are tools used to collect research data on people's opinions, perceptions and self-reported behaviours. Each survey comprises a set of closed and pre-determined questions asked of a group of respondents intended to be representative of the population of interest (Shaughnessy et al., 2011). This contrasts with interviews and polls: interviews involve personal interaction between the interviewer and interviewee and may include open questions or the collection of qualitative data; polls ask a single question rather than a set of questions.

While qualitative interviews are a more personal and revealing way of collecting population information compared to surveys, considerable time is required to code and analyse qualitative data and the number of participants is very limited.

Data collection using surveys is an important facet of research, particularly in the areas of health, psychology and sociology.

Health professionals, for example, may wish to directly assess patient perspectives about whether healthcare meets their needs (McDowell, 2009) because involvement of patients as partners in their own care is now considered best practice (Institute of Medicine, 2001). Survey data can be used to identify patient views about or preferences for healthcare services; to assess patient outcomes; and identify areas of unmet service needs. Patient or clinic characteristics that are associated with a higher risk of poor outcomes can also be identified and targeted for appropriate interventions. Surveys are, of course, also important in other research areas, for example political science (Pasek and Krosnick, 2010) and business (Weathers et al., 2005).

There are several features that enhance the quality of survey data. These include ensuring that data are collected from a representative sample and that questions are posed in a manner that maximises the reliability and validity of responses. Strategies that increase the acceptability of surveys through improving participant comprehension and ease of use of the survey tool will contribute to the aim of collecting high quality survey data.

Surveys are increasingly used as a data collection tool for topics as diverse as 'preferred times for a meeting' to 'workforce opinions on corporate strategy and function'. This paper discusses the ideal features and capabilities of a 'good' survey system as informed by health researchers, and shows that a Web-based environment naturally supports implementation of these ideals and improves the experience of both researchers and participants.

It is intended that the observations and ideas engrossed in this paper should provide valuable information to health researchers selecting a survey tool to support their research, and assist software developers working on design and implementation of web-based survey systems.

SURVEYS AS A RESEARCH TOOL

Ideally, survey-based measures should be capable of providing an accurate assessment of the behaviour or state of interest for a representative sample of consumers (McDowell, 2009), as well as be reliable, acceptable and easy to administer (Clinton-McHarg et al., 2010a). Several factors influence measurement accuracy and reliability, and these should be taken into account at the survey design phase. They include the ease with which the questions can be understood, and the acceptability

and relevance of the questions (Dillman et al., 2008). The Internet is now widely available to respondents (Paul et al., 2011), and the use of computers for interaction is acceptable (Paul et al., 2013a, ABS, 2011).

A multidisciplinary collaboration between behavioural scientists and information technology experts was formed to further investigate requirements and structure of the ideal Internet-based survey system. Their experience, and consultation with other researchers who regularly use surveys in their research, led to compilation of the following properties of a high quality survey:

Relevance

In contrast to paper surveys, electronic surveys have the capability to enable respondents to automatically "skip" questions that are not relevant to their circumstances (as determined from responses to previous questions). For example, respondents may be asked whether they are male or female. Those who indicate that they are male may then be automatically redirected to a next question asking whether they have had a recent PSA test, whereas females may be redirected to a question asking whether they have taken a mammogram in the past two years. Those who answer the 'PSA' question may then be automatically redirected to a 'indicate the value range of your result' question, and so on. This automatic assistance with question navigation streamlines the survey completion process and omits the need for respondents to follow complex instructions.

Respondent Acceptability

To increase participant completion rates and reduce missing data, it is important that survey respondents find the survey interesting, visually attractive, easy to understand and navigate with a logical user interface, and are able to complete the survey in a reasonable amount of time (Fan and Yan, 2010).

The tool used to conduct the survey is also important. The advent of easy-to-use tablet computers and smart phones has removed the need for use of cumbersome personal or laptop computers for computer-based surveys. Tablet computers are highly portable, provide privacy for survey completion through their more intimate form factor and immediate transfer of data, and have a high level of user acceptability (Paul et al., 2013a). However, web-based survey page layouts do not always automatically adjust from the space available on larger PC monitors to the smaller displays of tablet and hand-held devices, so care must be taken to render content that is appropriate to each individual user's screen.

Immediate Feedback

Creating immediate feedback for a survey respondent and/or the conductor of the survey, based on the respondent's answers, improves relevance and recall of information for the participant (McPherson et al., 2001) and can synthesise relevant answers for researchers and health care professionals. It can also be used to improve patient literacy and self-management by highlighting those areas in which patients may need additional information or personalised assistance.

For example, answers to questions about medication adherence could be inserted into a feedback template containing evidence-based recommendations about ways to improve adherence. This can be tailored to individual participants, based on their answers. The template could incorporate design features to enhance recall and understanding of information such as categorisation of information (Girgis and Sanson-Fisher, 1998, NHMRC, 2004), repetition of important information (Ley et al., 1973), and the use of simple language (Fallowfield and Jenkins, 2004). This improves the accessibility of information for the participant and assists those with low literacy.

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Immediate feedback from surveys can also be used by health care professionals in order to inform care delivery (Treweek et al., 2002). For example, an electronic screening tool for depression in a general medical setting may be used to identify patients who require further diagnostic assessment. In this way, electronic surveys could be used as an efficient and time-saving screening tool with improved detection rates.

Respondents can also benefit from immediate feedback. Evidence suggests patients and caregivers have unmet informational needs and desire more information during a consultation (Schoen et al., 2009). Health service providers may be limited by time constraints and unable to provide the amount of information desired in a single clinical encounter. Electronic surveys can produce personalised information sheets based on participants' demographic or disease characteristics, allowing information needs to be appropriately addressed. This may be used to improve patient self-management, information recall, and literacy.

Comprehension

Electronic surveys also have the potential to incorporate features that can enhance survey comprehension. For example, font size or mode of presentation (i.e. inclusion of visual or audio) can be customised to suit respondent preferences or needs, and embedded video clips can be used to demonstrate complex information. Such features may be particularly beneficial in improving comprehension among respondents with poor literacy skills (Murphy et al., 2000).

Respondent Privacy

Electronic surveys may be conducted in several ways, most commonly either by executing the survey software on a non-connected stand-alone PC or portable computer, or by using a Web browser to connect to a central server that uses the Internet to provide the survey content. Both approaches have different advantages, disadvantages and privacy issues. Assurance of data security and respondent privacy are critical issues for human research ethics committees (Bier et al., 1996).

The use of non-connected stand-alone or portable computers does not require an Internet connection for survey completion. Data collected during conduct of non-connected surveys are stored on the computer's local disk, with the data later aggregated for analysis. This is convenient in geographically isolated locations, or screened locations such as some factories or hospitals, where Internet connections cannot be established or are unreliable. However, this approach has the disadvantage that data (and thus respondent privacy and confidentiality) is vulnerable to compromise through unauthorised access, for example after theft or loss of the computer, or by a curious (or malicious) subsequent survey participant.

In contrast, use of a central Web server to generate survey content and collect and store participant responses means only one system needs to be secured. Encryption can be used to ensure confidentiality and privacy of transmitted data.

Data Quality

When technical difficulties are managed, electronic surveys have the potential to overcome problems with data quality by reducing respondent errors, missing data and errors in data entry (Galliher et al., 2008). Programming features can be applied to reduce the chance of respondent errors, for example, if a person enters a value outside the expected range for the question (e.g. age is entered as 221), then immediate feedback can be provided about this, giving the respondent the opportunity to correct their answer. Surveys may also be programmed so that a respondent cannot move to a subsequent question without completing the preceding questions, and partial answer sets can be used to determine dropout

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rates for particular questions. Furthermore, item response formats can be pre-specified, such as single response only, or multiple responses allowed, reducing the potential for respondent error (Boneveski et al., 1999).

Unlike paper surveys, electronic surveys automatically store participant responses in digital form, thereby avoiding potential transcription errors. Electronic data can be automatically downloaded in a variety of file formats (commonly csv) in order to conduct analysis.

More complicated response formats lead to greater opportunity for respondent error. For example rank-style items require participants to undertake the complex task of considering a list of variables, then rank, weight or distribute points between each, and finally ensure these total the pre-specified allocated value. (Clinton- McHarg et al., 2010b). Some rank-style items can most effectively be administered by a more labour intensive 'card-sort' approach (Shackley and Dixon, 2013). Electronic surveys can reduce that labour and facilitate completion by helping respondents to narrow down the list via the deletion of unimportant items, visually order options, calculate the cumulative and total value, and provide immediate instructions for the respondent to correct their answer.

Researcher Convenience

Use of a central Web server to generate the survey content and to collect and store responses has several advantages to do with researcher convenience: these may be categorised as participation management; data management; and response analysis.

With regard to participation management, paper and pencil survey responses require manual tracking to calculate completion rates or to determine whether reminder letters need to be sent to non-responders. As surveys typically include a large sample size, this requires considerable resources for data entry and monitoring. In contrast, electronic surveys may be embedded within the data management system that tracks survey responses and provides automatic prompts to the researcher, e.g. for follow-up surveys or reminders to people who have not yet responded. Reminders can also be fully automated so they go directly to the participant, e.g. via SMS.

Having a central Web server manage a survey also has several advantages related to data acquisition and management: respondents can take the survey using any client computing device with a Web browser, such as tablet computers, smart phones, or PCs and laptops; any changes to question wording are made in one place and immediately seen by all subsequent respondents; responses are centrally stored, which removes the need for aggregation and facilitates statistical analysis.

For optimal analysis of response data, survey results should be available to the researcher immediately, and in a format that is accessible to statistical programs such as STATA (Stata Corporation, 2013) or SAS (SAS Institute, 2013). This allows the researcher to review individual or group data as required.

In addition, recording and reporting of timing data (for example how long a respondent spent on each survey page; how many times a respondent stopped and restarted the survey; if a respondent watched a provided video clip or skipped past it) can enhance researchers' understanding of responses, help inform the interpretation of data, and inform the design of future surveys.

SPECIFYING A 'GOOD' SURVEY SYSTEM

The requirements of an ideal survey system were described above. In this section we use the same headings to discuss specific survey system features that deliver those requirements, and show that the Web provides an ideal delivery platform.

There are a number of successful existing survey systems, for example PC-based systems such as Digivey (CREOSO Corporation, 2013), and Web-based systems such as Survey Monkey (Survey Monkey, 2013).

These systems provide a set of core features required of ideal systems, for example: ability for researchers to define surveys without a need for computer programmer assistance; a set of pre-defined question types; and support for branching, i.e. skipping past questions based on previous responses.

These features require extension and enhancement to achieve the 'ideal', as follows

Enhancing Relevance

Support for definition of more complex branching rules is central to enhancing the relevance of surveys. It should be possible to include or exclude questions based on either raw answers or calculations (e.g. body mass index (BMI) or age) based on answers to ANY previous questions, not just the answer to the question immediately preceding the branch.

The set of core question types should include: Informational; Text; Checkbox; Radio Button; Drop Down; Calendar; Rank Order; Distribution of Points; and Likert Scale to account for all possible question formats.

There should also be support for dynamic questions (e.g. Dynamic Checkbox; Dynamic Rank Order; Dynamic Distribution of Points) that provide options based on a subset of respondent answers to previous questions.

Enhancing Acceptability

To enhance acceptability of surveys, modelling of dynamic survey screens with content based on participants' previous responses is required. Support for three forms of content modelling is recommended. It should be possible to dynamically:

Define the number of questions received by an individual based on their previous answers;

Construct the question stem containing content from previous answers; and

Set the possible response options (e.g. for checkbox or radio button questions) available for selection after implementation of a selection algorithm based on previous responses.

Use of Web browsers for researcher and participant interaction with the survey system makes use of an interface that is increasingly familiar to the user population and implemented on a wide range of Internet- connected devices.

Enhancing Feedback

It should be possible to generate on-the-spot printed or screen-based tailored feedback to respondents based on survey answers. In the case of Web-based surveys, printed feedback would be in a document form such as PDF, with the operator being able to send it to a printer to produce hard copy, or save to a file (that enables, for example, distribution by email).

Enhancing Comprehension

Comprehension is assisted by a number of features. Firstly, the ability to present related questions on a single screen assists the participant understand context. While this is available in some existing survey systems, it is a feature in need of enhancement, for example every question included on a

screen should be tailored based on previous answers, and those that are not relevant should not be included. In this way, multi-question screens are dynamic, and previous questions determine the content of the page and possible response options. The use of stimuli such as audio, still pictures or movies can assist respondents and/or provide content as the basis for questions. A wide range of stimulus file formats should be supported. Standardisation of Web browser support for such files is currently in progress and should be available in the next generation of browsers (W3C, 2013).

Enhancing Privacy

It should be possible to specify who can take a survey and how often. Appropriate options include that a survey can be taken by any participant, with no form of login or other identifying action required; participants who provide identification – in the case of multiple-response surveys, this supports participation by multiple linked respondents e.g. family members, or patients and their support person; or participants who authenticate by providing a username and password. Participants can provide their own ID, e.g. SURNAMEDDMM where DDMM is taken from their date of birth to achieve identification, or the researcher can associate a list of valid IDs with a survey. In the case of authenticated surveys, login details must be pre-prepared and individual details distributed to participants.

The survey system must also support privacy from the researcher viewpoint by, for example, ensuring that only survey owners are permitted to access responses or respondent lists. There should be support for multiple research groups, and a hierarchy of researcher users, for example: administrator with super user privileges including ability to create groups; group leader who can 'create' group members (researchers) and change survey ownership; and researcher, who can define individual surveys and access the corresponding data.

Web-based survey implementation allows the use of strong physical security of the server, and httpsbased encryption helps ensure security of data while in transit from the respondent's browser to the server.

Enhancing Data Quality

Centralisation of data storage through implementation of a Web-based survey system, and therefore automatic aggregation of the data, has an immediate positive effect on data quality because it removes the need for transcription or transfer of data.

Other features that enhance data quality include researcher-specified control over permissible responses (Dillman et al., 2008), with accompanying prompts that request the respondent re-enter non-compliant data.

It should also be possible to specify, on a field or individual character basis, whether input data is alpha and/or numeric. For answers that require a numerical response, a number pad or calendar can appear on the screen to assist respondents provide valid and correctly expressed responses.

Finally, the above-mentioned 'allocation of points' feature (Section 3.1), which allows participants to prioritise options as well as ranking them, provides researchers with richer and more meaningful data on which to gauge opinion and base decisions.

Enhancing Researcher Convenience

Having a central Web server responsible for generating and distributing survey screens and collecting responses provides a single point for participation monitoring and participant management. The central server software can provide features such as automatic generation of non-participation reports and other forms of follow up.

The server should render survey pages whose content and appearance are separately specified; appearance should be defined using a presentation semantics language such as CSS (Bos, 2013), with an optional WYSIWYG editor, allowing researchers to easily manage the style of the survey. In addition, the use of CSS provides the ability to differently render survey screens depending on the kind of device (tablet, smart phone, laptop) being used by the respondent, and even render the same survey in different languages.

Centralised management should reduce the need for researcher administration. It should be possible to specify participation in identified and authenticated surveys as being 'once only' or 'multiple permitted', providing support for linked input to a particular survey iteration (e.g. a participant's and their family member's opinion on the same point of interest), or to track changes in participant opinion over time. This assists researchers by removing the need to manually match responses.

The survey system should automatically record the date a survey was commenced, and the time (relative to commencement of the survey) at which the respondent receives and leaves every survey page, pauses and restarts the survey, and ultimately leaves the survey. This timing data helps researchers to picture respondents' behaviour while taking the survey, possibly highlighting those questions on which participants do not take much time to reflect, or those that require a longer time to understand.

Survey responses are best exported in a form such as CSV or XML, suitable for processing by popular statistical packages. Researcher understanding and statistical analysis are assisted by automatic inclusion of markers indicating questions that were visited but not answered, c.f. those not visited because of branching rules.

In addition to these convenience features, the system should provide survey definition assistance to researchers such as preview and branch checking capabilities. Branch checking should occur in preview mode, so that when a branch rule is encountered, the system displays the rule, its positive and negative destinations, and its outcome determined from the previous question(s).

Finally, the survey system should be extendable so that it is not too difficult to add new survey question types to the system.

BUILDING THE SURVEY SYSTEM

A generic survey generation system called QuON had been previously developed and addressed some if the above needs; that initial version of QuON (Paul et al., 2013b), grew out of a need to collect the survey- generated research data and to make its presence discoverable in ANDS (Australian National Data Service, 2013). The basic QuON package was subsequently enhanced in a collaboration of the Distributed Computing Research Group (DCRG), and the Health Behaviour Research Group (HBRG), involving behavioural scientists, statisticians, medical general practitioners and specialists, dieticians, biologists, psychologists, computer scientists and software engineers at the University of Newcastle to provide all of the desirable features presented in this paper.

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Design

The survey server is structured using three communicating components: the survey definition component; the survey generation component; and the storage system, which provides a receptacle for survey definitions and responses using an SQL database (Oracle, 2012).

The fundamental unit from which surveys are constructed is the survey object; each of these objects specifies either: a question; an information screen that may include text enhanced by sound, picture or movie content; a branching rule; a non-displaying calculation; or a wrapper that conditionally aggregates a number of survey objects into a single unit termed a meta object.

Survey objects can be created in any order. They are then imported into the survey and can be rearranged as required. The only restriction is that calculation, branching, or dynamic objects must be placed after any survey objects they reference. Each survey object has a unique identifier in the survey context. Survey objects are ordered in the knowledge that navigation is sequential unless the sequence is over-ruled by implementation of a branching rule.

Once a survey has been defined, it is executed using the survey-generating component, which can operate in either preview or user mode. The generation component executes a cycle; it extracts each next survey object from the database; interprets the object and takes the appropriate action (i.e. renders a survey screen, calculates and applies a branch condition, or calculates and returns a value); records timing information; and if appropriate, stores the participant's response and timing data.

Implementation

An enhanced version of QuON that engrosses the features suggested in this paper has been implemented; see (Henskens et al., 2014) for details including screen shots and evaluation. It uses a typical Model-View- Control (MVC) approach (Krasner and Pope, 1988) as provided by CakePHP (Cake Software Foundation, 2012). It utilises Web standards so that the same survey can be presented on different devices such as computers, tablets, and smart phones. To the extent possible, QuON also conforms to the W3C Web Content Accessibility Guidelines 2.0 (Caldwell et al.), though complete compliance is dependent on the question content entered by researchers.

QuON is covered by the open source MIT licence, so programmers can easily add new question types by creating new CakePHP Helpers, which define the attributes survey designers (researchers) are allowed to specify, how the question should be displayed, how responses should be validated, and how responses are stored.

Support is provided for easy inclusion of customised Cascading Style Sheets (CSS) to change the appearance of survey screens, and to specify different styles for mobile and non-mobile devices. Customised Javascript (Arnold and Gosling, 2000) is also possible, allowing researchers to implement custom client-side logic on the participants' devices while they are taking a survey.

CONCLUSION

This paper discusses the features of a good survey and possible survey applications; and presents a Web- based survey generation system architecture that delivers these features in a convenient and safe environment. The system provides all the building blocks necessary to create a fluid survey that 'learns' from and adapts to previous answers. Researchers, who are not required to have programming

knowledge, can assemble these blocks or objects, allowing them to construct customised surveys to meet their specific needs.

Surveys can be developed from scratch, modified, or reassembled from sections of one or more previous surveys. This flexibility, ease of use, participant specificity and provision of individual feedback make the presented system architecture unique and very attractive to any researcher seeking customer preferences and opinions.

Such a survey system has been implemented by the authors, and is called QuON. The initial version of QuON may be downloaded from <u>http://code.google.com/p/quon/</u> and can be freely used as a basis for development of advanced survey systems. The authors use such an enhanced QuON system that implements all the question types and features presented in this paper. They continue to work with survey-intensive researchers in a quest to identify and provide the most complete set of survey question types. For example, we recently learned of a need for a question type that allows a partitioned diagram to be displayed so that the survey client can select one or more of the regions using a touchscreen or mouse. The selected region(s) would be indicated by a change in fill colour or shading; the new question type will support questions such as 'On the body image, select the areas in which you feel pain'.

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Web-based Support for Population-based Medical Research Presenting the QuON Survey System

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Abstract: This paper discusses the needs of medical researchers working in the area of patientcentred medicine, in particular their use of survey data in measuring patient opinions, needs, perceived quality of care received, and priorities of health service interventions. Until quite recently, collection of survey data has been either paper-based, or achieved using computer software that largely duplicated paper-based processes with limited additional functionality. The authors investigate the use of web-based technology to support collection of such data from patients, including experiences and observations on enhanced/additional functionality made possible by its adoption. A novel software design termed QuON is presented, together with examples of its capabilities and uses in current research projects.

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INTRODUCTION

Public health research broadly focuses on measuring health behaviours and evaluating the effectiveness of innovations designed to improve the health of groups of people. The scope of public health is broad, covering for example: infectious diseases; vaccination programs; lifestyle risk factors such as tobacco smoking, diet, physical inactivity and weight; and participation in cancer screening programs. Detection and treatment of mental illnesses such as depression and anxiety also falls within this remit.

In 2001, the Institute of Medicine's report 'Crossing the Quality Chasm' nominated patient centredness as one of six domains of quality care (Institute of Medicine, 2001). The inclusion of patient-centred care in this seminal report signalled a shift from traditionally physician-centred models of care to patient-centred models that are structured around patients' physical, social and emotional preferences, values, and experiences. This led to changes, not only in the delivery of health care, but also in the approach used in research. Patient centred care emphasises the involvement of patients as partners in their healthcare. Directly assessing patient perspectives about whether healthcare meets their needs using patient-reported surveys is therefore considered best practice. Data collected via survey can be used for a number of purposes, including to: identify patient needs; measure changes in patient outcomes; provide feedback to healthcare systems about performance (e.g. as part of quality assurance activities); and guide clinical decision making.

Patient-centred health research often requires the use of survey-based assessments to gather data on health and health behaviours (McDowell, 2009). In order to accurately capture a representative sample of patients' perspectives without expending considerable resources, data collection must be efficient with high levels of participant acceptability. The production of high quality data requires that sources of bias be limited by achieving high response rates, minimising recall bias, obtaining reliable and valid responses (which may involve psychometric testing) and involving stakeholders in development processes (von Elm et al., 2007). A key element of both a patient-centred approach and maximising research rigor is the minimisation of participant burden in a manner that reduces participant time (e.g. via flexibility and participant tailoring), increases participant ease of use (flexibility of format) and minimises the literacy level required of participants. To meet these requirements, a multidisciplinary collaboration between health behavioural scientists and information technology experts was formed. This collaboration has produced a web-based survey package entitled QuON (Paul et al., 2013), which includes specific features designed to achieve high levels of participant acceptability.

