Pragmatic, consensus-based minimum standards and structured interview to guide the selection and development of cancer support group leaders.

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Contents

Abstract

Across the globe, peer support groups have emerged as a community-led approach to connecting people with cancer experiences and accessing support. Members of cancer support groups seek to help themselves and each other to reduce the negative or disabling effect that cancer may have on general health, relationships, coping, and daily functioning. With no centralised registry, the number of cancer support groups is unknown but thought to be considerable.

Peak cancer agencies have established relationships with support groups, in an effort to strengthen and sustain delivery of peer support. Agency funding, training, resources, and support staff are extended to groups, with the group leader being the primary recipient and point of contact. Group leadership is usually provided voluntarily by people with a personal experience of cancer. Challenges have been reported in maintaining group leaders' quality of life and preventing burn-out. The ability of an individual to function in the role and maintain this role over a period of time is important for group sustainability. However, little is known about the essential qualities required to lead a cancer support group, or how to determine a person's suitability for the role.

Initial scoping of the literature revealed the lack of a relevant role analysis and no accurate synopsis of the basic knowledge, skills, and attributes required for the group leader role. There are no published guidelines, standards, or tools to guide selection and development of peer support group leaders. This project aimed to generate pragmatic, consensus-based minimum standards for the cancer support peer group leader role, and to develop a structured interview and user manual to guide the selection and development of cancer support group leaders. The interview

was anchored in a comprehensive role analysis and validities were maximised by increasing structure in process and use of the interview data.

Following a systematic review of research relevant to the desirable qualities for support group leaders, an online Delphi study was used to reach expert-consensus on the 52 knowledge, skills, and attributes considered essential for cancer support group leaders. These 52 requisite knowledge, skills, and attributes describe the minimum standards for the role, and were used to develop the structured interview. The structured interview and accompanying user manual were piloted for aspects of clinical utility and determined to be appropriate, accessible, practical, and acceptable for use by cancer agency workers. The structured interview was field tested with 63 current support group leaders to determine a potential cut-off score for selection of group leader's suitability. However, a more comprehensive pool of participants and scores are required to determine reasonable cut-off scores. This PhD project used pragmatic, novel, and robust methods to respond to a real-world problem. Our study outputs are a first in the field, with scope for future research and development to apply the structured interview more broadly.

Declaration

I, Amanda Kay Pomery, declare that this thesis;

1. Comprises only my original work towards the Doctor of Philosophy except where indicated in the preface
2. Due acknowledgement has been made in the text to all other material used
3. This thesis is fewer than the maximum word limit of 100,000 in length, exclusive of tables, bibliographies and appendices.

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Amanda Kay Pomery

February 2018

Preface

This thesis is written as a “Thesis with Publications” in accordance with the Graduate Research Training Policy of The University of Melbourne. All the work presented henceforth was conducted during my candidature and in fulfilment of requirements of the Doctor of Philosophy. All projects and associated methods were approved by Melbourne School of Psychological Sciences, Department Human Ethics Advisory Group, The University of Melbourne (Minimum Risk Approved 1443027.1, Appendix 1) and in consultation with my appointed Advisory Committee and Supervisors. An amendment to the application was submitted to remove reference to proposed audio recordings of the field test interviews and approved in August 2016 (Minimum Risk Approved 1443027.2, Appendix 2).

Declaration for a thesis with publication forms and co-author authorisation forms have been uploaded with this thesis submission. Research publications are contained within the thesis in Chapters 4, 5, 6 and 8. I was the lead investigator, responsible for all major areas of concept formation, data collection and analysis, as well as manuscript composition. Professor Schofield, Associate Professor Gough, and Associate Professor Xhilaga. were supervisory authors on this project and were involved throughout the project in concept formation and contributed to manuscript feedback and edits. Associate Professor Gough was also involved in concept formation, analysis and manuscript composition. Sponsorship was provided by Prostate Cancer Foundation of Australia.

Acknowledgements

In 2012, I began working for the Prostate Cancer Foundation of Australia, in a role working directly with support group leaders which exposed me to the impact support groups can have during the cancer experience. Without any recommended structure or guidelines, I, along with my professional colleagues, was unsure how to implement a practice to best meet the needs of the community. Hence, this project was conceived out of desire to improve the quality of support provided in groups. My aim was to contribute to the field in a small way and hopefully develop a supportive framework, based on which cancer support agencies can adopt in a collaborative and unified manner.

Undertaking this project has been an extremely rewarding experience, based on the wonderful personal and professional support I have received. Firstly, my appreciation to Prostate Cancer Foundation of Australia and Associate Professor Anthony Lowe, for sponsoring me and allowing my professional role and research study to entwine. Thank you to Associate Professor Miranda Xhilaga, for your mentorship and vision for me to undertake this academic process. Thanks to Professor Penny Schofield, for trusting my commitment to the project and passing on your valuable experience. A huge thank you to Associate Professor Karla Gough, for your generosity of time, expertise and kindness you have shown me throughout.

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and Breast Cancer Network Australia. A big thank you to the cancer support group managers and support group leaders who kindly gave their time to participate in the project. Finally, I would like to express my gratitude to my family for their ongoing love and support.

1 THE RESEARCH PROBLEM

1.1 Chapter overview

Cancer is set to become the major cause of morbidity and mortality in the next few decades in every region of the world (Jemal, 2014) . In Australia, a rapid increase in the number of people living with a cancer diagnosis is expected and will require management strategies similar to those of a chronic condition. Currently, there is high demand for multi-layered cancer care with limited resources (Hutchison, Steginga, & Dunn, 2006; Porter & Lee, 2013). Peer support groups are considered to be an underutilised community-based resource that can be of benefit to those who choose to access them (Docherty, 2004; Ussher, Kirsten, Butow, & Sandoval, 2006; Yaskowich & Stam, 2003). Inconsistencies exist in how cancer agencies work with support groups in the community. Group leaders play a key role in offering support to group members, but little is known about the qualities required for the role. There are no recommendations in regards to who should be encouraged or trained to be a peer support group leader.

In response to these issues, this PhD study was undertaken to develop a systematic and acceptable process for selection and development of cancer support group leaders that would be valid in a community setting. This first chapter describes key factors impacting cancer survivorship, emergence of cancer support groups as a way for people to access community-based support, and the central role of the group leader. This chapter also outlines the research aims, thesis structure, and study scope for this PhD thesis.

1.2 Cancer incidence is increasing

With one in three people directly affected by cancer, the disease is one of the world's most pressing health concerns, killing over 8 million people per year – more than HIV/AIDS, Malaria, and TB combined (Jemal, 2014). Cancer is estimated to cost world economies as much as US$1.6 trillion annually (Union for International Cancer Control, 2014), and this cost is expected to grow exponentially if no action is taken to reduce the impact on both individual and broader healthcare budgets.

Furthermore, the global population is growing and aging, and the incidence of cancer is known to correlate with age (Balducci & Extermann, 2000; Eakin et al., 2006). New cancer cases are expected to reach 22 million in 2030, with up to 75 million people living with cancer (Jemal, 2014). The United Nations has set target goals focused on sustainable development to invest in non-communicable diseases, specifically cancer. To address these goals, good health and wellbeing, sustainable cities and communities, as well as partnerships have been outlined as broad strategies to increase the number of people with access to quality cancer treatment and supportive care services.

In 2017, it was estimated that there were 134,174 new cancer cases diagnosed and 47,753 deaths from cancer in Australia, with approximately 410,530 people living with cancer (Australian Institute of Health and Welfare, 2017). Survival rates have improved due to increased early detection and better access to effective treatment in high-income countries (Holland, 2003; Institute of Medicine and National Research Council, 2006). Importantly, this improvement in survival rates has meant that cancer is now considered a chronic condition (McCorkle et al., 2011). This is a significant change in a condition that was previously considered fatal.

1.3 Cancer survivorship: multiple factors influence how an individual copes

Change in the cancer landscape has led to an increase in the continuum of cancer care widely known as cancer survivorship. There are many definitions of cancer survivorship, with the most inclusive term defined as extending from diagnosis until death (Institute of Medicine and National Research Council, 2006). This results in more people living with cancer and has also changed the language applied to describe the experience from ‘patient’ to ‘survivor’ (Institute of Medicine and National Research Council, 2006).

The term cancer survivorship therefore represents the living of life after a cancer diagnosis, encompassing a complex interaction of the physiological, social, and psychological effects of the disease (Bloom, 2002; Institute of Medicine and National Research Council, 2006). This is a continuous and dynamic process resulting in high levels of uncertainty for the individual (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003). With more people now living with cancer as a chronic illness, consideration needs to be given to how we improve care for those impacted (Miller, 2010). Additionally, despite increasingly successful outcomes, cancer remains one of the most feared illnesses (Rasmussen & Elverdam, 2007; Tritter & Calnan, 2002), and survivors can experience mechanisms of stigma similar to HIV/AIDS (Fife & Wright, 2000). This fear and stigma sets cancer apart from other chronic conditions.

