

Understanding Consumers' Preferences for Health Service Change:

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

Elizabeth Alexandra Fradgley, BHSc (Hon I)

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School of Medicine and Public Health, University of Newcastle

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, Fradgley EA, Koller CE, Paul CL, Sanson-Fisher RW, Zucca A. How Do Health Researchers Benefit From Web-Based Survey Systems? e-Health. 2014; 254-262.

Henskens FA., Paul DJ, Wallis M., Bryant J, Carey M, Fradgley EA, 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, Fradgley EA. Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment. Patient Preference Adherence. 2015;9: 831-5.

Fradgley EA, 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

Fradgley EA, 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.

Fradgley EA, 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.

Fradgley EA, 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.

Fradgley EA, 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.

Fradgley EA, 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.

Fradgley EA, 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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Ethical approvals, participant information sheets, and consent forms

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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 patient-experience 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:

- (1) 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**).
- (2) 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 as 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 commonly-

selected 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**.

1. 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 implemented 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.