SURVEYS AS A RESEARCH TOOL

Survey-based measures need to be capable of providing an accurate assessment of the behaviour or health state of interest (McDowell, 2009). Measures also need to be reliable, so that results are reproducible. There are several factors that influence measurement accuracy and reproducibility, which need to be taken into account at the survey design phase. These include the ease with which the questions can be understood, and the acceptability and relevance of the questions (Dillman et al., 2008). The authors' own experiences and comprehensive discussions revealed a

raft of qualities required of a 'good' patient survey. It is valid, reliable, psychometrically robust, acceptable, easy to score, and easy to analyse (Clinton-McHarg et al., 2010).

To improve patient acceptability, surveys should be designed to be visually pleasing, interactive, and contain highly relevant item content. Electronic data collection strategies have a number of advantages over pen-and-paper modes of survey administration, as described below.

Tailoring to Improve Relevance

Paper and pencil surveys require respondents to follow (sometimes complex) instructions in order to ensure that only questions relevant to their circumstance are answered. For example, respondents may be asked to report on the amount of physical activity they did in the past week. Those who indicate that they did not engage in physical activity may be asked to skip a set of questions related to activity type.

Instructions of this type introduce a risk that respondents will misread or misinterpret instructions, potentially causing confusion for the respondent, and compromising data quality. In contrast, electronic surveys can be customised for each participant. For example, questions can be alternately skipped or presented depending on a respondent's answers to any previous question, not just the response immediately prior. This not only minimises respondent burden in reading irrelevant questions, but also results in better data quality through reduction in respondent error.

Immediate Feedback

The survey customisation features mentioned above can also be used to create immediate feedback for a patient and/or service provider, based on their answers. Tailoring of information to individual needs and preferences improves relevance and recall of health information (McPherson et al., 2001).

Answers can be inserted into a feedback template and recommendations can be added, based on the answers given. A number of strategies to enhance recall and understanding of information can be incorporated into feedback to patients or clinicians. These include explicit categorisation of information (Girgis and Sanson-Fisher, 1998, NHMRC, 2004), repetition of important units of information (Ley et al., 1973), and the use of plain language (Fallowfield and Jenkins, 2004).

The ability to provide immediate and tailored feedback from survey output opens up opportunities for survey data to become part of health care delivery. Surveys completed before the appointment with a clinician allow for a more focused consultation, with potential issues flagged and automatically documented. This streamlining enhances the overall provision of service. Data provided to the participant can form part of a health intervention. Large data sets aggregated for health services provide the opportunity to monitor patient- level perceptions and experiences, which are central to the provision of quality care.

For optimal data analysis, survey results should be available to the researcher in a timely manner. Outputs appropriate for use in popular statistical analysis packages such as STATA (Stata Corporation, 2013) or SAS (SAS Institute, 2013) give immediate access to group data.

Improved Comprehension

Electronic surveys may incorporate customised modes of presentation to enhance survey comprehension. For example, larger fonts or audio recordings of questions can be used to assist vision- impaired persons; the language of the survey text can be customised (e.g. from English to Vietnamese); and pop-up boxes can be used to explain difficult terms without interrupting the flow of the survey.

Graphics and interactive features may also be useful particularly for conveying complex information or additional material for groups with lower levels of literacy (Murphy et al., 2000).

Improved Data Quality

The quality of data collected using paper-and-pencil surveys can be compromised due to missing data and errors in responses. These quality issues can be largely overcome through use of electronic surveys.

Respondent errors can be minimised by programming features that notify respondents if they have provided an answer outside an expected range, and prompts them to re-enter their answer (e.g. postcodes, duration of illness, age). Similar features can be used to prompt for completion of missed items, thus reducing the amount of missing data (Boneveski et al., 1999).

Electronic surveys preclude the need for manual data entry (either item by item, or by scanning pages into a data reader), thus eliminating a time- consuming process and minimising data errors. Automatic summaries of survey data can be produced quickly and easily, and the ability to export data from the survey system to statistical programs allows complex statistical analysis to be undertaken.

Paper and pencil survey responses need to be manually logged into a database or spreadsheet to keep track of completion rates, and to determine whether reminder letters need to be sent to non-responders. Completion of electronic surveys, however, can be monitored electronically so that reminder emails, SMS, or prompts for researchers to make reminder phone calls can be sent automatically. This is a labour efficient feature, which assists in maximising completeness of data.

THE QUON SURVEY SYSTEM

The QuON survey software system was jointly developed by the Distributed Computing Research Group (DCRG), and the Health Behaviour Research Group (HBRG), at the University of Newcastle, Australia, and initially funded by the Australian Government Department of Innovation, Industry, Science and Research. The HBRG had previously used PC-based systems such as Digivey (CREOSO Corporation, 2013), and web-based systems such as Survey Monkey (Survey Monkey, 2013), and while useful, had found these systems to be increasingly restrictive. The joint development of QuON grew out of a need to facilitate data discovery in ANDS (Australian National Data Service, 2013), and a realisation that the growing sophistication of HBRG research required access to a richer set of survey question types and software functionality.

QuON enables researchers to build complex and personalised survey questions by providing a large tool box of item types and branching patterns. It also allows innovative question types, such as interactive point allocation exercises, that would be too burdensome to complete using a traditional pen and paper survey. Examples of the powerful features of QuON are described in Table 1. These are a combination of successful design features from other survey systems and powerful customised new additions developed by the QuON team.

Feature	Description	Benefit		
Tailoring to improve s	Tailoring to improve survey relevance to end users and to minimise respondent burden			
Complex branching capabilities	Allows questions to be included or excluded based on either raw answers, or calculations (e.g. body mass index (BMI)) based on answers to ANY previous questions, not just the answer to the question immediately preceding the branch. This is illustrated in Figure 1.	Allows creation of surveys that are high relevant for participants, reducing participa burden and survey completion time. This especially important if data are being collected healthcare settings where patients might be called into their consultation at any time and need mo than one session to complete the survey.		
Question composition features	Allows dynamic surveys to be modelled based on participants' responses on three levels:	Increases sophistication of survey items and improves comprehension of survey items for patients		

Table 1. Features	of the OuON	J Survey Soft	ware System
rable 1. reatures	of the Quor	v Survey Son	ware System.

Immediate and tailored feedback of data			
Real-time feedback	Generation of on-the-spot printed or screen- based feedback to patients based on survey answers	Allows data to be used not only for research purposes and to provide feedback to the healthcare system about performance, but for tailored feedback of health information to patients with the potential to directly affect patient health outcomes.	
Prioritisation	Allocation of points to prioritise desired changes (rather than simple ranking exercises)	Provides information and specificity about the relative weight of desired changes, not just a rank order.	
Design factors that a	ffect survey comprehension		
Specification of what is displayed on each screen	The ability to have more than one question on a screen	Reduces the time that it takes to load new pages for each item (Couper et al., 2001), and makes the survey more user friendly for participants. This feature is not exclusive to QuON; (e.g. it is also included in Survey Monkey), but QuON allows greater levels of customisation).	
Graphics	The capability to insert still or moving picture content to the text on survey screens	Improves comprehension and the overall appeal of the survey. Also allows creation of screens that are used exclusively for provision of content, without an accompanying question	
Definition of permissible responses	Allows the researcher to specify limits on the number of digits entered (e.g. limiting postcode to four digits and numbers between 1,000 and 8,000), and prompts that allow participants to re- enter their answer. Also allows specification of answer type, e.g. number vs. text.	Enhances data quality assurance (Dillman et al., 2008).	
Calendar functions and auto pop-up number pads	For answers that require a numerical response a number pad, or calendar, appears on the screen.	Reduces the amount of "free-style" typing required by participants, thereby increasing user friendliness and improving data quality	
Multiple survey completion.	Participation in identified and authenticated surveys can be set to 'once only' or 'multiple permitted',	The ability, for example, for a patient and their family/carer to provide linked input or to track a change over time.	

Privacy and confidentiality			
Flexible survey design to facilitate anonymity and/or confidentiality	The confidentiality of surveys can be specified so results can be anonymous; linked to individual participants; or linked to groups of related participants.	Ethical and analytical benefits.	
Study specific participant lists	The researcher has the option of adding participant details into the secure QuON server. Participant lists (identified and authenticated) are study specific and only visible to individual researchers from that study.	Ethical and pragmatic reasons.	
Restricted access	Access to survey results is restricted so that only the 'owner' of a survey is permitted to access them.	For ethical reasons.	
Improving usability	for researchers		
Survey item re-use	The ability to copy items from previously published surveys into a new survey, and to edit them for re-use.	Increases ease of use for research groups, particularly for questions that are routinely used e.g. gender, date of birth	
Auto-calculate study ID numbers	The ability to generate study numbers based on respondents' answers.	Allows for test-retest or sub-group follow-up.	
Timing statistics	QuON can be asked to record timing data such as time taken to complete the survey, as well as time spent on each question, and number of pauses and restarts.	Provides valuable information on patients' behaviour while taking the survey, for each item, as well as overall.	





Design and Implementation

QuON is a Web application, built using the CakePHP platform (Cake Software Foundation, 2012), that communicates with a MySQL database (Oracle, 2012) used to store both survey definitions and answers collected for each survey. It uses a typical Model-View-Control (MVC) approach (Krasner and Pope, 1988) and utilises Web standards, such as HTML5 and Semantic markup (W3C, 2013) so that the same survey can be presented on different devices such as computers, tablets, and smart phones. The QuON application executes on a central server; researchers and participants are clients of the application, and interact with QuON using a local web browser.

There are five kinds of QuON users:

Administrators, who set up system-wide properties, create new users and groups, and assign users to groups; Researchers, who define and modify surveys;

Survey Owners, who are researchers with the special assigned right to download result data for a particular survey;

Group Administrators, who are researchers with the additional permission to perform administrative tasks only for the group to which they belong. For example, a group administrator can add new users to their group, change owners of surveys, etc.;

Participants, who access and answer the surveys that have been published and allocated to them by the researchers.

Participants are specified on a per-survey basis, and can be either:

Anonymous: participants are not identified before starting the survey and the results are stored anonymously; Identified: participants need to be pre- registered in the system by the researchers responsible for the survey, and must provide their username before they can take the survey; Auto-identified: participants are asked to provide a name (e.g. James0911 – given name concatenated with day and month of birth) to identify themselves before taking the survey, but the username does not need to be pre-registered by the researcher(s) responsible for the survey;

Authenticated: participants need to be pre- registered in the system by the researchers responsible for the survey, and must provide their username and password before they can take the survey.

Each QuON survey comprises an ordered set of individually defined survey objects. A survey object can be:

A question, which displays some stimulus and requests a response from the participant;

A calculation, which evaluates an expression that is potentially based on previous answers. The result is stored but not displayed by the calculation object, and can be used later in the survey as part of a displayed message, or as an input into branching logic. An example would be the calculation of Body Mass Index from answers on height and weight, which will be used to generate appropriated feedback;

A branch object, which customises the order in which survey objects appear to individual participants by 'jumping' to a different location in the survey, based on a conditional expression typically involving previous participant responses;

An information object, which displays text, possibly augmented by still pictures or video, and does not require a participant's answer.

Different question types supported by QuON include: Informational; Text; Checkbox; Radio Button; Button Option; Drop Down; Calendar; Rank Order; Distribution of Points; and Likert Scale. There is also support for dynamic questions such as: Dynamic Checkbox; Dynamic Rank Order; Dynamic Distribution of Points, in which the presented options are based on a subset of answers provided to previous questions; and so-called meta questions that allow multiple questions to be conditionally displayed on the one screeen.



Figure 2: Meta-question and Dynamic Checkbox.

Figure 2 shows a dynamic checkbox question type combined with a meta question type. This presents a dynamic set of checkbox answers based on previous answers, as well as multiple questions for the user to complete on a single screen.

Further, programmers can easily add new question types to QuON by creating new CakePHP Helpers (Cake Software Foundation, 2012). These define the attributes survey designers (researchers) are allowed to specify, how the question should be displayed, how responses should be validated, and how responses are stored.

Several features embedded in QuON enable the survey designer to review the construct and check for errors. Tracking of complex branching is facilitated in survey preview, when a Branch Preview will appear at the location where the branch has been inserted. This displays the rule and what has been entered for the positive and negative destinations, as well as the outcome determined from the previous question:

For example, Figure 3 shows that the primary cancer site was not 2=breast (Result: false), thus the program will progress to the negative destination, in this case the branch which tests if prostate was selected. Surveys can also be validated so errors can be easily identified and remedied.

QuON makes it easy to include customised Cascading Style Sheets (CSS) to change the appearance of any question or information survey object. It is also possible to specify different styles for mobile and non-mobile devices. Customised Javascript (Arnold and Gosling, 2000) is also possible, allowing researchers to implement custom client-side logic on the participants' devices while they are taking a survey.



Figure 3: Branch Preview.

Conducting a Survey

The survey sequence is presented in the order in which the survey objects are inserted into the survey. Questions are processed by displaying the question, and waiting for the participant to provide a valid response. If an invalid response is entered, the respondent is presented with an error message, and asked to enter a new response. Once a valid response is provided, the system moves to the next survey object. Calculation objects evaluate an expression, after inclusion of values from the respondent's previous answers, before control moves to the next

survey object. Branches evaluate their researcher-defined logical condition and, if it is true, cause a jump to the survey object specified in the branch's positive condition; otherwise they cause a jump to the branch's negative destination. A participant may choose to leave the survey early; if the participant is an identified or authenticated user, the survey can be re-joined later, at which time the system presents the participant with the question they were viewing at the time of leaving the previous survey session. This functionality caters for timeouts caused if the participant forgets or is unable to complete a survey in one setting.

Once a participant has completed a survey, he/she can be presented with feedback sheets based on the participant's responses. The content of feedback sheets is defined using easily modifiable templates.

The Owner of a survey is able to view results and timing data online, or to download the data as a Comma-Separated-Value (CSV) file at any time.

Thus aggregated survey results are available immediately, and not delayed by the transcription or scanning necessary for paper-based surveys. QuON also allows researchers to provide survey metadata, in a form suitable for ingestion by ReDBox (Queensland Cyber Infrastructure Foundation, 2012) systems, resulting in production of RIF-CS (Global Registries, 2013) discoverable entries in the Australian National Data Service (ANDS, 2013). The adoption of open standards such as CSV and the RIF-CS formats ensures that researchers are not locked into any specific system for result analysis.

Figure 4 presents a high-level overview of the standard QuON deployment. Connectivity between participants and the QuON server will typically be by Internet, and may be either wired or wireless (including WiFi and 3G/4G/GPRS). The deployment options are flexible, with multiple database servers and web servers being supported under the CakePHP framework.

During the design of the QuON system a strong emphasis was placed on open standards and re-usable components. Open software development platforms such as PHP, combined with the MIT license structure ensures that any user of the system can extend the platform to their specific needs. This extension may, for example, add a new Helper that introduces a custom question type, or a custom 'branding' that tailors the survey output for a specific device or group of users.



Figure 4: High-level overview of a QuON deployment.

User Documentation

The development of specialised QuON software features was driven by the requirements of experts in health behaviour, but implemented by experts in software engineering and development. This process required close collaboration between the scientists and the software developers, and effective transfer of information between their respective disciplines.

To ensure that non-experts can put the capabilities of the developed system to its best use, it was necessary to prepare detailed documentation that described the required steps (and rationales) in a way that can be easily followed. This was achieved by logical organisation of the user document and detailed, step-by-step instructions, which were illustrated by corresponding screenshots.

Addition of new features such as extra question types, and other enhancements, required occasion updates of the user manual. This involved creation of a new version with the relevant changes made throughout the document, as well as a short summary of the changes in the 'Change History' section of the last chapter of the user manual.

Features such as defining branch conditions and the creation of the feedback sheet template require the use of expressions similar to those used in programming languages; these proved to be difficult for the researchers to understand and use. Syntax information was usually provided in the form of templates, with placeholders used to represent the data required by the template. The correct format for provision of such data was described, allowing relatively easy transfer of the syntax used in sample expressions into the specific context required for each survey situation. Detailed examples of desired outcome scenarios were provided which included the syntax used to achieve that outcome; an explanation of the syntax; and the output produced. However, despite the details provided, this aspect of survey design presents the biggest challenge to the researcher.

EVALUATION

A functional and comparative evaluation of the QuON system conducted by the Health Behaviour Research Group (HBRG) at the University of Newcastle. QuON was compared with the two incumbent survey systems, Survey Monkey and Digivey. The features presented in Table 1 were used to produce the comparisons shown in Table 2. Some evaluation results benefit from extra explanation, which is provided in the list of caveats that immediately follows Table 2.

Table 2: Comparison of Features.

Feature	QuON	Digivey	Survey Monkey
Complex branching capabilities	Yes	Partial (1)	Yes
Question composition features	Yes	No	No
Real-time feedback	Yes	No	Yes
Prioritisation	Yes	No	No
Specification of what is displayed on each screen	Yes	No	Partial (2)
Graphics	Yes	Yes	Yes
Definition of permissible responses	Yes	Yes	Yes
Calendar functions and auto pop-up number pads	Yes	No	Yes
Multiple survey completion.	Yes	Partial (3)	Yes
Flexible survey design to facilitate anonymity and/or confidentiality	Yes	Yes	Yes
Study specific participant lists	Yes	No	Yes
Restricted access	Yes	Partial (4)	Yes
Survey item re-use	Yes	No	Partial (5)
Auto-calculate study ID numbers	Yes	LNCY	PUNICA
Timing statistics	Yes	No	Yes

The following caveats apply to the above comparison:

Digivey does support complex branching via its "skip" and "branch" features, though researchers found the two separate concepts confusing and hard to work with in comparison to QuON's single "branch object" approach.

Survey Monkey does permit definition of multiple questions to be displayed on a screen but the selection is static. There is no ability to dynamically choose the displayed questions on the basis of previous answers

Digivey supports multiple runs of a survey but support for resuming a half-complete survey is limited.

Digivey stores all survey answers on the local PC, and unless the researcher chooses the encryption option these are accessible by any user of that PC.

Survey Monkey permits the export and import of survey questions but does not provide the survey or department level re-use that QuON implements.

CONCLUSIONS

Researchers in patient-centred medicine often gather data on health and health behaviours using surveybased assessments. Accurate representation of patients' perspectives is more readily achieved when data collection is efficient, and when participants feel comfortable with the tools used to elicit their opinions. Collected data is most useful when it is available in a timely manner, and in a form suitable for statistical analysis. This paper presents QuON, a software system that supports the definition and conduct of web- based surveys. QuON provides a rich set of question types, together with the ability to define surveys that are tailored to the circumstance of each individual participant. The system design supports a high level of flexibility in survey and participant administration, while ensuring appropriate confidentiality of participant responses. QuON has been specifically developed to fill gaps in the existing incumbent offerings to ensure surveys are as effective as possible a research tool in the public health domain.

The QuON software architecture allows programmers to easily add new question types. Additionally, appropriately skilled researchers can change the way question or information screens are displayed, including different configurations for mobile and non-mobile devices.

QuON continues to evolve to meet its users' needs. The initial version may be downloadedfrom <u>http://code.google.com/p/quon/.</u>

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Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment

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Priority Research Centre For Health Behaviour, University Of Newcastle And Hunter Medical Research Institute, Newcastle, NSW, Australia **Purpose:** The Institute of Medicine (IOM) identified patient-centeredness as crucial to quality health care. The IOM endorsed six patient-centeredness dimensions that stipulated that care must be: respectful to patients' values, preferences, and expressed needs; coordinated and integrated; provide information, communication, and education; ensure physical comfort; provide emotional support; and involve family and friends. Patient-reported measures examine the patient's perspective and are essential to the accurate assessment of patient-centered care. This article's objectives are to: 1) use the six IOM-endorsed patient-centeredness dimensions as a framework to outline why patient-reported measures are crucial to the reliable measurement of patient-centered care; and 2) to identify existing patient-reported measures that assess each patient-centered care dimension.

Methods: For each IOM-endorsed patient-centeredness dimension, the published literature was searched to highlight the essential role of patients in assessing patient-centered care and informing quality improvement efforts. Existing literature was also searched to identify examples of patient-reported measures that assess each patient-centeredness dimension.

Conclusion: Patient-reported measures are arguably the best way to measure patient-centeredness. For instance, patients are best positioned to determine whether care aligns with patient values, preferences, and needs and the Measure of Patient Preferences is an example of a patient-reported measure that does so. Furthermore, only the patient knows whether they received the level of information desired, and if information was understood and can be recalled. Patient-reported measures that examine information provision include the Lung Information Needs Questionnaire and the EORTC QLQ-INFO25. In relation to physical comfort, only patients can report the severity of physical symptoms and whether medications provide adequate relief. Patient-reported measures that investigate physical comfort include the Pain Care Quality Survey and the Brief Pain Inventory. Using patient-reported measures to regularly measure patient-centered care is critical to identifying areas of health care where improvements are needed.

Keywords: patient-centered care, quality of care, quality assessment, patient-reported measures

Measuring the quality of patient-centered care

The Institute of Medicine (IOM) recommended that to achieve high quality health care, improvements were needed to the delivery of patient-centered care.¹ Patient-centered care is responsive to patients' values and needs and patient preferences guide decision-making.¹ The IOM endorsed six dimensions of patient-centered care which stated that care must be: 1) respectful to patients' values, preferences, and expressed needs; 2) coordinated and integrated; 3) provide information, communication, and education; 4) ensure physical comfort; 5) provide emotional support – relieving fear

and anxiety; and 6) involve family and friends.¹ The six dimensions of patient-centered care endorsed by the IOM¹ were established by the Picker Institute.² During the development of the six patient-centeredness dimensions, Gerteis et al drew on empirical research, theory, and patient and provider surveys to maximize validity.² The Picker Institute³ and the International Association of Patients' Organizations (IAPO)⁴ have proposed alternative frameworks of patient-centered care. However, the principles in the Picker Institute's³ and IAPO's⁴ models of patient-centered care are similar to and largely overlap with the IOM-endorsed patient-centeredness dimensions.

Patient-reported measures developed to assess the quality of patient-centered care include measures of satisfaction with care and measures of experiences of care.^{5,6} Patient-reported measures are essential to quality improvement efforts as they provide the patient's perspective in relation to areas of health care that are of high quality and aspects of care where improvements are needed.⁷ Patient-reported measures are arguably the best way to assess constructs that relate to patient-centeredness given that patient-centered care is responsive to the patient and is guided by patient preferences.¹ Patient-reported measures are also able to collect information that can only be obtained from patients themselves such as whether the patient received adequate pain relief.⁸

Given the IOM used the six patient-centeredness dimen-sions developed by Gerteis et al² to recommend improvements to the delivery of patient-centered care,¹ the IOM-endorsed patientcenteredness framework is used in this article. The objectives were: 1) to use the six IOM-endorsed dimensions of patient-centered care as a framework¹ to highlight the crucial role of patient-reported measures in the accurate assessment of the quality of patient-centered care; and 2) to identify examples of existing patient-reported measures that measure each IOM-endorsed patient-centeredness dimension. To examine these objectives, the published literature was searched to obtain evidence in relation to the role of patients in the assessment of patient-centered care and the importance of patients' perspectives for informing quality improvement efforts. The published literature was also searched to identify examples of patient-reported measures that assessed each IOM-endorsed dimension of patient-centered care.