Cancer presents many people with a major life stress. An estimated one-quarter of people with cancer have depression (Mitchell et al., 2011). A study of older long-term cancer survivors revealed that approximately 25% of these patients presented with clinical levels of depression regardless of type of cancer, ethnicity, or

gender (Deimling, Kahana, Bowman, & Schaefer, 2002). Most patients affected by depression acknowledge that they have a need for support; however, the degree and type of support required can vary between social, interpersonal, or therapeutic support (van Beljouw et al., 2010). This indicates the relevance of a tiered model of support for cancer patients. Psychological issues such as mood disorders, anxiety, and fear of recurrence of cancer can place a heavy burden on the individual's psyche and those with whom they are in a close relationship (Allen, Savadatti, & Gurmankin Levy, 2009; Bloom, 2002). In addition, quality of life is often affected and influenced by other factors such as: treatment received, disease stage, comorbidities, and psychological characteristics of the individual (Miller & Massie, 2006). Therefore, how one copes with cancer can vary considerably, and is reflective of the individual's adaptation skills, emotional development, previous grief/loss, cognitive flexibility, locus of control, and spiritual beliefs (Miller & Massie, 2006; Zebrack, 2000). Social and external factors also have a role in providing individuals with support and facilitating coping (Zebrack, 2000). A large variation in these factors and many others results in unique experiences for every person diagnosed with cancer.

1.4 Cancer survivorship after treatment

For many cancer survivors, the time after treatment is reported to be more challenging than the treatment itself (Institute of Medicine and National Research Council, 2006). Reportedly, this is due to survivors needing to cope with the effects of cancer and the changes in support they receive. During treatment, patients are surrounded by health care professionals, but this level of contact stops once treatment ends. This can leave many patients feeling alone as they re-enter their lives post-treatment, deal with possible survivorship issues, and experience the

stress of day-to-day living. Many survivors are unaware of the issues they may face following treatment. In particular, reintegrating socially into society can be challenging; changes to roles and relationships can become concerning to the individual, with the realisation that things are not “back to normal” as was expected (Jefford et al., 2008). Many survivors describe feeling isolated, different, and unable to emotionally relate to others (Jefford et al., 2008). However growing evidence shows psychosocial support may reduce such stresses and improve quality of life for cancer survivors (Spiegel, 2011). An additional challenge throughout cancer treatment and recovery is the need to come to terms with many associated losses. These can include the loss of a job, physical comfort (i.e. loss of hair, pain, or loss of limbs), personal control, relationships, fertility, sexual functioning, and financial security (Bloom, 2002; Harpham, 1999).

Interestingly, some cancer survivors report beneficial changes. These changes include a sense of purpose and/or appreciation of life, creating a positive change of perspective (Alfano & Rowland, 2006). Many survivors have also reported a new found understanding of how precious life is, leading to revised priorities and changes to lifestyle, values, and connection to spiritual aspects (Alfano & Rowland, 2006; Jefford et al., 2008; Reuben & Leffall, 2006). Whilst each individual may experience cancer differently, there are important factors that play a role in how survivors experience quality of life. Location of residency, social support, access to health care, ethnicity, social-economic status, transportation, lifestyle, and cultural differences all have an impact on how one experiences and survives cancer. The variability experienced by patients indicates that one model of support would not be suitable for all.

1.5 Importance of psychosocial care in cancer survivorship

In the absence of a cure, effective and holistic chronic disease management must be addressed for those impacted by cancer. There is a clear need for improved outcomes that matter to patients and survivors relative to the cost of achieving those outcomes (Porter & Lee, 2013). The importance of psychosocial care as an integral part of oncology care has been well described (Holland, Watson, & Dunn, 2011). The focus has now shifted towards meeting the needs of patients and families across the health trajectory (Chambers et al., 2013).

There is a wealth of literature on how to identify and address the psychological needs of cancer patients in different contexts. However, published guidelines are limited (Surbone et al., 2010) and, given the significant variations between survivors both within and between countries, the implementation of a one-size-fits-all approach to psychosocial care is inadequate. Therefore, there is a need to evaluate models that can more easily be absorbed and integrated in diverse, local, and real-world settings, especially if we take into consideration the scarcity of health resources (Surbone et al., 2010). Some countries have developed clinical practice guidelines and standards to guide such care in adults with cancer (National Institute for Health and Care Excellence, 2013; Turner et al., 2005); with survivorship guidelines emerging with a psychological focus (Ligibel & Denlinger, 2013). In the UK, the National Institute for Health and Care Excellence (NICE) (2013) provided guidance on cancer services for improving supportive care, with emphasis placed on addressing the quality of life of individuals with cancer and their families. The International Psycho-Oncology Society developed an International Standard of Quality Cancer Care, which has subsequently been endorsed by the Union for International Cancer Control. These guidelines and statements provide support for

health service providers to ensure that psychosocial care is an integral part of the care plan; that care provided is evidence-based and targeted to the unique needs of the individual.

1.6 Demand for individualised cancer care

Cancer survivors have diverse psychosocial needs, which vary over time, and are influenced by life stage, gender, age, and background. This suggests that delivery of care should vary depending on the level of need. As such, a tiered model of psychosocial care with a multi-disciplinary approach that utilises services in partnership across both community and acute settings is essential (Hutchison et al., 2006). Health care systems are struggling with rising costs, and unsatisfactory and uneven quality of cancer care, with the greatest impact felt within low income countries (Porter & Lee, 2013). Hence, countries least equipped to respond to the financial and human impact of cancer have to manage this alongside significant public health and urban sustainability challenges. Cost and access to services should be a key consideration in care planning, with importance placed on strengthening the most basic universal care. A basic care level includes: patient health education, support to validate the emotional experience and allow expression, advice for practical concerns, peer support that may be in a group setting or one-to-one, physical activity and exercise, along with screening and referral. Peer support groups are therefore a prime example of a cost effective community service that could exist within a tiered model of care.

Based on current evidence and best practice, universal care should be offered and available to those experiencing cancer which then lays the foundation of care for more in-depth interventions for those with higher distress or needs. In order to adapt

the tiered model to a given setting, oncology and supportive care professionals need to shift from identifying the needs of the patient to a solution-based approach for people and to explore services provided by communities (Hutchison et al., 2006).

1.7 Universal care via support groups: what is the model?

There is considerable variation in the literature as to the definition of a support group. The terms support, treatment and self-help group are often used interchangeably (Gottlieb & Wachala, 2007; Herron, 2005; Scheidlinger, 2004). References to support groups suggest face-to-face meetings of a small number of people who share a common affliction, habit, disease, or stressful life event. Interestingly, this format is rapidly evolving to include online support groups and larger online communities (Lieberman, Wizlenberg, Golant, & Di Minno, 2005). The term can be applied to groups that vary in structure, duration, leadership, content, and activities (Gottlieb & Wachala, 2007).

Three categories of support groups are outlined by Cella and Yella (1993): 1) self-help groups, 2) professionally led psychosocial support groups, and 3) psychotherapeutic groups. Within the context of psychotherapy groups, the emphasis is on personal exploration in the context of group interaction with the goal of positive change and improved functioning for the individual. In comparison, the main purpose of support groups and self-help groups is to provide social support, with the aim of assisting participants to find a sense of belonging and meaning rather than changing them. Peer-based support groups aim to provide a safe place to connect and share with others who have been or are going through a similar experience (Davison, Pennebaker, & Dickerson, 2000). Peer groups adopt certain aspects of psychotherapeutic and education programs, but should not provide

therapy or education. The main characteristic that helps to define the type of group is the leadership of the group (Schopler & Galinsky, 1993). Leadership of groups is therefore different, with trained professionals leading psychotherapy groups, self-help groups having no appointed leader, and support groups having a designated leader, normally a peer, who adopts a non-authoritarian role within the group (Cella & Yellen, 1993). However, it is unclear how support group leaders are designated to the role.

1.8 Application of support groups to cancer

Support groups have been applied to diverse issues from health-related issues (e.g. weight management, substance abuse) to chronic conditions (e.g. diabetes, stroke, and cardiac issues), along with AIDS and cancer where the stage of disease impacts on whether the condition is treated as chronic or life threatening. Yalom (1995) described support groups as an effective support for those with chronic illness and therefore of growing relevance to the management of cancer survivorship. Groups may complement individual treatment and are a cost-effective means of delivering support within the broader health care system.

Owen et al. (2007) reviewed a large data set from the California Health Interview Survey Complementary and Alternative Medicine study (participants totalled 9187 including 1844 cancer survivors, 4951 non-cancerous chronic conditions, and 2392 non-chronic conditions). Study investigators conducted computer-assisted telephone interviews in English, Spanish, Korean, Cantonese, and Mandarin with an overall response rate of 77.3%. The study assessed the population-level use of health-related support groups among cancer survivors compared to survivors with and without chronic conditions. Results provided

evidence that characteristics associated with the use of health-related support groups were found to be similar for cancer, non-cancer, or other chronic conditions. Interestingly, cancer survivors made greater use of community-based support groups and were more likely to have used support groups in the last year than healthy participants or those with another chronic health condition (Owen et al., 2007). Additionally, self-reported physical health was not found to be associated with the likelihood of support group participation among cancer survivors. Owen et al. (2007) go on to suggest that “support groups have relevance to cancer survivorship regardless of the extent to which their health is impacted by their cancer” (p.2587).

1.9 Accessing cancer support groups

Assistance in identifying and accessing support groups as a standard of care for all patients receiving curative, follow-up, or palliative care for cancer has been suggested (Owen et al., 2007). However, physician referral or lack thereof (Gray, Fitch, Davis, & Phillips, 1997a; Owen et al., 2007; Steginga et al., 2007) indicate a current disconnect between patient care in the health centre and broader support services of support groups in the community. Identification of cancer support groups is also challenging, with no known registry for cancer support groups available nationally or internationally. This means that the number of support groups in operation is unknown but thought to be considerable. For example, within Australia, a scoping study conducted by Cancer Council Australia, reported approximately 600 cancer support groups were in operation across the country (Herron, 2005).

Although a current report is not available, a basic web-search of peak cancer bodies that recognise, or affiliate with, community-based support groups indicates a large number of active support groups both in Australia and globally. For example,

Macmillian Cancer Support in the UK is linked to over 900 support groups. For tumour specific support groups, Prostate Cancer UK have links to 128 support groups, and Prostate Cancer Foundation of Australia currently reports 170 plus affiliated support groups. Within Australia, general cancer support groups are reported to be the most common type of support group, followed by breast and prostate cancer support groups (Herron, 2005). This is consistent with the types of cancer most commonly diagnosed and their survival rates. It is considered that support groups may currently be an under-acknowledged and under-developed resource in public health.

1.10 Emergence of cancer support groups

In response to the need for support during the lived experience of cancer, support groups have developed somewhat organically over time and make up part of the broader category of self-help groups. Support groups for cancer patients were first reported in the 1970's (Fobair, 1997a) and are considered to be a particularly useful intervention. Many people turn to support groups in their local community to better cope with the emotional and practical challenges of their disease during and after cancer diagnosis and treatment (Barg & Gullatte, 2001; Bell, Lee, Foran, Kwong, & Christopherson, 2010; Davison et al., 2000). To reduce the negative or disabling effect that cancer may have on general health, relationships, coping abilities, and daily functions, members of cancer support groups not only seek to help themselves but also each other.

The motivations and experiences of cancer survivors, specifically Australian prostate cancer survivors, in forming community-based support groups has been reported (Dunn et al., 2017) to also be in response to a lack of psychosocial

oncology care and to have characteristics of an Embodied Health Movement framework. However, whether emerging support groups constitute a *movement* requires further investigation in other locales. This notion is not supported in other contexts (Oliffe, Gerbrandt, Bottorff, & Hislop, 2010; Oliffe et al., 2008) and hence such investigation would help to elucidate the role of culture, class, and gender in why support groups are formed.

1.11 Benefits of cancer support groups

The benefits of participating in common medical disease support groups including cancer, has been assessed previously (Docherty, 2004; Ussher et al., 2006; Yaskowich & Stam, 2003). Benefits reported by participants include: receiving information about their disease and treatments, obtaining emotional support, and learning how others have coped with management of the condition. Additionally, patients reported how support groups helped foster a sense of community, create hope for the future, and decrease feelings of isolation. Evidence suggests that there are psychological benefits to attending a cancer support group, including reduced levels of depression for both the patient (Montazeri et al., 2001) and their carers (Bultz, Speca, Brasher, Geggie, & Page, 2000), along with enhanced coping (Fawzy et al., 1990) and increased quality of life (Vakharia, Ali, & Wang, 2007). Benefits of support groups however, are unlikely to extend to increased cancer survival based on findings of a large randomised controlled trial (Kissane et al., 2007) and a systematic review (Coyne, Stefanek, & Palmer, 2007).

Ussher, Kirsten, Butow & Sandoval (2006) examined what cancer support groups specifically provide that other supportive relationships do not. The study consisted of observation, focus group interviews, and analysis grounded in

positioning theory. It used data obtained from 93 interviewees (women n=75; men n=18) representing nine Australian cancer support groups. Support groups were positioned as providing a unique sense of community, unconditional acceptance, and information about cancer and its associated treatments, in contrast to experiences outside the group. Importantly, support groups offered increased empowerment and agency, which at the same time facilitated positive relationships with family and friends by lessening the burden.

A sense of empowerment, hope, and confidence in attendees of cancer support groups has been related to other study findings (Gray et al., 1997a; Mok, Martinson, & Wong, 2004) and is thought to be of particular relevance with managing the long-term burden of survivorship. Loss of control following a cancer diagnosis has been commonly reported (Gray, 1991). Hence, intervention that can increase empowerment and feelings of control could potentially be of significant benefit to people with cancer (Ussher et al., 2006). Indeed, support groups have been thought to facilitate greater participation in community life (Gray, Fitch, Davis, & Phillips, 1997b) and interconnectedness with others (Mok & Martinson, 2000). Interestingly, both professionally trained and peer group leaders were positioned as playing a significant role in this constructed community, with no differences reported across leader type. Leaders provided personal support, modelling ways of coping, and facilitating an open and caring atmosphere with availability outside of the group.

1.12 Composition of cancer support groups

Background information on support groups is limited, however, Stevinson, Lydon, Amir (2010) found groups to be mostly inclusive in membership, welcoming anyone affected by cancer and recognising the positive involvement of partners and family

members (Docherty, 2004; Ussher et al., 2006). Groups were found to run for extended periods with an average of approximately 10 years. Average attendance at meetings was reported to be 19 group members. This was consistent with the findings of Butow et al. (2007) that showed 50% of participants thought 9-15 people to be the ideal number per group. Closed, time-limited, highly structured cancer support groups generally tend to be considered the “gold standard” in the field of psychosocial oncology, and by social workers, and psychologists. However open-ended, drop-in support groups tend to be more feasible for patients in a community setting due to the flexibility they offer (Fobair, 1997a). Studies considering the different compositions of cancer support groups, have found that there is no “ideal” group that produces optimal outcomes (Bell et al., 2010; Butow et al., 2007) nor is there a formula to attract a diverse audience. Thaxton et al. (2005) also noted that an overarching template should not be developed for cancer support groups.

Because the nature of support cannot be standardised among all support groups, it is thought that members of different groups may receive varying levels of benefit. Alternative ways need to be explored as to how support offered in groups can be standardised without imposing structure or templates onto the group format. The key component of the cancer support group may be the group leader (Butow et al., 2006; Lieberman & Golant, 2002; Sherman et al., 2004), and this role may present an opportunity for standardisation.

1.13 The support group leader role

Herron (2005) broadly defines a leader or facilitator as an individual who leads support group meetings, who may be trained or untrained, and who may be a cancer consumer or health professional or both. Support groups can be offered by the

healthcare system and delivered by professionals with knowledge of the specific disease or condition. Health professionals who are group leaders are largely social workers, psychologists, and nurses (Herron, 2005). However, more often than not, group leadership is provided voluntarily, mostly by those with a personal experience of the central topic or issue to the group. These leaders may be experienced patients, experienced carers, or community members. Peer-led support groups are a less resource-intensive alternative, with the potential to reach more people affected by the disease in the community (Gray, 2001). An important distinction is that a peer-led group can also provide the added benefit of having a leader who may share experiences with group members.

In 2005, Herron reported an approximately even number of Australian peer and professional group leaders, with 245 support groups peer-led and 253 groups professionally-led. In 2006, Kirsten et al. reported that of 173 active support groups, 61% were facilitated by a health professional (i.e. social workers, psychologists, nurses), some of whom also had a personal history of cancer. However, these figures are clearly out of date and suspected to be inaccurate. The lack of a cancer support group registry or comprehensive data means that background, characteristics, or experience of current support group leaders in Australia is largely unknown.

Stevinson, Lydon & Amir (2010) investigated the provision of support groups for cancer survivors in the United Kingdom, specifically the differences between professional and peer-led groups. A study of 315 participants, of which 72.1% were peer leaders and 27.9% health professional leaders, showed no differences in the number of years of experience leading a support group and previous support group training. Instead, peer-led groups were more likely to be run by a committee and

provide additional activities, than professionally led groups. More professional leaders perceived a need for training than peer leaders, despite similarities in the type of training desired. Similarly, Ussher et al. (2006) found no differences between professionally led and peer-led support groups with both types of leaders playing a significant role in the group.

Peer-group leaders are typically self-selected and motivated by the desire to help others and give back to the community (Zordan et al., 2015). Research indicates that experienced patients and carers also lead support groups to achieve mastery over their own cancer experience, re-frame a difficult life experience into something positive, and learn more about coping with the illness (Remmer, Edgar, & Rapkin, 2001). Within Australia, increased survivorship coupled with longevity has resulted in increased numbers of retirees, of whom some may choose to become involved in volunteer work (Hainsworth & Barlow, 2001) and as a result place themselves into a support group leader role that they may know very little about (Zordan et al., 2010). In short, there is no process for group leader selection to be found in the literature.

Literature identifies the group leader as a pivotal role for the group (Butow et al., 2006; Kirsten, Butow, Price, Hobbs, & Sunquist, 2006; Ussher, Kirsten, Butow, & Sandoval, 2008), however, challenges have been reported in burn out and maintaining quality of life in group leaders who are mainly volunteers, often with a diagnosis of cancer themselves. The ability of the individual to function within the role and maintain this role over a period of time is important for group sustainability (Zordan et al., 2010). However, little is known about the essential qualities of group leaders, the effects of leader behaviour on cancer support group members, or how to determine a person's suitability for the role.

1.14 Approaches to improving support group leadership

Based on professional group facilitation theory and principles, literature has recommended training group leaders as a way to support people in the role (Butow et al., 2006; Egan, 2002; Hermann, 2002; Klein, 2000; Nichols & Jenkinson, 2006; Zordan et al., 2010). However, there is currently no sufficient evidence to show the benefit of cancer support group leader training (Delisle et al., 2016). Zordan et al.,(2015) reported on the only randomised control trial (RCT) to be conducted on cancer support group leader training and identified issues relating to methodology applied, engagement, and lack of basic understanding by participants. Anecdotal reports by cancer agency workers raised concern that despite incorporating delivery or access to training for group leaders, some leaders remained inappropriate for the role.

1.15 What is currently needed?

Psychosocial support is already taking place in communities across the globe through peer-led cancer support groups. Although not suited to all, many people who go through a cancer experience choose to access this form of support. Whilst being cognisant of the general structure or framework with which support groups run, cancer agencies need to assist but not control support groups. Literature indicates that the role of the group leader is pivotal and can provide an avenue through which to maximise support offered to the group.

Investigation into training development and effectiveness, before determining what makes someone suitable for the role, appears premature. Unlike professional group facilitators who undertake training, the initial step of ‘selection’ for the role has not been undertaken for cancer support group leaders. In fact, little is known about the essential qualities required for the role. There are no published guidelines,

standards, or tools to guide the selection and development of leaders for cancer agencies to follow. Organisations providing assistance to cancer support groups and their leaders therefore require role specific information and standards to inform the selection of leaders and the development of program support. Establishing a process of identifying suitable leaders and determining preparedness for the role prior to commencement may decrease the likelihood of negative experiences for both the leader and group members.

1.16 Research aims

As support groups operate in a community context and the leader role is mainly occupied by peer volunteers, a pragmatic approach is imperative to the usefulness of any study outputs for cancer agencies. This PhD aims develop standard processes to improve the selection of peer group leaders. More specifically, this PhD aims to:

1. Identify and summarise literature describing qualities of cancer support group leaders
2. Identify minimum and best-practice standards for the role of a cancer support group leader
3. Produce, in draft form, a structured interview designed to assess the knowledge, skills, and attributes of individuals who seek to undertake the cancer support group leader role
4. Produce, in draft form, a user manual to facilitate standard delivery of the structured interview
5. Pilot test the structured interview to appraise aspects of clinical utility including usability and acceptability to end-users

6. Field test the structured interview and use results to establish a rational scoring model and produce preliminary data on the knowledge, skills, and attributes of current cancer support group leaders
7. Disseminate guidelines and minimum standards to audiences in academia and cancer agencies for uptake
8. Have an accessible study protocol to facilitate knowledge transfer and assist others to further develop the structured interview.

We aim to generate three main study outputs:

1. Pragmatic, consensus-based minimum standards for the role of a cancer support group leader
2. A structured interview to guide cancer agencies involved in the selection and development of support group leaders
3. A user manual for cancer agency workers conducting the structured interview.

Four mixed-method studies were undertaken to achieve these aims. These four studies were: a systematic literature review, an online reactive Delphi study, a pilot study, and a field test. These studies, and how they relate to the PhD aims, are described in more detail in section 1.17 below.

1.17 Thesis structure

This PhD was successive in nature, with findings from one stage informing content of the next.

Chapter One of this thesis has provided some background, and framed the research problem and research aims.

Chapter Two provides an overview of the literature with background information relevant to cancer support groups and group leaders. The aim of Chapter Two is to describe how cancer support group leaders have been previously investigated or referred to in the literature.

Chapter Three describes how our study design for the entire project had a pragmatic framework and was tailored to meet the contextual demands relevant to the subject through consultation, consensus, and clinical utility.

Chapter Four describes the protocol that was used to guide all of the studies completed within this PhD. By detailing this protocol in full, this chapter describes the mixed methodology approach and how it was applied to meet the necessary objectives for each study. A peer-reviewed published paper of this protocol is included in Chapter Four. Additional detail has also been provided in the chapter to explain how the structured interview was developed and how it addressed the key components of structure.

Chapter Five describes the systematic literature review that was undertaken to identify initial content relevant to the role of support group leader. This systematic literature review, and the qualitative synthesis of results, revealed the specific knowledge, skills, and attributes important to the support group leader role. These knowledge, skills, and attributes were then grouped into seven major themes or qualities. A peer-reviewed published paper of this systematic literature review is included in Chapter Five.

Chapter Six describes the development of pragmatic, consensus-based minimum standards for the role of a cancer support group leader. An online reactive Delphi study was undertaken with an expert panel to determine consensus. Results

were used to identify the requisite knowledge, skills, and attributes for the role, and to draft components of content and evaluation for the structured interview. A peer-reviewed published paper of this Delphi study is included in Chapter Six.

Chapter Seven describes the development of the structured interview and user manual for cancer agencies to use for the selection and development of cancer support group leaders. Literature on structured interview development is reviewed, with a definition of each component of structure outlined. Components are divided into two categories: components that influence content structure of the interview, and components that influence the evaluation process.

Chapter Eight describes how the structured interview and user manual were tested for clinical utility relating to appropriateness, accessibility, practicality, and acceptability by users. Secondly, field test results are described and provide a summary of support group leader characteristics and how suitability of potential cancer support group leaders are to be determined. A manuscript outlining these results has been submitted to a journal for review and is included in Chapter Eight.

Chapter Nine provides a discussion of the project findings in the context of existing literature, study strengths, and limitations, as well as suggestions for future research.

1.18 Study scope

A pragmatic approach was applied to the scope of the project because this is the first time either standards or a structured interview for selection and development of cancer support group leaders have been developed. Study design and outputs focused on being of greatest use to the most people, understanding that further development would be needed to tailor outputs to other, specific community-based

health groups, or specific population groups. This Australian-based study was nation-wide and therefore utilised online and telephone-based data collection. Expert panel members from major Australian cities participated in the process of establishing consensus for minimum standards for the role and drafting of the structured interview. To maximise the total amount and geographical representation of support group leader participants for the field test, national cancer agencies with the largest affiliated support group networks were engaged. These agencies were Prostate Cancer Foundation of Australia and Breast Cancer Network of Australia. Current support group leaders, who participated in the field test by way of telephone-based interviews, were based in metropolitan, regional, and rural locations.

Based on consultation with cancer agency workers and available literature on support group demographics in Australia, it was determined that we would be unable to obtain adequate participation numbers for specific population groups to generate reliable or valid findings (for example, gender, sexual orientation, culturally and linguistically diverse groups).

Anecdotally, most community-based support groups with links to cancer agencies were identified as operating face-to-face groups that predominately provided peer support to adults who have experienced cancer. Similarly, the foundation of knowledge gathered through peer-reviewed literature related to face-to-face support groups. Therefore, this study focused on the peer support group operating in a face-to-face capacity, with additional types of support groups not investigated, for example therapy groups, self-help groups, online support groups, or exercise groups.

2 OVERVIEW OF THE LITERATURE

2.1 Chapter overview

The aim of this chapter is to provide an overview of previous literature, identify relevant theories, and consider the recommendations for future research that have been outlined by other researchers. In order to understand the state of knowledge on peer cancer support group leaders, this chapter explores literature on the role itself and the context in which the role operates. Due to paucity of literature specific to cancer support groups, the literature search was broadened to cover peer support, support groups, and leadership more generally. The following paragraphs summarise the relevant individual studies that were identified and provide an overview of themes.

2.2 Scope and methods of this literature overview

This literature overview provides a panoramic outline of research on cancer support groups and cancer support group leaders. The literature search for the literature review described in this chapter was ad hoc and exploratory in nature, taking in qualitative, quantitative, and mixed methods research to provide an overview regarding the area of interest (Brien, Lorenzetti, Lewis, Kennedy, & Ghali, 2010). Key words and phrases were used to guide searching: cancer support group leader, cancer support group, qualities, review, standards. These search terms were then entered into the search engine Google Scholar and databases Medline and PsychINFO. Searches of the reference list of key papers were also undertaken. As this literature overview was for the purposes of general scoping, no time or methodology restrictions were applied; however, it was confined to English language and peer-reviewed literature.

General themes relating to the literature on cancer support group leaders included: effective cancer support group leaders (see section 2.7.1), the challenging characteristics and experiences (see section 2.7.2), and cancer support group leader training (see section 2.7.3). Interestingly, a comprehensive or systematic review of cancer support group leader qualities was unable to be found. No standards or expert consensus relating to the role of group leader were identified (see section 2.8). Where specific literature on cancer support group leaders was not available, themes were broadened to explore literature relevant to group work and leadership.

The literature overview in this chapter is independent from the systematic literature review reported in Chapter Five, with different aims and methods. The systematic review in Chapter Five was undertaken to identify and collate literature that specifically described qualities of support group leaders. The literature overview in this chapter, on the other hand, was undertaken to provide background and context for the entire PhD thesis.

2.3 Overview of theory relevant to cancer support group leaders

To date there is not a specific or all-encompassing theoretical model developed for peer support, with the evolution of group work spanning several behavioural science disciplines. The theoretical scope was expanded in order to access all theory relevant to cancer support group leaders. Therefore, the next section provides an overview of theory relating to peer support, support groups, leadership, personality, and group therapy.

2.3.1 The theoretical basis for peer support

Descriptive case studies of peer support emerged in the literature as early as the 1960's. Chambers et al. (2015) identified six theoretical approaches (or models) that

are specifically relevant to how peer support is expressed and consumed: social support, the helper-therapy principle, experiential knowledge, social learning theory, social comparison theory, and social identity theory (Chambers, Hyde, & Dunn, 2015). All six theoretical approaches will now be briefly explained.

Social support theory can be used to explain how peer support encompasses emotional, practical, and informational support in a way that facilitates adjustment and engagement in active coping strategies (Mastrovito, Moynihan, & Parsonnet, 1989). Peers with shared experience are perceived as more credible role models (social learning theory) (Bandura, 1999) with specialised information and perspectives (experiential knowledge) (Borkman, 1999). With significant life experiences, such as cancer, disruption of one's identity can occur and therefore the groups in which individuals perceive membership can be derived from these experiences. Part of an individual's self-concept can therefore be drawn from membership of a particular peer group (Tajfel, 1974), with peer support offering a real sense of belonging and identity (social identity theory). Additionally, many who engage in peer support express their desire to help others (the helper-theory principle) and satisfaction with developing interpersonal relationships (Riessman, 1965). However, a specific or all-encompassing model developed for peer support is yet to be described.

2.3.2 The theoretical basis of support groups

There are primarily four theories that aim to explain the processes by which support groups function and provide a framework to account for attendee benefits. These theories are described here and include: Narrative Theory, Social Comparison Theory, Helper-Therapy, and Cognitive Theory. First, the Narrative Theory suggests

that being given the opportunity to recreate events and extract meaning from negative experiences through narrative offers a cathartic experience for group members (Yaskowich & Stam, 2003). Some cancer patients report feeling unable to communicate with family and friends and find that a support group provides the opportunity to talk about their lived cancer experience without censorship. Furthermore, identification with others going through the same situation can lead to a sense of belonging and a reduction in the social isolation that can come with a cancer diagnosis. This is particularly true for those with a sense of stigmatisation associated with the cancer (Davison et al., 2000; McGrath et al., 1999; Payne, Smith, & Dean, 1999). Understanding that you are not alone in experiencing cancer can help relieve isolation and bring a sense of universality (Yalom, 1995).

Second, the Social Comparison Theory postulates that humans have an intrinsic drive to evaluate themselves relative to others, such that individuals seek out the abilities and opinions of others to compare with themselves. Comparative motivation to seek out opinion is further increased in times of uncertainty or anxiety (Festinger, 1954). This theory is therefore relevant to those who seek out others with a similar diagnosis via a support group in order to alleviate negative emotions.

The third theory relevant to the support group model is the Helper-Therapy, which suggests benefit is gained for the individual group member in modelling certain behaviours and helping other group members (Riessman, 1965). Finally, Cognitive Theory focuses on the ideology or meaning developed by the group in relation to the shared issue (Kurtz & Powell, 1987). This is a point of distinction for support groups compared to one-to-one peer support, in that the collective nature of the group itself supports and facilitates positive outcomes.

Taken together these theories provide a framework that explains support groups and the behaviours of support group members. Sections 2.4 to 2.6 below address theory specific to the group leader role.

2.4 Leadership theory in the context of peer support groups

A broad exploration of the literature was undertaken on leadership theory, traits, and attributes. Surprisingly, a specific and widely accepted definition of leadership currently does not exist (Antonakis & Day, 2017). Leadership can be formal or informal, goal-influencing, and a contextually rooted process between the leader and the group of followers. The study of leadership explores processes and its outcomes, as well as how these processes depend on the leader's traits and behaviours and observed attributes, in addition to observer inferences on leader's characteristics (Antonakis & Day, 2017).

In reviewing the leadership theory, House & Aditya (1997) outline several leader theories including 1) leaders are born (trait theory), 2) leaders are made (leadership behaviour), 3) leaders are contextual (contingency theories). Additionally, the transactional theory of leader-member exchange between leader and subordinates provides theoretical foundation for the relationship (Hogg et al., 2005). However, translation of these theories into practice has been limited given the variations related to the subject matter and places in which the leader operates. Theories and descriptions of leadership mainly refer to formal managerial roles leading teams of staff in a paid workforce. Based on the work of Rush, Thomas & Lord (1977) the implicit theory of leadership assumes that individuals understand the characteristics a leader should possess, and that these traits are then used as benchmarks to determine or infer leadership.

Over decades, several major reviews on leadership traits and attributes have been published (Bass, 1990, 1998; Day & Zaccaro, 2007; Hogan, Curphy, & Hogan, 1994; Judge & Long, 2012; Zaccaro, LaPort, & José, 2013). Meta-analyses have provided considerable evidence for the validity of a wide range of leader attributes being linked to leadership outcomes. Interestingly, Zaccaro et al. (2013) listed 49 attributes mentioned in conceptual and empirical reviews of leadership literature. Attributes were grouped into sets of *cognitive, social, personality, motives, self-beliefs, knowledge,* and *skills,* and these categories were justified based on the functional performance requirements of most leadership positions. It is understood that leadership performance requirements necessitate specification of different leader attributes grouped into categories of cognitive abilities, personality orientations, motives and values, social capacities, and core self-beliefs (Antonakis & Day, 2017), to which Zaccaro et al. (2013) add knowledge and expertise.

Some performance requirements appeared to be more relevant or desirable to the support group leader role than others. For example, social capacities such as emotional intelligence, self-monitoring, skills in perspective taking, communication, and conflict resolution have the potential to be relevant. Additionally, personality traits such as sociability and agreeableness to assist in successfully navigating social interactions (Judge, Bono, Ilies, & Gerhardt, 2002) would presumably be important in a group setting. However, many self-motivational attributes for leaders were seen as incongruent to the role and purpose of a support group, such as dominance, need for power, and achievement motivation. At a basic level, identifying the types of knowledge and skills of cancer support group leaders appeared to be a logical first step for our research problem. As an alternative perspective, personality

theory was explored to further examine attributes relevant to cancer support group leaders.

2.5 Personality theory relevant to support group leaders

Personality has been looked at, among other factors, to evaluate leadership. Personality traits are conceptualised as stable individual characteristics explaining individuals' disposition to particular patterns of cognition, behaviour, and emotions (Hogan, Hogan, & Roberts, 1996). Research has established empirically a five-factor structure of personality (McCrae & Costa, 1987), which includes the dimensions of Extroversion, Agreeableness, Conscientiousness, Emotional Stability, and Openness to Experience. Multiple meta-analyses have been undertaken on personality (Hoffman, Woehr, Maldagen-Youngjohn, & Lyons, 2011; Judge, Heller, & Mount, 2002), and all five facets of the Big Five Model (McCrae & Costa, 1987) have displayed high corrected correlations with leader emergence or leader effectiveness. Interestingly, extroversion and conscientiousness generally yielded the highest corrected correlations with leader outcomes.

Additionally, individuals high on the dimension of Openness have been found to have a positive attitude toward challenging learning experiences (Barrick & Mount, 1991). The trait of Agreeableness may be of particular relevance to cancer support group leaders. Wiggins (Wiggins, 1996) reports the primary motivational orientation of agreeable individuals is altruism, with the concern with others' interest and empathy for their condition (Digman, 1989; McCrae & John, 1992). Positive relationships have been found between several aspects of Agreeableness and charismatic leadership (Ross & Offermann, 1997), along with evidence of agreeable supervisors being perceived to be more approachable in the eyes of subordinates

(Hogan & Shelton, 1998). However, it is unknown how much of the knowledge gained on leadership is relevant to leaders of community-based support groups. House and Aditya (1997) outline that leadership theory has been developed within the context of Western, industrialised culture with promotion of individualistic values. The translation of such theories into the practice of support groups is limited. Although there has not been detailed investigation into the personality traits of cancer support group leaders, knowledge gained from professional leaders of therapeutic groups could be informative.

2.6 Theory relating to group therapy leaders

Within a therapeutic context, Lieberman, Yalom and Miles (1973) identified five discrete types of leader behaviour: 1) evocative, behaviours designed to action a response from group members; 2) coherence-making, behaviour with the intent to alter thinking; 3) support, behaviours associated with positive affective gestures; 4) management, behaviours associated with group interactions and overall group functioning; and 5) use of self, behaviour involved with modelling or demonstrating. From this the authors concluded that four dimensions drove a variety of leader behaviours: Emotional stimulation, Caring, Meaning-attribution, and Executive function. First, Emotional stimulation describes leader behaviour as revealing, challenging, participating as a group member and demonstrating emotional release. Second, Caring involved offers of friendship, love and affection, protection, and expressions of warmth, acceptance and genuineness. Meaning-attribution involved leader behaviours that provided concepts to explain, understand, and clarify thereby presenting a framework for change. Finally, Executive function included leader behaviours related to managing group dynamics and setting rules. Yalom (1995) went on to outline three fundamental roles of the group leader being: 1) creation and

maintenance of the group, 2) building the culture of the group and developing norms, and 3) the activation of the here-and-now. However, the roles outlined are for group therapists, in which the role assumes strong influence, employs expert knowledge, and facilitates self-reflection of group members as part of a therapeutic intervention. The transferability of knowledge gained from theory on leaders of therapy groups is not targeted to volunteer leaders of cancer peer support groups.

2.7 General themes relating to the literature on cancer support group leaders

2.7.1 Effective cancer support group leaders

In a review of issues relating to group processes, group management, and leadership of cancer support groups, Fobair (Fobair, 1997b) outlined several skills for effective group leadership. Leaders of counselling or support groups require skills in facilitating, enabling, and validating. However, leaders of educational groups require skills to assist members in understanding information. It is challenging therefore to define what a support group leader is or does and not surprising that comprehensive data on the experience of cancer support group leaders are not available.

Currently, there is a lack of literature on the role of cancer support group leaders or the effects of leader behaviour on cancer support group members, with three main studies identified (Adamsen & Rasmussen, 2003; Butow et al., 2006; Lieberman & Golant, 2002). Lieberman & Golant (2002) first examined the effects of leadership behaviour on members, undertaking a cross-sectional study of 269 cancer patients attending support groups. Members attended from a total of 21 groups from The Wellness Community which were led by professional group leaders trained in methodology specific to the centre. The five-dimension empirical model of

encounter-group leader behaviours, developed by Lieberman, Yalom & Miles (1973) was used to examine the direct effects of leader behaviour and helpful group experience. The study concluded that leaders perceived as being high on meaning attribution (provide meaningful structure) and executive management (navigate group dynamics and provide group rules) were associated with lower depression, increased wellbeing, fewer physical problems, and better functioning of group members. Additionally, members fared significantly better when their leader was reported to frequently intervene, compare, invite members to seek feedback, summarise and provided a framework for change and understanding of members' problems. This led to the important conclusion by the authors that what leaders do in their groups has a significant impact on how patients fare (Lieberman & Golant, 2002). However, it is important to note, given that roughly half of participants (54.5%) reported seeking other health professional services beyond the group, such findings may not be solely attributed to the group itself.

In 2003, Adamsen & Rasmussen conducted a qualitative study to describe the experiences of 21 patients with cancer and 12 oncology nurses participating in self-help groups, with a comparable format to a typical support group. Facilitators were from three hospitals and were required to have at least 12 months experience, however, no further information on facilitator training or skill level was reported. Leaders in this study were described as open, courageous, committed to work with the group over an extended period, able to get close to people, and to be involved in the group beyond normal working hours or conventional relationships. The role of the nurse within the group was to: provide an environment for a meeting to take place, provide professional knowledge on request, approach and organise contact with suitable candidates, facilitate expression of emotion, facilitate equality and

togetherness within the group, and commit for a period of time to maintain contact with the group.

Zeigler et al. (2004) conducted a small two-part investigation into the experience of group members (n=10) and group facilitators (n=2, nurses) of a breast cancer support group. Content analysis of facilitators' journal entries of their personal experiences at 6 months and 12-months post initial support group meeting was undertaken. This study found that sharing leadership responsibility reduced the challenges and unmet needs experienced by facilitators. Specific needs were addressed through the exchanges facilitators had with each other and regular meetings held with the supervisory body, highlighting co-facilitation to be of benefit.

Of relevance was the study conducted by Butow et al. (2006) which stated that if support group leaders are to continue carrying out their important role there is a need for greater understanding. Three specific points of understanding were noted: 1) essential components of the role, 2) barriers to success, and 3) needs for training and support. The study explored the views of 179 leaders of 184 cancer support groups in one state in Australia regarding the issues of characteristics, barriers, and training needs of leadership. A total of 416 support group members from 50 groups completed The Cancer Support Group Survey (Smoczyk, Zhu, & Whatley, 1992) which consisted of 40 items assessing organisational aspects of support groups and developed from findings of individual interviews, materials accompanying support groups, and review of literature. Group leader characteristics rated by participants as important or very important included: facilitators providing members enough time to talk, welcoming new members, using humour in the group, facilitator's personality, and understanding group members' individual experience. Qualitative data from this study found three main themes as important to effective group leadership: 1)

educational qualities, 2) facilitation skills, and 3) personal qualities. To provide further explanation, educational qualities referred to the leader's ability to impart information and organise guest speakers to educate group members. Facilitation skills related to the leader's ability to ensure the appropriate level and manner of member contribution, communication skill, and organisational ability. Important personal characteristics of group leaders included being caring, enthusiastic, and available. Of all of the themes, the authors noted personal characteristics to be the most important to group members. Whilst characteristics gleaned from this study offer important and relevant information, it does not provide a comprehensive role analysis or incorporate varied perspectives to provide consensus on the essential qualities of cancer peer support group leaders.

Cella et al.(1993) investigated community-based support groups and asked participants to rate their professionally trained facilitators using 13 one-word descriptors of facilitator characteristics. Participants rated their group leader's characteristics inconsistently, with lower ratings for confident (65%), fair (44%), and active (56%). However, 90% of participants indicated that they found their facilitator to be caring, involved, sensitive, and understanding. An extremely positive rating by group members was also found by Butow et al. (2006), however, this study provided a broader background of group leaders to include both professional and peer-led support groups. This study showed that from a group member's perspective, professional background or qualifications did not influence the perception of satisfaction of the group leader. In contrast, Ussher et al.(2008) investigated why individuals stopped attending or did not attend a support group. Many reasons provided by respondents were external to the group such as time constraints, or personally feeling like it was time to move on. Of interest, 27% of respondents

reported dissatisfaction with the group as their primary reason for no longer attending. For these respondents, problems relating to the group leader were reported such as lack of organisation, dissatisfaction with the way the group was conducted, and male dominance resulting in exclusion of partners. These findings provide evidence of the crucial role group leaders' play within the support group and the impact they have in determining group attendance for those that seek this model of support during a cancer experience.

Overall findings in this area are inconsistent, with polarising levels of satisfaction with group leaders (Butow et al., 2006; Cella et al., 1993; Ussher et al., 2008). Group members appear to rate their group leaders very highly (Butow et al., 2006; Cella et al., 1993) or are dissatisfied to a degree that prevents them attending the group altogether (Ussher et al., 2008). There does appear to be a potential risk of bias when participants are asked to rate their own leader. Further to this, it has been found that both vulnerable and assertive group members often defer to the leader as the central figure in the group during challenging conversations (Smokowski, Rose, & Bacallao, 2001). It is surmised that given the complex relationship between group member and leader, which at times has an imbalance of power and authority within the group itself, rating leaders is a difficult task. This task is even more problematic given there is currently no agreed definition or set of qualities to benchmark peer group leaders against. Previous research has also highlighted possible methodological issues when investigating cancer support groups via the leaders themselves (Schopler & Galinsky, 1993). For example, Zeiger et al. (2004) reported no barriers or challenges to the leadership process, indicating a reluctance to report negative aspects of the role or potential learning opportunities.

2.7.2 The challenging characteristics and experiences of group leaders

Interestingly, not all leader behaviours mentioned in the literature are reported as positive. Smokowski et al. (2001) attributed almost all behaviours that led to a damaging group experience as originating from the group leader. Negative leader behaviour was reported by participants to be not supportive, giving non-helpful feedback, criticising, monopolising the group, giving bad advice, pressuring group members, and not being competent or qualified. The authors identify two types of leaders who were linked to damaging member experience, the passive leader and the overstimulating or confrontational leader. Passive group leaders were described as allowing toxic group members to behave in ways that were detrimental to the group. By failing to address poor behaviour, group leaders were viewed as condoning the behaviour and failing to provide a safe environment for group members. Passive group leaders were also seen to be unable to establish the group's purpose, protective norms, and goals therefore creating an environment of conflict for group members. In comparison, confrontational leaders tended to impose their own values on the group and allow little space for difference. Additionally, leaders with a confrontational style failed to appreciate that the approach taken could negatively affect vulnerable members of the group. It should be noted that this study was not specific to cancer support groups and included a variety of group types: therapy, education, and supervision groups. However, group leaders were not required to be trained in group facilitation, dynamics, or group therapy, positioning the leader role in this study to be of a similar experience level to peer support group leaders. The results of this study provide further evidence that the group leader role is central to the group and the experience of its members. Furthermore, the group

leader role has the potential to alter the experience of group members to either damage or maximise the support provided.

Within the group, leaders have a considerable amount of power, prestige, responsibility, and status, with many not able to manage or even recognise these factors (Smokowski et al., 2001). Not surprisingly, alongside the many benefits, leaders have reported a range of difficulties associated with cancer support group leadership. Some struggle to deal with issues like difficult and demanding personalities, unclear group goals, irregular group attendance by members, maintaining adequate group numbers, along with group facilitation on disease progression and death (Galinsky & Schopler, 1994).

Available literature indicates that leaders experience challenges in maintaining their own quality of life and avoiding burnout. This concern reported by leaders is particularly relevant given that workload responsibilities with sole leadership contribute to group demise (Galinsky & Schopler, 1994; Kirsten, Butow, et al., 2006; Lieberman & Golant, 2002; Maram & Rice, 2002; Oliffe et al., 2008). In fact, parallels of stress and burnout of support group leader has been made to health professionals (Plante & Bouchard, 1996). Suggestions were raised to counteract the negative impact on group leaders through access to co-facilitation and opportunities to de-brief, along with a minimum level of staffing, and access to appropriate supervision (Plante & Bouchard, 1996).

In 2006, Kirsten et al. considered the experience of being a cancer support group leader and examined challenges associated with the role through qualitative exploratory methods. This study provides relevant and specific information on cancer support group leaders. Participants included 27 active cancer support group leaders

purposively sampled from 173 identified support groups. Leaders involved were from varied backgrounds and geographical areas (i.e. urban, rural, and remote). Quantitative and qualitative methods (short questionnaire and focus groups/individual interviews) were used to collect data and demographic information. Focus groups were used to explore commonality of experience among participants and a demographic questionnaire assessed the following: group skills training, personal experience with cancer, current group commitment, number of co-facilitators, opportunities to debrief or receive supervision, length of time in the leader role, and main roles in the group. Four dimensions critical to aspects of the group were used to select a representative cohort to include: group leaders being professionally qualified and having a personal experience of cancer or not, heterogeneity of group membership, and community versus hospital base. These dimensions were previously identified through a stakeholders' workshop. However, the study sample was selected based on the geographical location of only one Australian state (New South Wales), with over-representation of participants living in urban or larger regional areas.

Results from the study provided interesting demographic information regarding the amount of time leaders spent in the role. The average age of group leaders was found to be 58.6 years, with leaders spending on average 26.5 hours per month on group activities, in a role that was undertaken between 6 months and 17 years (mean = 6 years). Many themes emerged from the interviews with difficulties identified by leaders to be: dealing with people's different communication styles and needs; dealing with reassurance, metastases, and death; practical issues; maintaining personal balance and preventing burn out; establishing and maintaining group credibility; group cycles; and leading groups in rural areas. Specific difficulties

for leaders of geographically isolated groups were identified to include the leader personally knowing group members. Leaders without professional training and/or a personal cancer diagnosis identified more issues relating to group dynamics, psychologically unwell members, and counter-transference. The authors suggest that training in how to respond appropriately to these issues is likely to be required by leaders with and without health professional training. Consistent with previous research, the maintenance of adequate group numbers was found to be one of the practical challenges in running and maintaining cancer support groups (Galinsky & Schopler, 1994). However, these difficulties were placed in the context of the group's credibility among health professionals and organisations and provision of funding. Interestingly, leaders argued that formal provision of funding would increase group recognition and credibility among key stakeholders, which in turn would serve to reduce fluctuations in the group numbers. Kirsten et al. (2006) suggest strategies be developed to encourage more trust and contact between medical staff and support groups, especially for those operating outside the formal health system.

Problems reported by leaders pertaining to maintaining individual balance and preventing burnout are consistent with findings by Butow et al.(2006) and unrelated to the background of leaders. Difficulties, however, are often outweighed by the rewards. Rewards include feeling part of members' lives, own self-development, and being part of the process that helps members' adjustment and empowerment following a cancer diagnosis (Kirsten, Butow, et al., 2006). This study was largely exploratory in nature with no causal conclusions. Limitations of this study were the absence of data on level of education and training of participants, and limited sample size. Whilst burnout of leaders was acknowledged in this study, a systematic investigation of the psychological wellbeing of cancer support group leaders is yet to

be undertaken. It is thought that untrained or ill-equipped cancer support group leaders could be further burdened by stress due to lack of skill. Conclusions drawn by the authors also suggest a better understanding of the characteristics of group leaders which allow them to overcome difficulties would contribute to more effective preparation and training. Recommendations are outlined for guidelines and interventions to be developed to better address the difficulties identified, and to reduce stress and burn out experiences of group leaders.

Further to this, Maram and Rice (2002) investigated the dilemmas experienced by support group facilitators who share the same problem as group members, a similar experience to peer leaders. Sixty-seven of five hundred professional support groups completed an 18-item questionnaire. Demographics, support group data, and information on participants' experience were collected in five areas including: counter-transference, self-disclosure, giving advice, considering oneself a group member, and balancing own needs against the needs of the group. Open-ended questions allowed participants to provide further information and strengthened data collection for this study. The study found that leaders who shared the same problem as members struggled significantly more with self-disclosure. Furthermore, analysis using Pearson correlation and demographic variables found leaders were significantly more likely to struggle with counter-transference if they facilitated meetings more frequently or were younger. Interestingly, the longer the facilitator had been leading the group, the more likely they were to struggle with balancing their own needs with those of the group members. However, it was noted that responses to open-ended questions often indicated the facilitator was experiencing a higher degree of difficulty than what was indicated on the 5-point Likert scale. This possibly indicates reluctances to disclose challenges experienced

and potential response biases. For those with a personal diagnosis of cancer potential concerns raised by group members relating to disease reoccurrence or survivorship issues could further compound stress.

2.7.3 Leader training: A premature step in developing cancer support group leaders

Within Australia, peak cancer agencies who work to serve the community have recognised independently run, peer-led support groups as a support option for those impacted by cancer. As a less resource-intensive alternative to professional support offered in health institutions, community-based peer groups have the potential to reach more patients and survivors. The volume of support able to be provided is relevant given the predicted ‘tsunami’ of increase in cancer survivors (Bluethmann, Mariotto, & Rowland, 2016).

Literature suggests that ongoing education and training for group leaders, regardless of professional or peer background, is beneficial (Coreil & Behal, 1999) (Butow et al., 2006; Zeigler et al., 2004; Zordan et al., 2010). In recent times cancer agencies have provided funding, training, resources, and support staff to group leaders, as a way of strengthening the delivery of support provided by groups. Formal training of cancer support group leaders has been introduced by cancer agencies as a way to address some of the challenges relating to the role and improve the experience of group leaders and members. Training programs have typically focused on teaching support group leaders how to structure group meetings, manage group dynamics and difficult group members.

In 2006, Price et al. undertook a review of the support and training needs of cancer support groups. The aim of the study was to systematically review existing

data and literature on four key areas: 1) impact of different leadership qualities on patient outcomes; 2) the needs of support group leaders; 3) interventions developed for support group leaders; and 4) available training or support services for group leaders. It was noted by the authors that due to the paucity of literature specific to cancer support group leaders the search was broadened to include leaders of other health and non-health related support groups. A search of three databases (Medline, PsychInfo, CINAHL) found eight articles meeting criteria. Only one study was identified that evaluated the direct impact of cancer support group leader behaviours on group participants (Lieberman & Golant, 2002). Two small studies identified several group leader needs including additional training and practical support and dealing with common difficulties (Coreil & Behal, 1999; Galinsky & Schopler, 1994). Three articles identified in the review most relevant to our topic have been expanded and included in the literature overview. Of interest was Galanes (2003) qualitative study on qualities of effective group leadership. Peer nominated group leaders (women n=13, men n=10) were recruited to participate and complete a semi-structured interview. Themes generated from data analysis included: a) establishing clear and compelling goals; b) group building with recognition of group members needs and feelings of inclusion; c) monitoring and managing group interactions by encouraging participation and checking in; d) managing group tasks and maintaining group focus; e) communication behaviours and personal characteristics to include inspiring confidence, motivating without dominating, listening, asking good questions, being flexible and supportive, and able to self-monitor. However, authors of the review conclude that there is still insufficient data available to identify any differences in the needs of cancer support group leaders. Furthermore, it is suggested that more

research is needed to provide an evidence-base for group leader training to evaluate its impact.

In 2010, Zordan et al. surveyed a total of 358 support group leaders in Australia and found that more than 80% had minimal to no training in support group facilitation. This finding was consistent with Stevinson, Lydon and Amir (2010). Interestingly, the study also found that leaders ranked access to web-based support (i.e. website and DVD plus manual) specific for support group leaders as the most preferred type of intervention. A further 45% of leaders stated they would benefit from group facilitation training. Limited research suggests the need for ongoing training for both professional and peer leaders (Galinsky & Schopler, 1994; Hoey, Sutherland, Williams, & White, 2011; Price et al., 2006). Specifically, leaders without training experience challenges with group dynamics, countertransference when issues of members reflect their own, and dealing with psychologically unwell members (Kirsten, Butow, et al., 2006). Importantly, it has been found that leaders who are more skilled and experienced create better outcomes for group members (Lieberman & Golant, 2002; Sheard & Maguire, 1999).

Zordan et al. followed up in 2012 to report on their pilot results for the development of training and support interventions to address the unmet support and training needs of cancer support group leaders. Although rationale for selection of interventions came from a number of sources, the authors reported a lack of scientific data to support these strategies. It was surmised that inadequate literature specific to cancer support group leaders meant that broader leadership literature often formed the foundation of the interventions. In addition, the authors commented that the majority of literature often stemmed from personal experience or anecdotal evidence, lacking strong empirical evidence. The recommendation taken from this

study was that any future research should be specific to the role and not adapted from other fields.

There continues to be a scarcity of validated interventions targeting cancer support group leaders for cancer agencies to work from. A recent systematic review undertaken by Delisle et al. (2016) identified only Zordan et al.'s underpowered randomised control trial that evaluated the effects of support group peer-facilitator training programs on peer-facilitator and support group member outcomes. Zordan et al. (2015) evaluated the confidence and self-efficacy of 65 cancer support group leaders randomised to either a 4 month high-resource intervention (i.e., website, discussion forum, 2-day face-to-face training) or a low-resource intervention (i.e., website, discussion forum). No statistically significant differences were found between the two groups, or any differences for self-efficacy or confidence of facilitators. Interestingly, this finding is consistent with previous ones in that no differences in reported difficulties exist between leaders with training or qualifications and untrained leaders (Butow et al., 2006). Furthermore, these studies suggest that neither training nor personal experience protects against difficulties in group leadership.

Delisle et al. (2016) noted the limitations of Zordan et al. (2015) study to draw conclusions about the potential effects of support group facilitator training programs; mainly the sample size and participant mix of peer and professional support group facilitators. Risk of bias was also rated as unclear for the study related to incomplete data, allocation concealment, and sequence generation. Additionally, there was a high risk of bias related to blinding of participants, personnel, and outcomes assessors (Delisle et al., 2016). Again, this is consistent with Schopler & Galinsky's (1993) earlier findings that methodological challenges exist when investigating the

experience of leaders. Zordan et al. (2015) indicate further that leaders operating in a volunteer capacity may be even more vulnerable to this response bias due to their personal investment in the role. Possible explanations for the findings were that the length of intervention for support group leaders was not sufficient, given existing literature suggests longer interventions to be more effective (Delvaux et al., 2004). Additionally, Zordan et al. (2015) identified the possibility that the workshops were too advanced for some leaders, particular those with limited prior training. Furthermore, the workshops were designed with an assumption that participants would have a basic understanding of group leadership practice (Zordan et al., 2015). This basic understanding was not evident, despite participants not reporting the training as being too technical or intense. This leads to the question of whether support group leaders simply do not know what is required of the role, with some potentially not having the basic knowledge or skills needed to benefit from training provided. Importantly, despite reported challenges and potential benefits of interventions to assist leaders, there was under-utilisation of the interventions by group leaders (Zordan et al., 2015). Issues of engagement by a minority of group leaders, although not investigated, appear to be present. Zordan et al. (2015) reported that some leaders were reluctant to apply training principles to their practice despite the empirical evidence presented in favour of the principles.

2.8 Summary of previous research recommendations regarding cancer support group leaders

Specific recommendations were gleaned from four key papers and assisted in defining the research aims for this PhD. First, there is need for a specific and comprehensive analysis of the cancer support group leader role, and second that development of standards for the role is needed. First, Kirsten et al. in 2006

recommended that group leaders could be more effectively prepared and trained if there was a better understanding of the characteristics of group leaders that allow them to overcome difficulties. A clear need was also identified to develop guidelines and interventions to better address these difficulties and to reduce stress and burnout experienced by group leaders. Second, Butow et al. (2006) stated that if support group leaders are to continue carrying out their important role, there is a need for greater understanding of the essential components of the role. Third, Zordan et al. (2010) recommended that it may be appropriate to develop a set of minimum standards or process of accreditation of cancer support group leaders. Furthermore, Zordan et al. (2015) stated that the leaders of cancer support groups have been woefully understudied, with further research suggested to address barriers to resource usage and methods to overcome these. These seminal studies all suggest that there is a gap in the literature in regards to the qualities that make an effective and resilient group leader, and that there is a need for standards around who is selected as a leader.

2.9 Conclusions

Current literature has uncovered variability in the definition of a support group and differs markedly in group structure, process, and content. It is not clear which support groups produce optimal outcomes given there is no ideal or standard support group to benchmark against (Bell et al., 2010). There is strong evidence to support the idea that the group leader plays a crucial role in the success of the group (Galinsky & Schopler, 1994; Lieberman & Golant, 2002; Price et al., 2006; Ussher et al., 2005; Zordan et al., 2010) with leaders expected to have a wide range of skills (Butow et al., 2007). Yet studies specific to the role are currently lacking.

Most reported studies found are exploratory or descriptive, with research being carried out on small sample sizes. A common theme relating to study limitations of literature in the field of support groups and group leaders is the considerable bias from participants. The desire to positively report or compare leader abilities, needs, or characteristics provides an unrealistic and sometimes perfectionistic view of the people occupying the role. Importantly, biases exist through virtue of self-selection whereby the cancer patient has already chosen to attend the group due to positive attitudes about the benefits of support groups and adaptive coping approaches (Grande, Myers, & Sutton, 2006). There is a limited perspective covered in the literature on the role of group leaders given the broad community-setting in which support groups operate and possible stakeholders. For example, many studies focused solely on the perspective of the group member or group leader. No study has undertaken a comprehensive analysis of the cancer support group leader role with objective input from various experts.

Findings on cancer support group leaders are buried in the literature and often lack specificity to the subject matter, with the constant need to broaden searches to other models and types of leaders and groups. As an additional consequence, generalisability of studies across group leaders is limited due to findings being reported for a single setting or disease.

Methodological limitations within many studies prevent definitive results or application to the context in which community-based support group leaders operate. Previous literature in the field has identified the limitations of studies to be the design of the studies themselves. In recent years, the objective of supporting leaders in their role has focused on training the group leader. Whilst training programs for peer support group leaders could increase the effectiveness of groups, there is insufficient

evidence to suggest that training alone is adequate to prepare leaders for the role and maximise support offered in the group. In addition, some leaders are unclear as to what the role requires, have skill deficits, or simply do not engage with the intervention provided regardless of its effectiveness. There is perhaps a need to go back and revisit Butow et al.'s (Butow et al., 2006) first hypothesis that if support group leaders are to continue carrying out their important role there is a need for greater understanding the essential components of the role. This literature overview failed to identify a systematic or comprehensive summary of leader qualities or criteria for the role. In fact, the suggestion that someone may not be suited to the role, given its challenges, importance and complexities, has not been raised at all in the literature.

Importantly, a need for minimum standards to be developed was identified in the literature, along with maximisation of existing links between other groups and state bodies to assist the leadership role (Butow et al., 2006). There is, however, currently insufficient evidence to guide cancer agencies on how best to support and work with community-based support group leaders.

3 STUDY DESIGN

3.1 Chapter overview

The literature overview presented in Chapter 2 identified some of the challenges associated with the support group leader role and recognised the unique environment in which support groups operate. Establishing minimum standards to be used across cancer agencies, for the selection of mainly inexperienced peer volunteers, poses unique demands on the study approach taken for this PhD. This chapter will articulate how we ensured that a pragmatic and real-world approach was applied to development of systematic and robust measures to the entire project. Importantly, how the contextual demands for cancer agency workers were addressed through consultation, consensus, and clinical utility. The importance of undertaking a job analysis is discussed, along with the use of a structured interview and accompanying user manual. This information provides an introduction to the approach taken for the entire study, with detail on study methods described in Chapter 4 and Chapter 7.

3.2 Theoretical framework: A pragmatic approach

The philosophical perspective adopted by this research was that of a pragmatic approach, using complementary methods best suited to the selection and development of cancer support group leaders. Finding practical solutions to a real-world problem, appropriate to the community context and acceptable to various stakeholders was paramount. Therefore, a pragmatic approach guided the use of both qualitative and qualitative methods and allowed for integration of different perspectives to help elucidate the data interpretation process (Saunders, Thornhill, & P, 2009). Pragmatism also linked transparency and replicability of methods as much

as possible to establish an agreement of what constitutes good-quality research and outcomes for this subject matter (Hammersley, 2008). It was our desire to produce socially useful knowledge and outputs that serve to address an actual need. Above all, a realistic, respectful, and practical approach was required for it to be incorporated successfully into a community health setting.

3.3 Addressing contextual demands

It has been suggested that, to some extent, limitations in research on peer support arise from the community-based environment and the naturally random dynamics that occur (Dunn, Steginga, Rosoman, & Millichap, 2003). Additionally, research methods that attempt to transpose experimental paradigms, such as randomised controlled design, do not recognise how peer support programs typically develop or operate. There has also been criticism of traditional trials lacking relevance in the real world (Celermajer, 2001). We need to bridge the gap between research and practice (Bero et al., 1998; Grol & Wensing, 2004) whereby methodologies are tailored to better suit the naturalistic and community-based context of peer support group leaders. This study has utilised three approaches to address the contextual demands related to the field: consultation, consensus, and clinical utility. The importance of each of these approaches to the selection and development of cancer support group leaders is outlined in sections 3.4 to 3.6 below.

3.4 Consultation

There was an integration of theory and practical knowledge in both the conceptualisation of the project and study design as the PhD student researcher was working for a peak cancer body, collaboratively with other cancer agencies, and directly with affiliated peer-led support groups. Patton (1999) emphasised the

importance of such integration to imply enhanced and deep understanding for the researcher. Applied research planning also emphasises that researchers come to understand the problem or issue and refine study questions, considering feedback that interested parties or end users may provide (Hedrick, Bickman, & Rog, 1993). The focus of this research and the criteria for practical significance was set in consultation with the key stakeholders. Specifically, cancer agency workers were identified as the stakeholder with the greatest investment in the research outcomes. Additionally, consultation with cancer agency workers helped to increase the likelihood that the study results, once generated, would actually be used to change programs and policy (Hedrick et al., 1993). As proposed by Arskey and O'Malley (2005) the role key stakeholders play in project scoping provides perspectives of others with knowledge of, and a vested interest in, the area under examination. Furthermore, capturing and respecting multiple perspectives (i.e. triangulation) beyond that of the researchers was also considered an important component of quality (Patton, 1999).

Consultation was included as an agenda item of an already established inter-cancer agency meeting specifically for cancer support group workers. This approached was utilised to reduce the burden of input and maintain consistency throughout the entire project. The overall purpose of the meetings was to provide peer support on challenges faced in the role, communicate on projects and services to reduce duplication and share strategies developed to improve services to cancer support groups. The aim of these meetings allowed for relevant and organic discussions to occur naturally whilst maintaining the focus on practice rather than research. Face-to-face meetings were held quarterly in Victoria, with an open invitation provided to all cancer agencies working with support groups. Cancer

agencies represented at these consultation meetings were: Prostate Cancer Foundation of Australia, Breast Cancer Network Australia, Cancer Council Victoria, Ovarian Cancer Australia, Think Pink, Unicorn Foundation, Cure Brain Cancer, and Myeloma Foundation of Australia. It should be noted that attendance fluctuated between meetings, with a core group of five cancer agency workers attending most meetings.

Consultation provided valuable insights about issues relating to the appropriateness of group leaders and engagement with group leaders that literature alone would not have alerted us to. Important additional dimensions to the literature review process occurred that informed the study design and added value to the project aims (Arksey & O'Malley, 2005). For example, contributors approached the concept in a more pragmatic and holistic way that encompassed several related themes: lack of shared understanding of the role, gaps in staff knowledge and high turnover, need for assessment tools, limited capacity of resources and provision of support to group leaders, desire for consistency with decision making, and useable and acceptable outcomes for cancer agencies. It was also reported that agencies wanted to work with group leaders in a more consistent and effective way, incorporate evidence into the development of training and support services, recognising the need to bring credibility to the peer support group model.

Consultation also provided multiple advantages such as immediate feedback on each stage of project development, endorsement of the project to stakeholders, participant recruitment, and direct implementation of study outputs. