PILOTING A TELEPHONE SUPPORT SERVICE	1
'Positive Talk for Positive Health': Piloting a Telephone Support Service for People Livin	ng
with HIV	
~ · · · · · · · · · · · · · · · · · · ·	
David Wilkinson	

BPsych (Hons)

This thesis is submitted in partial fulfilment of the requirements for the degree of

Master of Clinical Psychology at the School of Psychology, University of Newcastle, Australia

November 2019

Declarations

Statement of Originality

This 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. I give consent to this copy of my thesis, when deposited in the University Library**, being made available for loan and photocopying, subject to the conditions of the Copyright Act 1968.

**Unless an Embargo has been approved for a determined period.

Acknowledgement of Collaboration

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers from the University of Newcastle (UON) The larger project design, and ethics application were conducted collaboratively by Professor Jenny Bowman (UON) and Karen Nairn (HNELHD), Todd Heard (HNELHD), and Glen Ferrero (ACON). I assisted the project team in survey and intervention manual development, support caller recruitment, project delivery, and data collection. I was primarily responsible for the review of literature, data analysis, and writing of the manuscript contained within this thesis. My work was forwarded to my supervisor Jenny Bowman for review, and amendments were made based on feedback received.

21	.11	.2019

David Wilkinson Research Student Date

21.11.2019

Prof. Jenny Bowman Research Supervisor Date

Acknowledgements

I would like to thank my supervisor Professor Jenny Bowman for providing her guidance, insight, and patience during this project and throughout my time at University. I have greatly appreciated the support I have received over the years and I am incredibly grateful for the opportunities studying at The University of Newcastle has provided. I would also like to thank Todd Heard, Karen Nairn, Glen Ferrero, Cath Adams, and Maya Lindsay for their work, enthusiasm, and passion for the Positive Talk for Positive Health Service.

Thank you to my friends, colleagues, and clinical program peers who have been part of this journey. I look forward to spending more time with you soon. A special thanks to Catt Smiley, Jesse Bourke, Jessica Gordon, Mitch Jones, Karen Calabria, and Bec Moseley. The support and encouragement you have all provided has been vital in helping me get to the finish line. Finally, thank you to my parents for believing in me unconditionally.

Table of Contents

Declarations	2
Statement of Originality	2
Acknowledgement of Collaboration.	2
Acknowledgements	3
List of Tables.	5
List of Figures	5
List of Appendices.	5
Manuscript Title Page	6
Abstract	7
Introduction	8
Method	16
Results	21
Discussion.	23
References	29

List of Tables

1. Demographics and Clinical Characteristics at Baseline	42
2. Program Implementation and Feasibility	44
3. Participant Acceptability and Satisfaction	45
4. Participant Implementation Feedback	47
5. Pre and Post Measures	48
List of Figures	
1. Participant Reasons for Participating	43
2. Perceived Impact of Program	46
List of Appendices	
A. Scope and Instructions for Authors of AIDS Patient Care and STDs	49
B. Ethics Approval.	55
C. Recruitment advertising	62
D. Participant Information Statement and Consent Form	65
E. Baseline and Follow-up Survey	68
F. Exit Survey	80
G. Follow-up survey participant program comments	83

Manuscript is formatted to comply with the Instructions for Authors from the Journal of
AIDS Patient Care and STDs (see Appendix A).

'Positive Talk for Positive Health': Piloting a Telephone Support Service for People Living
with HIV

David Wilkinson¹ & Jenny Bowman^{1*}

¹School of Psychology, University of Newcastle, University Drive, Callaghan, NSW, 2308, Australia

*Corresponding Author: Professor Jenny Bowman, School of Psychology, University of Newcastle, Callaghan, NSW 2308, Australia.

Email: Jenny.Bowman@newcastle.edu.au Phone: +61 0249215958

Word Count: 6174

PILOTING A TELEPHONE SUPPORT SERVICE

ABSTRACT

7

The human immunodeficiency virus (HIV) has progressed from an acute illness to a chronic

condition that requires ongoing care. Telephone based programs have shown potential for

providing support to people living with HIV and have been described as an intervention

modality that may overcome traditional barriers to care. The current study explored the

acceptability and feasibility of a pilot telephone support program utilising a single group, pre-

post design. Participants were invited to complete a baseline and follow-up survey, in addition

to an exit survey providing feedback on program satisfaction and acceptability. The program

consisted of six, monthly information support calls aimed at increasing treatment adherence,

psychosocial wellbeing, and support service access of people living with HIV in two New

South Wales (NSW, Australia) health districts. The sample included 24 participants who

commenced the program and 21 participants who completed the full intervention,

demonstrating an 88% retention rate. Almost all participants (94% (15/16)) rated the program

information as very or fairly useful; and two-thirds (69% (11/16)) reported accessing support

services as a result of information received during the program. This study provides the first

preliminary support for the feasibility and acceptability of a HIV-specific telephone

intervention within an Australian setting and provides directions for future research in HIV

care.

Key words: HIV Treatment; Adherence; Telephone Support; Feasibility

'Positive Talk for Positive Health': Piloting a Telephone Support Service for People Living
with HIV

The human immunodeficiency virus (HIV) continues to contribute to the global burden of disease, with over 37.9 million people living with HIV worldwide at the end of 2018. In Australia, 27,545 people were estimated to be living with HIV at the end of 2017. This does not account for the estimated 10% of people living with HIV (PLWHIV) who are undiagnosed. Addressing the morbidity and mortality of HIV and the acquired immunodeficiency syndrome (AIDS) remains an ongoing international health challenge. Consequently, this requires increased and sustained efforts in treatment and management responses on a global scale.

HIV is a blood-borne retrovirus that is typically acquired through sexual intercourse, exposure to infected blood, or perinatal transmission.⁵ Retroviruses are Ribonucleic acid (RNA) viruses comprised of reverse transcriptase, a polymerase that synthesises pro-viral Deoxyribonucleic acid (DNA) from RNA. This DNA becomes integrated into an individual's cellular genome and as a result, manifests as a persistent life-long infection.⁵ HIV attacks the body's immune system and causes the gradual destruction of CD4 T lymphocyte cells which assist the immune system to protect the body from infection.⁶ As a result, HIV progressively makes an individual more susceptible to opportunistic infections or cancers.⁷ AIDS is the result of chronic HIV infection and consequent depletion of CD4 cells. It is defined using a threshold cell count of less than 200 CD4 cells/microL or the presence of any AIDS defining conditions regardless of the CD4 count.⁷

Antiretroviral therapy (ART) has significantly improved the health and quality of life of PLWHIV, and considerably reduced HIV-related mortality.⁸ Improvements in HIV treatment have substantially increased the life expectancy of PLWHIV to a level comparable to that of uninfected individuals.⁹ Consequently, ART has significantly contributed to HIV

now being considered a chronic health condition that requires ongoing care.⁸ Research has suggested that ART is the most important factor for predicting an individual's likelihood to achieve and maintain the suppression of HIV viral load.¹⁰

There is growing evidence that ART may also play a vital role as a preventative strategy that may reduce the transmission of HIV.¹¹ Viral load is the greatest risk factor for HIV transmission and ART operates by reducing viral load to undetectable levels, which may consequently interfere with HIV transmission, preventing further morbidity and mortality.¹¹ Systematic reviews have indicated that ART mediated virologic suppression may reduce sexual transmission and perinatal transmission of HIV ^{12,13} Currently, in Australia HIV is primarily transmitted through sexual contact between men. In 2017, this accounted for 63% of new HIV diagnoses, followed by heterosexual contact (25%), and male-to-male sex and injecting drug use (6%) and injecting drug use only (3%).²

It is well established that strict adherence to ART (95% or greater) is a key determinant of managing the progression of HIV, and contributing to enhanced overall health and quality of life. 14-16 In contrast, low adherence to ART has been connected to drug resistance and treatment failure. 17 There has been a high rate of HIV treatment uptake across Australia, with recent research suggesting 87% of all PLWHIV are using ART. 2 PLWHIV in Australia are living longer and are becoming more experienced with various forms of ART. 18 However, ART treatment regimens are often complicated and may interfere with an individual's daily life due to the demanding medication schedule. 19 As a result, an individual's capacity to cope with their treatment regime varies broadly and may have considerable impact on their psychosocial wellbeing and disease progression. 19 Thus, supporting the uptake and treatment adherence of ART is widely accepted as a critical action for addressing the needs of PLWHIV and as a preventative measure to stop the transmission of HIV. 11

HIV treatment adherence refers to the ability of an individual to be involved in selecting, commencing, managing, and maintaining a given medication and treatment regimen to control viral replication and improve immune function.²⁰ Research has reported mixed findings in regard to medication adherence for PLWHIV; adherence rates have been found to vary from 70% to 95%.^{19,21,22} However, there is considerable disagreement in the literature in regard to identifying a gold standard treatment adherence measure for HIV.^{22,23} Further evidence has noted that 10% of PLWHIV report missing one or more pills on any typical day, 30-50% indicate missing pills in the past two to four weeks, and as many as 50% report failing to take ART medication in accordance with dosage, time, and dietary instructions.^{24,25}

Non-adherence to ART may be associated with a number of structural, behavioural, and psychosocial factors. These include alcohol and substance use, low health literacy, low levels of social support, stigma, non-disclosure of HIV status, and homelessness. ^{26–28} In addition, adherence to ART is closely associated with how prepared individuals are to manage the side-effects of these medications. ²⁹ When PLWHIV are asked to describe reasons for missing doses and taking less ART medication than prescribed, four clusters of reasons have been shown to emerge. The four clusters include poor medication tolerability, regimen burden or complexity, conflicts with daily routines, and financial and access barriers to treatment. ³⁰ Moreover, there are still negative perceptions associated with HIV treatment including doubts about the need to be on medication, concerns over harmful side-effects, and frustration regarding their inconvenience. ^{31,32} Further research has suggested that there is some community apprehension surrounding ART which may be a result of lack of knowledge and information surrounding HIV treatment. ³³

Many PLWHIV experience considerable psychological and existential issues that may impact their quality of life and psychological functioning.³⁴ Research has indicted that these

issues have continued since the advent of ART medication.³⁴ This suggests that while ART has greatly improved physical health and wellbeing, these improvements have not necessarily translated into improved psychological coping.³⁴ It is well documented that PLWHIV experience disproportionate rates of depression and anxiety and these disorders may be exacerbated by the physiological side effects of ART.³⁵ Research has suggested that an estimated 50% of PLWHIV have been diagnosed with a comorbid mental illness that may affect HIV treatment outcomes.³⁶ Depression and perceived stress have been strongly correlated with ART non-adherence.²⁴ Further research has indicated many PLWHIV experience increased anxiety related to the need for stringent levels of medication adherence.³⁷

Substance use is also highly prevalent among PLWHIV, ranging from 40-74% reporting comorbid substance use or related disorders.³⁸ Substance use has been associated with the presence of other mental health problems for PLWHIV, such as depression and anxiety.^{36,39} Furthermore, substance use may negatively impact medication adherence, CD4 T-Cell count, and suppression of viral load, leading to poorer medical outcomes.⁴⁰⁻⁴³ Furthermore, rates of smoking tobacco have been shown to be two to three times higher for PLWHIV compared to the general population.⁴⁴ These health behaviours have been reported to place PLWHIV at an increased risk of non-AIDS related morbidity and mortality. While the relative impact of lifestyle factors compared to HIV-related factors is often debated, there appears to be an emerging trend that cardiovascular disease and non-AIDS malignancies are now a major cause of death for PLWHIV.^{44,45}

In addition to health related behaviours, the psychosocial environment and wellbeing of PLWHIV are important aspects of coping with the disorder. These factors have not only been considered to have significant consequences on the behavioural management and treatment of HIV, but has also been suggested to impact the biological aspects of disease

progression. And Psychoneuroimmunology research has investigated the psychological factors relevant in the physical illness of HIV. And Research in this field is still emerging, however a number of studies have provided evidence that aspects of psychosocial functioning may influence the response of the immune system to HIV. Stress, depression, social support, and denial may influence the progression of HIV/AIDS. And Burack et al. Reported men with HIV who were depressed showed greater declines in numbers of CD4 lymphocyte cells over a subsequent five year period compared to a non-depressed control group. Markers of the importance of social connectedness have also been investigated with studies showing lower levels of social support are associated with a significantly faster progression in CD4 cell decline. The death of an intimate partner due to AIDS may increase markers of disease progression and decrease effective lymphocyte cell function in bereaved partners. These findings statistically controlled for demographic characteristics, health behaviours, sexual behaviours, ART, mental health problems and social support.

HIV has been shown to have significant effects on individuals' physical, psychological, and sociocultural determinants of health-related quality of life (QOL).⁵¹ PLWHIV may find it difficult to attend to daily responsibilities and experience activity limitations as a result of progress of the disease or side effects of treatment.⁵² The side effect profile of ART can be considerable and PLWHIV may need to manage adverse effects such as fatigue, muscle weakness, oedema, myalgia, nausea, and lipodystrophy.³¹ As PLWHIV are living longer, they experience a wide array of physical and cognitive impairments such as wasting, neuropathies, blindness, and AIDS dementia complex.⁵³

Research has outlined a number of psychological challenges of living with HIV, including fear of physical pain, debilitation, disfigurement and death, the prospect of real and anticipated losses, being abandoned by loved ones, and dealing with uncertainty. 54,55

Preserving a sense of hope is an ongoing psychological challenge that may impact the quality

of life for PLWHIV across illness progression. Depression is common among PLWHIV and may become severe, particularly for those who try to cope using avoidance strategies or believe their illness is punishment for past misdeeds. Furthermore, PLWHIV may be rejected by friends or family following disclosure and this may exacerbate depression. PLWHIV experience challenges unique to the condition in regard to the extent of stigma associated with it and the consequences of HIV being an infectious disease that may be potentially fatal to others. Following a HIV positive diagnosis, individuals must integrate this new information into their sense of identity.