This article makes an important contribution to the ^{improved} literature by collectively examining all six IOM-endorsed provided Page **363** of **464**

patient-centeredness dimensions and discussing reasons why it is important to measure each dimension of patientcentered care. Examples of measures that assess the patient-centeredness dimensions are provided to encourage rigorous assessment of patient-centered care. Using a suite of measures to comprehensively and accurately assess from the patient's perspective all dimensions of patient-centered care could assist with prioritizing areas of patient-centeredness where improvements are most needed and facilitate quality improvement efforts.

Respectful to patients' values, preferences, and expressed needs

The IOM recommended that health care should be respectful of patients' cultural and other values, preferences, and needs.¹ Patients should feel able to express views, be involved in decision-making according to their preferences, and receive respectful care.¹ Patient-centered communication delivered by health care providers has been associated with better patient emotional health,⁹ and answering patient questions associated with better long-term patient psychosocial adjustment.¹⁰ Furthermore, patients with a good health care provider relationship indicated greater satisfaction with care and adherence to prescribed treatment.¹¹

A mismatch between physicians' understanding of patients' preferences for treatment and decision-making has been found.¹¹ However, patients themselves are most knowledgeable about whether care aligns with their values, preferences, and needs. The mismatch between physicians' perspectives and patients' views regarding the delivery of care highlights the need to regularly measure patients' preferences and experiences to ensure that care is responsive to patient values and needs. Examples of patient-reported measures that assess patient values, preferences, and needs include the Measure of Patient Preferences, that examines the manner physicians deliver care about cancer diagnosis and management¹² and the modified version of the Perceived Involvement in Care Scale.¹³

Coordinated and integrated care

The IOM stated that health care should be coordinated and integrated and include timely transfer of up-to-date patient information to health care professionals, and efficient transition of patients between health care settings.¹ A systematic review reported that effective interventions that improved the coordination of cancer care were those that provided follow-up, case management, and one-stop clinics.¹⁴ Research with newly diagnosed colorectal cancer patients indicated that problems with coordination of care were associated with poorer ratings of overall cancer care.¹⁵

obstructive pulmonary disease, demonstrated improvements to length of stay, readmission rates, and hospital admissions per patient per year.¹⁶

As health care increasingly occurs across various settings and involves several health care professionals, it may be dif- ficult for these providers to determine whether overall patient care was coordinated and integrated. Therefore, patientreported measures could be used to capture patients' perspectives of the delivery of coordinated and integrated care and this information could supplement health care records in order to assess the quality of this aspect of care. Patientreported measures that assess the delivery of coordinated and integrated care include the Cancer Care Coordination Questionnaire for Patients,¹⁷ the Client Perceptions of Coordination Questionnaire,¹⁸ and the Care Coordination Measure for the Consumer Assessment of Healthcare Providers and Systems (CAHPS[®]) Medicare Survey.¹⁹

Information, communication, and education

The IOM recommended that patients receive clear, accurate, and understandable information about all aspects of care according to the patient's preference, including in relation to diagnosis, prognosis, treatments, follow-up, and support services.¹ A systematic review of cancer patient informational needs indicated that 10%–24% of patients had unmet information needs at diagnosis and 11%–97% had unmet information needs during treatment.²⁰ A survey of advanced cancer patients reported that they were least satisfied with information regarding prognosis and pain management.²¹ Diabetes patients have also reported dissatisfaction with information about the disease and medications (24%).²²

Only the patient knows whether they received the level of information desired, communication was appropriate, and if information was understood and recalled, highlighting the importance of using patient-reported measures to accurately assess the quality of information delivery in regards to patient care. Examples of patient-reported measures that assess information provision in relation to health care include the Lung Information Needs Questionnaire, developed with chronic obstructive pulmonary disease patients,²³ and the EORTC QLQ-INFO25 a measure for cancer patients.²⁴

Furthermore, a specialized respiratory coordinated care community program for people with advanced chronic

Physical comfort

The IOM recommended that health care promptly provide appropriate pain relief to patients and attend to physical symptoms and needs.1 Cancer patients, particularly those with advanced disease, commonly experience fatigue (60%–90%)^{25,26} and pain (64%).²⁷ Fatigue after stroke ranges between 38% and 77%,²⁸ and nociceptive pain is experienced by 5%-84% of stroke patients.²⁹ Despite the availability of efficacious treatments, almost 50% of cancer patients with pain are under-treated,30 and 40%-73% reported receiving no assistance or treatment for cancer-related fatigue.^{26,31} Cancer patients who experience fatigue use health care services more frequently than those who do not experience fatigue.³² Additionally, more than two-thirds of stroke patients with longterm pain had no or inadequate prescribed pain treatment.²⁹ Patient-reported measures are recognized as the gold standard for assessing cancer pain and fatigue.³³ Only patients themselves can report the severity of fatigue, pain or physical symptoms, and whether medications provide adequate pain relief. This highlights the importance of using patient-reported measures to determine whether health care appropriately attends to patient comfort. Patient-reported measures that assess physical comfort include the Pain Care Quality Survey,³⁴ the Brief Pain Inventory used for clinical pain assessment across cultures,³⁵ and the Patient-Reported Outcomes Measurement Information System Pain Interference measure.36

Emotional support – relieving fear and anxiety

The IOM stated that health care should address patients' emotional and spiritual concerns, including anxiety due to uncertainty, fear, financial impact, or effect on family.¹ Anxiety ranges from 10%–49% in cancer patients and depression from 0%–49% and are highest during cancer diagnosis and recurrence.³⁷ A literature review indicated that 9%–26% of stroke survivors experience severe depression, 16%–52% acute depression, and 17% agoraphobia.³⁸ Unmet need among cancer patients for psychological assistance ranges from 12%–85%, with such unmet needs most common during treatment.²⁰ Furthermore, almost one quarter (23%) of people with diabetes wanted more reassurance and psychological support.²²

Clinician accuracy of patient psychosocial well-being can Page **364** of **464**

be poor, as demonstrated by only 17% of cancer patients classified as clinically anxious and 6% as clinically depressed perceived as such by oncologists.³⁹ Using patient-reported measures to assess the level of emotional support provided can inform quality improvement efforts by determining if health care services adequately address patients' emotional needs and reduce psychological distress. Widely used patient-reported measures for assessing the emotional well-being of patients include the Hospital Anxiety and Depression Scale⁴⁰ and Beck Depression Inventory.⁴¹

Involvement of family and friends

The IOM recommended that family and friends are involved in patient care and decision-making according to patient preferences and that care is responsive to the needs of family and friends.¹ Family and friends can improve patient-provider rapport, facilitate information exchange, encourage decisionmaking involvement, and increase patient satisfaction.⁴² However, families and friends of stroke patients have reported feeling inadequately informed about and involved in patient care.⁴³ A review found that major issues faced by cancer caregivers included managing their own and patient's psychological concerns, medical symptoms, side effects, and daily activities.⁴⁴ Family members of cancer patients have been found to be more likely to have unmet needs about information in relation to supportive care than for medical information.⁴⁵

Only the patient can determine if family and friends were involved in care according to the patient's wishes. A systematic review of patient-reported measures examining patient-centered care among cancer patients reported that few patient-reported measures assess whether the involvement of family and friends in health care aligns with patient preferences.⁷ Family and friends are best able to accurately assess if their own concerns and needs were adequately addressed during the provision of health care. Measures that assess the needs and experiences of family and friends include the Support Person Unmet Needs Survey⁴⁶ and the Quality of Family Experience measure, that assesses the experiences of families with a patient with a serious illness.⁴⁷

Conclusion

Accurate measurement of the quality of patient-centered care is essential to informing quality improvement efforts. Using patient-reported measures to measure patient-centered

care from patients' perspectives is critical to identifying and prioritizing areas of health care where improvements are needed. Patients are well positioned to provide reliable and valid information about the delivery of patient-centered care. For instance, only patients are able to accurately determine whether care was respectful to patients' values, preferences, and needs. Regularly using patient-reported measures to accurately assess the quality of patient-centered care could assist with promptly identifying areas of care where improvements are required and consequently may facilitate advancements to the delivery of patient-centered care.

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Disclosure

The authors declare that they have no conflict of interest.

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A narrative overview of the cancer patient-journey: minimising delay and improving access to an ideal cancer care system.

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Abstract

Access to coordinated and multidisciplinary cancer services is associated with improved patient outcomes. Inequitable or delayed use of cancer services has been reported and additional evidence is needed to identify those groups who may experience barriers to accessing optimal cancer care. This narrative overview summarizes patient experiences of timely and comprehensive services across the cancer journey and identifies factors which result in inequitable use. The results present a complex picture in which individual, provider, and system factors influence patient experiences and service use across the cancer journey. Recognizing cancer symptoms and completing cancer screening was associated with patient demographic characteristics, and psychological barriers influenced willingness to seek care. Within primary care settings, the poor positive predictive value of cancer symptoms was suggested as a major cause of delay. Within specialist care, specific socioeconomic and ethnic groups were more likely to be diagnosed with advanced disease and had differential access to cancer treatments. Other factors associated with inequitable or delayed access include workforce capacity, geographic distribution of services, and diagnostic imaging. Given the complexity of cancer services, barriers exist when transitioning between the phases of the cancer journey and include inconsistent referral processes and ineffective information transfer. Case studies of health service interventions are provided in which technology-based approaches improved patient outcomes via easily accessible, coordinated cancer services. These cost-effective approaches are promising opportunities to overcoming barriers to equitable and timely cancer care.

Introduction

The incidence and prevalence of cancer is increasing with a greater proportion of individuals living with and surviving cancer.^{1,2} Cancer diagnosis and treatment involves navigating a complex set of services which poses a system-level challenge for the delivery of high-quality care. The Institute of Medicine (IOM) proposes six components to high-quality care: equity, effectiveness, safety, efficiency, accessibility, and patient-centeredness.³

The IOM provides a further ten recommendations for cancer care which focus on receiving timely evidence-based and multidisciplinary care with supportive services available (ie services to meet patients' physical, informational, financial, emotional, psychological, social, spiritual, and daily living needs).⁴⁻⁶ This represents ideal care from a patient perspective.^{4,5} The IOM recommends additional evidence is also needed to understand why specific groups may not receive ideal cancer services including those who choose to forgo, delay, limit or cease care.⁴ A recent review suggests that while progress has been made in relation to these recommendations, there remains further opportunity to improve the equitable and timely provision of multidisciplinary comprehensive cancer care.⁵

For individuals with sudden onset of a chronic condition, such as cancer,⁷ accessing healthcare is a continuous experience involving multiple interactions with health services and professionals. This process is commonly referred to as the 'cancer journey'. Phases of this journey have been outlined in the Aarhus Statement and the Model of Pathways to Treatment and typically include: 1) pre-diagnostic phase including patient symptom appraisal or abnormal cancer screening results; 2) primary care with appraisal and investigation from a health professional; and, 3) specialist care with further appraisal and treatment initiation (Figure 1).^{8,9} This is not a linear process and individuals will receive care across phases by a range of health professionals. More than half of cancer patients will experience some level of concern regarding delays at one or more phases of the cancer journey.¹⁰ Inequitable access or delays across the cancer journey are the focus of this narrative overview.



Figure 1: The cancer journey, with phases adapted from the Models of Pathways to Treatment and Aarhus Statement

Equitable Access to Cancer Care

The concept of access to care is complex but essentially involves the ability to receive timely and equitable healthcare relative to individual need with the goal of optimising health outcomes.¹¹ The ability to access care will depend on both patient and service characteristics.¹¹ Perceived or real barriers to optimal services can alter an individual's help-seeking behaviours such that they may choose to forgo, delay, limit or cease healthcare. Barriers include those which impede or reduce the availability, accessibility, affordability, accommodation or acceptability of care.¹² Addressing barriers to oncology care may be particularly relevant given continuity of care and treatments are critically linked to improved patient outcomes.^{13,14}

The global economic cost of the premature death and disability associated with cancer is USD 900 billion and the costs of treatment and survivor care are projected to increase.^{15,16} Equitable access to healthcare may be cost-effective through efficient cancer care provision whereby: i) individuals rely upon less-costly preventative or primary care and are referred only when more complex care is required; and ii) early cancer detection reduces morbidity and mortality, thus alleviating medium- to long- term costs.¹⁷Timely and equitable access to healthcare has not yet been achieved in many high-income countries including those with publically-funded insurance or 'free at the point of use'

schemes inthe United Kingdom (UK), Canada and New Zealand.^{18,19} Bleich and colleagues (2012) provided a comprehensive review of key national policy and recommendations to address the inequities experienced by disadvantaged groups in high-income countries.²⁰

Timely Access to Cancer Care

Defining timely care or the absence of delay is complex and is influenced by patient, provider and system factors, such as health seeking behaviours, referral practices, and service availability. Recognizing this, the Cancer and Primary Care Research International Network formed a consensus working group with the resulting Aarhus statement defining specific intervals at which a patient may experience acceptable or unacceptable delay.⁸

Delay can occur at any phase of the cancer journey and timely access to a range of services has been associated with increased patient satisfaction and improved emotional wellbeing.^{10,21} Patient-perceived delays in receiving a cancer diagnosis are a leading cause of medical litigation in general practice.²² A systematic review of upper gastrointestinal cancers indicated that the delays reported in the prior five years are comparable to those reported 20 years ago.²³

National initiatives to encourage e early cancer diagnosis and treatment have been adopted in several countries such as the UK's National Awareness and Early Diagnosis Initiative.^{24,25} These programs frequently define goals for wait-times based on clinically significant patient outcomes and include triage systems for referral.²⁵ For example, in the UK a patient with an urgent referral to a medical oncologist should be seen within 14 days.

Access to Coordinated Multidisciplinary and Comprehensive Cancer Care

Multidisciplinary cancer care requires patients to transition between and within various locations or settings (eg primary care, radiology, pathology, surgical, or oncology services). For example, the average cancer patient in the UK will access a total of 28 services.²⁶ With growing evidence on the value of supportive care following patient-centered approaches, the number of health professionals involved and service complexity is likely to increase.²⁷

Coordination of multidisciplinary services and professionals is challenging, but essential to high-quality healthcare.³ For example, primary care providers who received detailed summaries of chemotherapy regimens were more likely to report greater satisfaction and confidence in treating adverse events at follow-up phases.²⁸ For oncology patients with depression, collaborative care involving a cancer nurse coordinator, routine screening and a multidisciplinary team (MDT) resulted in a significant, sustained and cost-effective reduction in depression.²⁹ MDTs are endorsed by the European Partnership Action Against Cancer as a strategy to encourage communication and coordination and are associated with improved patient outcomes.²⁷

Examining the patient experience with poor or inequitable access to timely and comprehensive services

While a number of studies explore access to particular aspects of care, literature providing an overview of access across multiple phases of the patient journey is needed.³⁰ Just as access to care is a continuous process, in order to truly provide quality care, it is important to gather evidence regarding timely and equitable access across multiple phases of the patient journey. This may also identify where transitioning between phases results in a poor experience of care. Such information will assist from a system perspective in improving delivery of patient-centred access to timely and comprehensive cancer care.

Objectives:

To explore equitable access to timely and comprehensive care across the cancer journey, the purpose of this narrative overview was to:

- 1. Describe oncology patients' experiences when accessing services.
- 2. Identify the factors associated with access barriers.
- 3. Examine the barriers to coordinating and transitioning between phases of the cancer journey.
- 4. Provide a short case study of a health service intervention that addressed barriers and thus led to increased access to ideal cancer care.

Methods

An interpretive review was conducted following narrative summary methods where evidence was selected with the intent to inform health policy and intervention.³¹ The volume and scope of the evidence on the accessibility and quality of cancer is large and a number of approaches are required to explore a complex and sequential process, such as the cancer journey. A narrative review is a more-flexible approach to generate an overarching summary inclusive of multiple forms of evidence.

Several methods generated a comprehensive pool of peer-reviewed qualitative and quantitative articles. Studies were retrieved from sources such as the Cochrane Database of Systematic Reviews; PubMed; key health organization websites (e.g. World Health Organization and International Agency for Research on Cancer) and country-specific organizations (National Health Service, IOM, and Australian Institute of Health and Welfare). The reference listings of all articles also were soft-searched for additional studies. This review also drew upon the experience of the research team, which includes several health service researchers, behavioural scientists, one primary care provider, one surgeon, and two medical oncology specialists.

Raw data from retrieved studies were recorded and used to generate thematic headings relating to timely and equitable access to multidisciplinary cancer care. Themes were generated iteratively by the research team and based on recurrent concepts within the articles. Themes were classified according to the phase of the cancer journey. Articles were extracted from sources until thematic saturation was achieved.

While articles were not excluded based on study design or quality, to provide robust evidence several data types and samples were sought. This included: randomized controlled trials; cohort and population-based samples; systematic reviews or meta-analyses; and studies using national cancer datasets (e.g. International Cancer Benchmarking Partnership and National Audit of Cancer Diagnosis in Primary Care). Only articles focusing on differences in access to cancer care in high-income OECD (Organisation for Economic Co-operation and Development) countries were included.³² These countries generally have the full range of cancer care options available, and therefore, within-country

access disparities can be more clearly examined. Adolescent, palliative and survivorship services were deemed out of the scope of this review and excluded. These groups report specific care needs which warrant separate discussion.

The PICO (Population, Intervention, Control, and Outcome) framework was used to describe casestudies of health service interventions for each phase of the cancer journey. These studies were selected based on the APEASE criteria, whereby interventions possessed one or more of the following attributes: affordable; practical; effective/cost-effective; acceptable; safe; and/or equal.³³

Results and Discussion

1. Pre-diagnosis Phase: i) Patient recognition of symptoms and ii) Uptake of screening Patient recognition of symptoms

Experiences: Delays in this phase of the cancer journey have been classified as 'patient' delay'¹, with health-seeking behaviour and literacy level playing an influential role. ^{8,9} A Danish population-based cohort study reported the median time interval for recognizing symptoms and presenting to a health professional, was 21 days.³⁴ However, the median time varies according to cancer type and delays upwards of nine months have been reported for lung cancer patients.³⁴⁻³⁷ This phase of the cancer journey may not apply to individuals who experience an asymptotic cancer which is detected through screening, completed by primary care professionals or population-based initiatives.

Associated factors: Systematic reviews suggest delayed patient presentation to a health professional is largely due to an inability to recognize symptoms and the potential seriousness of those symptoms.^{23,36,38} To explore patient symptom recognition and subsequent health-seeking behaviours, articles using the Cancer Awareness Measure (CAM) or Awareness and Beliefs about Cancer Measure (adapted from the CAM for use in the ICBP) were selected.³⁹⁻⁴² Both measures are validated assessments of an individual's ability to recognize a hypothetical symptomatic cancer and the time they would take to seek care with such symptoms.^{43,44}

A British population-based study found poor recognition of cancer symptoms, such as unexplained bleeding, changes in a mole's appearance or lumps and swelling, in lower socioeconomic groups (defined by an individual's occupation level).³⁹ Caucasian participants were also able to recognize significantly more cancer symptoms than participants of other ethnic groups, even after controlling for socioeconomic status (SES). This finding has been replicated and a study of six ethnic minority groups found differential ability to recognize common cancer symptoms.^{40,41} This study also reported time taken to present to a health professional was associated with ethnic group.⁴¹ However, inconsistent findings on the relation of demographic characteristics and help- seeking behaviours suggest patient-appraisal is complex and multifactorial.⁴⁰ Additional characteristics associated with ability to recall a greater number of symptoms include: increasing age, female gender, being married, and higher education levels.³⁹⁻⁴¹

ii) Equitable uptake of screening

Experiences: A Canadian review of service access suggests high levels of inequity are experienced at screening phases.³⁰ Furthermore, disparate use of screening services may have widened health disparities.^{30,45,46} Given the considerable debate surrounding the evidence base informing screening standards, this section focuses on two relatively uncontroversial forms of screening – faecal occult blood testing (FOBT) for colorectal cancer (CRC; or bowel cancer) and

Papanicolaou (Pap) smear for cervical cancer. Population-based screening is a national priority for many high-income countries and has resulted in government-subsided FOBT programs such as those found within the UK, Canada and Australia.^{24,47-49}

Associated factors: To explore CRC screening uptake rates, articles evaluating the implementation and success of the UK population-based FOBT screening program, the National Bowel Cancer Screening Program (BCSP) were reviewed.^{45,48,50,51}

In the first 30 months of the program, only 32% of individuals living within most socio- economic deprived areas completed screening compared to 49% in the least deprived area.⁴⁵ Lower uptake was also significantly associated with higher ethnic diversity of the respondent's community, transiency and

poorer health. After controlling for these factors, the area socioeconomic deprivation accounted for 62% of the variation in uptake rates. The SES gradient was also observed after 2.6 million invitations were distributed.⁵⁰ Additional factors associated with poor FOBT uptake include: limited health literacy; male gender; increasing age; and, poorer self-reported health.^{48,51} Income- related inequity in cancer screening has been identified within other countries, such as Canada.³⁰

Individual characteristics are also associated to Pap smear uptake. For example, older and lower SES individuals report lower screening rates in a population-based, retrospective cohort study with medical record linkage.⁵² An Australian cross-sectional survey of three cohort samples (20-24; 40-44; and 60-64 years of age) using administrative data linkage reported variables associated with increased odds of screening.⁵³ Significant variables in multivariate models included (in decreasing order strength): greater health service use; not reporting childhood sexual abuse; younger age; non- smoking and no lifetime history of drug-use; having children; no/low levels of anxiety; not being welfare reliant and employed; not being obese; and better physical functioning. Of these variables, nine observable traits accounted for 74% of non-participation.

For some ethnic-minority groups, cancer screening can be incongruent with cultural norms or not wellunderstood within the community. For example, focus groups conducted with Native American women (5 groups including 102 individuals) suggest the possibility of non-Indigenous health professionals and medical mistrust are important considerations when deciding to screen or vaccinate for cervical cancer.⁵⁴ A meta-analysis of cervical cancer risk within Australian, Canadian, New Zealander and American Indigenous communities experienced greater cancer-specific morbidity and mortality than their non-indigenous counterparts.⁶⁶ Authors suggest the disparate outcomes were largely a result of limited participation in screening programs.

Seeking primary care services

Experience: Ideally, individuals access healthcare soon after symptom recognition or receiving an abnormal screening. However, individuals may delay care based on practical or psychological factors.

Associated factors: As part of the UK BCSP, nurse specialists contacted individuals with an abnormal FOBT result and offered direct access to colonoscopy. A small but significant amount of variation in colonoscopy uptake was explained by area socio-economic deprivation, age and gender, self-assessed health, and non-white ethnicity diversity.⁵⁵ Other studies using medical administrative data have reported similar associations with patient characteristics for any type of CRC screening (FOBT, colonoscopy, or CT colonography).^{46,56} A sub-optimal proportion of individuals receiving an abnormal Pap smear result also completed subsequent diagnostic investigations.⁵² This was associated with socioeconomic group and age.

Complex psychological reasons may underpin individuals' reluctance to seek subsequent care and transition into the next phase of the cancer journey. This includes fear, anxiety or embarrassment about screening procedures, or a general medical mistrust. ^{23,41,42,48,57} A systematic review also suggests patients may rationalize delaying care as watchful waiting, or attribute symptoms to a more benign condition.³⁶ Conversely, cancer fatalism, wherein an individual believes they have cancer but it unavoidably lead to death, has been associated with decreased screening uptake and is more common within specific ethnic groups.^{48,58}

Some cancer types may be stigmatised due to the respective causes, treatments or outcomes; potentially causing an access barrier.⁵⁹ For example, individual interviews with lung cancer patients show that patients delay reporting symptoms due to anticipation of blame associated with smoking.⁶⁰ Similarly, a UK focus group study of females representing diverse ethnic backgrounds reported concerns that a positive cervical cancer test could result in blame or accusations of being unfaithful.⁶¹

Within the general public, those who perceived practical or psychological barriers were more likely to delay seeking care for a suspected cancer symptom or abnormal screening result.^{36,42,62} A cross-sectional study using the CAM reported practical barriers to help-seeking included being too busy, or having other things to worry about.⁴² An additional study reported one in two patients reported a barrier to seeking care following an abnormal cervical screening result.⁶² This increased delay and was associated with comorbidity; limited or lack of insurance coverage; not believing it was a priority; being from out of town; employment demands; and having a system problem, such as difficulty with scheduling an

appointment. Hispanic, Spanish-speaking, married, younger and uninsured participants were more

likely to report a barrier.

Box - Case Study 1.1 Improving access to and uptake of screening using patient navigation A randomized controlled trial by Lasser et al (2011) demonstrated positive results for a telephone delivered, patient navigation intervention for increasing CRC screening rates in 465 participants across low-income populations in the US⁷⁴:

Population: Mean age was 61.3 years and sample was predominantly female (61.5%). Approximately half indicated English as their primary language (48.2%), with the remainder speaking Portuguese (20.0%), Spanish (13.8%), or Haitian Creole (18.1%).

Intervention: A mailed information brochure and up to 6 hours of telephone contact from trained multilingual community health staff consisting of tailored education and support to encourage CRC screening. *Control:* Usual care.

Outcomes/effectiveness: Findings showed that those allocated to the intervention group were significantly more likely to be screened at 1 year (33.6% vs 20%; p < 0.001).

When applying the APEASE criteria:

Affordability: The authors suggested that having navigators trained across multiple cancer screenings and at reduced contact time would improve feasibility regarding cost. A subsequent study has demonstrated that navigation interventions can be cost-effective, with 1 hour navigations particularly cost saving⁷⁵. *Practicability:* The authors described the training program undertaken by staff and described the planned content of the telephone contact as per the intervention.

Acceptability: Not addressed.

Side effects/safety: N/*A*.

Equity: This intervention was shown to be effective in low-income populations, which are reported to under-represent cancer screening practices.

Primary care phase: i) Equitable access to primary care services and ii) Timely access to coordinated diagnostic investigation

In most high-income countries, the first point of care for individuals with a suspected malignancy is a primary care practitioner (PCP). Delays in this phase have been attributed to the practitioner and system with PCP availability, professional ability to differentiate symptoms, access to diagnostic investigations, and referral processes influencing delay. ^{8,9,34} Equitable access is frequently assessed by examining the patterns of service utilization according to demographic, clinical, or health insurance characteristics. This information is collected by national administrative databases and cancer registries such as the Surveillance, Epidemiology and End Results – Medicare database (US) and National Cancer Data Repository (UK). To explore differential access to PCPs, diagnostic services, and associated outcomes, articles using such information sources were reviewed.⁶⁵⁻⁶⁸ Articles evaluating diagnostic processes and subsequent referral were also reviewed and include those assessing the National Awareness and Early Diagnosis Initiative (NAEDI) and associated National Audit of Cancer Diagnosis in Primary Care.^{34,37,69-78} This was supplemented by qualitative research exploring professionals' and patients' perspectives on providing, receiving, or transitioning between, primary and specialist care.⁷⁹⁻⁸¹

Equitable access to primary care services

Experiences: Equitable access to primary care is a precursor to an ideal cancer care system with PCPs playing a vital role in cancer screening, detection and subsequent referral for specialist confirmation and treatment. Up to 90% of cancer cases will involve a PCP in the diagnostic process, and for some patients, PCPs also coordinate ongoing cancer treatment or survivorship care. ^{34,82,83}

Associated factors: Disparate PCP use can be linked to poor patient outcomes largely as a result of delayed detection or reliance on acute, emergency services. This has been reported in countries with healthcare systems designed to encourage universal access. For example, a Canadian population based study reported fewer primary care visits (as well as fewer specialist appointment and greater length of hospital stays) was significantly associated with a shorter time to death for

1885 individuals with CRC.⁶⁵ Within the UK, patients diagnosed within emergency settings had significantly lower one-year survival rates and were more likely to be impoverished.⁶⁸ A large cohort study using administrative medical data reported black patients within the US were significantly more likely not to have visited a physician prior to receiving a cancer diagnosis.⁶⁷ Increased PCP supply has been associated with decreases in cervical cancer incidence and mortality.⁶⁶

Timely access to coordinated diagnostic investigations

Experiences: Patients should have equitable access to diagnostic investigations to quickly confirm a possible cancer malignancy with subsequent referral to specialist care. Reviews of upper gastrointestinal cancers and other common symptomatic cancers reported inaccurate tests and previous negative results were associated with increased delay.^{23,36} In a Danish population-based cohort study, most PCPs initiated diagnostic investigations immediately upon patient presentation.³⁴ This may include referral for biopsy, imaging, or endoscopy. Some individuals will be immediately referred without diagnostic investigation.

Associated factors: Many benign and common conditions share similar symptoms to some cancer types, and can often lead to misdiagnosis and subsequent delay. Cohort studies report low positive predictive values for symptom associated with some cancer types (typically under 5%) and low positive predictive values for PCP suspicion (approximately 10%).^{69,70} Accordingly, a review of upper gastrointestinal cancer diagnosis found treatment for a benign condition (identified through use of acid suppression treatment) was a common reason for diagnostic delay.²³

Working through differential diagnoses for common symptoms may require multiple PCP visits. The number of pre-referral consultations was associated with further delay in the National Audit of Cancer Diagnosis in Primary Care.⁷¹ This finding is supported by a cross-sectional survey completed by 65 192 National Health Service (UK) patients (UK) where individuals who had not seen their PCP before diagnosis experienced shorter diagnostic delay.⁷³ This maybe largely due to screening practices and reemphasises the importance of early phases in the cancer journey, particularly equitable uptake of screening. Qualitative research with 242 CRC patients also found having a regular PCP was associated with greater diagnostic delay.⁷⁴

For PCPs, symptom appraisal is a delicate balance between over-investigation, with implications for patient distress and cost-efficiencies, and the threat of missing a critical but low incidence cancer diagnosis. An ecological study of 19 European countries found lower one-year cancer survival scores in those countries where PCPs act as gatekeepers to subsequent specialist care.⁷² This may signal a system deficit where PCPs are expected to quickly identify and transition patients to the next phase of the cancer journey, but are limited by system structure and resources.

PCPs have variable access to timely diagnostic testing and poor availability of diagnostic services may be a more pronounced barrier in areas with fewer resources.⁸⁴ Rural or socioeconomically deprived areas report differential survival rates and this disparity is widening for colorectal, breast, lung and prostate cancers.^{86,87} In countries characterized by large areas of geographic remoteness, such as Australia where 32% of the population resides outside of a state Capital city.⁸⁵ this disparity may affect large subsections for the community who are already at risk for worse health outcomes. For example, Australians of Aboriginal or Torres Strait Island descent are more likely to reside within remote communities and are reported to experience greater social disadvantage with relatively worse health outcomes.^{86,87} PCPs may be the only readily available source of cancer care in rural areas. Survey and interview data provided by Australian PCPs indicate coordinating cancer services is largely viewed as within the scope of the local services and PCPs in these areas desire greater knowledge and confidence in ongoing cancer care. ^{75,79} Delay in this phase of the cancer journey is not solely attributable to the way in which a cancer manifests or the availability of high quality services. Patient demographic characteristics, such as SES and education, have been associated with greater delay.^{74,76} Qualitative interviews with 242 CRC patients including medical data linkage found patients' and professionals' willingness and ability to discuss symptoms (based on Relational Communication Scale) was essential to quickly differentiate symptoms and decide upon a course of action.⁷⁴ Communication styles differ by participants and those who reported difficulties in expressing symptoms experienced greater delay.

Coordinating primary and secondary care

Experiences: In a national audit of 13 035 cancer cases the median delay between first presenting to a PCP and a subsequent referral to a specialist was approximately 5 days; 82% of patients were referred after one or two PCP consultations.⁷¹

Coordinating and referring individuals to multidisciplinary and specialist care presents a number of barriers. Research exploring PCPs' perceptions of their role in coordinating cancer care have reported a lack of referral guidelines, complex or non-standardised referral pathways, and ineffective information transfer and communication with specialists.^{77,79,80} For example, a qualitative study of 53 patients, caregivers, and health professionals identified six areas resulting in fragmented care: confusion surrounding health professionals' roles and primary contacts for patients; inconsistent or unsuccessful adoption of MDT meetings; difficulty transitioning between care sites; inadequate communication between primary and specialist physicians; inequitable service distribution, including regional disadvantage and limited public-funded supportive services; and physician shortages.⁸⁰

Associated factors: A US cross-sectional study reported 3 in 5 physicians experience at least one barrier in the referral process (1562 PCPs and 2144 specialists) with barriers associated with lower physician satisfaction.⁷⁸ Restrictive provider networks were the most frequently cited barrier (42%) followed by insurance preauthorization requirements (34%) or patients' inability to afford specialist care (34%).

Referral practices have been shown to vary by PCPs and cancer type – likely due to the wellacknowledged difficulties in differentiating between symptoms. ^{34,36,37,71,84} Patients have identified slow referral processes and poor continuity and communication as sources of dissatisfaction.⁸¹ To reduce variation and dissatisfaction, many national healthcare systems are looking closely at fast- track referral initiatives and diagnostic guidelines in primary care settings.^{25,37,82,88}

Box - Case Study 2.1: Improving timely PCP referral to diagnostic investigation using electronic prompts

Primary care physicians play an important role in referring patients to specialist investigation when suspected of cancerous symptoms. Fast-track referrals may assist patients in expediting the wait period to enable timely access to medical test in urgent instances. In some countries, such as the US, UK and Canada, national guidelines recommend PCP make referrals within two weeks of abnormal FOBT results to minimise diagnostic delay^{2, 105, 106}.

A before and after study by Larson, Ko and Dominitz (2009) examined the effectiveness electronic reminders for timely referrals following positive FOBT results¹⁰⁷:

Population: 1,102 veteran patients attending primary care clinics across the US. Mean age was 64.5 years, with majority represented by males (95.1%).

Intervention: Patients identified as having an abnormal FOBT in 2005-2006 were classed as cases. This group had an electronic prompt programmed into their electronic medical record, which alerted respective PCPs to refer for colonoscopy examination when they next logged into the medical record system. *Control:* Patients identified as having an abnormal FOBT test between 2004-2005 were classed as controls. This group received usual care.

Outcomes/Effectiveness: Findings showed that the intervention was significantly associated with improved gastroenterology consultation within 14 days (increased by 20.3%, p < 0.001) and significantly prompter consultation. During the intervention, the median time to colonoscopy decreased by 38 days ($P \le 0.0001$).

When applying the APEASE criteria:

Affordability: Not addressed, however other studies suggest electronic reminders can be a low-cost tool to assist in colorectal cancer screening 4 .

Practicability: The authors described the system used to facilitate the electronic prompts ("Lab Check Note"), the patient management options in association to the reminders and the needed time to administer the intervention. However, it is noted that this intervention can be implemented within any health-care settings that utilise computerised electronic records.

Acceptability: Not addressed.

Side effects/safety: N/A.

Equity: This intervention targeted and was shown to be effective in veterans, a population who may be vulnerable to health disparities¹⁰⁸.

<u>Treatment Phase: i) Timely confirmation of a cancer diagnosis and stage; ii) Equitable access to</u> <u>timely specialist care and treatment</u>

In this phase, individuals should have equitable and timely access to a range of specialist care and treatment options including surgical, medical and radiation oncologists. Delays in this phase have been largely attributed to practitioner and system factors.^{8,9} This includes limited specialist availability or access to further diagnostic investigations, and delays to first treatment or surgery. Similar to the previous section, studies using administrative databases or cancer registries were retrieved to provide population-level descriptions and factors associated with inequitable access and use of specialist care.^{67,86,93-99} Studies exploring geographic distribution of services were also reviewed.^{97,100,101}

Timely confirmation of a cancer diagnosis relating to disease staging

Experiences: In a Danish population cohort study, patients experienced greater median wait- times in specialist care phases; 29 days between specialist referral and diagnosis/referral to treatment and an additional 14 days between referral to treatment and initiation.³⁴

Associated factors: The time taken to confirm a cancer diagnosis and stage at diagnosis varies across patient groups. For example, African Americans were diagnosed at more-advanced stages for eleven of thirteen cancers and had relatively worse survival rates for thirty-two of the thirty-four tumour sites studied, of which 26 sites reached statistical significance.⁹³ As this study used the SEERS heterogeneous dataset, this finding could not be solely explained by differences in tumour biology or predisposing risk factors.

An Australian matched cohort study of Indigenous and non-Indigenous cancer records reported Indigenous cases were 1.2 times more likely to have distant metastases, 1.1 times more likely to have regional cancers and 1.3 times more likely to be missing staging information in their medical records.⁸⁶ This was adjusted for place of residence (remoteness), age, year of diagnosis and cancer type.

Disparities in cancer staging have also been reported according to SES and insurance coverage.^{94,102} A UK registry analysis of 39 619 CRC cases reported patients who resided in the most deprived areas

were significantly more likely to receive stage four rectal cancer diagnoses with a weaker association reported for colon cancer.⁹⁴

Equitable access to timely specialist care and treatment

Experiences: Healthcare resources, including specialist physician availability, are a critical system factor within this phase of the cancer journey. Physician shortages and insufficient workforce capacity has been reported with many of these shortages projected to increase.^{95,103,104} These shortages can compound the problem by causing professional 'burn-out' and individuals leaving the profession.¹⁰⁵

The time to treatment or surgery is an important consideration. An audit of 29 lung cancer patients showed that 20% awaiting radiotherapy (RT) with a (potentially) curative intent became incurable while they were on the waiting list.¹⁰⁶ A systematic review found RT wait-times were frequently reported barriers within the Canadian healthcare system.¹⁰⁷ This may have result in patients forgoing RT treatment either by choice or physicians who choose to refer to a different treatment modality. A population-based of 10 223 individuals with colon cancer reported wait-times from surgical consultation to surgery was 31 days (median) but have significantly increased yearly (from 2002-2008).⁹⁶

Associated factors: Cancer care has become increasingly specialized and centralized. For example, surgical procedures at high volume hospitals have increased and have been associated with improved patient outcomes for some cancer types.^{5,97} For those patients who reside outside of metropolitan areas, this may signal an unequitable distribution of cancer resources with administrative data suggesting individuals are required to travel greater distances.^{97,100,104} An environmental scan of 161 regional Australian hospitals administering chemotherapy reported only 21% had a resident medical oncology services; 41% had a visiting service; 7% had a radiation oncology clinic; 39% had an oncology counselling service ; and 32% reported MDT clinics.¹⁰¹ The proportion of MDTs decreased with increasing remoteness.

Systematic reviews and population-based audits suggest other factors influencing the use and delay of treatment include SES, insurance coverage, physician knowledge on treatment, and need for additional diagnostic or imaging services.^{94,96,102,107,108} Those in the most deprived areas were less likely to

receive treatment for CRC after controlling for the effect of age, sex and cancer staging in a population-based sample.⁹⁴ Similarly, a meta-analysis of 23 articles reported lower SES groups were less likely to receive any form of lung cancer treatment in private- and public-funded healthcare systems.¹⁰⁸ A study on breast cancer found lower-SES women experienced longer surgery and RT wait-times with lower access to adjuvant RT in the US but not in Canada.⁹⁹ Additional work by the same authors found similar associations between wait-times, income, and country of residence for colon cancer.⁹⁸ A Canadian population-based study also reported surgical wait-times experienced by colon cancer patients was not associated with income.⁹⁶

Ethnicity has been associated with treatment rates. Across several treatment types, black individuals in the US were significantly less likely to receive treatment than white patients; there was no observable change in magnitude of this gap between 1992 and 2002.⁶⁷ This disparity persisted after controlling for prior physician access and SES. In Australia, Indigenous patients were less likely to receive treatment and waited longer for surgery.⁸⁶ While such wide-spread disparity certainly has multiple causative system-level factors, a systematic review suggests treatment preferences may also depend on patients' cultural beliefs.¹⁰⁷ For example, Chinese women were more likely to decline adjuvant RT, as they did not believe the treatment would eliminate a physical manifestation such as a tumour.¹⁰⁹

Case Study 3.1: Improving access to coordinated care via nurse-led telephone contact and automated symptom monitoring

Use of information and communication technology can increase the capacity for additional consultations, reduce the need for travel; link health professionals for direct communication and information transfer; and assist to coordinate multidisciplinary care. As such, telehealth can improve access to optimal cancer care particularly for those experiencing a geographical barrier.

The Indiana Cancer Pain and Depression Trial^{106, 125} assessed the effectiveness of telecare and automated symptom monitoring on cancer-related pain and depression:

Population: A total of 405 patients diagnosed with moderate to severe depression and/or pain were recruited from 16 oncology practices, including 10 rural services. The sample was mostly white (79%), had lower education, employment status or income, and the mean age was 58.7 years.

Intervention: A total of 202 patients were randomized to receive a multi-component intervention consisting of telephone nurse-led management, automated symptom monitoring (via interactive voice-recorded telephone calls, or web-based survey), and medication management with a treatment/referral algorithm. Patients received at least four calls, with additional calls when results from symptom monitoring indicated side-effects, non-adherence, inadequate symptom improvement or suicidal ideation.

Control: A total of 203 patients were randomized to the usual care group. Patients and oncologists were informed of the depressive and pain symptoms identified during baseline screening.

Outcomes/Effectiveness⁵¹: Intervention patients with pain and/or depression had significantly greater improvement than usual care over a 12 month reporting period (p<.0001). Effect sizes for between-group differences at 1, 3, 6, and 12 months ranged from 0.36 to 0.67 for pain, and 0.31 to 0.45 for depression. The intervention group also reported better outcomes for several health-related quality of life domains.

When applying the APEASE criteria to the intervention:

Affordability: Although cost per intervention case was greater, due to significant increases in depressionfree days and quality-adjusted life years, this intervention was reported as cost-effective¹²⁶. The cost of delivering telehealth interventions has decreased in a ten year period (1995-2005¹²⁷).

Practicability: Additional work by the study authors found 95% of individuals had access to a touch-tone phone¹²⁸.

Acceptability and safety: Participants used the symptom monitoring program and in general reported satisfaction with the number and length of calls¹²⁹. A systematic review of telemedicine approaches for follow-up care reported this technology is acceptable to patients and was safe¹³⁰.

Equity: While overall adherence was good, younger, black, or unmarried patients, and those with blood cancers or recurrent/progressive completed fewer symptom reports¹²⁹. Authors note the participating clinic sites provided care for rural patients, underserved populations, or veterans⁵¹. As such this is a promising approach for reducing geographical barriers.

Conclusion

This review provides a broadly scoped summary of the experiences and factors influencing equitable and timely access to coordinated cancer care. The results present a complex picture in which patient, provider, and system factors will influence the accessibility of services. Across the cancer journey, each individual's experience will be unique and shaped by a constellation of barriers to timely and comprehensive cancer care.

Within pre-diagnostic phases, patient factors include an individual's SES, ethnicity, and possible cancer type. However, underlying these demographic characteristics is the individual's willingness and ability to complete cancer screening or seek care for possible symptoms. For many minority groups, cancer symptom awareness and recognition was poor and these individuals reported a number of practical and psychological barriers to seeking primary care. Studies also suggest that cancer screening uptake rates are disparately low in particular subgroups and the benefits (such as early detection of cancers) are not equally conferred across all members of the community. This trend is observed even within government subsided programs and for tests that are seemingly simple to complete.

Within primary care services, health professionals' ability to recognize symptoms as a malignancy was consistently suggested as a barrier to timely cancer care. This was complicated by the poor positive predictive value of cancer symptoms and a patient's inability to clearly communicate symptoms. System-factors also became apparent within this phase, with several studies citing inconsistent or unclear referral processes for diagnostic investigation with inequitable access to these facilities. Within specialist care, a pervasive disparity was reported whereby specific socioeconomic and ethnic groups were more likely to be diagnosed with advanced disease.. This may limit the value of many cancer treatments and increase mortality and morbidity rates within these groups. Several groups also reported differential access to treatment.

A number of barriers also exist when transitioning between the phases of the cancer journey. This suggests there is opportunity to improve the coordination of multidisciplinary care, particularly the referral process between primary and specialist services.

While this review did not directly report on the barriers caused by the affordability of care, an individual's socio-economic position was consistently cited as a factor to receiving timely cancer services in public- and private- funded health systems. This suggests gaps in public-funded coverage may exist and warrants continual investigation. Furthermore, while private insurance coverage notionally reduces affordability barriers, it does not guarantee timely referral processes.⁵ The relationship between SES and access is complex and is likely to be a product of both system structuring and a range of additional variables such as region, education, and access to private insurance schemes.^{98,99}

Important considerations and practice implications for healthcare managers and professionals

Unfortunately, several studies noted widening or persistent disparities for sub-groups of the general community. To address this, we need to consider not only those situations that cause additional disadvantage, but also those successful approaches that have led to increased and equitable access to care. This review provided three short-case studies, each of which used a novel technology-based approach to providing and coordinating cancer care.. Telephone consultations, electronic-based monitoring and prompting, and online information support offer real and promising opportunities to overcoming many barriers to care. These should be carefully evaluated to ensure benefits are equally conferred and are sustainable.

In summarizing the findings of this narrative overview, a few practice implications for healthcare leaders emerge:

Firstly, interventions to provide equitable access to quality cancer care must be tailored to the SES, cultural and educational characteristics of the intended health service users. This requires a detailed scoping assessment of health service users with the results compared to the general community in order to identify any groups who may be over- or under-represented within the clinic setting. Continual monitoring of intervention uptake should be completed, with 'booster' components available for groups reporting lower use or advantage. Previous work examining effective care models outline strategies such as cultural awareness training for staff, trained interpreters, provision of outreach services for remote communities, and engaging members of the disadvantaged group in

developing health service interventions.¹¹⁷ By engaging a consumer in this process, services may gain a better understanding of how a community's normative values and literacy may influence healthseeking behaviours with the view to facilitate more equitable and timely use.

Secondly, improving a group's willingness to seek and use services will be an "exercise in futility"(Martin-Moreno et al., pg.2214)¹⁷ if the system is insufficiently resourced to provide this care. This requires health leaders to consider where additional capacity within the healthcare system is needed and ensure resources are allocated in an evidence-based, equitable and efficient manner.¹⁷ A review of European National Cancer Control programs found that while initiatives were largely evidence-based and clearly outlined, they were poorly-resourced with unclear financing structures.¹¹⁸ Recently, the IOM suggested cancer care is in a state of crisis in the US due to the increasing patient numbers, cost and complexity of care coupled with a declining workforce.¹⁰⁴ With growing demand for high-quality cancer care, it is now more important than ever to ensure service interventions are equitable and efficient uses of limited resources.

This review highlights a number of issues exist across the cancer journey and contribute to poor health outcomes and experiences for patients. Focusing singularly on a phase of care may shift the delay to another part of the system. This suggests a systems approach with multi-faceted interventions is required to meet the IOM's recommendations for equitable and timely access to optimal cancer care.

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Appendix C Conference abstracts

2015 Hunter Cancer Research Symposium, 27 November 2015, Newcastle, Australia

Advancing collaborative quality improvement in tertiary settings: Do chronic disease outpatients and health professionals identify similar types and numbers of quality initiatives?

Fradgley EA, Paul CL, Bryant J, Collins N, Ackland S, Bellamy D, Levi C

Background: Very few studies have directly compared patients' and health professionals' priorities for quality improvement in tertiary care. Quantifying the ways in which priorities vary can identify potential obstacles to collaborative improvement while areas of agreement are strategic targets to address both groups' preferences.

Aims: This cross-sectional study compared the number and types of quality improvement initiatives selected outpatients and health professionals.

Methods: Outpatients and health professionals were recruited from three tertiary clinics, including two medical oncology clinics. Participants selected up to 23 initiatives to improve in-clinic experiences. The number and types of initiatives selected by each group were compared using summary statistics and Chi-square tests. The ten most-frequently selected initiatives are listed and compared for each group.

Results: A total of 541 outpatients (71.1% consent, 73.1% completion) and 124 professionals (47.1% response) participated, including 336 (62.0%) oncology outpatients and 67 (52.3%) professionals with an interest in cancer. On average, outpatients selected 2.4 (median= 1, IQR= 1-3) initiatives; professionals selected 10.7 (median=10, IQR=6-15) initiatives. Compared to outpatients, a greater proportion of professionals selected each initiative (p < 0.001). Information-based initiatives were included in both groups' top ten most-frequently selected. Initiatives relating to service accessibility were included in outpatients' top ten only, patient communication and care coordination were only included in professionals' top ten.

Conclusions: Outpatients selected few improvement targets potentially reducing the complexity of service change and resources required. Comparatively, professionals indicated a greater degree of change is needed and emphasised aspects related to daily practise.

Translational research aspect (T3): Government policy mandates patient engagement in health evaluation and professionals' support is essential to sustained quality improvement. However, patients and professionals vary in the degree and type of change desired. A collaborative model is needed to translate both groups' preferences into improved chronic disease care.

2015 Hunter Cancer Research Symposium, 27 November 2015, Newcastle, Australia

Aiming For The Right Quality Improvement Target: Cross-Sectional Data Exploring Outpatients' Priorities And Preferences For Quality Improvement In Tertiary Clinics.

Fradgley EA, Paul CL, Bryant J, Zucca A, Oldmeadow C

Background: Patient-experience tools have not been designed specifically to inform health service change. Use of this data as a quality improvement mechanism has proven difficult with limited effects. To provide clear and actionable improvement messages, detailed evidence on patients' preferences and priorities for service change is needed.

Aims: To report the: proportion of outpatients selecting each general quality improvement initiative; detailed initiatives corresponding to commonly-selected (>10%) general initiatives; and, commonly-selected initiatives in order of relative priority.

Methods: Outpatients completed a touch-screen survey in three tertiary clinics, including two medical oncology clinics. Participants selected up to 23 general initiatives that would improve in-clinic experiences. Using novel survey software, participants could select an additional 110 detailed initiatives and complete relative prioritization exercises.

Results: A total of 541 outpatients participated (71.1% consent, 73.1% completion), including 336 (62.0%) oncology outpatients. In order of relative priority, examples of commonly-selected general initiatives included: up-to-date information provision (15.0%); access to information at home (12.8%); reduced wait-times (19.8%); and information on medical emergencies (11.1%). To address general initiatives, 40 detailed initiatives were selected. For example, to improve up-to-date information provision, participants selected: providing information on treatment steps (72.8%) and condition progress when possible (67.9%); and, to receive test results quickly (58.0%). Participants selected access to a list of trust-worthy sources (45.1%) to improve information provision at home. To manage medical emergencies, participants selected information on emergency symptoms (71.7%) and information for family (61.7%) as specific initiatives.

Conclusions: Information-based were commonly-selected and are of relatively greater perceived priority. Improved wait-times was commonly selected but was a relatively lower priority.

Translational research aspect (T3): Using this survey approach, patients are able to specify and prioritise strong quality improvement preferences. This data provides clear improvement messages and assists health services to strategically allocate resources to changes of greatest value to patients.

IPOS 16th World Congress of Psycho-Oncology and Psychosocial Academy, 20 – 24 October 2014, Lisbon, Portugal

A data collection tool to enable consumer participation in quality improvements for oncology care: Development and evaluation of an interactive survey to identify preferred service initiatives

Fradgley EA, Paul CL, Bryant J, Roos IA.

Background: With increasing attention given to the quality of oncology care, a measurement approach that facilitates consumer participation in quality assessment and enables services to systematically introduce patient-centered initiatives is urgently needed. Current evidence suggests needs assessment tools may not be the optimal data sources for informing service initiatives. This study included developing and evaluating an information-generating tool capable of identifying and prioritizing patient-centered initiatives with comprehensive practice ready evidence produced for outpatient oncology services.

Methods: In Phase I, the touchscreen Consumer Preferences Survey was developed based on a structured literature review and iterative feedback from service providers and consumers. The survey includes: 23 general initiatives; an additional 110 specific initiatives available through complex branching patterns; and a relative prioritization exercise. In Phase II, a pilot study was conducted to evaluate test retest reliability, patient-perceived acceptability, and average completion times and rates. Eligible participants attending outpatient clinics were approached to complete the survey, demographic, and acceptability items. Participants with a subsequent appointment within 14 days were asked to complete the survey for a second time.

Results: A total of 741 individuals consented to participate (71.1% consent), 529 completed the survey (78.9%), and 39 completed a second survey. Substantial or moderate reliability (Cohen's kappa>0.4) was reported for 20 of the 24 general initiatives with observed percentage agreement ranging from 82.1-100.0%. An oncology subsample (n=386) indicated the survey was easy to complete (98.8%) and comprehensive (98.1%). Furthermore, patients reported the prioritization exercise was easy to complete (98.5%) and a valuable exercise (84.4%). Average completion time was 8.7 minutes (SD=4.0) and the Flesch-Kincaid reading level is 6.8. Overall, 84.8% of oncology participants indicated they would be willing to complete a similar survey again.

Conclusions: This study outlines a systematic development and evaluation process for a novel webbased survey. The Consumer Preferences Survey provides a method to: generate a personalized list of health service initiatives relevant to oncology patients' experiences of outpatient care; identify a comprehensive set of targets that are modifiable on a service level; and generate a list of prioritized initiatives to ensure change is introduced strategically. Pilot study results suggest the tool is sufficiently reliable and acceptable to patients. Results can be used to develop research initiatives that align closely to patients' preferences and priorities for quality improvement within oncology care.

Implications for researchers: Web-based software allows researchers to develop novel and interactive surveys. Study results suggest these surveys can be highly acceptable to patients. Researchers may consider adapting current pen and paper measures or developing web-based surveys as a method for assessing patients' perceptions of oncology care. Additionally, study participants indicated the prioritization exercise was helpful and easy to complete. With limited healthcare resources available, similar exercises may be an appropriate patient-centered approach to strategically determine funding priorities.

Implications for clinicians: The Consumer Preferences Survey can be completed in less than 10 minutes and does not require a high literacy level. This suggests the tool can be easily integrated into existing clinic routine. The data is systematically collected and provides sufficient detail to develop specific patient-centered health initiatives. Results can be used to select initiatives for a specific group (e.g. information initiatives for newly-diagnosed oncology patients) or initiatives appropriate for service wide implementation (e.g. parking).

IPOS 16th World Congress of Psycho-Oncology and Psychosocial Academy, 20 – 24 October 2014, Lisbon, Portugal

A multi-site study to explore patient-identified and prioritized health service initiatives to improve oncology outpatient care: Are we aiming for the right targets?

Fradgley EA, Paul CL, Bryant J, Zucca A.

Background: Patient reported data has become an essential component of health-care evaluations and can be used to improve the quality of psycho-oncology care. Using the touchscreen Consumer Preferences Survey, oncology patients can easily participate in quality evaluation by identifying and prioritizing those areas of care requiring improvement in outpatient settings. This multi-site study reports 1) frequency and types of clinic initiatives identified by oncology outpatients, and 2) possible associations with patient demographics or health status.

Methods: Participants were approached in public and private oncology outpatient clinics to complete the Consumer Preferences Survey. Previous research indicates the survey has sufficient item reliability and is acceptable to patients. It includes: 23 general initiatives; 110 specific initiatives available through adaptive questioning; and a relative prioritization exercise. Demographic information on age, gender, marital status, education, time since diagnosis, appointment frequency, and reason for attending the clinic, was collected. Associations between identified initiatives and demographics were explored using t-tests for continuous variables, and chi square tests for categorical variables. The age and gender of non-consenters was estimated to ascertain consent bias.

Results: A total of 335 patients consented and completed the survey (71.4% consent, 77.6% completion). On average, participants were 61.1 years of age (SD=13.6) and female (54.0%). Participants identified an average of 2.2 (SD=2.5) general and 5.2 (SD=8.3) specific initiatives. Frequently selected general initiatives included: parking (64.0%), wait-times (17.0%), up-to-date information on treatment progress (12.7%), and knowledge on potential medical emergencies (10.6%). Selecting a greater number of initiatives was significantly associated with being female (p=0.017), attending a public facility (p=0.001), and increased appointment frequency (p=0.05). Patients attending for intravenous treatment only were most likely to select no general initiative (p=0.01).

Conclusions: While the average number of initiatives selected was low, participants consistently identified several initiatives regardless of cancer type or time since diagnosis. These initiatives, such as improved parking or continual information provision, can be implemented on a service-wide level and are strategic and efficient approaches to improve the quality of care received by all outpatients. In contrast, study results also highlighted a sub-sample of frequent service users who identified a greater number of initiatives. This group may have experienced a greater range of services and therefore

could provide a more accurate indication of the quality of care. Additional research targeting this group is warranted.

Implications for researchers: The Consumer Preferences Survey provides a highly detailed list of potential health service initiatives. For example, specific initiatives identified by participants included: closer proximity parking (60.5%) with patient-only zones (65.0%), being informed of estimated wait-times (17.0%), and being given test results as soon as possible (37.1%) with information on potential next treatment steps provided (53.2%). Using this patient report data, researchers are able to select the right targets for single or multi-component health service initiatives.

Implications for clinicians: Using the Consumer Preferences Survey, clinicians and health services can quick elicit patients' preferences for improvements. This includes a range of initiatives directly related to the care delivered by clinicians, such increased treatment decision involvement or information on self-management of physical symptoms. Study results demonstrated significant variation in the number of initiatives selected between treatment centres. This evidence may provide a systematic method to identify high performing clinics in order to adopt a similar model of care.

11th Behavioural Research in Cancer Control Conference, 8-10 May 2013, Adelaide, Australia

Making It Real: Operationalising Medical Oncology Outpatients' Preferences For Health Service Change In Hunter New England Clinics

Fradgley EA, Bryant J, Paul CL, Sanson Fisher R.

Introduction: Existing need assessment measures do not directly measure patients' preferences for health service change. This limitation may be responsible for the minimal impact of interventions on patient-centered outcomes such as improved patient experiences with oncology care. The Consumer Preferences Survey has been developed to identify the specific changes to clinics that patients believe would be of benefit at each phase of the care interaction; and to quantify the relative importance of the specified changes. The aim of this pilot-test is to describe the survey design and a pilot-test of the identified and prioritized health service changes reported by medical oncology out-patients.

Methods: An extensive literature search and iterative expert review process was followed to identify survey domains and items. Pilot study participants (n=200) will be recruited from outpatient clinics by trained volunteers. Eligible participants will: be able to read English; be 18 years of age or older; have a confirmed cancer diagnosis and; have attended the clinic at least once prior to recruitment.

Measures: 1) The Consumer Preferences Survey contains 23 items to identify patients' perceptions of potential changes to care that would improve their overall wellbeing in: accessing clinic services, arriving at or during a clinical appointment, and home-based management. The survey includes a preference valuation exercise to prioritize identified health service changes. 2) Demographic and disease-related information will also be collected.

Progress and anticipated results: The pilot project commences in November 2012. Anticipated results include reporting:

•The relative priority of specified changes;

•Any possible associations between identified or high priority changes and patient demographics. •Survey acceptability results.

So What? The Consumer Preferences Survey will provide patients with a standardized method to express their preferences about health service change, in prioritized order. This has great potential for informing health service interventions, and targeting patient-centered interventions appropriately.

Australasian Society of Behavioural Health and Medicine 10th Annual Scientific Conference, February 6-8 2013, Newcastle, Australia

Assessing health service intervention preferences among chronic disease outpatients

Fradgley EA, Bryant J, Paul CL, Sanson Fisher R

Introduction: The aim of this pilot-test is to describe the identified and prioritized changes to Hunter New England clinics reported by chronic disease out-patients when completing the Consumer Preferences iPad survey. This will be some of the first work internationally to provide a broadly scoped view of quality of care across chronic disease patient groups with a highly specific set of preferred actions for improving the quality of patient care

Methods: Participants will be recruited from neurology, cardiology and medical oncology outpatient clinics by trained research support people. Eligible patients will: be able to read English; be 18years of age or older; have a confirmed chronic disease diagnosis and; have attended the treatment center at least once prior to recruitment. Participants will complete the iPad survey while waiting for their appointment. A pilot-population of 200 outpatients will be recruited by December 2012.

Measures: The Consumer Preferences Survey contains 23 items to identify patients' perceptions of the degree to which general changes to care would improve their overall wellbeing. Complex branching software allows patients to identify increasingly specific changes based on previous responses. The survey includes a preference valuation exercise modeled on willingness to pay. 2) Demographic information will also be collected.

Data analysis: Reading ease, time to complete, completion rates, skipped questions, and patient satisfaction with the survey will also be analyzed. Any possible associations between identified or high priority changes and patient demographics will be explored using t-tests for continuous variables and chi square tests for categorical variables.

Appendix D Additional data analysis, and summary tables, and survey development information

Comparison of the types and number of initiatives selected by recruiting site

General initiatives	All	Number of participants (%) by clinic Test				tatistic
	n=573	Onco	ology	Cardio/Neuro,	χ2 (df)	Р
		Public,	Private,	n=220		
		n=287	n=66			
Selected at a similar frequency across all clinic settings						
Keep you up-to-date on your treatment and condition progress	89 (15.5)	42 (14.6)	4 (6.1)	43 (19.6)	*	0.02^{\dagger}
Information on how to manage medical emergencies	69 (12.0)	34 (11.9)	6 (9.1)	29 (13.2)	0.8(2)	0.7
Access to help in order to maintain activities of daily living	59 (10.3)	25 (8.7)	5 (7.6)	29 (13.2)	3.3(2)	0.2
Access to help or information to manage emotional symptoms	55 (9.6)	20 (7.0)	4 (6.1)	31 (14.1)	*	0.02^{\dagger}
Provide good hospital catering	54 (9.4)	34 (11.9)	9 (13.6)	11 (5.0)	8.4(2)	0.02^{\dagger}
Access to help or information to manage physical symptoms	53 (9.3)	26 (9.1)	2 (3.0)	25 (11.4)	*	0.1
Ensure your concerns are discussed with healthcare professionals	51 (8.9)	31 (10.8)	2 (3.0)	18 (8.2)	*	0.1
Help to arrange transport to and from the clinic	37 (6.5)	18 (6.3)	2 (3.0)	17 (7.7)	*	0.4
Involve you in treatment decisions	35 (6.1)	15 (5.2)	0 (0)	20 (9.1)	*	0.01^{+}
Ensure good interactions with all clinic staff	33 (5.8)	16 (5.6)	1 (1.5)	16 (7.3)	*	0.2
Access to help or information for family support	33 (5.8)	13 (4.5)	2 (3.0)	18 (8.2)	*	0.1
Access to help or information relating to finance, work, insurance	32 (5.6)	15 (5.2)	4 (6.1)	13 (5.9)	*	0.9
Better coordination of your care	31 (5.4)	18 (6.3)	1 (1.5)	12 (5.5)	*	0.4
Provide more information about treatment or condition during	29 (5.1)	16 (5.6)	1 (1.5)	12 (5.5)	*	0.4
Minimize pain or discomfort during treatment	18 (3.1)	12 (4.2)	0 (0)	6 (2.7)	*	0.2
Ensure family and friends are comfortable within waiting rooms	13 (2.3)	3 (1.1)	3(4.6)	7 (3.2)	*	0.08
Provide a comfortable and pleasant waiting room	11 (1.9)	4 (1.4)	0(0)	7 (3.2)	*	0.2
Provide a comfortable and pleasant treatment room	8 (1.4)	2 (0.7)	0(0)	6 (2.7)	*	0.1
Selected more or less frequently in one clinic setting						
Improve car parking	346 (60.4)	221 (77.0)	6 (9.1)	119 (54.1)	109.4(2)	< 0.001 [‡]
Reduce waiting times	121 (21.1)	63 (22.0)	1 (1.5)	57 (25.9)	*	< 0.001 [‡]
Provide more convenient appointment times	86 (15.0)	39 (13.6)	1 (1.5)	46 (20.9)	*	< 0.001 [‡]
Make it easier to contact the clinic	80 (14.0)	31 (10.8)	3 (4.6)	46 (20.9)	*	< 0.001 [‡]
Access to information at home	74 (12.9)	32 (11.2)	2 (3.0)	40 (18.2)	*	0.002‡

Table 1: Proportion of study participants selecting general quality improvement initiatives and goodness of fit statistics, by recruiting clinic

Table 2: Univariate and multivariate or	dinal logistic odds of selecting	g a greater number of initiative	s (recruiting clinic highlighted)
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Demographic and clinical variables		Univariate			Multivariate	
	OR	CI	p-value	OR	CI	p-value
Age (continuous by year)	0.98	0.97-0.99	< 0.001	0.98	0.97-0.99	0.002
Gender						
Male	0.87	0.64-1.19	0.38	0.99	0.71-1.37	0.94
Marital status						
Married or living with partner		reference			reference	
Single (never married/divorced/widowed)	1.45	1.04-2.03	0.03	1.34	0.94-1.91	0.10
Education						
10 years or less completed		reference			reference	
High school completion (12 years)	1.22	0.73-2.04	0.45	1.12	0.66-0.90	0.66
Diploma or trade certification	1.32	0.89-1.96	0.17	1.28	0.85-1.93	0.24
Post-secondary completion	1.07	0.69-1.68	0.75	1.23	0.75-2.02	0.40
Private insurance coverage	0.72	0.53-0.98	0.04	0.76	0.54-1.07	0.11
Recruiting clinic						
Public medical oncology		reference			reference	
Public cardiology/neurology	1.03	0.74-1.45	0.85	1.01	0.71-1.51	0.61
Private medical oncology	0.15	0.09-0.26	< 0.001	0.13	0.07-0.25	<0.001
Condition						
Oncology		reference			reference	
Neurology	1.59	1.10-2.29	0.01	1.25	0.79-1.98	0.34
Cardiology	1.11	0.67-1.82	0.70	0.98	0.55-1.74	0.94
Reason for attending						
For a routine exam		reference			reference	
Discuss diagnosed symptoms or tests	0.82	0.52-1.29	0.39	0.83	0.52-1.32	0.43
Discuss undiagnosed symptoms or tests	1.46	0.76-2.81	0.26	1.11	0.56-2.20	0.76
To receive tests or treatment	0.53	0.37-0.76	0.001	0.44	0.27-0.71	0.001
Appointment frequency in last three months	0.17			0.06		
Only once in last six months		reference			reference	
2-3	1.28	0.85-1.92	0.24	1.87	1.18-2.99	0.008
4-5	0.84	0.52-1.34	0.46	1.59	0.91-2.77	0.10
6 or more	0.74	0.47-1.15	0.18	1.41	0.82-2.45	0.22

Proportion of study participants selecting those initiatives reviewed in discussion section, by paper

Communication, self-management, and information	Number of respondents (%) by chapter:					
initiatives	Chapter 3 (n=541)	Chapter 4 (<i>n</i> =475)	Chapter 5 (<i>n</i> =263)	Chapter 6 (<i>n</i> =128)		
	Public- and private-	Public-funded	Public-funded	Health professionals		
	funded outpatients	outpatients only	oncology outpatients	only		
			only			
Keep you up-to-date on treatment and condition progress	81 (15.0)	77 (16.2)	52 (19.8)	60 (46.9)		
Information on how to manage medical emergencies	60 (11.1)	54 (11.4)	39 (14.8)	76 (59.4)		
Access to information at home	69 (12.8)	67 (14.1)	31 (11.8)	78 (60.9)		
Help/information to manage physical symptoms	48 (8.9)	45 (9.5)	39 (14.8)	86 (67.2)		
Help/information to manage emotional symptoms	48 (8.9)	44 (9.3)	29 (11.0)	64 (50.0)		
Help/information for family support	28 (5.2)	26 (5.5)	39 (14.8)	57 (44.5)		
Help/information to manage activities of daily living	53 (9.8)	49 (10.3)	37 (14.1)	78 (60.9)		
Ensure good interactions with all clinic staff	33 (6.1)	31 (6.5)	32 (12.2)	57 (44.5)		
Provide more information during appointment	26 (4.8)	25 (5.3)	24 (9.1)	55 (43.0)		
Ensure concerns are discussed with health professionals	44 (8.1)	42 (8.8)	21 (8.0)	62 (48.4)		
Involve you in treatment decisions	32 (5.9)	32 (6.7)	18 (6.8)	37 (28.9)		

 Table 1: The sample proportions selecting communication, self-management, and information initiatives, by chapter

Accessibility and accommodation initiatives	Number of respondents (%) by chapter:					
	Chapter 3 (n=541)	Chapter 4 (<i>n</i> =475)	Chapter 5 (<i>n</i> =263)	Chapter 6 (<i>n</i> =128)		
	Public- and private-	Public-funded	Public-funded oncology	Health professionals		
	funded outpatients	outpatients only	outpatients only	only		
Reduce waiting times	107 (19.8)	106 (22.3)	46 (17.5)	85 (66.4)		
Provide more convenient appointment times	77 (14.2)	76 (16.0)	32 (12.2)	55 (43.0)		
Improve car parking	326 (60.3)	319 (67.2)	135 (51.3)	112 (87.5)		
Make it easier to contact the clinic	70 (12.9)	67 (14.1)	13 (4.9)	42 (32.8)		
Improve hospital catering	49 (9.1)	41 (8.6)	42 (16.0)	31 (24.2)		
Help to arrange transport to/from the clinic	35 (6.5)	32 (6.7)	6 (2.3)	72 (56.3)		
Help/information related to finance, work, insurance	28 (5.2)	24 (5.1)	-	50(39.1)		
Help/information relating to finance assistance	-	-	48 (18.3)	-		
Help/information relating to work leave or insurance	-	-	16 (6.1)	-		

Table 2: The sample proportions selecting accessibility and accommodation initiatives, by chapter

Results from principal component analysis

Prepared by: the CREDITSS (Clinical Research Design, IT and Statistical Support) team, Alessandra Bisquera and Dr Christopher Oldmeadow

Objectives

To undertake principal component analysis on the Consumer Preferences Survey data.

Statistical methods

Summary frequencies: Frequencies and percentages are presented for each variable.

Principal component analysis: PCA was undertaken using the 25 unmet needs items. Observations with missing data on any of the items were excluded using list wise deletion. Eigenvalues from the PCA are presented as well as the factor loading from each item. The number of factors retained (clusters) was determined using the number of factors with eigenvalue > 1 rule and a cluster of items must contain at least three items that load onto the component. PCA loadings for each variable are presented, with the proportion loading greater than >40 highlighted in yellow

Internal consistency: Correlations between each item and all other items within a component are presented. Cronbach's alpha is also presented to quantify the overall reliability of the variables in presenting the variation in the dataset, and for the reliability of the component when a single item is removed.

Results

Summary frequencies: 49 of 355 observations in data set will be omitted due to missing values (Table 1).

		Total
Variable	Category	(N=355)
make1_convenappt	0	268 (86%)
	1	42 (14%)
	Missing	45
make2_cont	0	290 (94%)
	1	20 (6.5%)
	Missing	45
make3_transp	0	293 (95%)
-	1	17 (5.5%)
	Missing	45
make4_refwtime	0	278 (90%)
	1	32 (10%)
	Missing	45
arrive5_park	0	152 (49%)
	1	158 (51%)
	Missing	45
arrive6_wrooms	0	302 (97%)
	1	8 (2.6%)
	Missing	45
arrive7_wtimes	0	251 (81%)
	1	59 (19%)
	Missing	45
arrive8_infoprep	0	292 (94%)
	1	18 (5.8%)
	Missing	45
during9_info	0	273 (89%)
	1	35 (11%)
	Missing	47
during10_concern	0	279 (91%)
	1	29 (9.4%)
	Missing	47
during11_involve	0	279 (91%)
	1	29 (9.4%)
	Missing	47
during12_uptodate	0	245 (80%)
	1	63 (20%)
	Missing	47
during16_coord	0	282 (92%)
C –	1	26 (8.4%)
	Missing	47
during 13 staff	0	263 (85%)
during15_start	1	205(05/0)
		45 (15%)
	Ivitssing	4/
during14_troom	0	293 (95%)
	1	15 (4.9%)
	Missing	47

Table 1: Summary frequencies and missing values

	C /	Total
Variable		(N=355)
during15_calering	1	237(83%)
		51 (17%)
1 . 17	Missing	4/
during1/_minpain	0	278 (90%)
		30 (9.7%)
	Missing	47
home18_psymp	0	254 (83%)
	1	53 (17%)
	Missing	48
home19_esymp	0	269 (88%)
	1	38 (12%)
	Missing	48
home23_info	0	266 (87%)
	1	41 (13%)
	Missing	48
home25_emerg	0	258 (84%)
	1	49 (16%)
	Missing	48
home20_adl	0	260 (85%)
	1	46 (15%)
	Missing	49
home22_fin	0	246 (80%)
	1	60 (20%)
	Missing	49
home21 insurleave	0	281 (92%)
_	1	25 (8.2%)
	Missing	49
home24 famsupp	0	254 (83%)
	1	52 (17%)
	Missing	49

Principal component analysis: Table 2 indicates that 9 Factors should be retained using the Eigenvalue > 1 rule, however there are only 2 components with at least 3 items. The majority of the variance between participants is summarized in the first Principal component: 19 of the 25 variables show similar responses between participants and thus load over 40% onto the first component (section 3.2.2). There are some variations seen between make 3 and during 9 and 16, with those answering positively on make 3 answering negatively on during 9 and 16.

Number of factors	Eigenvalue	Proportion of variance explained
1	5.30	0.21
2	1.59	0.06
3	1.45	0.06
4	1.33	0.05
5	1.28	0.05
6	1.20	0.05
7	1.18	0.05
8	1.08	0.04
9	1.01	0.04
10	0.95	0.04
11	0.87	0.03
12	0.79	0.03
13	0.74	0.03
14	0.72	0.03
15	0.67	0.03

Table 2: Eigenvalues from principal component analysis

Variable	PC1	PC2	PC3	PC4	PC5	PC6	PC7	PC8	PC9
make1_convenappt	0.48	0.02	0.24	0.11	-0.02	-0.20	0.48	0.27	0.09
make2_cont	0.35	-0.24	0.39	-0.55	0.01	0.10	0.04	-0.23	-0.15
make3_transp	0.41	-0.51	0.03	0.16	0.05	-0.47	-0.14	0.05	0.00
make4_refwtime	0.33	0.19	-0.51	-0.04	-0.35	0.02	0.00	-0.23	0.30
arrive5_park	0.13	-0.12	0.31	0.26	-0.18	0.51	0.04	0.12	0.24
arrive6_wrooms	0.39	0.37	0.35	0.25	0.02	-0.24	-0.28	-0.03	-0.20
arrive7_wtimes	0.40	0.16	-0.01	-0.28	0.02	-0.31	0.19	-0.04	0.52
arrive8_infoprep	0.52	0.25	-0.08	-0.18	-0.32	-0.33	0.03	0.10	-0.35
during9_info	0.50	-0.42	0.00	0.05	-0.14	-0.05	0.23	0.34	-0.23
during10_concern	0.53	0.01	0.31	-0.42	-0.03	0.25	-0.10	0.01	0.01
during11_involve	0.46	0.00	0.12	0.22	0.28	-0.26	-0.07	-0.35	0.01
during12_uptodate	0.45	-0.23	-0.08	0.25	0.05	0.01	-0.43	0.37	0.01
during16_coord	0.45	0.41	-0.12	-0.21	-0.16	0.09	-0.44	0.08	-0.20
during13_staff	0.54	-0.29	0.26	0.06	-0.09	0.13	-0.22	-0.22	0.12
during14_troom	0.45	0.39	0.26	0.29	-0.09	0.08	0.08	-0.11	0.14
during15_catering	0.43	0.28	0.11	-0.16	0.04	0.13	-0.07	0.48	0.15
during17_minpain	0.54	0.20	0.09	0.11	-0.15	-0.16	0.31	-0.11	-0.02
home18_psymp	0.49	-0.13	-0.27	0.20	-0.34	0.23	0.23	-0.06	-0.13
home19_esymp	0.56	-0.22	-0.13	-0.17	-0.22	0.15	0.10	-0.14	-0.13
home23_info	0.50	-0.07	-0.29	-0.20	0.17	-0.07	-0.17	-0.07	0.16
home25_emerg	0.57	-0.20	0.06	0.03	0.27	0.09	-0.03	-0.27	0.03
home20_adl	0.47	0.23	-0.10	0.40	0.16	0.27	0.02	-0.16	-0.16
home22_fin	0.43	0.18	-0.06	-0.10	0.58	0.12	0.13	0.23	0.10
home21_insurleave	0.34	0.06	-0.36	-0.07	0.48	0.18	0.27	-0.03	-0.33
home24_famsupp	0.55	-0.18	-0.37	0.07	0.01	0.02	-0.17	0.11	0.24

Table3 : Variable loadings associated with first principal component analysis



Figure 1: Variable loadings on PC1 and PC2

Internal consistency: The table below shows high internal consistency for PC1, with all variables having similar correlations, and low consistency for component 2 (not surprising as most of the variation is already captured by the first PC). Consistency increases when during 16 is removed from the Principal component – this is because this variable has a very low correlation with the other two variables.

Factor and items identified	Alpha	Correlation with total
PC 1	0.83	•
make1_convenappt	0.82	0.39
make3_transp	0.82	0.35
arrive8_infoprep	0.82	0.41
during9_info	0.82	0.44
during10_concern	0.82	0.44
during11_involve	0.82	0.38
during12_uptodate	0.82	0.40
during16_coord	0.82	0.35
during13_staff	0.82	0.45
during14_troom	0.82	0.37
during15_catering	0.82	0.35
during17_minpain	0.82	0.44
home18_psymp	0.82	0.42
home19_esymp	0.81	0.47
home23_info	0.82	0.42
home25_emerg	0.81	0.48
home20_adl	0.82	0.39
home22_fin	0.82	0.35
home24_famsupp	0.81	0.48
PC 2	0.37	
make3_transp	0.20	0.28
during9_info	0.06	0.31
during16_coord	0.51	0.09

Table 4: Internal consistency for first principal component analysis

Analysis 2 – Removing complex items

Items that load onto more than one component are considered complex, and should be removed from the PCA analysis. We redid the PCA removing the complex items (highlighted in green above), results are given below:

Number of factors	Eigenvalue	Proportion of variance explained
1	4.77	0.22
2	1.45	0.07
3	1.39	0.06
4	1.29	0.06
5	1.26	0.06
6	1.06	0.05
7	1.04	0.05
8	0.96	0.04
9	0.93	0.04
10	0.89	0.04
11	0.85	0.04
12	0.74	0.03
13	0.71	0.03
14	0.66	0.03
15	0.65	0.03

Table 5: Eigenvalues and accounted variance in second principal component analysis

Table 6: Variable loadings associated with second principal component analysis

Variable	PC1	PC2	PC3	PC4	PC5	PC6	PC7
make1_convenappt	0.48	0.25	0.18	-0.12	-0.08	0.09	0.18
make2_cont	0.34	0.30	-0.61	-0.25	-0.07	-0.22	0.10
make4_refwtime	0.33	-0.46	0.17	0.01	-0.41	0.03	-0.07
arrive5_park	0.14	0.27	-0.12	0.50	-0.02	0.31	0.38
arrive6_wrooms	0.40	0.44	0.37	0.05	0.07	-0.10	-0.35
arrive7_wtimes	0.41	0.01	0.05	-0.44	-0.19	0.15	-0.12
arrive8_infoprep	0.50	0.01	0.21	-0.28	-0.38	-0.06	-0.07
during10_concern	0.54	0.28	-0.40	-0.15	-0.04	0.12	0.11
during11_involve	0.47	0.10	0.11	0.04	0.22	-0.38	-0.25
during12_uptodate	0.41	-0.11	-0.06	0.33	0.21	0.32	-0.32
during13_staff	0.55	0.17	-0.36	0.34	-0.03	-0.11	-0.23
during14_troom	0.48	0.32	0.37	0.16	-0.05	-0.02	0.05
during15_catering	0.44	0.16	0.07	-0.18	0.06	0.57	0.07
during17_minpain	0.56	0.13	0.26	-0.06	-0.24	-0.13	0.18
home18_psymp	0.49	-0.30	0.01	0.33	-0.28	-0.08	0.28
home19_esymp	0.56	-0.18	-0.27	0.05	-0.25	-0.12	0.15
home23_info	0.51	-0.32	-0.15	-0.16	0.08	0.08	-0.27
home25_emerg	0.58	-0.01	-0.20	0.08	0.26	-0.22	-0.09
home20_adl	0.49	-0.07	0.31	0.29	0.24	-0.17	0.21
home22_fin	0.45	-0.06	0.08	-0.30	0.52	0.20	0.17
home21_insurleave	0.35	-0.37	0.06	-0.23	0.43	-0.22	0.37
home24_famsupp	0.54	-0.41	-0.07	0.14	0.02	0.24	-0.20

Factor and items identified	Alpha	Correlation with total
PC 1	0.81	
make1_convenappt	0.80	0.40
arrive7_wtimes	0.80	0.33
arrive8_infoprep	0.80	0.38
during10_concern	0.80	0.43
during11_involve	0.80	0.38
during12_uptodate	0.80	0.36
during13_staff	0.80	0.44
during14_troom	0.80	0.39
during15_catering	0.80	0.36
during17_minpain	0.80	0.46
home18_psymp	0.80	0.40
home19_esymp	0.80	0.46
home23_info	0.80	0.42
home25_emerg	0.79	0.47
home20_adl	0.80	0.39
home22_fin	0.80	0.37
home24_famsupp	0.79	0.46
PC 2	0.33	
make4_refwtime	0.12	0.25
arrive6_wrooms	0.42	0.07
home24_famsupp	0.02	0.28

Table 77: Internal consistency for second principal component analysis

Discussion

We investigated clustering of responses to the 25 items on unmet needs. The aim of this investigation into clustering was to reduce the number of items that we assess for association in later analyses. We found evidence for 1 cluster of items, consisting of 14 items that load uniquely onto that factor (highlighted in purple above), evidence for more than one cluster was weak, since the items that made up the additional factors were either complex (ie they loaded on more than one component) or had less than three items.

Additional information on survey development

Methods: The Consumer Preferences Survey was developed in three steps:

Phase I: Content development based on a structured literature review

Phase II: Refinement based on several rounds of feedback from consumer advocates and service providers

Phase III: Development of an electronic survey with branching and features to improve participant acceptability

Phase I: Developing a comprehensive item pool of possible health service initiatives

Given the extensive qualitative work underpinning measures of need and satisfaction with patient-centered care [1, 2], a literature-based approach rather than a qualitative approach was used to construct a comprehensive item pool and a list of the areas or domains in which specialist outpatient care could be improved. Searches were conducted in April 2012 – Table 1 includes the search strategy and inclusion criteria.

Search terms focused on prevalent chronic diseases in high income health systems; such as arthritis, asthma, cancer, cardiovascular disease, diabetes, and mental illness which account for the majority of disease burden and health system expenditure [3]. No search term for hospital-based specialist services was included as there is considerable variation in the terms used to define this setting. Although search terms emphasized quantitative methods, such as survey tools or scales, qualitative research was not excluded. International and national policy or government reports assessing the quality of chronic disease health care were also included. Once searches were complete, the following four steps were undertaken to develop survey content.

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Table 1: Details of structured literature review for developing survey content

Step 1: Reviewing eligible articles for possible health service initiatives

Eligible articles were reviewed for item content. This included items within previously applied measures regardless of whether or not psychometric testing had been conducted. A checklist

(Figure 1) was used to systematically determine the eligibility of an item or domain/theme for inclusion in the item pool. This checklist was developed by study researchers to ensure retrieved items were: relevant to informing health service initiatives in hospital-based specialist settings; relevant across chronic diseases, generalizable to all health service users; and were patient-centered. Items that could not be suitably reframed to fit these criteria were removed. Original wording was retained as much as possible.

ITEM INCLUSION CHECKLIST

Include if item content, theme or result is applicable to:		
	One of the specified chronic illnesses	
	Hospital based non-acute services	
	Patients' experiences, satisfaction, unmet needs within healthcare setting	
	Applicable to all phases of a chronic illness trajectory (diagnosis, treatment, remission)	
	Applicable to multiple chronic illness groups	
	Content can be appropriately adapted to web-based survey administration	
	Components of patient-centred care	
Exclude if item content, theme or result is applicable to:		
	Acute illness or acute presentation of a chronic illness	
	Emergency or community-based care	
	Applicable only to one specific chronic illness group	
	Provider or support person perceptions of care	
	Only specific patient sub-groups in remission, diagnostic or treatment phases	
	Assessing severity of symptoms, health-related quality of life, or efficacy of treatments.	
OUTCOME:		
	All measure content included in item pool	
	Some measure content included in item pool	
	No measure content included in item pool	

Figure 1: Checklist used to systematically determine the eligibility of an item or domain/theme for inclusion in the item pool.

Step 2: Reviewing articles for possible domains or organizational structure for health service

initiatives

Domains of measures were also recorded. For example, domains within the Supportive Care

Needs Survey [4], included: physical; activities of daily living; patient care; psychological;

relationships and support; socioeconomic; self-management and health literacy; and future orientation

[4]. This step created a list of potential domains and organizational structures.

Step 3: Item stems or 'Ways of Asking'

Multiple ways of asking were developed based on existing response scales, item stems, and question types. There are several different forms of response scales within unmet needs and satisfaction measures. This can range from simple Yes/No responses to ten point Likert scales. These formats aim to balance participant burden and complexity with richness of data.

Step 4: Developing a priority setting exercise for health service initiatives

Several preference eliciting techniques, including willingness-to-pay and contingent-valuation approaches were reviewed in order to select an approach to prioritising health service initiatives [5-11]. Willingness-to-pay is a methodology used in health economics to assess preferences for particular outcomes according to the relative values patients will accept for such outcomes. Given its emphasis on consumer preferences [5], a modified version of the method is a patient-centered and acceptable approach to quantifying patients' preferences for alternative services [7]. A rapid appraisal of willingness-to-pay approaches was undertaken, with emphasis placed on those methods appropriate for use in health care settings and with high patient acceptability.

Phase II: Refinement based on iterative feedback from consumer advocates and service experts Stakeholder groups reviewed the data generated in Phase 1 to assist in achieving a comprehensive set of potential targets for change that are modifiable at a service level and allowed participants to generate a personalized and prioritised list of targets for change.

Step 1: Review by outpatient service experts

All items were circulated to a committee of twenty chronic disease physicians, health service managers, community-based chronic disease experts, and health behaviour researchers. This committee represented a wide range of professional experience recruited from local hospital-based

specialist services, medical organizations or foundations (such as Cancer Council New South Wales) and research collaborators. Committee feedback was supplemented by comments from an academic biostatistician and a health economist.

All committee members were asked to review the item pool of health service initiatives, ways of asking and possible domains or organizational structure. This included possible priority setting exercises. Individuals were encouraged to suggest additional initiatives and to remove items that may not be relevant to their health service, disease speciality, or research experience. Items that were perceived to be non-modifiable at a service level were noted and reviewed in detail by the study working group. If deemed non-modifiable the item was removed.

Individuals electronically recorded all potential modifications to the survey content and this was supplemented with telephone conversation for clarification as required. Committee comments were collated and discussed by all of the authors. The committee review process was repeated on the refined item pool, domains and ways of asking to facilitate comment on the appropriateness of changes to achieve consensus.

Step2: Review by consumers and health service users

Draft versions of the survey were circulated to a wide range of consumer advocates and health service users within cancer, neurology, and cardiology fields. Seven consumer advocates provided comments electronically in a similar process to the outpatient service experts committee. Twentyseven patients provided comments during an informal face-to-face interview with a study researcher (EF). All consumer participants were asked to comment on the comprehensiveness or redundancy of items, organization of items into appropriate domains, length of survey, and ease of comprehension. Consumers were asked if directions were adequate and clear, the survey missed any relevant initiatives to outpatient clinics that could improve their experience, and whether they would be able to assist another participant to complete the survey. Consumers were also asked to comment on the perceived value of the survey and if they thought the survey would accurately summarize the initiatives that were important to their personal experiences. Directions and value of the priority setting exercise were also discussed.

This process was repeated twice. A select sample of chronic disease patients also completed a final touch-screen version to gain qualitative feedback on readability, comprehension, comprehensiveness and on the administration mode as described below.

Phase III: Development of an electronic survey with branching and features to improve participant acceptability

As this survey may be applied within busy healthcare settings, an electronic format has multiple advantages. These include: convenient data entry with instant availability, reduction of missing data, sophisticated question branching, and reduced administration times as compared to pen and paper versions [12-14]. It may also minimize social desirability bias, as participants perceive this mode of administration as highly private [15]. Studies suggest patients prefer touch-screen electronic versions, regardless of age or gender [13, 14].

Results

Phase I: Developing a comprehensive item pool of potential health service initiatives

A total of 336 articles were reviewed for item content, domains, and response scales. Of the 336 articles, saturation was achieved after approximately 50 articles.

Items and domains: A total of 179 unique items were identified through the structured literature review; these mapped to approximately 21 possible categories. For example, help to deal with uncertainty and help with feeling anxious are contained within the larger category of 'help with psychological symptoms or negative emotions'. These categories could then in turn be mapped to the larger domains.

The domains within retrieved articles were conceptually similar, with very little variation across chronic diseases regarding domain type. However, there were notable differences in the scope of the domains (i.e. differences in the number of items, breadth of items or specificity of items within a particular domain) and several measures did not specify any domains. A total of 6 unique domains were identified: physical symptoms or side-effects; activities of daily living; patient care; psychological concerns; relationships and support; socioeconomic; self-management and health literacy; and future orientation or spirituality.

Ways of asking: Approximately five unique ways of asking were identified. Item stems incorporated concepts such as satisfaction, impact or value of the initiative, and perceived importance. Several of these stems included a specified time frame and ranged in complexity from 'What impact would the following have on your well-being if the outpatient clinic provided this immediately' to 'Select the changes to your outpatient clinic that would improve your experiences within the outpatient clinic'. Response formats included 5 or 7 point Likert scales and dichotomous pick formats. Several options allowed participants to specify whether a change would have a negative impact on their experience of care and whether changes to clinic practice were required.

Priority setting exercise: Four exercises were developed. Contingent valuation exercises were deemed inappropriate given that the outcome and cost of a health service initiative was not known.

Exercises included: ranking processes, modified willingness-to-pay questions (using points or dollar values); visual apportioning of a pie chart to respective health service initiatives; and a visual analogue scale in which participants were asked to place initiatives according to importance.

Phase II: Refinement based on iterative feedback from service expert and consumer advocate groups

Items and domains: After two rounds of feedback from expert groups, a total of 23 general initiatives categories were identified with approximately 107 specific health service initiatives. Figure 2 outlines this process. Expert groups selected an organizational structure that was presented according to four areas or steps within the process of care: scheduling an appointment; arriving at your appointment; during your clinical appointment; and managing your condition at home. Three general initiatives are within scheduling an appointment; four within arriving at your appointment; seven within during your clinical appointment; and eight within managing your condition at home.

Ways of asking: Ways of asking were reviewed twice by both expert groups. During the first review, the outpatient service expert group suggested an additional 'Way of Asking', with the consumer and health service user group reviewing a total of six items stems and response scales. Consumers suggested three of the six options were inappropriate and difficult to understand. The second review produced a clear preference with both groups preferring the simplest item stem and response scale. Both groups emphasized the need to reduce the cognitive burden placed on participants and survey completion time. The preferred way of asking requires participants to identify the initiatives that would greatly improve their experience within the health service by selecting items on the touch-screen. Those initiatives not selected are interpreted as not relevant to the participant's experience of

care. If a general initiative is selected, the participant will receive a question exploring specific health service initiatives: "On the last screen, you indicated that [general health service initiative] could improve your experience. What specifically could the clinic change to help you?".

Priority setting exercise: Similar to response scales and ways of asking, both consumers and outpatient service experts opted for those exercises that were seen to be the simplest and quickest. Following a willingness-to-pay approach, a modified resource allocation exercise was selected. This exercise asks participants to allocate 100 points across their top five desired changes. Additional feedback on the relative prioritisation exercise included discussion of allocating points versus dollars, total number of initiatives that should be included within the exercise, the total number of points to allocate, and increasing the emphasis on eliciting an individual's priorities for their own care.

As participants may select more than five general health service initiatives, an additional exercise asking participants to select the five initiatives that are most important to their personal experience was added. Individuals who do not select any initiatives will not receive the prioritization exercise.

Final formatting of the Consumer Preferences Survey: Feedback during the development process suggested that the Consumer Preferences Survey should contain simple instructions, clear examples of how clinics can introduce health service initiatives across areas of care and ensure the measure is not interpreted by patients as complaining. Therefore, the introduction describes initiatives as changes that would improve or enhance existing care. Participants are encouraged to select as few or as many initiatives as relevant to their personal experience.

Touch screen administration was well received by consumer advocates and patients. Several modifications to the priority setting exercise were incorporated into a final version. Directions for the
priority setting exercise were altered to clearly specify: 1) an individual could allocate as many or as few points to each initiative; and 2) the more points allocated to a specific health initiative, the more important the initiative is to their personal experience of care.

Phase III: Development of an electronic survey with branching and features to improve participant acceptability

All participants must navigate through the 4 areas of care and will be presented with 23 possible broad health service initiatives. However, only those participants who select all 23 broad health service initiatives will view all 107 detailed health service initiatives contained within the Consumer Preferences Survey. Table 2 lists the 107 items and outlines the relationship between areas of care, broad health service initiatives, and detailed health service initiatives. Using the example of parking, only those who believe their outpatient service should address parking concerns will be asked to select more detailed initiatives such as increased numbers of spaces, drop off zones, or more affordable parking options.

This complex branching pattern is essential to the survey design. However, the research team could not find a readily available web-based software program with this capability. A novel software program was developed in collaboration with health behaviour researchers and information technology experts. Paul et al have described this process in detail elsewhere [16]. The content developed and refined in Phase I and II was adapted into this survey packages and will be administered using touch-screen computers. The software and use of this technology allows for improved readability and comprehension with simplified question formats. For example, the point allocation exercise within the Consumer Preference Survey is auto-filled with those health service initiatives previously identified by the participant. The program includes a calculator to ensure the participant allocates all 100 points. This calculator feature also maintains a running tally so the

participant knows the number of remaining points to allocate across remaining initiatives. The

development of survey content by phases is presented in Figure 2.



Figure 2: Development of survey content by phase.

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Appendix E

Ethical approvals, participant information sheets, and consent forms

Overarching ethical approvals granted for studies outlined in Papers 2, 3, 4 and 6



28 May 2014

Laureate Professor Rob Sanson-Fisher HBRG W4 HMRI Building

Dear Professor Sanson Fisher

Re: Assessing willingness to participate in future research and health service preferences among chronic disease out-patients (12/08/15/4.04)

HNEHREC Reference No: 12/08/15/4.04 NSW HREC Reference No: HREC/12/HNE/173 SSA Reference No: SSA/12/HNE/370 - JHH SSA/12/HNE/446 - CMN

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has granted ethical approval for the following amendment requests:

- To recruit a convenience sample of health professionals and support staff from participating pilot sites to complete a short online survey at their convenience;
- For Attachment A: Provider Preferences Survey (Version 1 dated 25 May 2014);
- For Attachment B: Provider Information Statement (Version 1 dated 25 May 2014);
- For Attachment C: Provider Email Invitation (Version 1 dated 26 May 2014);
- For Attachment D: Provider Recruitment Poster (Version 1 dated 26 May 2014); and
- For Attachment E: Provider Reminder Email (Version 1 dated 26 May 2014)

For the study: Assessing willingness to participate in future research and health service preferences among chronic disease out-patients

Approval from the Hunter New England Human Research Ethics Committee for the above study is given for a maximum of 3 years from the date of the approval letter of your initial application, after

> Hunter New England Human Research Ethics Committee Locked Bag 1 New Lambton NSW 2305 Telephone: (02) 49214950 Faceimile: (02) 49214818 Email: HNELHD-HREC@inhehealth.nsw.gov.au http://www.hnehealth.nsw.gov.au/research.ethics.and.governance.unk



4 September 2012

L/Professor R Sanson-Fisher Health Bohaviour Research Group HMRI Building (W4)

Dear L/Professor Sanson Fisher.

Re: Assossing willingness to participate in future research & health service preferences among chronic disease out-patients (12/08/15/4.04)

HNEHREC Reference No: 12/08/15/4.04 NSW HREC Reference No: HREC/12/HNE/273

Thank you for submitting the above protocol for single ethical review for a multi-centre study. This project was first considered by the Hunter New England Human Research Ethics Committee at its meeting held on **15 August 2012**. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review. The Committee's Terms of Reference are available from the Hunter New England Local Health District website: http://www.hnehealth.nsw.gov.au/Human Research Ethics.

I am pleased to advise that following acceptance under delegated authority of the requested clarifications and revised Information Statement by Dr Nicole Gerrand Manager, Research Ethics & Governance in consultation with reviewers, the Hunter New England Human Research Ethics Committee has granted ethical approval of the above project.

The following documentation has been reviewed and approved by the Hunter New England Human Research Ethics Committee:

- For the Participant Information Sheet Overall Survey (Version 2 dated 4 September 2012);
- For the Participant Information Sheet Qualitative Interviews (Version 2 dated 24 August 2012);
- For the Participant Consent Form Qualitative Interviews (Version 2 dated 24 August 2012);
- For the Participant Information Sheet Lest Retest (Version 1 dated 31 July 2012), For the Consent Form - Test (Version 1 dated 31 July 2012);
- For the Semi-Structured Interview Guide (Version 1 dated 31 July 2012);
- For the Consumer Preferences Survey (Version 1 dated 31 July 2012); and
- For the Out-patient Clinic Survey (Version 2 dated 28 August 2012)

Hunter New England Research Ethics & Governance Unit

(Locked Bag Norf) (New Lambton, NSW, 2905) Relephone (02) 49214 950 Facsimile (02) 40214 818 Email: Intebreo@hnehealth.nsw.gov.au http://www.hnehealth.nsw.gov.au/reseat2i_ethics_and_governsmco_unit



<u>Newcastle Private Medical Advisory Committee</u> <u>Oncology Clinical Trials</u> <u>Letter of Support and Acknowledgement</u>

Re: Assessing willingness to participate in future research and health service preferences among chronic disease outpatients

Investigator: Laureate Professor Rob Sanson Fisher, Director of the University of Newcastle Priority Research Centre for Health Behaviour

The above protocol was presented at the last medical advisory committee held

15 08 2013 (date) at Newcastle Private Hospital.

The Medical Advisory Committee has had opportunity for clinical trial review, discussion and comment, and supports the implementation of the trial at Newcastle Private provided all the necessary approvals are in place, as per the Healthscope Clinical Trials and Research Policy – 2.11.

MAC Chairperson

Name: PETER BERTON

Signature: ____

Date: 15 ANGUST 2013

CI Rob Sanson Fisher

For NPH Medical Advisor Committee Review

Participant information statements and consent forms: Papers 2, 3, 4 and 6

Prof. Rob Sanson-Fisher School of Medicine and Public Health, University of Newcastle University Drive, Callaghan NSW 2308 Ph: 02 4042 0713 Fax: 02 4042 0040 Rob.Sanson-Fisher@newcastle.edu.au



Information Statement for the Research Project:

Willingness to participate in future research and health service preferences

Version #5: 24/01/2013

As a patient attending an outpatient clinic, we would like to invite you to participate in a research study to i) assess your willingness to participate in future research and ii) if you have previously attended this outpatient clinic, provide your opinion about what could be done to improve patients' experiences at treatment centres. This research is being conducted by a research team from the University of Newcastle.

Why is the research being done?

Surveys are commonly used to identify patients' unmet needs or preferences for care. However, none of these surveys allow participants to identify what changes should be made to out-patient clinics. The Consumer Preference Survey has been developed to fill this gap and will be used in future studies to improve the quality of care received by patients within New South Wales. This research project will assess the accuracy and reliability of this new survey. Additional questions about your willingness to participate in future research will be asked so that we can contact you in the future about research opportunities that might interest you.

Who can participate in the research?

We are seeking English-speaking patients over the age of 18 years to participate in this study.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. Your healthcare providers will not be informed of your decision. If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

What would you be asked to do?

If you agree to participate, you will be asked to complete a touchscreen survey on an iPad. The survey will include questions about you, such as your age, gender, and marital status, reason for attending today, and your willingness to participate in future research. If you have visited this outpatient clinic before (today is not your first appointment), you will also be asked questions about how we can improve the out-patient

clinic you attend,. You may be offered opportunities to participate in future research projects as part of this survey.

You will be invited to complete the survey in the waiting room prior to your appointment today. If there is a more private area available, you will be offered this option. If you are not able to complete the survey at your appointment today, you may be approached to participate at a later date. However, we cannot guarantee that you will be able to participate at a later date.

How much time will it take?

It is expected that the survey will take approximately 20 minutes to complete, but it could take up to 30 minutes. You may get called into your appointment before finishing the survey. If this happens, you have the option to finish the survey after your appointment. You are not obligated to finish the survey after your appointment, and the research support person will not approach you. When pausing the survey, the research support person will ask if you are willing to submit your partially completed survey if you do not return. If you do not return and had indicated you are not willing to submit your partial survey, the Research Support Person will remove your information from the study. If you do return to the research support person, the survey will start from where you left off.

What are the risks and benefits of participating?

We cannot promise you any benefit from participating in this research. We do not expect that there will be any risks associated with participating. There is a small possibility that completing the survey may cause you to reflect on your cancer care, and might cause distress. If you do have questions or are distressed after completing the survey, we recommend that you discuss these issues with your doctor. Cancer patients can also contact the Cancer Helpline at 13 11 20. This service is staffed by cancer nurses who provide information and support to people with cancer and their families.

How will your privacy be protected?

Information collected will be de-identified upon receipt. This means that a unique identification code (ID) will be stored with your survey results. If you provide your name and contact information it will be stored separately from your survey data, and will only be able to be re-linked by the ID code. Any identifying information will be stored securely in a password protected file on the University of Newcastle server. This information will only be accessed by the researchers unless you consent otherwise, except as required by law. Data will be retained for at least 7 years in a locked filing cabinet and password protected files at the University of Newcastle. De-identified data may be made available for secondary analysis, however separate ethics approval will be sought beforehand. Where data is used for further analysis, it will not contain any identifying information.

How will the information collected be used?

Some of the research being conducted is part of Elizabeth Fradgley's post graduate studies at the University of Newcastle, supervised by Associate Professor Chris Paul, Prof. Rob Sanson-Fisher and Dr's Jamie Bryant and Mariko Carey from the School of Medicine and Health. The information collected will be reported in scientific journals and in a peer-reviewed thesis for Ms. Fradgley's degree. Additionally, the information collected will be presented at national and international conferences and published in

scientific journals. Only group data will be presented in any reports of publications arising from this research. In this way, no individual can be identified in any publications. If requested by clinic, we will also provide them with group, de-identified information about psychosocial outcomes of patient attending their clinic.

At the end of the study we can send you a summary of the key findings of the project. If you would like this information sent to you, please check the appropriate box at the end of the iPad survey.

Is there additional research I can participate in?

A screen on the iPad will describe a short follow-up study and ask if you are also interested in participating in this additional survey. If you are not interested, you will not be asked any other questions. If you select that you are interested, you will be provided with a short information sheet and consent form and be asked to provide some contact details. You do not need to participate in this additional research in order to complete the survey.

What do you need to do to participate?

Please read this Information Statement and be sure you understand all its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher, whose details are below. Informed consent is implied if you choose to complete the survey. If you would like to participate, please inform the Research Support Person and complete the survey now.

Further information

If you would like further information, please contact Prof. Rob Sanson-Fisher (02 4042 0713) or Ms Liz Fradgley (02 4042 0642).

Thank you for considering this invitation.

Rob Sanson-Fisher	
Laureate Professor of Health Behaviour	Elizabeth Fradgley
University of Newcastle	
Complaints about this research	PhD Candidate. Health Behaviour
This project has been approved by Hunter New Englar	nd's Human Research Ethics Committee, Reference
No.12/08/15/4.04.	University of Newcastle

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Manager, Research Ethics and Governance, Hunter New England Human Research Ethics & Governance Unit, Locked Bag 1, New Lambton NSW 2305, Australia, telephone (02) 49214950, email <u>hnehrec@hnehealth.nsw.gov.au</u>

Prof. Rob Sanson-Fisher School of Medicine and Public Health, University of Newcastle University Drive, Callaghan NSW 2308 Ph: 02 4042 0713 Fax: 02 4042 0040 Rob.Sanson-Fisher@newcastle.edu.au



Information Statement for the Research Project:

Willingness to participate in future research and health service preferences (Medical Oncology)

Version #2: 17/06/2013

As a patient attending a medical oncology outpatient clinic, we would like to invite you to participate in a research study to i) assess your willingness to participate in future research and ii) if you have previously attended this outpatient clinic, provide your opinion about what could be done to improve patients' experiences at treatment centres. This research is being conducted by a research team from the University of Newcastle.

Why is the research being done?

Surveys are commonly used to identify patients' unmet needs or preferences for care. However, none of these surveys allow participants to identify what changes should be made to out-patient clinics. The Consumer Preference Survey has been developed to fill this gap and will be used in future studies to improve the quality of care received by patients within New South Wales. This research project will assess the accuracy and reliability of this new survey.

Questions about your willingness and preferences for participating in future research will be asked so that we can contact you in the future about research opportunities that might interest you. Additionally, you will be asked questions on your views and opinions regarding human tissue donation for research purposes (please note you will not be asked to donate tissue based on your survey responses, the research only aims to gain insight into your opinions on this issue).

Who can participate in the research?

We are seeking English-speaking patients over the age of 18 years to participate in this study.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. Your healthcare providers will not be informed of your decision. If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

What would you be asked to do?

If you agree to participate, you will be asked to complete a touchscreen survey on an iPad. The survey will include questions about you, such as your age, gender, and marital status, reason for attending today, and your willingness to participate in future research. If you have visited this outpatient clinic before (today is not your first appointment), you will also be asked questions about how we can improve the out-patient clinic you attend. You may be offered opportunities to participate in future research projects as part of this survey

You will be invited to complete the survey in the waiting room prior to your appointment today or while you receive treatment today. If there is a more private area available, you will be offered this option. If you are not able to complete the survey at your appointment today, you may be approached to participate at a later date. However, we cannot guarantee that you will be able to participate at a later date.

How much time will it take?

It is expected that the survey will take approximately 20 minutes to complete, but it could take up to 30 minutes. You may get called into your appointment before finishing the survey. If this happens, you have the option to finish the survey after your appointment. You are not obligated to finish the survey after your appointment, and the research support person will not approach you. When pausing the survey, the research support person will ask if you are willing to submit your partially completed survey if you do not return. If you do not return and had indicated you are not willing to submit your partial survey, the Research Support Person will remove your information from the study. If you do return to the research support person, the survey will start from where you left off.

If you are completing this survey while receiving treatment, you can pause or choose to end the survey at any time. You do not need to provide a reason for choosing to stop.

What are the risks and benefits of participating?

We cannot promise you any benefit from participating in this research. We do not expect that there will be any risks associated with participating. There is a small possibility that completing the survey may cause you to reflect on your cancer care, and might cause distress. If you do have questions or are distressed after completing the survey, we recommend that you discuss these issues with your doctor. Cancer patients can also contact the Cancer Helpline at 13 11 20. This service is staffed by cancer nurses who provide information and support to people with cancer and their families.

How will your privacy be protected?

Information collected will be de-identified upon receipt. This means that a unique identification code (ID) will be stored with your survey results. If you provide your name and contact information it will be stored separately from your survey data, and will only be able to be re-linked by the ID code. Any identifying information will be stored securely in a password protected file on the University of Newcastle server. This information will only be accessed by the researchers unless you consent otherwise, except as required by law. Data will be retained for at least 7 years in a locked filing cabinet and password protected files at the University of Newcastle. De-identified data may be made available for secondary analysis, however separate ethics approval will be sought beforehand. Where data is used for further analysis, it will not contain any identifying information.

How will the information collected be used?

Some of the research being conducted is part of Elizabeth Fradgley's post graduate studies at the University of Newcastle, supervised by Associate Professor Chris Paul and Dr's Jamie Bryant and Mariko Carey from the School of Medicine and Health. The information collected will be reported in scientific journals and in a peer-reviewed thesis for Ms. Fradgley's degree. Additionally, the information collected will be presented at national and international conferences and published in scientific journals. Only group data will be presented in any reports of publications arising from this research. In this way, no individual can be identified in any publications. If requested by clinic, we will also provide them with group, de-identified information about psychosocial outcomes of patient attending their clinic.

Is there additional research I can participate in?

A screen on the iPad will describe a short follow-up study and ask if you are also interested in participating in this additional survey. If you are not interested, you will not be asked any other questions. If you select that you are interested, you will be provided with a short information sheet and consent form and be asked to provide some contact details. You do not need to participate in this additional research in order to complete the survey.

What do you need to do to participate?

Please read this Information Statement and be sure you understand all its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher, whose details are below. Informed consent is implied if you choose to complete the survey. If you would like to participate, please inform the Research Support Person or your clinic nurse and complete the survey now.

Further information

If you would like further information, please contact Prof. Rob Sanson-Fisher (02 4042 0713) or Ms Liz Fradgley (02 4042 0642).

Thank you for considering this invitation.

Rob Sanson-Fisher

Laureate Professor of Health Behaviour

University of Newcastle

Elizabeth Fradgley PhD Candidate, Health Behaviour University of Newcastle

Complaints about this research

This project has been approved by Hunter New England's Human Research Ethics Committee, Reference No.12/08/15/4.04. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Manager, Research Ethics and Governance, Hunter New England Human Research Ethics & Governance Unit, Locked Bag 1, New Lambton NSW 2305, Australia, telephone (02) 49214950, email hnehrec@hnehealth.nsw.gov.au.

Prof. Rob Sanson-Fisher School of Medicine and Public Health, University of Newcastle University Drive, Callaghan NSW 2308 Ph: 02 4042 0713 Fax: 4042 0040 Rob.Sanson-Fisher@newcastle.edu.au



Information Sheet for the Research Project:

Testing the reliability of the Consumer Preferences Survey

Version #1: 31/07/2012

Thank you for completing the Consumer Preferences Survey. We would like to invite you to participate in the research project identified above which is being conducted by The Research Team from the University of Newcastle.

Why is the research being done?

The Consumer Preferences Survey is a recently developed survey that asks questions about what changes could be made to out-patient clinics to improve patients' experiences. To ensure the survey is accurate in providing a comprehensive summary of patients' preferences, this study will examine if the survey consistently reports patients' preferences by asking patients to complete the survey on two separate occasions. You will not be asked questions regarding your willingness to participate in future research again. *Who can participate in the research?*

We are seeking English-speaking patients over the age of 18 years with a chronic disease diagnosis, who have attended an appointment at their out-patient clinic on at least one previous occasion, to participate in this study. Participants must have a scheduled appointment within 14 days of first completing the survey.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. Healthcare providers will not be informed of your decision. If you do decide to participate you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

What would you be asked to do?

If you have an appointment scheduled at your out-patient clinic in the next two weeks, you will be asked to complete the survey for a second time on an iPad when you come in for that appointment. You will complete this survey in the waiting room prior to your appointment just as you did today. If there is a more private area available, you will be offered this option.

If you agree to participate, you will be asked to provide the date and time of your next appointment on the iPad today. This will be recorded in a log-book so the researchers can identify you at your next appointment. You will receive a study number and will be asked to provide contact details. This will only be used by the

researchers to link together your two surveys. It could also be used to follow up with you if your appointment is cancelled or rescheduled.

How much time will it take?

It is expected that the survey will take approximately 15 minutes to complete. If you start completing the survey but get called into your appointment before finishing, you have the option to finish the survey after your appointment. You will have the option of deleting all of the information entered, or submitting the partially-completed information.

What are the risks and benefits of participating?

We cannot promise you any benefit from participating in this research. However, we do expect that the results of this research will help to highlight how care can be improved for future patients.

We do not expect that there will be any risks associated with participating. It is possible that participation may cause you to reflect on your care and may raise questions. Many patients have completed similar surveys, but there is a small possibility that the questions will cause some distress. If you have questions about your condition, we recommend that you discuss these with your doctor. If you have cancer, you can also contact the Cancer Helpline at 13 11 20 to discuss questions or anything that may have distressed you. This service is staffed by cancer nurses who provide information and support to people with cancer and their families.

How will your privacy be protected?

Information collected in the study will be de-identified upon receipt. This means that a unique identification code (ID) will be stored with your survey results. Your name and contact information will be stored separately from your survey data, and will only be able to be re-linked by the ID code. Any identifying information will be stored securely in a password protected file on the University of Newcastle server. This information will only be accessed by the researchers unless you consent otherwise, except as required by law. Data will be retained for at least 7 years in a locked filing cabinet and password protected files at the University of Newcastle. Your contact information will only be used by the researchers for the purposes of contacting you if your appointment is cancelled or rescheduled.

Only group data will be presented in any reports or publications arising from this research. In this way, no individual will be identifiable and your privacy will be protected.

How will the information collected be used?

Some of the research conducted is part of Elizabeth Fradgley's post graduate studies at the University of Newcastle, supervised by Dr. Chris Paul, Dr. Mariko Carey, and Prof. Rob Sanson-Fisher from the School of Medicine and Health. The information collected will be reported in scientific journals and in a peer-reviewed thesis for Ms. Fradgley's degree.

Additionally, the information collected will be presented at national and international conferences and published in scientific journals. Only group data will be presented in any reports or publications arising from this research. In this way, no individual will be identifiable and your privacy will be protected.

What do you need to do to participate?

Please read this Information Statement and be sure you understand all its contents before you sign and date a consent form to participate. If there is anything you do not understand, or you have questions, contact the researchers whose details are below.

If you would like to participate, please complete the attached consent form attached and return it to the Research Support Person.

Further information

If you would like further information, please contact Prof. Rob Sanson-Fisher (02 4042 0713) or Ms Elizabeth Fradgley (02 4042 0642).

Thank you for considering this invitation.

Rob Sanson-Fisher Laureate Professor of Health Behaviour University of Newcastle Elizabeth €radgley PhD Candidate, Health Behaviour University of Newcastle

Complaints about this research

This project has been approved by Hunter New England's Human Research Ethics Committee, Reference No.12/08/15/4.04.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Manager, Research Ethics and Governance, Hunter New England Human Research Ethics & Governance Unit, Locked Bag 1, New Lambton NSW 2305, Australia, telephone (02) 49214950, email <u>hnehrec@hnehealth.nsw.gov.au</u>.

Prof. Rob Sanson-Fisher School of Medicine and Public Health, University of Newcastle University Drive, Callaghan NSW 2308 Ph: 02 4042 0713 Fax: 02 4042 0040 Rob.Sanson-Fisher@newcastle.edu.au



Consent Form for the Research Project: Testing the reliability of the Consumer Preferences Survey

Version #1: 31/07/2012

I agree to participate in the research project – Testing the reliability of the Consumer Preferences Survey and give my consent freely. I understand I do not need to participate in this additional research as part of the research project I just completed.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to:

Completing the Consumer Preferences Survey on an iPad at my next appointment scheduled within the next two weeks,

Providing my appointment details and personal contact information so researchers can arrange to administer the Consumer Preferences Survey at my next appointment

Researchers using my contact details to contact me regarding the survey in the event that my next appointment is rescheduled or cancelled.

I will contact the listed individuals on the provided information sheet if I have any questions or concerns. I understand that my personal information will remain confidential to the researchers, and will be stored securely.

I have had the opportunity to have questions answered to my satisfaction.

Print Name:	
Signature:	Date:

If you have agreed to participate and signed this document, please return it to the Research Support Person and provide your appointment and contact details on the iPad.

Thank you for considering this invitation.

Rob Sanson-Fisher Laureate Professor of Health Behaviour University of Newcastle Elizabeth Adgley PhD Candidate, Health Behaviour University of Newcastle

Complaints about this research

This project has been approved by Hunter New England's Human Research Ethics Committee, Reference No.12/08/15/4.04.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Manager, Research Ethics and Governance, Hunter New England Human Research Ethics & Governance Unit, Locked Bag 1, New Lambton NSW 2305, Australia, telephone (02) 49214950, email <u>hnehrec@hnehealth.nsw.gov.au</u>.

Prof. Rob Sanson-Fisher School of Medicine and Public Health, University of Newcastle University Drive, Callaghan NSW 2308 Ph: 02 4042 0713 Fax: 02 4042 0040 Rob.Sanson-Fisher@newcastle.edu.au



Information Statement for the Research Project: Willingness to participate in future research and health service preferences Version #5: 24/01/2013

As a patient attending an outpatient clinic, we would like to invite you to participate in a research study to i) assess your willingness to participate in future research and ii) if you have previously attended this outpatient clinic, provide your opinion about what could be done to improve patients' experiences at treatment centres. This research is being conducted by a research team from the University of Newcastle.

Why is the research being done?

Surveys are commonly used to identify patients' unmet needs or preferences for care. However, none of these surveys allow participants to identify what changes should be made to out-patient clinics. The Consumer Preference Survey has been developed to fill this gap and will be used in future studies to improve the quality of care received by patients within New South Wales. This research project will assess the accuracy and reliability of this new survey. Additional questions about your willingness to participate in future research will be asked so that we can contact you in the future about research opportunities that might interest you.

Who can participate in the research?

We are seeking English-speaking patients over the age of 18 years to participate in this study.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. Your healthcare providers will not be informed of your decision. If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

What would you be asked to do?

If you agree to participate, you will be asked to complete a touchscreen survey on an iPad. The survey will include questions about you, such as your age, gender, and marital status, reason for attending today, and your willingness to participate in future research. If you have visited this outpatient clinic before (today is not your first appointment), you will also be asked questions about how we can improve the out-patient clinic you attend,. You may be offered opportunities to participate in future research projects as part of this survey.

You will be invited to complete the survey in the waiting room prior to your appointment today. If there is a more private area available, you will be offered this option. If you are not able to complete the survey at your appointment today, you may be approached to participate at a later date. However, we cannot guarantee that you will be able to participate at a later date.

How much time will it take?

It is expected that the survey will take approximately 20 minutes to complete, but it could take up to 30 minutes. You may get called into your appointment before finishing the survey. If this happens, you have the option to finish the survey after your appointment. You are not obligated to finish the survey after your appointment, and the research support person will not approach you. When pausing the survey, the research support person will ask if you are willing to submit your partially completed survey if you do not return. If you do not return and had indicated you are not willing to submit your partial survey, the Research Support Person will remove your information from the study. If you do return to the research support person, the survey will start from where you left off.

What are the risks and benefits of participating?

We cannot promise you any benefit from participating in this research. We do not expect that there will be any risks associated with participating. There is a small possibility that completing the survey may cause you to reflect on your cancer care, and might cause distress. If you do have questions or are distressed after completing the survey, we recommend that you discuss these issues with your doctor. Cancer patients can also contact the Cancer Helpline at 13 11 20. This service is staffed by cancer nurses who provide information and support to people with cancer and their families.

How will your privacy be protected?

Information collected will be de-identified upon receipt. This means that a unique identification code (ID) will be stored with your survey results. If you provide your name and contact information it will be stored separately from your survey data, and will only be able to be relinked by the ID code. Any identifying information will be stored securely in a password protected file on the University of Newcastle server. This information will only be accessed by the researchers unless you consent otherwise, except as required by law. Data will be retained for at least 7 years in a locked filing cabinet and password protected files at the University of Newcastle. De-identified data may be made available for secondary analysis, however separate ethics approval will be sought beforehand. Where data is used for further analysis, it will not contain any identifying information.

How will the information collected be used?

Some of the research being conducted is part of Elizabeth Fradgley's post graduate studies at the University of Newcastle, supervised by Associate Professor Chris Paul, Prof. Rob Sanson-Fisher and Dr's Jamie Bryant and Mariko Carey from the School of Medicine and Health. The information collected will be reported in scientific journals and in a peer-reviewed thesis for Ms. Fradgley's degree. Additionally, the information collected will be presented at national and international conferences and published in scientific journals. Only group data will be presented in any reports of publications arising from this research. In this way, no individual can be identified in formation about psychosocial outcomes of patient attending their clinic.

At the end of the study we can send you a summary of the key findings of the project. If you would like this information sent to you, please check the appropriate box at the end of the iPad survey.

Is there additional research I can participate in?

A screen on the iPad will describe a short follow-up study and ask if you are also interested in participating in this additional survey. If you are not interested, you will not be asked any other questions. If you select that you are interested, you will be provided with a short information sheet and consent form and be asked to provide some contact details. You do not need to participate in this additional research in order to complete the survey.

What do you need to do to participate?

Please read this Information Statement and be sure you understand all its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher, whose details are below.

Informed consent is implied if you choose to complete the survey. If you would like to participate, please inform the Research Support Person and complete the survey now.

Further information

If you would like further information, please contact Prof. Rob Sanson-Fisher (02 4042 0713) or Ms Liz Fradgley (02 4042 0642).

Thank you for considering this invitation.

Chris Paul Associate Professor of Health Behaviour University of Newcastle Elizabeth Fradgley PhD Candidate, Health Behaviour University of Newcastle

Complaints about this research

This project has been approved by Hunter New England's Human Research Ethics Committee, Reference No.12/08/15/4.04.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Manager, Research Ethics and Governance, Hunter New England Human Research Ethics & Governance Unit, Locked Bag 1, New Lambton NSW 2305, Australia, telephone (02) 49214950, email hnehrec@hnehealth.nsw.gov.au.

Invitation: Tell us how to improve Hunter New England outpatient clinics

The University of Newcastle is seeking your views about how chronic disease outpatient clinics could be improved. This is part of a multi-site study focused on identifying and prioritising health service initiatives that are important to health professionals, clinic support staff, and patients. Both patients and health care providers are completing similar surveys. Approximately 650 patients have already provided their feedback.

If you are a health professional or clinic staff member involved in providing outpatient care, we would greatly appreciate your opinion. This online survey can be completed at your convenience and will take at most 5 minutes.

Please find attached an information statement describing the survey. While we encourage individuals to take part in this study, participation is completely voluntary.

The questionnaire can be accessed via the following link:

[LINK]

For further information about the research, please contact one of the researchers at the University of Newcastle:

Associate Professor Chris Paul (<u>chris.paul@newcastle.edu.au</u>; 02 4042 0693) Elizabeth Fradgley (<u>elizabeth.fradgley@newcastle.edu.au</u>; 02 4042 0642)

Thank you for considering this invitation.

Reminder: Invitation to participate in research exploring health service intervention priorities

You may recall being sent information regarding the department's involvement in research seeking health professionals' and support staffs' opinions on how chronic disease outpatient clinics could be improved. This is part of a University of Newcastle multi-site study focused on identifying and prioritising health service initiatives that are important to providers and patients. Both patients and health care providers are completing similar surveys. Approximately 650 patients have already provided their feedback.

Participation involves completing an anonymous online questionnaire that will take approximately 5 minutes to complete. Individuals can access the questionnaire at their convenience via the following link:

[LINK]

While we encourage individuals to take part in this evaluation, participation is of course completely voluntary. **If you have already completed the survey, please disregard this email.**

For further information about the research, please contact one of the researchers at the University of Newcastle:

Associate Professor Chris Paul (<u>chris.paul@newcastle.edu.au</u>; 02 4042 0693) Elizabeth Fradgley (<u>elizabeth.fradgley@newcastle.edu.au</u>; 02 4042 0642)

Thank you for considering this invitation.

HNEHREC12/08/15/4.04, V1 26/05/14

Overarching ethical approvals granted for Paper 5



16 December 2014

L/Professor Rob Sanson-Fisher Health Behaviour Research Group W4 HMRI Building

Dear Professor Sanson-Fisher,

Re: Improving cancer treatment systems: a randomised controlled trial of consumer action model for cancer patient receiving chemotherapy (13/08/21/4.07)

HNEHREC Reference No: 13/08/21/4.07 NSW HREC Reference No: HREC/13/HNE/340 NSW SSA Reference No: SSA/14/HNE/517

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- Manning Rural Referral Hospital

As part of the process of the governance review process for this protocol, the following documents were reviewed for use at the Manning Rural Referral Hospital site:

- For Attachment A: Participant Information Sheet (ARRH, TRRH & Taree Version 1 dated 4 April 2014) based on Master Version 6 dated 4 April 2014;
- For the Attachment B: Survey Modules (ARRH, TRRH & Taree Version 1 dated 4 April
- 2014) based on Master Version 2 dated 4 April 2014; For Attachment C: Patient Brochure (ARRH, TRRH & Taree Version 1 dated 24 March 2014) based on Master Version 2 dated 24 March 2014;
- For Attachment D: One page document for Participants (ARRH, TRRH & Taree Version 1 dated 24 March 2014) based on Master Version 2 dated 24 March 2014;
- For Attachment E: Indicative Timeline (Version 2 dated 14 May 2014);
- For Attachment F: Overview Information Statement (ARRH, TRRH & Taree Version 2 dated 15 May 2014) based on Master Version 2 dated 14 May 2014;
- For Attachment G: Hospital Administration Letter (Version 2 and 14 May 2014);
- For Attachment H: Oncology Department Head Letter (Version 2 dated 14 May 2014); For Attachment K: Study Design (Version 2 dated 14 May 2014);
- For Attachment L: Study Protocol (ARRH, TRRH & Taree Version 2 dated 15 May 2014)
- based on Master Version 2 dated 14 May 2014; and For Attachment N: Letter (Version 2 dated 14 May 2014)

Hunter New England Research Ethics & Governance Unit Locked Bag 1 New Lambton NSW 2305 Telephone: (02) 49214950 Facsimile: (02) 49214818 Email: HNELHD-HREC@hnehealth.nsw.gov.au http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

Calvary Health Care Newcastle Limited ABN 75 081 149 126 Trading as

Calvary Mater Newcastle Onr Edith & Platt Streets Waratah NSW 2298 Phone: 02 4921 1211 Locked Bag 7 Hunter Region Mail Centre NSW 2310



www.calvarymator.org.au

4 June 2014

L/Professor Rob Sanson-Fisher Health Behaviour Research Group W4 HMRI Building

Dear Professor Sanson-Fisher,

Re: Improving cancer treatment systems: a randomised controlled trial of consumer action model for cancer patient receiving chemotherapy (13/08/21/4.07)

HNEHREC Reference No: 13/08/21/4.07 NSW HREC Reference No: HREC/13/HNE/340 NSW SSA Reference No: SSA/14/HNE/146

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

Calvary Mater Newcastle

As part of the process of the governance review process for this protocol, the following documents were reviewed for use at the Calvary Mater Newcastle site:

- For Attachment A: Participant Information Sheet (CMN Version 1 dated 4 April 2014) based on Master Version 6 dated 4 April 2014;
- For the Attachment B: Survey Modules (CMN Version 1 dated 4 April 2014) based on Master Version 2 dated 4 April 2014;
- For Attachment C: Patient Brochure (CMN Version 1 dated 24 March 2014) based on Master Version 2 dated 24 March 2014;
- For Attachment D: One page document for Participants (CMN Version 1 dated 24 March 2014) based on Master Version 2 dated 24 March 2014;
- For Attachment E: Indicative Timeline (Version 2 dated 14 May 2014);
- For Attachment F: Overview Information Statement (CMN Version 2 dated 15 May 2014) based on Master Version 2 dated 14 May 2014;
- For Attachment G: Hospital Administration Letter (Version 2 and 14 May 2014);
- For Attachment H: Oncology Department Head Letter (Version 2 dated 14 May 2014);
- For Attachment K: Study Design (Version 2 dated 14 May 2014);
- For Attachment L: Study Protocol (CMN Version 2 dated 15 May 2014) based on Master Version 2 dated 14 may 2014; and
- For Attachment N: Letter (Version 2 dated 14 May 2014)

Calvary Mater Newcanle

In The Tradition of The Sisters of The Little Company of Mary



4 June 2014

L/Professor Rob Sanson-Fisher Health Behaviour Research Group W4 HMRI Building

Dear Professor Sanson-Fisher,

Re: Improving cancer treatment systems: a randomised controlled trial of consumer action model for cancer patient receiving chemotherapy (13/08/21/4.07)

HNEHREC Reference No: 13/08/21/4.07 NSW HREC Reference No: HREC/13/HNE/340 NSW SSA Reference No: SSA/14/HNE/147

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- Armidale Rural Referral Hospital
- Tamworth Rural Referral Hospital

As part of the process of the governance review process for this protocol, the following documents were reviewed for use at the Armidale and Tamworth Hospital sites:

- For Attachment A: Participant Information Sheet (ARRH/TRRH Version 1 dated 4 April 2014) based on Master Version 6 dated 4 April 2014;
- For the Attachment B: Survey Modules (ARRH/TRRH Version 1 dated 4 April 2014) based on Master Version 2 dated 4 April 2014;
- For Attachment C: Patient Brochure (ARRH/TRRH Version 1 dated 24 March 2014) based on Master Version 2 dated 24 March 2014;
- For Attachment D: One page document for Participants (ARRH/TRRH Version 1 dated 24 March 2014) based on Master Version 2 dated 24 March 2014;
- For Attachment E: Indicative Timeline (Version 2 dated 14 May 2014);
- For Attachment F: Overview Information Statement (ARRH/TRRH Version 2 dated 15 May 2014) based on Master Version 2 dated 14 May 2014;
- For Attachment G: Hospital Administration Letter (Version 2 and 14 May 2014);
- For Attachment H: Oncology Department Head Letter (Version 2 dated 14 May 2014);
- For Attachment K: Study Design (Version 2 dated 14 May 2014);
- For Attachment L: Study Protocol (ARRH/TRRH Version 2 dated 15 May 2014) based on Master Version 2 dated 14 May 2014; and
- For Attachment N: Letter (Version 2 dated 14 May 2014)

Hunter New England Research Ethics & Governance Unit Locked Bag 1 New Lambton NSW 2305 Telephone: (02) 49214950 Facsimile: (02) 49214818 Email: HNELHD-HREC@hnehealth.nsw.gov.au/research_ethics_and_governance_unit

Participant information statements for Paper 5

Prof. Rob Sanson-Fisher School of Medicine and Public Health, University of Newcastle University Drive, Callaghan NSW 2308 Ph: 02 4042 0713 Fax: 02 4042 0040 Rob.Sanson-Fisher@newcastle.edu.au



Information Statement for the Research Project: A consumer action model for improving cancer treatment systems for cancer patients receiving chemotherapy Master Version #6: dated 04/04/2014 Calvary Mater Version #1: dated 04/04/2014

As a cancer patient attending a treatment centre, we would like to invite you to participate in a research study to provide your opinion about what aspects of cancer care are important to patients, and what could be done to improve patients' experiences at treatment centres. This research is being conducted by The Research Team from the University of Newcastle and Cancer Council New South Wales (CCNSW).

Why is the research being done?

The purpose of the research is to improve aspects of cancer care which have been identified as priorities by chemotherapy patients. This will be the first trial of consumer driven change for improving quality of cancer care that involves cancer patients in identifying, implementing and evaluating strategies of change. It is expected that these changes to cancer treatment systems will reduce patients' unmet needs and improve overall quality of life.

Who can participate in the research?

We are inviting English-speaking patients 18 years or over with a diagnosis of cancer, who have attended an appointment at their oncology clinic on at least one previous occasion, to participate in this study.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

What would you be asked to do?

If you agree to participate, you will be asked to complete a touchscreen survey on an iPad. The survey will include questions about your background (e.g. age, gender, marital status), cancer treatment, needs for support, services and information, wellbeing and your preferences for improvements in the quality of your cancer care. This survey may be completed in the waiting room prior to your appointment today or in the chemotherapy treatment centre while you receive treatment. If you are not able to complete the survey at your appointment today, you may be approached to participate at a later date. However, we cannot guarantee that you will be able to participate at a later date. Grouped information provided by all of the people completing the survey will be provided to a committee at the hospital, who will work together to try and improve the care that is provided to patients.

How much time will it take?

It is expected that the survey will take approximately 20 minutes to complete. If you start completing the survey but get called into your appointment before finishing, you have the option of choosing to submit or withdraw the data you have provided. If this happens, the Cancer Council volunteer will ask if you would like to delete all of the information entered, or submit the partially-completed information.

What are the risks and benefits of participating?

We cannot promise you any benefit from participating in this research. However, we do expect that the results of this research will help to highlight how care can be improved for future cancer patients. We do not expect that there will be any risks associated with participating. There is a small possibility that completing the survey may cause you to reflect on your cancer care, and might cause distress. If you do have questions or are distressed after completing the survey, we recommend that you discuss these issues with your doctor. You can also contact the Cancer Council Helpline on 13 11 20. This service is staffed by cancer nurses who provide information and support to people with cancer and their families.

How will your privacy be protected?

The questionnaire is confidential and it will not be possible to identify you from your answers. Information collected will be de-identified upon receipt. This means that a unique identification code (ID) will be stored with your survey results. Any identifying information will be stored securely in a password protected file on the University of Newcastle server. This information will only be accessed by the researchers unless you consent otherwise, except as required by law. Data will be retained for at least 7 years in a locked filing cabinet and password protected files at the University of Newcastle. De-identified data may be made available for secondary analysis, however separate ethics approval will be sought beforehand. Where data is used for further analysis, it will not contain any identifying information.

How will the information collected be used?

Some of the research being conducted is part of Elizabeth Fradgley's post graduate studies at the University of Newcastle, supervised by Associate Professor Chris Paul and Dr Jamie Bryant, from the School of Medicine and Public Health. The information collected will be reported in scientific journals and in a peer-reviewed thesis for Ms. Fradgley's degree.

Additionally, the information collected will be presented at national and international conferences and published in scientific journals. Only group data will be presented in any reports of publications arising from this research. In this way, no individual will be identifiable and your privacy will be protected. If requested by the clinic, we will also provide them with group, deidentified information about psychosocial outcomes of patients attending their clinic.

What do you need to do to participate?

Please read this Information Statement and be sure you understand all its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher. Informed consent is implied if you choose to complete the survey. If you would like to participate, please inform the CCNSW volunteer and complete the survey now.

Further information

If you would like further information please contact Prof. Rob Sanson-Fisher (02 4042 0713) or Ms Alix Hall (02 40420641).

Thank you for considering this invitation.

Rob Sanson-Fisher Laureate Professor of Health Behaviour University of Newcastle

The Research Team: The research team includes members of the School of Medicine and Public Health at the University of Newcastle: Prof Rob Sanson-Fisher, Drs. Jamie Bryant, Mariko Carey, Flora Tzelepis, Associate Professors Patrick McElduff and Chris Paul, Professor Chris Doran, Ms Alix Hall and Ms. Elizabeth Fradgley; and investigators from the Cancer Council New South Wales: Ms. Kathryn Chapman, Ms. Anita Tang, and Ms Elizabeth Humphries.

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 13/08/21/4.07 Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager Research Ethics and Governance, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email <u>Hnehrec@hnehealth.nsw.gov.au</u>