Across the progression of HIV, individuals are particularly vulnerable to acute distress, including when they receive their diagnosis, the initial onset of physical symptoms, abrupt deteriorations in CD4 cell count, the first opportunistic infection, or the first hospitalisation. However, as HIV has transitioned from an acute to chronic condition the stages of illness have also been suggested to impact access and adherence to treatment. Research has suggested that stage of illness may be a barrier for uptake and retention in care, with non-symptomatic individuals being less inclined to seek help. 57,58

Stigma and social isolation are significant factors impacting wellbeing for PLWHIV. HIV-related stigma has been shown to have a significant effect on the adjustment of PLWHIV and their families.⁵⁹ Stigma and discrimination have been said to occur for a variety of reasons for PLWHIV. Some of the most prominent reasons include the public fear of HIV/AIDS being considered a terminal illness, often misunderstood perceptions of how HIV is transmitted, an irrational fear of acquiring HIV from people infected with it, and the disease often being associated with homosexuality and drug abuse.⁶⁰ The result of these perceptions manifest in felt stigma (the fear of being discriminated against), enacted stigma (prejudicial attitudes and actual discriminatory behaviours), and courtesy stigma (prejudice and discrimination against individuals who are associated with stigmatised others).⁵⁹

Consequently, both the individuals afflicted by the disease, and their family members, caregivers, friends, and romantic partners may be affected by stigma and discrimination and this may negatively impact their access to social support. Stigma may be exhibited differentially depending on the status of other social groupings to which the person belongs. Consequently, men who have sex with men, injection drug users, and other minority groups may experience a compounded stigma burden.

Despite efforts to reduce HIV related stigma since the beginning of the epidemic, it's impact continues to be a significant barrier for HIV prevention and optimal treatment.⁶⁴ Fear of stigma is a consistent barrier to engagement and retention in care and may discourage individuals from getting tested for HIV, accessing support, and attending HIV clinics.^{59,64,65} Furthermore, stigma related barriers may provide even greater impact within rural communities.^{66,67} HIV related stigma and discrimination is widely recognised as a barrier to both the delivery of quality services by health providers and their utilisation by PLWHIV.⁶⁸ Consequently, reducing HIV related stigma in health settings and promoting access to care has been described as a leading priority for health care managers.⁶⁸

Research has highlighted the need for low-cost interventions that may support the uptake of medication, psychosocial wellbeing, and treatment adherence of PLWHIV to sustain better health outcomes and quality of life.⁶⁹ Telephone support options for HIV have been described as an intervention modality that may overcome traditional barriers such as transportation problems, lack of money, concerns about privacy, and the stigma sometimes associated with attending a clinic for HIV treatment.⁷⁰ These barriers have been identified in a number of qualitative and quantitative studies investigating access to and retention in care.

71–75. The use of mobile phones is widespread across countries which make them a viable method for the delivery of healthcare interventions.⁷⁰ There is considerable potential for telephone interventions to improve healthcare access and support across a wide-variety of

health issues, including HIV/AIDS.⁷⁶ Telephone support models have been shown to have some evidence for PLWHIV in delivering mental health interventions, providing test results, and supporting client contact with primary care settings.^{77–79}

Current evidence is inconclusive regarding the feasibility and efficacy of telephone support interventions in relation to the medication adherence and psychosocial wellbeing of PLWHIV. Outcome trials have shown mixed findings in regard to the efficacy of telephone support for ART adherence with no data currently available in an Australian context.

Overseas studies have demonstrated mixed support to date, ranging from showing moderate effect sizes to no effect. A meta-analysis conducted by Gentry et al. in 2013 reviewed the findings of 11 eligible studies and concluded that while there is some evidence that telephone interventions may have a role in improving medication adherence and psychological wellbeing.

Studies to date have primarily addressed single focus interventions, as opposed to targeting multiple treatment adherence associated factors, such as attitudes to treatment, HIV medication information, general health behaviours, psychological wellbeing, and social and community participation. These are considered important for treatment uptake and adherence in Australia ³³. In regard to medication adherence, a 2019 meta-analysis has suggested telephone interventions may have limited impact on improving adherence. ⁸⁰ However, outcomes are improved when interventions are combined with text message reminder systems and multiple targets associated with improved medication adherence are addressed. ⁸⁰

In Australia, the New South Wales HIV Strategy 2012-2015 encouraged Local Health Districts to implement initiatives which aim to promote the uptake and adherence to treatment for all people living with HIV.⁸¹ The current study was initiated by the Hunter New England Local Health District (HNELHD) in collaboration with ACON, a national nongovernment organisation HIV support service. The initiative sought to contribute to the NSW

health directive and respond to the increasing demand on services in the area to provide information and support to PLWHIV. A goal of this support was to provide cost-free and accessible support that may benefit both consumers in rural and metropolitan areas; given the growing number of PLWHIV in rural areas where access to information and support is limited.^{2,33,81} As a result, the current study aims to explore the feasibility and acceptability of a Pilot Telephone Support Program designed to support treatment adherence, psychosocial wellbeing, and support service access for PLWHIV in an Australian setting. The study will also explore pre versus post measures of treatment adherence and psychosocial wellbeing.

Method

Design and Setting

The present study was designed to evaluate the feasibility and acceptability of the 'Positive Talk for Positive Health' service, run in partnership by Hunter New England Population Health, ACON, and the University of Newcastle. The program was a telephone-delivered information support intervention aimed at facilitating better access to support services, encouraging the uptake of and adherence to ART treatment, and supporting the psychological and physical wellbeing. The program was available to PLWHIV in the HNE and Western NSW (WNSW) local health districts. HNELHD has a population of 920,370 people across a region of 131,785 square kilometres. The district consists of a major metropolitan centre, regional communities, and a small percentage of people living in remote communities. ⁸² WNSWLHD has a population of 270,775 people within approximately 250,000 square kilometres. ⁸³ The district is diverse and is made up of cities, inner regional, outer regional, and remote communities. The study was conducted as a single group, pre-post design exploratory pilot study. Ethics approval was granted by the Hunter New England and

the University of Newcastle Human Research Ethics Committees (13/12/11/4.13) (See Appendix B).

Participants

Participants were 27 PLWHIV (26 men and 1 woman) aged between 29 and 63. Participants were recruited through existing providers of HIV testing, treatment, and community support across the HNE and WNSW local health districts. Eligible participants were invited to participate in the program via convenience advertising at recruitment sites (See Appendix C). In addition to the provision of information about the project in routine correspondence from existing providers of HIV/AIDs care to potential participants. Eligible participants were English speaking, 18 years of age or older, had a current phone number, were not currently highly dependent on medical care (e.g. receiving inpatient care) and self-reported as being HIV positive. Potential participants were provided an outline of the study and informed consent was obtained electronically from all individual participants (See Appendix D). The study did not offer any external incentives for participation.

Procedure

Potential participants entered the study by contacting the service through telephone or in person at ACON Newcastle. Potential participants completed an expression of interest, providing name and contact details (the option to use an Alias was also made available at their discretion). An initial registration call was scheduled which covered eligibility criteria, preferred day and time of support calls to be received (choosing between two weekday options within a 1-8pm timeframe). Recruitment was completed across a 6-month period. Participants were provided with a link to the online baseline survey. If participants were not able to complete the baseline survey online they were given the option to complete it in person at ACON or via telephone with a project supervisor who did not deliver any support call content.

Twenty-seven participants completed a baseline survey (online or over the telephone) before commencing the program (See Appendix E). The telephone support intervention was made up of six, monthly calls. Twenty-one participants completed the program and 17 participants completed a post-intervention follow-up survey online or via telephone interview. In addition to the follow-up survey, all participants (whether they completed the program or exited early) were invited to complete a telephone exit survey (See Appendix F). This survey gathered information regarding the acceptability and feasibility of the program and feedback concerning areas for improvement. Exit survey calls were completed by program supervisors independent of support callers. Fifteen participants completed an exit survey. Exit surveys and follow-up surveys were conducted as soon as possible following program termination.

Measures

Where possible, survey questions were sourced from existing population based surveys including HIV Futures Seven Survey, Gay Community Periodical Survey, and the NSW Adult Population Health survey. 84–86 Survey questions included demographic information, HIV clinical characteristics (e.g., CD4 cell count and viral load), and smoking behaviours. 84

Primary feasibility and process measures included length of support calls, call attempts, uptake and participant retention rates. Furthermore, all participants were offered the opportunity to answer questions pertaining to program acceptability and satisfaction which were adapted from a previous telephone support service evaluation project.⁸⁷ These items primarily required participants to choose from pre-determined answers or Likert response scales. An example item pertaining to uptake included asking participants 'What were your reasons for deciding to participate in the service?'. Acceptability questions included items

such as 'To what extent did the telephone support sessions address your needs?' and 'How would you described the average length of the telephone support sessions?'.

The Barriers to Care Scale (BACS) was included in the survey.⁸⁸ The BACS is a 12-item measure that enables PLWHIV to specify the severity of various barriers to care. The BACS includes four subscales assessing barriers related to: geography/location barriers, medical and psychological service barriers, community stigma barriers, and personal resource barriers. The BACS scale uses a four-point Likert scale (1 = 'No problem at all', 2 = 'Very slight problem', 3 = 'Somewhat of a problem', and 4 = 'Major problem'.⁸⁸

Pre verses post measures assessing treatment adherence included the HIV treatment and adherence self-efficacy scale (HIV-ASES) and the Perceived Self Competence scale. 20,89 The HIV-ASES has an 11-point Likert scale designed to measure self-efficacy for adherence to HIV treatment plans, including but not limited to taking ART. 20 Participants are asked 12 questions such as 'In the past month, how confident have you been that you can: Integrate your treatment into your daily routine?'. The response scores range from 0 ('cannot do at all') to 10 ('completely certain can do'). The scale has previously demonstrated robust internal consistency (Raykov's coefficient ρ = .91) and 3-month (r = .71) and 15-month (r = .49) test-retest reliability. Additionally the Perceived Self-Efficacy Scale was also utilised which consisted of 4 items regarding management of HIV care such as 'I feel confident in my ability to manage my HIV', the scale consists of a 1 ('Not at all true') to 7 ('Very true') Likert Scale. Standardised psychosocial and general health secondary outcome measures included the Kessler K6 psychological distress scale, perceived stress scale, CDC Healthy Days Core Module, and Functional Assessment of HIV Infection Emotional and Social Wellbeing subscales. $^{90-93}$

Intervention

Calls were proactively delivered to participants by a volunteer support caller. Participants were not matched with a specific caller throughout the program. Each support call addressed topics that have been demonstrated to influence the uptake and adherence of HIV treatment. Call content was guided by an intervention manual developed by the project team which included members of the Hunter New England HIV Sexual Health team, ACON, and The University of Newcastle. The program was delivered in six standalone calls and covered material including introduction and orientation to program, HIV information and symptom management, physical and psychological wellbeing, social and community participation, and access to support services. Calls were designed to deliver information support material and self-management strategies within a 45-minute time frame. Support callers were volunteers who had recently graduated from a Bachelor of Psychology or who were currently enrolled in third or fourth year of undergraduate Psychology at the University of Newcastle. Volunteers completed a two day training workshop which was designed to introduce the intervention manual, develop callers' knowledge of HIV/AIDs aetiology and treatment, and build general competency motivational interviewing skills. Calls were conducted at ACON, under the supervision of an experienced HIV-counsellor who provided support call supervision.

Analysis

Analyses were undertaken using SPSS version 23. Descriptive statistics were used to describe the participants' demographic information, and clinical characteristics; including pre and post rates of HIV treatment uptake and adherence. Furthermore, descriptive statistics were used to describe process data and measures of program feasibility and acceptability. Paired sample t-tests have been utilised to explore pre and post measures of HIV treatment adherence, and associated factors such as the Kessler K6 psychological distress scale,

Perceived Stress Scale 4, CDC Healthy Days Core Module, and the Functional Assessment of HIV Infection scale.

Results

Demographics and Clinical Characteristics of the Sample

Of the 27 participants who completed the baseline survey, 26 were male, 1 was female, and the large majority (96.3%) were Non Aboriginal or Torres Strait Islander. On average, participants were 48 years of age, reported a mean of 14 years since testing HIV positive, and over two thirds (70.4%) had an undetectable viral load. The majority of the sample were single (92.6%), on a social security pension (77.8%), and 11 (40.7%) participants identified as being a daily smoker. Demographic and clinical characteristics of the sample are shown in Table 1.

Reasons for participating

Participants were asked to identify their reasons for participating in the service. Almost all participants answered 'someone to talk to' (91.76%), with the majority endorsing the items 'convenience/no travel involved' (83.33%), 'it's a free service' (75%), 'one to one support/privacy' (75%) and 'source of information (70.83%). Half of participants reported 'like / prefer telephone based support (50%). Participant's reasons for participating are outlined in Fig. 1.

Program implementation and feasibility

The program commenced with 24 participants in total, 20 from HNE LHD and 4 from WNSW LHD. Based on the NSW HIV strategy 2012-2015 data report of people accessing ART therapy in NSW, this provided a recruitment rate of 5.35% (20/374) for HNE LHD and 5.97% (4/67) of WNSW LHD.⁸¹ Of the 24 participants who completed call one, 21 went on to complete the program resulting in an 88% retention rate for program completion.17

participants completed follow-up data, providing a response rate of 71% (17/24). During the program a total of 131 support calls were made to program participants, with an average call length of 30 minutes across all calls made. Table 2 program implementation and feasibility provides an overview of participant attrition and support calls made during the program.

Acceptability and satisfaction

Participants that accessed the service were generally very positive in regard to their experience and perceived benefits it brought them. Overall, 94% of participants (15/16) reported the program as very or fairly useful with one participant finding the program not very useful. Almost all participants (14/15) indicated that they would recommend the program to other people living with HIV if the program was to be run in the future. In regard to their evaluation of support caller competency, participants gave generally positive reviews with 93% rating callers as 'very supportive' or 'quite supportive', and 87% describing callers as 'very able' or 'quite able' to offer information or advice about the issues raised by participants. See Table 3 for participant acceptability and satisfaction.

Participants were asked to rate the extent to which certain aspects of their lives had been influenced as a result of participating in the program. Most participants reported that as a result of the program they felt better informed, less isolated, more confident, more able to make changes in their lives, and more able to take their medication as described. Perceived impact of program feedback is provided in Fig. 2.

The large majority of participants reported positive feedback across a number of acceptability and implementation measures, including ease of scheduling calls, and average call length. Participants reported preferring monthly calls, and the majority had no preference for telephone content to be delivered by the same caller. Implementation feedback is provided in Table 4.

Participant measures from Baseline to Follow-up

The majority of participants (26/27) were using ART medication upon program commencement. Paired sample t-tests were conducted on baseline and follow-up measures. There were no significant findings in regard to primary medication uptake or treatment adherence. Paired sample t-tests suggested a significant decrease in the Functional Assessment of HIV Infection Emotional wellbeing subscale scores (t(16)=2.515, p=0.023), suggesting an improvement in subjective HIV related emotional wellbeing scores of program participants from baseline (M=14.85, SD=8.17) to follow-up (M=9.24, SD=7.33). In addition, of participants who reported as current smokers at baseline and follow-up, cigarettes smoked per day decreased significantly (t(4)=2.956, p=0.042) from baseline (M=20.42, SD=7.87) to follow-up (M=13.17, SD=6.05). Participant pre and post measures are presented in Table 5.

Discussion

Due to advances in treatment, HIV has progressed to a chronic health condition that requires ongoing care to manage disease progression and promote quality of life for PLWHIV. The current exploratory study sought to evaluate the feasibility and acceptability of a telephone support intervention aimed at promoting the uptake of medication, treatment adherence, and psychosocial wellbeing for PLWHIV. This is the first study to the author's knowledge that has piloted a telephone support intervention for PLWHIV in an Australian setting and provides preliminary support for further investigation into the utilisation of proactive telephone support programs.

The current study demonstrated high retention rates for program participants. The findings suggested that once participants were engaged with callers and orientated to the program during call one, they were very likely to go on to complete the program. Retention is an ongoing priority in assessing the feasibility and acceptability of HIV interventions and a core component of feasibility studies. Previous randomised controlled trials have primarily

focused on single-focus interventions including medication adherence, psychosocial wellbeing, and smoking cessation interventions. ^{94–96} However, recent research investigating retention in HIV care has indicated a desire for holistic interventions by consumers of HIV services, and suggest that this may improve retention in services. ⁵⁸ The current study implemented an accessible holistic information support service which may have contributed to the favourable retention rates demonstrated in the program.

While desired retention rates were achieved, the study did not recruit as many participants as anticipated by the project team. It is possible the avenues of recruitment and purpose of the intervention within overall HIV care was not defined clearly enough within HIV services, and thus acted as a barrier to increasing referrals at recruitment sites. It is likely that novel interventions such as the current program need adequate time and development to become known and accepted within communities and treatment facilities. Future interventions may need to further educate services on how telephone information services may fit within a stepped care model, in a way that may complement existing clinical or counselling services. Furthermore, relying on print posters in clinics may not be an optimal recruitment strategy, especially for hard-to-reach individuals who may not often attend care settings. Future interventions might benefit from the growing potential of including social media and internet based advertising, to assist in addressing the ongoing challenges of traditional recruitment methods. 97,98

The current study design, purpose, and sample precluded outcome analysis and conclusions regarding the effect of the intervention on pre and post measures. Nevertheless, these were tentatively explored as a secondary component of the pilot study. These findings suggested minimal changes in pre-post measures for the majority of measures. However, there was a significant improvement on participants Functional Assessment of HIV Infection Emotional wellbeing scores. This may potentially correspond with the perceived benefit

reported in acceptability and satisfaction measures. No changes were found in regard to treatment adherence. This finding is consistent with a recent systematic review and meta-analysis by Shah ⁸⁰ suggesting telephone support has limited ability to improve adherence as a stand-alone intervention. However, when implemented with text message reminders improvements in outcomes are strengthened. Furthermore, telephone support services that broadly address a range of factors related to medication adherence are more likely to be efficacious. ⁸⁰ Future support programs may benefit by adding an additional text reminder component to increase the impact of the intervention on medication adherence outcomes.

Almost all participants were already using ART prior to commencing the program, and thus a ceiling effect for any changes to ART uptake was noted. However, the one participant who was not currently using ART at commencement of the program did begin using ART during the study, which may have been coincidental. The high rates of ART usage was not unexpected, with the majority of PLWHIV prescribed ART medication in accordance with HIV treatment guidelines.² Engaging the minority of PLWHIV who do not engage with treatment may be an ongoing challenge that needs novel solutions. Telephone support may be an option for accessing 'hard to reach' populations, however this was not achieved in the current study. This is likely a result of the convenience sampling of participants primarily through existing providers of HIV care and the relatively lower total population of PLWHIV in the HNE and WNSW health districts compared to larger health districts.⁸¹

The results of the participant feedback suggested that the intervention was well received by the majority of participants. Average call attempts remained low across the program, suggesting effective scheduling of support calls and positive receptivity from participants. Participant-reported subjective benefit and satisfaction with the program remained high over indicators of program satisfaction, acceptability, and implementation. A

minority of participants identified that the service 'did not meet there needs or was not appropriate for their situation', and this may be a result of the largely heterogeneous sample in regard to years since testing HIV positive, which may account for some difference in needs.

Participants provided positive feedback in regard to the usefulness of information received and ability of callers to deliver informational support. This suggests that the delivery of an information support service by callers with no previous HIV experience may be feasible and acceptable to participants. In addition, this provides some evidence that a brief (two day) training package in addition to a manualised support call program may be sufficient in providing informational support to PLWHIV. Interestingly, the majority of participants reported not having a strong preference to receive support calls from the same caller, which is contradictory to expectations given the well documented nature of therapeutic relationships. 99 However, this may provide some evidence that within an information and referral-based support service that independent callers is sufficient to deliver program content.

Given the relationship between mental health problems, HIV, and financial disadvantage, it is important to continue to develop low-cost interventions that can contribute to the support options available to PLWHIV. The current study suggests that non-clinical volunteers with undergraduate training in psychology were perceived as helpful and able to provide information support by the majority of participants. This may be a promising area for future research given the cost-saving potential of volunteers. Furthermore, the option of not pairing participants with a single caller may further increase intervention feasibility and logistical planning, while concurrently reducing costs.

Low-cost interventions may play a key role in facilitating preventative health care and early intervention. There is a growing importance for HIV and chronic health co-morbidity management, and this could be a target of future telephone supports. Given the suggestion

that PLWHIV who are asymptomatic may be less likely to access care, efforts are needed to engage this group. ^{57,58} Proactive telephone interventions may be able to reduce transport, financial and motivational barriers to increase the likelihood of providing early intervention through informational support and referral to further care as required. The majority of participants in the current study reported accessing external support services as a result of information received during the program. This finding suggests the utility of an information service that may link participants with relevant local support services to address needs that may be outside the scope of the current intervention. This approach is consistent with the Australasian Society for HIV guidelines outlining stepped care for PLWHIV in Australia and may promote early intervention and support. ^{100,101}

Limitations

Results of the current study should be interpreted in light of its limitations. This study was an exploratory pilot study and these results should only be considered preliminary and may not be generalizable to larger sample sizes. The sample were already engaged to some extent with providers of HIV care and described moderate treatment adherence levels at baseline. It is unclear if the intervention would have offered different findings in regard to the feasibility and acceptability of the study to a less treatment adherent population, however previous research has suggested telephone interventions may be acceptable in non-adherent samples in the US. 102 Future research should aim to include PLWHIV who are not currently connected with HIV services. It is possible that non-response bias may have influenced some outcomes of participant feedback given the small sample size, however the response rate was considered sufficient. Some barriers were identified with participants having limited computer access and literacy. Future research could consider providing incentives for follow-up survey completion to increase completion rates.

Conclusion

The current study provides the first preliminary support for the feasibility and acceptability of a telephone support service for PLWHIV in an Australian setting. The service aimed to address multiple information support needs in regard to treatment adherence, physical and psychological health and wellbeing, and access to additional support services. Consistent with research suggesting holistic interventions may promote retention in care for PLWHIV, the current study demonstrated that the majority of participants who commenced the program went on to complete the full intervention. Furthermore, the majority of participants reported subjective benefit and satisfaction with the program over indicators of program satisfaction, acceptability, and implementation. Utilising non-clinical staff in telephone support programs may show potential for providing cost-effective support within local health districts. Future research might aim to expand the uptake of future interventions, and further target rural and hard-to-reach populations who may benefit most from access to information support that does not require face to face clinical contact. Given the increasing number of PLWHIV and the associated demand for support services, expanding research into the role of telephone support models may be an important opportunity to address this need in Australia.

Acknowledgments

Funding was provided by Hunter New England Population Health. The authors gratefully acknowledge ACON for providing support in facilitation of the program site and resources.

The authors sincerely thank all participants for their time and participation in the study.

Author Disclosure Statement

No competing financial interests exist.

References

- World Health Organization. WHO fact sheet on HIV/AIDS [Internet]. 2019. Available from: https://www.who.int/news-room/fact-sheets/detail/hiv-aids
- 2. Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2018. UNSW; 2018.
- 3. Frank TD, Carter A, Jahagirdar D, et al. Global, regional, and national incidence, prevalence, and mortality of HIV, 1980–2017, and forecasts to 2030, for 195 countries and territories: a systematic analysis for the Global Burden of Diseases, Injuries, and Risk Factors Study 2017. Lancet HIV [Internet]. 2019 Aug 19;0(0). Available from: https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(19)30196-1/abstract
- 4. Larson HJ, Bertozzi S, Piot P. Redesigning the AIDS response for long-term impact. Bull World Health Organ. 2011 Nov 1;89(11):846–52.
- Hidalgo JA, Macarthur RD, Crane LR. An overview of HIV infection and AIDs: Etiology, pathogenesis, diagnosis, epidemiology, and occupational exposure. Semin Thorac Cardiovasc Surg. 2000 Apr;12(2):130–9.
- 6. Maartens G, Celum C, Lewin SR. HIV infection: epidemiology, pathogenesis, treatment, and prevention. The Lancet. 2014;384(9939):258–271.
- 7. Bartlett JG. The natural history and clinical features of HIV infection in adults and adolescents. In: Hirsh MS, editor. UpToDate [Internet]. Waltham, MA: UpToDate; 2015 [cited 2016 Apr 9]. Available from: http://www.uptodate.com/contents/the-natural-history-and-clinical-features-of-hiv-infection-in-adults-and-adolescents?source=search_result&search=hiv+etiology&selectedTitle=1~150

- 8. HIV-CAUSAL Collaboration. The effect of combined antiretroviral therapy on the overall mortality of HIV-infected individuals. AIDS. 2010;24(1):123–37.
- 9. van Sighem AI, Gras LAJ, Reiss P, et al. ATHENA national observational cohort study. Life expectancy of recently diagnosed asymptomatic HIV-infected patients approaches that of uninfected individuals. AIDS Lond Engl. 2010 Jun 19;24(10):1527–35.
- 10. Paterson DL, Swindells S, Mohr J, et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. Ann Intern Med. 2000 Jul 4;133(1):21–30.
- 11. World Health Organization. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. [Internet]. 2014 [cited 2016 Apr 9]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK294008/
- 12. Anglemyer A, Rutherford GW, Egger M, Siegfried N. Antiretroviral therapy for prevention of HIV transmission in HIV-discordant couples. Cochrane Database Syst Rev. 2011 May 11;(5):CD009153.
- 13. Granich R, Crowley S, Vitoria M, et al. Highly active antiretroviral treatment as prevention of HIV transmission: Review of scientific evidence and update. Current Opinion HIV AIDS. 2010 Jul;5(4):298–304.
- 14. Bangsberg DR, Hecht FM, Charlebois ED, et al. Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. AIDS Lond Engl. 2000 Mar 10;14(4):357–66.
- 15. Haubrich RH, Little SJ, Currier JS, et al. The value of patient-reported adherence to antiretroviral therapy in predicting virologic and immunologic response. California Collaborative Treatment Group. AIDS Lond Engl. 1999 Jun 18;13(9):1099–107.

- Nieuwkerk PT, Sprangers MA, Burger DM, et al. Limited patient adherence to highly active antiretroviral therapy for HIV-1 infection in an observational cohort study. Arch Intern Med. 2001 Sep 10;161(16):1962–8.
- 17. Iacob SA, Iacob DG, Jugulete G. Improving the Adherence to Antiretroviral Therapy, a Difficult but Essential Task for a Successful HIV Treatment—Clinical Points of View and Practical Considerations. Front Pharmacol [Internet]. 2017 Nov 23 [cited 2019 Nov 15];8. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5703840/
- 18. Jansson J, Wilson DP. Projected Demographic Profile of People Living with HIV in Australia: Planning for an Older Generation. PLoS ONE [Internet]. 2012 Aug 9 [cited 2019 Nov 15];7(8). Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3415409/
- Wilson HS, Hutchinson SA, Holzemer WL. Reconciling Incompatibilities: A Grounded Theory of HIV Medication Adherence and Symptom Management. Qual Health Res. 2002 Dec 1;12(10):1309–22.
- 20. Johnson MO, Neilands TB, Dilworth SE, et al. The role of self-efficacy in HIV treatment adherence: validation of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES). J Behav Med. 2007 Oct;30(5):359–70.
- 21. Gifford AL, Groessl EJ. Chronic disease self-management and adherence to HIV medications. J Acquir Immune Defic Syndr 1999. 2002 Dec;31 Suppl 3:S163-6.
- 22. Beith A, Johnson A. Interventions to improve adherence to antiretroviral therapy: a review of the evidence. Manag Sci Health [Internet]. 2006 [cited 2016 Apr 17];

 Available from: http://pdf.usaid.gov/pdf_docs/Pnadg527.pdf

- 23. Williams AB, Amico KR, Bova C, et al. A proposal for quality standards for measuring medication adherence in research. AIDS Behav. 2013 Jan;17(1):284–97.
- 24. Reynolds NR, Testa MA, Marc LG, et al. Factors influencing medication adherence beliefs and self-efficacy in persons naive to antiretroviral therapy: a multicenter, cross-sectional study. AIDS Behav. 2004 Jun;8(2):141–50.
- 25. Reynolds NR. The problem of antiretroviral adherence: a self-regulatory model for intervention. AIDS Care. 2003 Feb;15(1):117–24.
- Carr RL, Gramling LF. Stigma: a health barrier for women with HIV/AIDS. J Assoc Nurses AIDS Care JANAC. 2004 Oct;15(5):30–9.
- 27. Halkitis PN, Shrem MT, Zade DD, et al. The physical, emotional and interpersonal impact of HAART: exploring the realities of HIV seropositive individuals on combination therapy. J Health Psychol. 2005 May;10(3):345–58.
- 28. Stirratt MJ, Remien RH, et al. The Role of HIV Serostatus Disclosure in Antiretroviral Medication Adherence. AIDS Behav. 2006 Sep 1;10(5):483–93.
- 29. Wroe AL, Thomas MG. Intentional and unintentional nonadherence in patients prescribed HAART treatment regimens. Psychol Health Med. 2003 Nov 1;8(4):453–63.
- Atkinson MJ, Petrozzino JJ. An evidence-based review of treatment-related determinants of patients' nonadherence to HIV medications. AIDS Patient Care STDs. 2009 Jul 30;23(11):903–14.
- 31. Carr A, Cooper DA. Adverse effects of antiretroviral therapy. The Lancet. 2000 Oct 21;356(9239):1423–30.

- 32. Kremer H, Ironson G. To tell or not to tell: why people with HIV share or don't share with their physicians whether they are taking their medications as prescribed. AIDS Care. 2006 Jul;18(5):520–8.
- 33. The Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014 HIV supplement [Internet]. Sydney: UNSW; 2014 [cited 2016 Apr 10]. Available from: https://kirby.unsw.edu.au/sites/default/files/hiv/resources/HIVASRsuppl2014_online.pd
- 34. Schönnesson LN. Psychological and existential issues and quality of life in people living with HIV infection. AIDS Care. 2002 Jun 1;14(3):399–404.
- 35. Shor-Posner G, Lecusay R, Miguez M-J, Moreno-Black G, Zhang G, Rodriguez N, et al. Psychological burden in the era of HAART: impact of selenium therapy. Int J Psychiatry Med. 2003;33(1):55–69.
- 36. Gaynes BN, Pence BW, Eron JJ, Miller WC. Prevalence and comorbidity of psychiatric diagnoses based on reference standard in an HIV+ patient population. Psychosom Med. 2008 May;70(4):505–11.
- 37. Horne R, Cooper V, Gellaitry G, et al. Patients' perceptions of highly active antiretroviral therapy in relation to treatment uptake and adherence: the utility of the necessity-concerns framework. J Acquir Immune Defic Syndr 1999. 2007 Jul 1;45(3):334–41.
- 38. Gonzalez A, Barinas J, O'Cleirigh C. Substance Use: Impact on Adherence and HIV Medical Treatment. Curr HIV/AIDS Rep. 2011 Dec 1;8(4):223.

- 39. Bing EG, Burnam MA, Longshore D, et al. Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. Arch Gen Psychiatry. 2001 Aug;58(8):721–8.
- 40. Arnsten JH, Demas PA, Grant RW, et al. Impact of active drug use on antiretroviral therapy adherence and viral suppression in HIV-infected drug users. J Gen Intern Med. 2002 May;17(5):377–81.
- 41. King W, Larkins S, Hucks-Ortiz C, et al. Factors Associated with HIV Viral Load in a Respondent Driven Sample in Los Angeles. AIDS Behav. 2009 Feb;13(1):145–53.
- 42. Azar MM, Springer SA, Meyer JP, et al. A systematic review of the impact of alcohol use disorders on HIV treatment outcomes, adherence to antiretroviral therapy and health care utilization. Drug Alcohol Depend. 2010 Dec 1;112(3):178–93.
- 43. Malta M, Strathdee SA, Magnanini MMF, et al. Adherence to antiretroviral therapy for human immunodeficiency virus/acquired immune deficiency syndrome among drug users: a systematic review. Addict Abingdon Engl. 2008 Aug;103(8):1242–57.
- 44. Giles ML, Gartner C, Boyd MA. Smoking and HIV: what are the risks and what harm reduction strategies do we have at our disposal? AIDS Res Ther [Internet]. 2018 Dec 12 [cited 2019 Nov 17];15. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC6291979/
- 45. Trickey A, May MT, Vehreschild J, et al. Cause-Specific Mortality in HIV-Positive Patients Who Survived Ten Years after Starting Antiretroviral Therapy. PLOS ONE. 2016 Aug 15;11(8):e0160460.

- 46. Ostrow DG. The search for the elusive psychosocial modulators of human immunodeficiency virus disease progression. Psychosom Med. 1996 Jun;58(3):232–3.
- 47. Cohen S, Herbert TB. Health psychology: psychological factors and physical disease from the perspective of human psychoneuroimmunology. Annu Rev Psychol. 1996;47:113–42.
- 48. Burack JH, Barrett DC, Stall RD, et al. Depressive symptoms and CD4 lymphocyte decline among HIV-infected men. JAMA. 1993 Dec 1;270(21):2568–73.
- Theorell T, Blomkvist V, Jonsson H, et al. Social support and the development of immune function in human immunodeficiency virus infection. Psychosom Med. 1995
 Feb;57(1):32–6.
- 50. Kemeny ME, Weiner H, Duran R, et al. Immune system changes after the death of a partner in HIV-positive gay men. Psychosom Med. 1995 Dec;57(6):547–54.
- 51. Basavaraj KH, Navya MA, Rashmi R. Quality of life in HIV/AIDS. Indian J Sex Transm Dis. 2010;31(2):75–80.
- 52. Rusch M, Nixon S, Schilder A, et al. Impairments, activity limitations and participation restrictions: Prevalence and associations among persons living with HIV/AIDS in British Columbia. Health Qual Life Outcomes. 2004 Sep 6;2:46.
- 53. Prachakul W, Grant JS. Informal Caregivers of Persons with HIV/AIDS: A Review and Analysis. J Assoc Nurses AIDS Care. 2003 May;14(3):55–71.
- 54. Flaskerud JH. AIDS: psychosocial aspects. J Psychosoc Nurs Ment Health Serv. 1987 Dec;25(12):8–16.

- 55. Remien RH, Rabkin JG. Psychological aspects of living with HIV disease. West J Med. 2001 Nov;175(5):332–5.
- 56. Maj M. Psychiatric aspects of HIV-1 infection and AIDS. Psychol Med. 1990 Aug;20(03):547.
- 57. Brennan A, Browne JP, Horgan M. A systematic review of health service interventions to improve linkage with or retention in HIV care. AIDS Care. 2014 Jul 3;26(7):804–12.
- 58. Bulsara SM, Wainberg ML, Audet CM, et al. Retention in HIV Care in Australia: The Perspectives of Clinicians and Clients, and the Impact of Medical and Psychosocial Comorbidity. AIDS Patient Care STDs. 2019 Oct;33(10):415–24.
- 59. Bogart LM, Cowgill BO, Kennedy D, et al. HIV-related stigma among people with HIV and their families: A qualitative analysis. AIDS Behav. 2008 Mar;12(2):244–54.
- 60. Sarafino EP, Caltabiano ML, Byrne D. Health Psychology: Biopsychosocial Interactions. Milton: John Wiley & Sons; 2008. 560 p.
- 61. Alonzo AA, Reynolds NR. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. Soc Sci Med. 1995 Aug;41(3):303–15.
- 62. Wight RG, Aneshensel CS, Murphy DA, et al. Perceived HIV stigma in AIDS caregiving dyads. Soc Sci Med. 2006 Jan;62(2):444–56.
- 63. Reidpath DD, Chan KY. A method for the quantitative analysis of the layering of HIV-related stigma. AIDS Care. 2005 May;17(4):425–32.
- 64. Earnshaw VA, Chaudoir SR. From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures. AIDS Behav. 2009 Dec 1;13(6):1160.

- 65. Thanh DC, Moland KM, Fylkesnes K. Persisting stigma reduces the utilisation of HIV-related care and support services in Viet Nam. BMC Health Serv Res. 2012 Nov 25;12(1):428.
- 66. Reif S, Golin CE, Smith SR. Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences. AIDS Care. 2005 Jul 1;17(5):558–65.
- 67. Golin C, Isasi F, Bontempi JB, et al. Secret Pills: HIV-Positive Patients' Experiences

 Taking Antiretroviral Therapy in North Carolina. AIDS Educ Prev. 2002 Aug

 1;14(4):318–29.
- 68. Nyblade L, Stangl A, Weiss E, et al. Combating HIV stigma in health care settings: what works? J Int AIDS Soc. 2009 Aug 6;12:15.
- 69. van Velthoven MHMMT, Car LT, Car J, et al. Telephone Consultation for Improving Health of People Living with or at Risk of HIV: A Systematic Review. PLoS ONE [Internet]. 2012 May 17 [cited 2019 Oct 20];7(5). Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3355163/
- 70. Gentry S, van-Velthoven MH, Tudor Car L, et al. Telephone delivered interventions for reducing morbidity and mortality in people with HIV infection. The Cochrane Collaboration, editor. Cochrane Database Syst Rev [Internet]. 2013 May 31 [cited 2016 Apr 5]; Available from: http://doi.wiley.com/10.1002/14651858.CD009189.pub2
- 71. Dombrowski JC, Simoni JM, Katz DA, et al. Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program. AIDS Patient Care STDs. 2015 May 1;29(5):279–87.

- 72. Christopoulos KA, Massey AD, Lopez AM, et al. "Taking a Half Day at a Time:"

 Patient Perspectives and the HIV Engagement in Care Continuum. AIDS Patient Care

 STDs. 2013 Apr 1;27(4):223–30.
- 73. Yehia BR, Stewart L, Momplaisir F, et al. Barriers and facilitators to patient retention in HIV care. BMC Infect Dis. 2015 Jun 28;15(1):246.
- 74. Beer L, Fagan JL, Valverde E, et al. Health-Related Beliefs and Decisions about Accessing HIV Medical Care among HIV-Infected Persons Who Are Not Receiving Care. AIDS Patient Care STDs. 2009 Aug 2;23(9):785–92.
- 75. Rajabiun S, Mallinson RK, McCoy K, et al. 'Getting me back on track': the role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. AIDS Patient Care STDs. 2007;21 Suppl 1:S20-29.
- 76. Waegemann CP. mHealth: the next generation of telemedicine? Telemed J E-Health Off J Am Telemed Assoc. 2010 Feb;16(1):23–5.
- 77. Roffman RA, Picciano JF, Ryan R, et al. HIV-Prevention Group Counseling Delivered by Telephone: An Efficacy Trial with Gay and Bisexual Men. AIDS Behav. 1997 Jun 1;1(2):137–54.
- 78. McKinstry LA, Goldbaum GM, Meischke HW. Telephone notification of HIV test results: impact in King County, Washington. Sex Transm Dis. 2007 Oct;34(10):796–800.
- Morrison RE, Black D. Telephone Medical Care of Patients with HIV/AIDS. AIDS
 Patient Care STDs. 1998 Feb 1;12(2):131–4.

- 80. Shah R, Watson J, Free C. A systematic review and meta-analysis in the effectiveness of mobile phone interventions used to improve adherence to antiretroviral therapy in HIV infection. BMC Public Health. 2019 Jul 9;19(1):915.
- 81. NSW Ministry of Health. NSW HIV Strategy 2012-2015. NSW Ministry of Health; 2012.
- 82. Hunter New England Local health districts [Internet]. [cited 2020 Oct 6]. Available from: https://www.health.nsw.gov.au/lhd/pages/hnelhd.aspx
- 83. Western NSW Local health districts [Internet]. [cited 2020 Oct 6]. Available from: https://www.health.nsw.gov.au/lhd/pages/wnswlhd.aspx
- 84. Grierson J, Pitts M, Koelmeyer R. HIV Futures Seven: The Health and Wellbeing.

 Melbourne: LaTrobe University;
- 85. Hull P, Mao L, Lea T, et al. Gay Community Periodic Survey: Sydney 2017. National Centre in HIV Social Research: University of New South Wales; 2013.
- 86. New South Wales Population Health. Adult Population Health Survey. New South Wales Population Health; 2013.
- 87. Hall N, Day L, Gardner R. Extended Telephone Support Service Pilot Evaluation.

 Department for Children, Schools and Families; 2009.
- 88. Heckman TG, Somlai AM, Peters J, et al. Barriers to care among persons living with HIV/AIDS in urban and rural areas. AIDS Care. 1998 Jun;10(3):365–75.
- 89. Perceived Competence Scales selfdeterminationtheory.org [Internet]. Available from: https://selfdeterminationtheory.org/perceived-competence-scales/

- 90. Kessler RC, Green JG, Gruber MJ, et al. Screening for serious mental illness in the general population with the K6 screening scale: results from the WHO World Mental Health (WMH) survey initiative. Int J Methods Psychiatr Res. 2010 May 31;S1(19):4–22.
- 91. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav. 1983 Dec;24(4):385–96.
- 92. Hagerty MR, Cummins RA, Ferriss AL, et al. Quality of Life Indexes for National Policy: Review and Agenda for Research. Soc Indic Res. 2001 Jul 1;55(1):1–96.
- 93. O'Brien KK, Bayoumi AM, Strike C, et al. How do existing HIV-specific instruments measure up? Evaluating the ability of instruments to describe disability experienced by adults living with HIV. Health Qual Life Outcomes. 2010 Aug 19;8(1):88.
- 94. Heckman TG, Carlson B. A Randomized Clinical Trial of Two Telephone-Delivered, Mental Health Interventions for HIV-Infected Persons in Rural Areas of the United States. AIDS Behav. 2007 Jan 1;11(1):5–14.
- 95. Reynolds NR, Testa MA, Su M, et al. Telephone support to improve antiretroviral medication adherence: a multisite, randomized controlled trial. J Acquir Immune Defic Syndr 1999. 2008 Jan 1;47(1):62–8.
- 96. Vidrine DJ, Arduino RC, Lazev AB, et al. A randomized trial of a proactive cellular telephone intervention for smokers living with HIV/AIDS. AIDS Lond Engl. 2006 Jan 9;20(2):253–60.
- 97. Gelinas L, Pierce R, Winkler S, et al. Using Social Media as a Research Recruitment

 Tool: Ethical Issues and Recommendations. Am J Bioeth AJOB. 2017 Mar;17(3):3–14.

- 98. Sitar S, Hartman B, Graham B, et al. P15-17. Social media as a tool for engaging and educating audiences around HIV vaccine research and clinical trial participation.

 Retrovirology. 2009 Oct 22;6(Suppl 3):P218.
- 99. Norcross JC. The therapeutic relationship. In: The heart and soul of change: Delivering what works in therapy, 2nd ed. Washington, DC, US: American Psychological Association; 2010. p. 113–41.
- 100. Cheever LW. Engaging HIV-Infected Patients in Care: Their Lives Depend on It. Clin Infect Dis. 2007 Jun 1;44(11):1500–2.
- 101. The Australian Standards for psychological support for adults with HIV ASHM [Internet]. 2019 [cited 2019 Nov 14]. Available from: https://www.ashm.org.au/products/product/9781920773717
- 102. Belzer ME, Kolmodin MacDonell K, Clark LF, Huang J, Olson J, Kahana SY, et al. Acceptability and Feasibility of a Cell Phone Support Intervention for Youth Living with HIV with Nonadherence to Antiretroviral Therapy. AIDS Patient Care STDs. 2015 Jun 1;29(6):338–45.

Table 1. Demographic and Clinical Characteristics at Baseline

Characteristic	N= 27 (%)
Age	()
<i>M</i> = 48.22, <i>SD</i> =9.40, <i>Range</i> = 29-63	
Gender	
Male	26 (96.3%)
Female	1 (3.7%)
Relationship Status	
Single	25 (92.6%)
Regular relationship/Married	2 (7.4%)
	,
Education level	0 (19 50/)
Less than year 12 Year 12 education	9 (18.5%) 5 (18.5%)
Tertiary Diploma/Trade	9 (33.3%)
certificate/TAFE	7 (33.370)
Undergraduate University degree or	2 (7.4%)
diploma	, ,
Postgraduate University degree or	2 (7.4%)
diploma	
Cultural Identity	
Aboriginal or Torres Strait Islander	1 (3.7%)
Non Aboriginal or Torres Strait Islander	26 (96.3%)
Employment status	
On pension/social security	21 (77.8%)
Employed part-time	3 (37.1%)
Un-employed	1 (3.7%)
Student	1 (3.7%)
Other	1 (3.7%)
Smoking Status	
Daily smoker	11 (40.7%)
Occasional smoker	1 (3.7%)
Ex-smoker	8 (29.6%)
Non-smoker	7 (25.9%)
Years since testing HIV+	
M=14.52, $SD=8.40$, $Range=2-31$	
Most recent CD4 cell count	
Greater than 500 cells/uL	19 (70.4%)
Between 500 and 350 cells/uL	5 (18.5%)
Less than 350 cells/uL	3 (11.1%)
Vival Load	` '
Viral Load Undetectable	20 (74 10/)
Detectable	20 (74.1%) 6 (22.2%)
Don't know	1 (3.7%)
Don t know	1 (3.770)

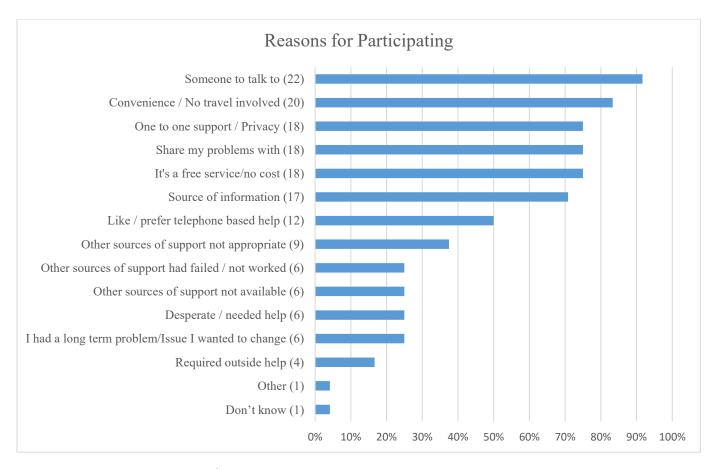


Figure 1. Participant reasons for participating

Table 2. Program implementation and feasibility

Call	Completed	Participant exits	Average Call length (min)	Average Call attempts
Registration/Baseline Survey	27	3 (prior to program commencement)	n/a	n/a
One: Introduction + support services info	24	-	25 (SD = 8.9)	2.3 (<i>SD</i> = 1.9)
Two: Maintaining a healthy immune system	24	-	31 (<i>SD</i> = 13.5)	2.6 (SD = 2.5)
Three: Monitoring changes in body and mind	21	1	34 (<i>SD</i> = 13.2)	1.8 (<i>SD</i> = 1.6)
Four: Maintaining a healthy mind	20	1	37 (<i>SD</i> = 14.8)	1.8 (SD = 1.3)
Five: Maintaining a healthy body	21	1	30 (<i>SD</i> = 10.1)	2.6 (SD = 2.1)
Six: Developing a plan for maintenance	21	-	28 (<i>SD</i> = 16.0)	3 (SD = 4.1)

Table 3. Participant acceptability and satisfaction

Participant rated acceptability and satisfaction (N=17*)

Response	N	%
Overall how useful was the support or information you received?		
Very Useful	8	50.0
Fairly useful	7	43.8
Not very useful	1	6.2
Not at all useful	0	0
Don't know	0	0
To what extent did the telephone support sessions address your needs	?	
To a great extent	8	47.1
To some extent	4	23.5
Not very much	4	23.5
Not at all	1	5.9
How appropriate do you feel the service was for your situation?		
Very appropriate	7	41.2
Fairly appropriate	5	29.4
Not very appropriate	3	17.6
Not at all appropriate	2	11.8
How supportive was your positive talk support caller?		
Very supportive	10	66.7
Quite supportive	4	26.7
A little supportive	1	6.7
Not at all supportive	0	0
How able were they to offer information or advice about issues you raised?		
Very able	7	50.0
Quite able	6	42.9
Somewhat able	1	7.1
Not at all able	0	0
Would you recommend the PTFPH support service to other PLWHIV	?	
Yes	14	93.3
No	1	6.7

^{*}sample size varies due to missing data

How has your participation in the Positive Talk for Positive Health support service changed things, to what extent do you?

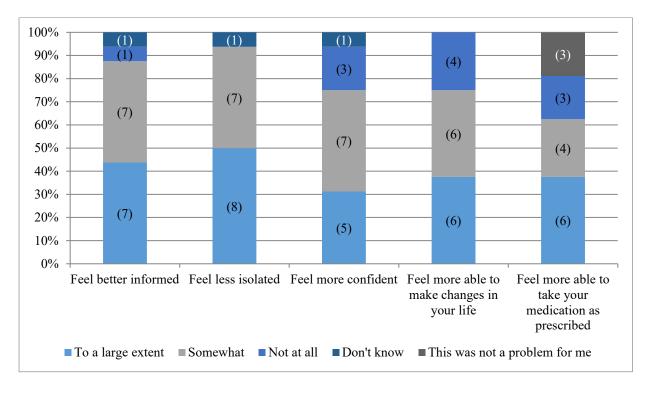


Figure 2. Perceived impact of program

Table 4. Participant implementation feedback

Response	N	%
Program calls completed:		
6 (entire program)	15	88.2
4	1	5.9
2	1	5.9
Preferred call frequency:		
One every week	0	0
One every fortnight	2	15.4
One every three weeks	0	0
One every month	11	84.6
Other	0	
How would you describe the average call length:		
About right	10	76.9
Too long	2	15.4
Too short	0	0
Other	1	7.70
How easy did you find scheduling calls at a time that suited you?		
Very easy	11	84.6
Usually easy	1	7.7
Not easy	1	7.7
Same vs different callers preference:		
Different callers is fine	11	64.7
Slight preference for same caller	3	17.6
Strong preference for same caller	3	17.6
Have you accessed support services as a result of information or adv program:	ice received	d during the
Yes	11	64.7%
No	4	23.5%
Did not require support services	2	11.8

^{*} sample size varies due to missing data

Measurement	Baseline (N=27)	Follow-up (N=17)
Currently using ART medication	26 (96.3%)	17 (100%)
HIV treatment and adherence self- efficacy scale ASES	<i>M</i> =7.41, <i>SD</i> =2.25, <i>Range</i> = 3.92 - 10	<i>M</i> =7.78, <i>SD</i> =2.09, <i>Range</i> = 2.92 - 10
Perceived self- efficacy scale	<i>M</i> =5.76, <i>SD</i> =1.22, <i>Range</i> = 2.50 - 7	<i>M</i> =5.88, <i>SD</i> =1.60, <i>Range</i> = 1.75 - 7
Kessler-6 Distress scale		
Low to Moderate	20 (74.1%)	13 (76.5%)
Severe Distress	7 (25.9%)	4 (23.5%)
Barriers To Care Scale	<i>M</i> =2.53, <i>SD</i> =0.67, <i>Range</i> = 1.17-3.92	<i>M</i> =2.09, <i>SD</i> =0.50, <i>Range</i> = 1.00-3.08
Functional Assessment of HIV Infection: Emotional wellbeing*	<i>M</i> =14.85, <i>SD</i> =8.17, <i>Range</i> = 1-33	M=9.24, SD =7.33, $Range$ = 1-27
Functional Assessment of HIV Infection: Social wellbeing	<i>M</i> =13.92, <i>SD</i> =7.22, <i>Range</i> = 0-27	M=17.00,SD=8.43, Range=0-28
HRQOL – Healthy days	<i>M</i> =11.48, <i>SD</i> =10.82, <i>Range</i> = 0-30	M=16.29, SD =9.79, Range = 0-30
Current smokers* Cigarettes per day	<i>M</i> =20.42, <i>SD</i> =7.87, <i>Range</i> = 2-35	<i>M</i> =13.17, <i>SD</i> =6.05, <i>Range</i> = 7-20
Currently in contact with HIV/AIDS related organisations		
Yes No	22 (88.9%) 3 (11.1%)	10 (81.5%) 5 (18.5%)

Note: Sample size varies to missing data due to missing survey values

Table 5. Participant pre and post measures

^{*} significant difference from baseline to follow-up on paired samples t-test

Appendix A: Journal Scope and Instructions for Authors

AIDS Patient Care and STDs

Editor-in-Chief: Jeffrey Laurence, MD

ISSN: 1087-2914 | Online ISSN: 1557-7449 | Published Monthly | Current Volume: 33

Impact Factor:* 3.742

*2018 Journal Impact Factor, Journal Citation Reports (Web of Science Group, 2019)

The premier peer-reviewed journal delivering critical peer-reviewed coverage of diagnostics and therapeutics for providing optimal care for HIV/AIDS patients.

View Aims & Scope

Aims & Scope

AIDS Patient Care and STDs is the foremost journal providing the latest developments and research in diagnostics and therapeutics designed to prolong the lifespan and improve quality of life for HIV/AIDS patients. The Journal delivers cutting-edge clinical, basic science, sociologic, and behavior-based investigations in HIV/AIDS and other sexually transmitted infections. Clinical trials, quantitative and qualitative analyses of pilot studies, comprehensive reviews, and case reports are presented from leading experts and scientists around the world.

AIDS Patient Care and STDs coverage includes:

- Prominent AIDS medications, therapies, and antiretroviral agents
- HIV/AIDS-related diseases, infections, and complications
- Challenges of medication adherence
- Current prevention techniques for HIV
- The latest news and developments on other STDs
- Treatment/prevention options, including pre- and post-exposure prophylaxis

AIDS Patient Care and STDs is under the editorial leadership of Editor-in-Chief **Jeffrey Laurence**, **MD**, Weill Cornell Medical College, Laboratory for AIDS Virus Research at New York Blood Center; Senior Consulting Editor **Robert C. Gallo**, **MD**, Institute of Human Virology, University of Maryland School of Medicine; and other leading investigators. View the entire <u>editorial board</u>.

Audience: HIV/AIDS clinicians, nurses, and psychologists; behavioral and social scientists; infectious disease specialists; immunologists; pathologists; virologists; hospital and AIDS treatment facility staff; and municipal health department staff; among others.

Information For Authors

Mary Ann Liebert, Inc. Submission Benefits Package

Your submission to *AIDS Patient Care and STDs* provides you with robust tools and support to ensure maximum impact and readership for your work. By submitting your manuscript, you'll receive:

- Rapid, rigorous peer-review and editorial attention
- Immediate deposit to PubMed and other indexing services upon online publication
- Exposure to thousands of thought-leaders in your field, maximizing readers, citations, and downloads
- Fast Track online-ahead-of-print publication
- Global availability in over 170 countries
- Open Access publication options

Submitting Your Manuscript

Submitting your manuscript to *AIDS Patient Care and STDs* delivers a comprehensive benefits program that ensures high-quality review of your research and maximum impact for your work. *AIDS Patient Care and STDs* carries a manuscript processing charge* of \$50.00 USD upon submission of each new manuscript.

Upon payment, you will be provided a Manuscript Submission Code, and will be prompted to enter this information when uploading your files to our peer-review system. *Please*note: Securing a token does not automatically create an account in our peer-review system. If you do not already have an account, you will be asked to create one before you can begin your submission.

Submissions do not need to be completed at once. Submitting authors/agents may begin the submission process, save their work, and return to the site to complete the upload(s) at a later time. There is no limit on the number of times one can save their work and subsequently resume the submission. Doing so will not incur additional charges.

<u>Click here</u> to submit your paper via our fast and user-friendly electronic submission system.

Manuscript Revisions

Processing charges and submission codes are NOT required for revisions to previously submitted papers. To upload a <u>revision</u> of a paper, the submitting author should log in to their Author Center at http://mc.manuscriptcentral.com/aidspatientcare and click on "*Revised Manuscripts in Draft*." The paper will appear in this area, and the submitting author will be able to upload revised files without paying any charges or entering a submission code.

Please be sure to follow the Instructions for Authors below on Manuscript Preparation. Authors whose submissions do not comply with the Instructions for Authors will have their papers un-submitted so that the file(s) may be adjusted accordingly. Directions

regarding the necessary corrective actions will be provided in an email to the corresponding author at the time the paper is un-submitted. The submitting author/agent will then be provided the opportunity to re-upload the corrected file(s). If a paper is un-submitted, the paper will reside in the corresponding author's "Author Center" as a draft, and the submitting author/agent will be able to make the necessary adjustments and re-upload the paper without incurring another manuscript processing charge.

Preparation of Manuscript

Be sure these instructions are followed exactly.

We welcome Original Research and Review submissions on topics of major significance in biotherapy, radiopharmaceuticals, and related fields. Each coauthor accepts responsibility for the entire contents of the manuscript. Contributions to the journal are published at no charge to the author. Once a paper has been accepted for publication, it cannot be withdrawn. Authors will have the option to indicate one reviewer who should be excluded (non-preferred) from review of their manuscript. Authors will also have the option to suggest preferred reviewers during the submission process if they like.

Note: AIDS Patient Care and STDs does not publish Short Communications.

Abstracts

ABSTRACT should be capitalized and centered on the page and have one space below. The text of the abstract is single spaced and should be limited to 250 words. This should appear on a separate page.

Manuscript keywords (search terms): On the title page of the manuscript, include a minimum of three (3), maximum of six (6), search terms that will aid in the discoverability of the article in indexing services and search engines. These terms may or may not be different from the terms you selected for the peer review process and areas of expertise. You will be asked to retype these search terms in the submission form when uploading your manuscript. These keywords will be included in the published article. If the search terms entered do not match the manuscript, the manuscript will serve as the default.

Keywords (Areas of Expertise)

^{*}The manuscript processing charge is independent of editorial decision and is non-refundable.

To facilitate the peer review process, select 4-6 keywords from the drop-down list of preselected terms when submitting your manuscript. These keywords will assist in the selection of skilled reviewers in the field for the purposes of peer review.

Tables and Figures

Each table should be prepared in a separate file. Tables should be cited in the text (see Table 1). Tables should be submitted in Microsoft Word.

Each figure should be prepared in a separate file with the figure number visible. Each figure should be cited in text (Fig. 1). Legends should be on a separate page from the figures.

Please follow these guidelines for submitting figures:

- Do **NOT** embed art files into a Word or PDF document.
- Line illustrations should be submitted at 1200 dpi.
- Halftones and color should be submitted at a minimum of 300 dpi.
- Save as either TIFF or EPS files.
- Color art must be saved as CMYK not RGB.
- Black and White art must be submitted as grayscale **not RGB.**
- Do **NOT** submit PowerPoint, PDF, Bitmap or Excel files.

Please name your artwork files with the submitting author's name i.e. SmithFig1.tif, SmithTable2.tif etc. Label figures and tables inside the files in addition to naming the file with the figure or table number. (ie: When figures or table files are opened, the figure or table number should appear inside the file.) Authors who do not follow these guidelines may have their submission returned to them without being reviewed.

You will be given directions on how to correct any files which do not pass.

ADDITIONAL INFORMATION ABOUT ART FILES

Converting Word or Excel files: Perhaps the best and easiest way to convert Word or Excel files into a format which is suitable for print is to scan them using the guidelines below:

- All files should be scanned at 100% size.
- 300 dpi
- Final color mode: cmyk
- save file as: .tif or .eps

If you need directions on how to **convert a Power Point slide** to acceptable format go to https://home.liebertpub.com/MEDIA/pdf/ppconvert.pdf

Footnotes

Footnotes should be typed single spaced at the bottom of the appropriate page and separated from the text by a 3-inch line starting from the left margin with one space above and below it. Footnotes should be used only when essential.

Acknowledgments

Collaborations, sources of research funds, and other acknowledgments must be listed in a separate section at the end of the text ahead of the REFERENCES section.

AUTHOR DISCLOSURE

All authors are expected to disclose any institutional or commercial affiliations that might pose a conflict of interest regarding the publication of a manuscript. Institutional affiliations, as indicated on the title page, should include all corporate affiliations and any funding sources that support the work. Other types of affiliation, including consultantships, honoraria, stock ownership, equity interests, arrangements regarding patents, or other vested interests should be disclosed in the Acknowledgments section.

References

Use order-of-citation format for references. Cite references within the text by a superscripted Arabic number as in the following example: [. . .as described previously. ^{1,4}]. Provide a list of references, in numerical order, and in the order in which they appear in the text. Reference section should be double spaced.

<u>For journal citations:</u> (1) surname of author(s) and initials; (2) title of article; (3) journal; (4) year of publication: (5) volume number; (6) inclusive page range of citation.

<u>For book citations:</u> (1) surname of author(s) and initials; (2) title of book; (3) editor of book (if applicable); (4) edition of book (if applicable); (5) publisher; (6) city of publication; (7) year of publication (not in parentheses); and (8) page reference (if applicable).

<u>For patents:</u> (1) country of original registration; (2) patent number; and (3) month, day, and year of issuance. When data from an unpublished source are given, supply complete information (e.g., researcher's name and location). If work is in press, give journal in which it is to be published or publisher.

For book and journal references, if there are more than four authors, list only the first three, followed by et al.

IMPORTANT

Please upload individual files of all manuscript material—do NOT upload a single PDF file containing all text, figure, and table files of your paper. Once all individual files are uploaded onto Manuscript Central, the system will automatically create a single PDF proof for you and the peer-review process.

Permissions

Written permission to use copyrighted material must be obtained from the publisher (not the author or editor). The publication from which the figure, table, or text is taken must be listed in REFERENCES. Finally, the first footnote of a reprinted table, or the last sentence of the legend of a reprinted figure, should read "reprinted by permission from Ref. (00)," using appropriate reference number. All permissions must be listed.

Correspondence

Be sure to provide the complete name and address to which correspondence should be directed.

Disclosures

Funding sources for research must be disclosed for all manuscripts accepted for publication.

Reprints

Reprints may be ordered by following the special instructions that will accompany page proofs, and should be ordered at the time the corresponding author returns the corrected page proofs to the Publisher. Reprints ordered after an issue is printed will be charged at a substantially higher rate.

Publisher

The Journal is published 12 times per year by Mary Ann Liebert, Inc., 140 Huguenot Street, New Rochelle, NY 10801-5215. Telephone: (914) 740-2100; fax: (914) 740-2101; e-mail: info@liebertpub.com; online: www.liebertpub.com.

Appendix B: Ethics Approval



21 January 2014

Dr Jenny Bowman School of Psychology University of Newcastle

Dear Dr Bowman,

Re: HIV Telephone Support Program (13/12/11/4.13)

HNEHREC Reference No: 13/12/11/4.13 NSW HREC Reference No: HREC/13/HNE/526

Thank you for submitting the above application for single ethical review. This project was first considered by the Hunter New England Human Research Ethics Committee at its meeting held on 11 December 2013. 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.

I am pleased to advise that following acceptance under delegated authority of the requested clarifications and revised Information Statement and Survey by Dr Nicole Gerrand Manager, Research Ethics & Governance, 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 Statement (Version 2 13 December 2013);
- For the Participant Consent Form (Version 2 dated 13 December 2013);
- For the Baseline Participant Survey (Version 2);
- For the Study Brochure; and
- For the Study Poster (Version 2)

For the study: HIV Telephone Support Program

Approval has been granted for this study to take place at the following site:

Hunter New England Population Health

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

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 3 years from the date of this letter, after which a renewal application will be required if the protocol has not been completed.

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfil this function, it requires:

- A report of the progress of the above protocol be submitted at 12 monthly intervals. Your
 review date is January 2015. A proforma for the annual report will be sent two weeks prior to
 the due date.
- A final report must be submitted at the completion of the above protocol, that is, after data
 analysis has been completed and a final report compiled. A proforma for the final report will be
 sent two weeks prior to the due date.
- All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.
- The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
 - any serious or unexpected adverse events
 - Adverse events, however minor, must be recorded as observed by the
 Investigator or as volunteered by a participant in this protocol. Full details
 will be documented, whether or not the Investigator or his deputies considers
 the event to be related to the trial substance or procedure. These do not
 need to be reported to the Hunter New England Human Research Ethics
 Committee
 - Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Manager, Research Ethics & Governance, of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.
 - All other safety reporting should be in accordance with the NHMRC's Safety
 Monitoring Position Statement May 2009 available at
 http://www.nhmrc.gov.au/health-ethics/hrecs/reference/files/090609-nhmrc-position-statement.pdf
 - Serious adverse events are defined as:
 - Causing death, life threatening or serious disability.
 - Cause or prolong hospitalisation.
 - Overdoses, cancers, congenital abnormalities whether judged to be caused by the investigational agent or new procedure or not.
 - Unforeseen events that might affect continued ethical acceptability of the project.
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand, as soon as possible.

Hunter New England Research Ethics & Governance Unit

Locked Bag 1 New Lambton NSW 2305 Facsimile: (02) 49214818

Telephone: (02) 49214950 Facsimile: (02) 49214818 Email: HNELHD-HREC@hnehealth.nsw.gov.au

http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Should you have any concerns or questions about your research, please contact Dr Gerrand as per the details at the bottom of the page. The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Please quote 13/12/11/4.13 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Professor M Parsons

Chair

Hunter New England Human Research Ethics Committee



4 November 2014

Dr Jenny Bowman Associate Professor School of Psychology University of Newcastle CALLAGHAN NSW 2308

Dear Dr Bowman,

Western NSW & Far West Local Health Districts HREC Project No. HREC/13/HNE/526 SSA Application No. SSA/14/GWAHS/101

HIV Telephone Support Project

Site Specific Assessment Application

Thank you for submitting a site specific assessment application to conduct research within the Western NSW & Far West Local Health Districts.

I am pleased to inform you that authorisation has been granted for this study to take place at the following sites within the Western NSW & Far West Local Health Districts:

- Western NSW LHD
 - Orange Sexual Health Clinic
 - Dubbo Sexual Health Clinic

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

- 1 Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the Research Governance Officer; and
- 2 Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the Research Governance Officer.

Research Governance

PO Box 143 Level 1, 230 Howick Street BATHURST NSW 2795 Tel: (02) 6330 5941 Fax: (02) 6332 3140 Should you have any queries regarding your project, please do not hesitate to contact the Western NSW & Far West Local Health Districts Research Governance Officer on (02) 6330 5941 or via email <u>WNSWLHD-EthicsCommittee@health.nsw.gov.au</u>.

Please quote SSA Reference No. SSA/14/GWAHS/101 in all correspondence.

The Western NSW & Far West Local Health Districts wish you every success in your research.

Yours sincerely

Sužanne Degiorgio
Ethics & Research Governance Officer
Western NSW & Far West Local Health Districts

HUMAN RESEARCH ETHICS COMMITTEE



Notification of Expedited Approval

To Chief Investigator or Project Supervisor: Associate Professor Jennifer Bowman

Mr David Wilkinson

Cc Co-investigators / Research Students: Ms Karen Nairn

Mr Todd Heard

Re Protocol: HIV Telephone Support Project

Date: **06-Mar-2014**

HREC Reference No: H-2014-0063

External HREC Reference No: 13/12/11/4.13

Date of Initial Approval: **04-Mar-2014**

Thank you for your **Initial Application** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited Review of External Approval** review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is **External HREC Approval Noted** effective **04-Mar-2014**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research*, 2007, and the requirements within this University relating to human research.

As the approval of an External HREC has been "noted" the approval period is as determined by that HREC.

The full Committee will be asked to note this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is **H-2014-0063**.

PLEASE NOTE:

As the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's HREC.

Linkage of ethics approval to a new Grant

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

Best wishes for a successful project.

Professor Allyson Holbrook

Chair, Human Research Ethics Committee

For communications and enquiries:

Human Research Ethics Administration

Research Services
Research Integrity Unit
The Chancellery
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 17894
F +61 2 492 17164
Human-Ethics@newcastle.edu.au

RIMS website - https://RIMS.newcastle.edu.au/login.asp

Linked University of Newcastle administered funding:

Funding body	0. ,	First named investigator	Grant Ref
	Investigation of Telephone Support for people living with HIV in the Hunter New England Region	Bowman Jennifer,	G1300875

Appendix C: Recruitment Advertising

Poster



Brochure

HEALTHY BODIES



The "Positive Talk for Positive Health" program is a free telephone based service for

health and wellbeing goals that are relevant to your individual needs across the following

- Maintaining your social & emotional wellbeing;
 Living a healthy life;
 Discussing treatment

- 4. Managing your symptoms; &5. Planning for your health and support needs.

POSITIVE TALK

What the service offers ...

- Access to trained telephone support staff.
- Participation in six free confidential support calls over a period of six months.
- The opportunity to discuss issues that are important to you.
- Up-to-date information on issues that affect your health and wellbeing and support services available in your community.
- Support to develop the skills & motivation needed for self-management.

The "Positive Talk for Positive Health" team is designed to support you to live healthy.

HEALTHY MINDS How do I participate?

Step 1:

Call 02 49246373 to register

Step 2:

A member of the team will call you to learn about your individual needs.

Step 3:

Commence participation in the information support service in 2014

Local HIV Support Services

The Pacific Clinic Level 2, 670 Hunter Street, Newcastle Phone: (02) 4016 4536

HIV Support Services John Hunter Hospital Phone: (02) 4922 3444

Clinic 468 468 Peel Street, Tamworth Phone: (02) 6764 8080

Manning Clinic Taree Community Health Centre 64 Pultney Street, Taree Phone: (02) 4016 4536

ACON Health Hunter 129 Maitland Road, Islington, Phone: (02) 4962 7700

Karumah Positive Living Centre

Emergency Contacts:

Lifeline 24 hour service 13 11 14

Medical emergency call 000

TAKE THE FIRST STEP!



For more information about participating

in the free and confidential service

please register your

interest by calling:

Phone: 02 49246373

Available Monday - Friday (9am-5pm), you can leave a message out of hours.

"Positive Talk for Positive Health"

Confidential Information Support Service

Positive

Positive Talk
Healthy Minds
Healthy Bodies
Positive Health

allbeing

Appendix D: Participant Information Statement and Consent Form





Participant Information Statement for the HIV Telephone Support project "Positive Talk for Positive Health"

You are invited to participate in the "Positive Talk for Positive Health" project. The "Positive Talk for Positive Health" is a project for people living with HIV in the Hunter New England Area. The project is being conducted by a research team from the Hunter New England Local Health District (HNELHD) and the University of Newcastle and led by Principal Investigators, Dr Jenny Bowman and Ms Karen Nairn.

Why is the research being done?

The HNELHD and the University of Newcastle are committed to providing information and support to people living with HIV across the HNELHD. The 'Positive Talk for Positive Health' project will investigate whether a telephone delivered information and support service will contribute to improving treatment and quality of life outcomes for people living with HIV.

What does the research involve?

The 'Positive Talk for Positive Health" pilot project will provide information and support for people living with HIV via telephone. The telephone support will be delivered by trained support callers over six, monthly calls. To measure the project's effectiveness, information will be collected from project participants by surveys at the commencement of the project, the completion of the project and four months following the project.

Who can participate in the research?

People 18 years of age or over living with HIV across the HNELHD will be invited to participate in the project. Participants must also be fluent in English and be able to give consent to take part.

What choice do you have?

Participation in this research is entirely your choice. Your decision to participate, or not, will not influence in any way the health care provided to you by any existing HNELHD health care services or providers. If you do decide to participate, you may withdraw at any time without giving a reason, and any information you have provided relating to you will be destroyed.

What would you be asked to do?

If the project is suitable for you and you decide to participate, you will be asked to indicate your consent and complete the first survey; which you will have the option of completing online or by telephone and will take about 20 minutes. The survey will ask questions about your age, background, sexual orientation, HIV diagnosis and progress, health related behaviours, psychological and general quality of life, health service use and barriers to care and support.

After completing the baseline survey, you will be contacted by a member of the research team who will schedule a time for your first support call. During that first support call, we will discuss what would suit you with regards to arranging for further calls (5 calls at approximately 1 month intervals). On two further occasions following your completion of the "Positive Talk for Positive Health" program you will be asked to complete a follow up survey: immediately after completing the program and then again four months later. These surveys will ask similar questions to the first survey and also seek your feedback on the project.

How will your privacy be protected?

If you agree to participate, your name and contact details will be recorded. Your survey will have been allocated a randomly generated I.D. number. Your name and contact details with the associated I.D. number will be stored securely and separately from your answers to the survey questions. When analysing survey responses, your name and any identifying information will not be included. You may request a summary report of your own survey responses be provided to yourself, but complete confidentiality of your responses will otherwise be maintained.

What are the risks and benefits of participating?

It is expected that the benefits will include an increased level of information and support that may assist participants to make decisions that contribute to improved treatment and quality of life outcomes. There is the possibility that answering questions about your personal circumstances may sometimes be upsetting. Should you feel in any way upset by participating, we recommend you discuss this with one of the Principal Investigators, your ongoing provider of HIV information support, your GP or your local mental health service (Mental Health Hotline phone no. 1800011511). The "Positive Talk for Positive Health" project will provide contact details for sources of mental health support in your local area as a standard part of the information provided.

How will the information collected be used?

All data collected in the project will be analysed on a group basis only, with no individual identifying information. Any reports or publications regarding the project will discuss results on a group basis only. Information collected as part of the project will be stored securely in electronic files and paper copies will be stored in a locked filing cabinet. Access to data will be restricted to members of the research team. Data that is non-identifying will be kept for a period of 15 years to allow for ongoing analyses. Identifying information (e.g. the list of names, contact details and I.D. numbers) will be destroyed at the completion of the project.

What do you need to do to participate?

Please read this information statement carefully. If you think you might like to take part, or have further questions about the project, please contact Todd Heard by phone on 0249246373 or email todd.heard@hnehealth.nsw.gov.au . Your enquiry will be treated in strictest confidence.

Thank you for considering this invitation.

Dr. Jenny Bowman
Associate Professor
School of Psychology
University of Newcastle
ph 02 49215958
email jenny.bowman@newcastle.edu.au

Ms Karen Nairn
Director, HIV and Related Programs
Hunter New England Population Health
Hunter New England Local Health District
ph 02 49246022
email Karen.nairn@hnehealth.nsw.gov.au

Complaints: This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 13/12/11/4.13. 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 being 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 Health, Locked Bag 1, New Lambton NSW 2305. Telephone (02) 4921 4950. Email Nicole.Gerrand@hnehealth.nsw.qov.au





Consent Form for the HIV Telephone Support project "Positive Talk for Positive Health"

People living with HIV in the Hunter New England Area, are invited to participate in the "Positive Talk - Positive Health" pilot project, which is being conducted by a research team from the Hunter New England Local Health District (HNELHD) and the University of Newcastle and led by Primary Investigators, Dr Jenny Bowman and Ms Karen Nairn.

Please refer to the Participant Information Statement before completing this form, for detailed information regarding the project and participation.

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Participant 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 understand that my personal information will remain confidential to the researchers, except in the situation where I have provided my consent to my answers being shared with my ongoing provider of HIV treatment and support.

I have the opportunity to have questions answered to my satisfaction.

-coi	nca	nT.	TO:

ise	nt to;
•	Being contacted on the number provided for the purpose of participation in this project Yes
•	Completing a baseline survey prior to participating in the project (online or by phone) ☐ Yes
•	Completing a survey at the completion of the project (online or by phone) ☐ Yes
•	Completing a further follow up survey at approximately 4 months (online or by phone) ☐ Yes

Appendix E: Baseline/Follow-up Survey

Positive Talk for Positive Health: Follow-up survey

Variation Key:

- Questions previously approved for use in baseline survey
- Additional follow-up Questions

Survey Question:	
Q1. Please enter your survey ID which is six characters long, n	nade up of: The first two
letters of your first name, the first two letters of your mother's	
form of the month you were born in.	
E.g. Participant: John Smith	
Participant's mother: Melinda Smith	
Month Participant born: February	
Participant ID = JOME02	
Survey ID	
Q2. In what year were you born?	
Q3. What is the postcode or suburb/town where you live?	
Q4. Are you:	
- Employed full-time (1)	
- Employed part-time (2)	
- On pension/social security (3)	
- A student (4)	
- Unemployed (5)	
- Other (6)	
Q5. Where do you currently live?	
- Own or purchasing house or flat	(1)
- Private rental accommodation	(2)
- Public rental accommodation (government owned)	(3)
- Rent-free (e.g. provided by friends, family, etc.)	(4)
- Community housing/housing co-operative	(5)
- Other (please describe)	(6)
Q6. Who do you live with? (tick as many as apply to you)	
- No-one (1)	
- Partner/spouse (2)	
- Dependent children (3)	
- Other family members (4)	
- Friend(s)/Flatmate(s) (5)	
- Other (please specify) (6)	
Q7. Are you now in a regular relationship/married?	
- Yes (1)	
- No (2)	
O8 What is your partner's HIV status?	

- HIV positive (1)					
- HIV negative (2)					
- Don't know (3)					
Q9. In what year did you first test po					
Q10a. Have you had a T-cell (CD4)	test in the last 1	2 month	ıs?		
- Yes	(1)				
- No - why not?	(2)				
- Don't know	(3)				
Q10b. What was the result of your m	ost recent T-ce	11 (CD4)	test?		
- Greater than 500 cells/μL	(1)				
- Between 500 and 350 cells/μl	L (2)				
- Less than 350 cells/μL	(3)				
OR	, ,				
- cells/μL	(4)				
Q10c. When was your most recent T	-cell (CD4) test	t?			
- Month year	,				
Q11a. Have you had a viral load test	in the last 12 n	nonths?			
- Yes			(1)		
- No - why not?	(skip to O25)		(2)		
- Don't know (skip to Q25)	(r ()		(3)		
Q11b. What was the result of your m	ost recent viral	,			
- Undetectable		1044 105		(1)	
- Don't know				(2)	
- Don't know (2) - Detectable, specify test result (if known): copies/mL (3)					
Q12. How many viral load tests have				(3)	
Q13. What is your experience of HIV		pust 12	monuis.		
- Currently taking antiretroviral drugs for HIV					
·					
(1) Here taken entire traviral drugs for HIV in the past, but not currently taking them					
- Have taken antiretroviral drugs for HIV in the past, but not currently taking them (2)					
- Never taken antiretroviral drugs for HIV					
(3)	155 101 111 v				
Q14.					
V14.					
Please indicate how you feel about th	e following sta	tements:			
Trease mercare new you reer about an	Strongly	Agree	Disagree	Strongly	Don't
	agree	Agree	Disagree	disagree	know
	(1)	(2)	(2)	(4)	(5)
	(1)	(2)	(3)	(' '	(0)
14.1 I am healthy now and					
don't need to use	_		_	_	
combination antiretroviral					
drugs					
14.2 Combination antiretroviral					
drugs are harmful					
14.3 Combination antiretroviral					
drugs are			П		
ineffective.					
I IIICIICOLIVC.					

14.4 New treatments will be developed in time for					
me to gain benefits					
14.5 HIV treatments will stop me dying from AIDS					
14.6 My doctor knows a lot more about the treatment of HIV than I do					
14.7 My doctor and I work together to find the best treatment for me					
14.8 The side-effects of antiretoviral drugs outweigh the benefits					
14.9 Medical treatments for HIV/AIDS make safe sex less important than it was					
14.10 Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom					
Q15. Do you believe that combination	n antiretroviral	drugs m	ean better p	rospects for	r most
people with HIV? - Yes (1)					
- Yes (1) - No (2)					
- It's too soon to tell (3)					
- Don't know (4)					
Q16. Which of the following best des	cribes your sm	oking sta	atus? This in	ncludes ciga	arettes,
cigars and pipes.				(1)
I smoke dailyI smoke occasionally					1) 2)
- I don't smoke now, but I used	to (Skip to O2	7)			3)
- I've tried it a few times but ne	` ·	· /	Skip to Q27		4)
- I've never smoked(Skip to Q2				(2	5)
Q17a. How soon after you wake up d	o you smoke y	our first	cigarette?		
- Within 5 minutes (3) - 6-30 minutes (2)					
- 6-30 minutes (2) - 31-60 minutes (1)					
- After 60 minutes (0)					
Q17b. How many cigarettes per day of	do you smoke?				
- 10 or less (0)					
- 11-20 (1)					
- 21-30 (2) - 31 or more (3)					
Q17c. Number of cigarettes you smol	ke per day:				

Q18. Have you ever tried to quit smoking? And if so, how many times?
- Yes – Once (1)
- Yes - Once (1) - Yes - 2 to 3 times (2)
- Yes – More than 3 times (3)
- Never tried to quit (4)
Q19 In the last year, have you made any quit attempts where you did not smoke for at least
24 hours?
- No (1)
- Yes (2)
Q20. In the last 6 months, have you made any quit attempts where you did not smoke for at
least 24 hours?
- No (1)
- Yes (2)
Q21. Are you seriously thinking of cutting down the number of cigarettes you smoke?
- No (1)
- Yes (2)
Q22. Are you seriously thinking about quitting smoking?
- No (1)
- Yes (2)
Q23. Do you plan to quit smoking?
- No (1)
- Yes (2)
Q24. If you plan to quit smoking, by when do you plan to quit?
- 1 month (1)
- 3 months (2)
- 6 months (3)
- More than 6 months (4)
Q25. Since your HIV positive diagnosis, has any health care provider ever advised you to
quit smoking?
- No (1)
- Yes (2)
Q26. If there were a free or low-cost smoking cessation program to help you quit, how
likely would you be to use it?
Not at all likely to use the pregram (1)
 Not at all likely to use the program (1) Maybe would use the program (2)
 Maybe would use the program (2) Would definitely use the program (3)
Q27. How many serves of vegetables do you usually eat each day? [1 serve = 1/2 cup
cooked or 1 cup of salad vegetables]
- serves per day
Q28. How many serves of fruit do you usually eat each day? [1 serve = 1 medium piece or
2 small pieces of fruit or 1 cup of diced pieces
- serves per day
Q29. In the last month how many days a week did you usually do 30 minutes or more of
physical activity?
- No days (1)
- One (2)
` /

	Two	(3)	
_	Three		
_		(4)	
-	Four	(5)	
-	Five or more	(6)	
-	Don't know	(7)	
-	Can't for health or trea		41 4 9
Q30a.	_	e a drink containing alcohol in	the past year?
-	Never	(1)	
-	Monthly or less	(2)	
-	2 to 4 times a month	(3)	
-	2 to 3 times per week	(4)	
-	4 or more times a weel		
		aining alcohol did you have or	n a typical day when you were
drinki	ng in the past year?		
-	1 or 2 (1)		
-	3 or 4 (2)		
-	5 or 6 (3)		
-	7 to 9 (4)		
-	10 or more (5)		
Q30c.	How often did you have	e six or more drinks on one oc	casion in the past year?
-	Never	(1)	
-	Monthly or less	(2)	
-	2 to 4 times a month	(3)	
-	2 to 3 times per week	(4)	
ı	4 or more times a weel	k (5)	
Q31.	Which of the following l	have you used in the last 12 m	onths? (Please tick as many as
apply)	_	·	•
		I -	
	rystal Meth	☐ Heroin (injected)	☐ Steroids (injected)
\square Sp	peed (injected)	☐ Cocaine (not injected)	☐ GHB/GBH/Fantasy
\square S _I	peed (not injected)	☐ Ecstasy	☐ Viagra or similar
	SD/trips	☐ Amyl	☐ Methadone (prescribed)
	one	☐ Marijuana	☐ Other (please specify)
O32a.	Would you say that in	general your health is?	
_	Excellent (1)	,	
_	Very good (2)		
_	Good (3)		
_	Fair (4)		
_	Poor (5)		
O32h	\ /	our physical health, which incl	udes physical illness and
_	•	ring the past 30 days was your	± •
-	Number of days	and past 50 days was your	par notice food.
032c		ur mental health, which includ	es stress denression and
		ow many days during the past	<u> </u>
-	not good?	ow many days during the past	Jo days was your mentar
	Number of days		
_	radified of days		

Q32d. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?							
- Number of days							
Q33. Have you been diagnosed with a sexual	ly transm	issible in	fection in	the last 1	2		
months?							
- No (1)							
- Yes (2)							
Q34. Below is a list of statements that other p	eople wi	th your ill	lness have	e said are			
important.	1	J					
- Please mark one box per line to indic	ate vour i	response a	as it appli	es to the 1	past 7		
days	J	1	11	•			
							
	Not at	A little	Some-	Quite	Very		
	all	bit	what	a bit	much		
	(1)	(2)	(3)	(4)	(5)		
	(-/	(-)	(0)	(- /	(0)		
34.1 I feel sad							
040 15 1							
34.2 I feel nervous							
24.2. Lucemar ale aut divine							
34.3 I worry about dying	34.3 I worry about dying						
34.4 I worry that my condition will get							
worse							
34.5 I am unhappy with my appearance							
34.5 Talli dilliappy with my appearance							
34.6 It is hard to tell other people about							
my infection	J			J	J		
24.7 Lworry shout aproading my							
34.7 I worry about spreading my infection							
Infection							
34.8 I am concerned about what the	П				П		
future holds for me	J	_	J	J]		
24.0. Lam ambarraged by my illness							
34.9 I am embarrassed by my illness							
Q35. Below is a list of statements that other p	20010 11/1	th woun ill	lnogg hovy	a said ara			
_	beopie wi	ın your m	iliess liave	saiu aic			
important.	oto violim d	****	sa it ammli	og to the	nast 7		
- Please mark one box per line to indic	ate your i	response a	as it appii	es to the	past /		
<u>days</u>							
		A		.	.,		
	Not at	A little	Some-	Quite	Very		
	all	bit	what	a bit	much		
	(1)	(2)	(3)	(4)	(5)		
35.1 I feel close to my friends							
	_	J		J	J		

35.2 I get emotional support from my family					
35.3 I get support from my friends					
35.4 My family has accepted my illness					
35.5 I am satisfied with family communication about my illness					
35.6 I feel close to my partner (or the person who is my main support)					
35.7 I have people to help me if I need it					
Regardless of your current level of sex question. If you prefer not to answer it, p sec 35.8 I am satisfied with my sex life	<i>lease ma</i> tion	rk this bo	x □ and	go to the	next
I 33.0 I AIII SAUSHEU WILII IIIV SEX IIIE					
Q36. The following questions ask about how days. For each question, please mark the box	•		_		
Q36. The following questions ask about how	•		_		
Q36. The following questions ask about how days. For each question, please mark the box	that best All of the	describes Most of the	Some of the	A little of the	d this None of the
Q36. The following questions ask about how days. For each question, please mark the box	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Q36. The following questions ask about how days. For each question, please mark the box feeling. During the past 30 days, about how	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Q36. The following questions ask about how days. For each question, please mark the box feeling. During the past 30 days, about how often did you feel	All of the time (5)	Most of the time	Some of the time	A little of the time	None of the time
Q36. The following questions ask about how days. For each question, please mark the box feeling. During the past 30 days, about how often did you feel 36.1nervous?	All of the time (5)	Most of the time (4)	Some of the time (3)	A little of the time (2)	None of the time
Q36. The following questions ask about how days. For each question, please mark the box feeling. During the past 30 days, about how often did you feel 36.1nervous? 36.2hopeless?	All of the time (5)	Most of the time (4)	Some of the time (3)	A little of the time (2)	None of the time (1)
Q36. The following questions ask about how days. For each question, please mark the box feeling. During the past 30 days, about how often did you feel 36.1nervous? 36.2hopeless? 36.3restless or fidgety 36.4so depressed that nothing could	All of the time (5)	Most of the time (4)	Some of the time (3)	A little of the time (2)	None of the time (1)

Q37. The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate how often you felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly often	Very often
In the last month	(0)	(1)	(2)	(3)	(4)
37.1 How often have you felt that you cannot control the important things in your life?					
37.2 How often have you felt confident to handle your personal problems?			٥		
37.3 How often have you felt that things were going your way?					
37.4 How often have you felt that difficulties were piling up so high that you could not overcome them?					

Q38. Please indicate to what extent each of the following circumstances makes it difficult for you to receive the care, services or opportunities you wish to obtain

	No problem at all	Very slight problem	Some- what of a problem	Major problem
	(1)	(2)	(3)	(4)
38. a) Long distances to medical facilities and personnel				
38. b) Medical personnel (e.g. physicians, nurses), who decline to provide direct care to persons with HIV/AIDS				
38. c) The lack of health care professionals who are adequately trained and competent in AIDS care				
38. d) The lack of transportation to access the services I need				
38. e) The shortage of psychologists, social workers and mental health				

counsellors who can help address mental health issues							
38. f) The lack of psychological support groups for persons with HIV/AIDS							
38. g) The level of knowledge about HIV/AIDS among residents in the community							
38. h) Community residents' stigma against persons living with HIV/AIDS							
38. i) The lack of employment opportunities for people living with HIV/AIDS							
38. j) The lack of supportive and understanding work environments for people living with HIV/AIDS							
38. k) My personal financial resources							
38. I) Lack of adequate and affordable housing							
Q39. Many people find it difficult to take all their HIV medications exactly as prescribed. How many doses of your HIV medication did you miss in the last 7 days? (Number of doses)							
Q40. What percentage would be your best guess		•	-				
medication you have taken in the last month? We would be surprised if this were 100% for							
most people(%)							
Examples:							
- 0% means you have taken no medication							
- 50% means you have taken half your me		our modice	tion				
- 100% means you have taken every single dose of your medication							

Q41. The following questions ask about situations that could occur during your treatment for HIV. Treatment can involve different things for different people. Sometimes this might refer to taking medications, and other times it could refer to other things that you do to deal with HIV such as diet and exercise or taking vitamins. So, when these questions ask about your 'treatment' or your 'treatment plan', we are talking not only about any medications that you might be taking for your HIV, but also other things that make up your self care. For the following questions, please answer for the last month, including today, how confident you have been that you can do the following things. Use a response scale ranging from 0 ('cannot do at all') to 5('moderately certain can do') to 10 ('completely certain I can do').

- a. Stick to your treatment plan even when side effects begin to interfere with daily activities
- b. Integrate your treatment into your daily routine
- c. Integrate your treatment into your daily routine even if it means taking medications or doing other things in front of people who don't know you are HIV-infected
- d. Stick to your treatment schedule even when your daily routine is disrupted
- e. Stick to your treatment schedule when you aren't feeling well
- f. Stick to your treatment schedule when it means changing your eating habits
- g. Continue with your treatment even if doing so interferes with your daily activities
- h. Continue with the treatment plan your physician prescribed even if your t-cells drop significantly in the next 3 months
- i. Continue with your treatment even when you are feeling discouraged about your health
- j. Continue with your treatment even when getting to your clinic appointments is a major hassle
- k. Continue with your treatment even when people close to you tell you that they don't think that it is doing you any good
- 1. Getting something positive out of your participation in treatment, even if the medication you are taking does not improve your health

Q42. Please respond to each of the following items in terms of how true it is for you with respect to dealing with your HIV

Use a response scale ranging from 1 to 7 (1 = not at all true, 4 = somewhat true, 7 = very true)

- a) I feel confident in my ability to manage my HIV
- b) I am capable of handling my HIV now
- c) I am able to do my own routine HIV care now
- d) I feel able to meet the challenge of controlling my HIV

Q43. Overall how useful was the support or information you received during the positive							
talk for positive health telephone sessions?							
 Very useful Fairly useful Not very useful Not at all useful Don't know 	(1) (2) (3) (4) (5)						
Q44. How has your participation in the positive talk for positive health support service changed things, to what extent do you?							
	To a large extent	Somewhat	Not at all	Don't know	This was not a problem for me (N/A)		
a) Feel better informed							
b) Feel less isolated							
c) Feel more confident							
d) Feel more able to make changes in my life							
e) Feel more able to take my medication as prescribed							
0.4% x0.1:			1.1				
Q45 . If this service were to be available in the future, would you recommend the positive talk for positive health support service to other people living with HIV?							
YesNoUnsure	(1) (2) (3)						

Pharmacy servicesOther (please specify)

		he positive talk support caller who conducted your sessions on
the follo	owing issues?	
How su	pportive was your pos	sitive talk support caller?
-	Very supportive	(1)
-	Quite supportive	(2)
-	A little supportive	(3)
-	Not at all supportive	(4)
Q47b. I	How able were they to	o offer information or advice about the issues you raised?
_	Very able	(1)
	Quite able	(2)
	Somewhat able	(3)
-	Not at all able	(4)
O49 In	41	recorded contact with one HIV/AIDC related argonizations?
		you had contact with any HIV/AIDS-related organisations?
	Yes (1) No (2)	
	\ \	ent in these organisations? (tick as many as apply)
	I am an employee	ent in these organisations: (tick as many as appry)
	I am a member	
	I am a client/use their	r services
	I receive newsletters	
	Access information of	
	I am a volunteer	
		nisation(s) do you have contact with?
		· · · · · ·
O51 D1		64. 6.11
		f the following services you have used through HIV/AIDS-
	organisations in the la Treatments advice	IST IIIOIITII
	Counselling	
	Financial assistance	
	Financial advice	
	Legal advice	
	Peer support	
	Social contact with o	ther PLHIV

Appendix F: Exit Survey

Positive Talk for Positive Health – Exit Survey

	Attempt Time of call	Finish	Call Length	Code *	Comment
		Finish			
Day	call				
<u>/</u>		time			
	nade to I One One One One	e every to e	nost helpf week fortnight three wee	ul for po	be run in the future, how often do you think support calls should beeple? (1) (2) (3) (4) (5)
Qu2	- Too - Too - Abo	long short out right	vould you		ribe the average length of the telephone support sessions? (1) (2) (3) (4)
Qu	- Ver	i) How e y easy ually eas easy		ou find	d scheduling calls at a time that suited you?
		l) Are th	ere any p	particula	ar topics or information that you would have liked to be included i

Qu5a. (CHCE) To	what extent did the tele	lephone support sessions address your needs?
- To son	ne extent (ry much ((1)(2)(3)(4)
Qu5b. (OPEN) Are	there any needs in pa	articular that the sessions did address well?
Qu5c. (OPEN) We	re there any needs in լ	particular that were not addressed well?
Qu6a. (CHCE) Hov	พ appropriate do you fe	feel the positive talk support service was for your situation?
- Fairly a - Not ve	ppropriate appropriate ry appropriate all appropriate	(1) (2) (3) (4)
* If Qu6a = 1 go to * If Qu6a = 2, 3, or		
Qu6b. (OPEN) Wh	y do you think the serv	vice was not really appropriate to your situation?
Qu7. (OPEN) Is the	ere anything that you v	would identify about the telephone service that was positive?
Oue (CHCE) Moot	t poople talk to more th	han and support caller during the program do you believe
		han one support caller during the program, do you believe have had the same caller to be speaking with each time?
- Slight	nt callers is fine preference for same ca preference for same c	
Qu9. (OPEN) Is the	ere anything you would	d identify about the caller(s) you spoke to that was positive?
Qu10. (OPEN) Is to good?	here anything that you	would identify about the telephone service that was not so

82

PILOTING A TELEPHONE SUPPORT SERVICE

End survey

Appendix G: Follow-up Survey Participant Program Comments

'Thank you for taking the time to see how I am travelling.'

'Please could there be more programs in the rural for social isolation and stigma.'

'Enjoyed talking to callers as they were friendly and supportive.'

'Thanks guys. Doing a great job. Much appreciated.'

'It was a beneficial course to do. Even though I felt already informed it updated the information I had regarding HIV/AIDS treatments in the Newcastle area.'

'I enjoyed receiving the calls as the information helped me with ways I could help myself in my life. Very useful service and convenient'

'I would do it again, I hope it will continue'

'Service was good but a consistent referral service with HIV would be good around meds, doctors, nutrition.'

'It was a fantastic program and I would participate in it again.'

'Great program'

'I think this was a program that should be continued as many people don't share this sort of information with others and it's good for learning. The calls were just great and I commend all the staff working in the program.'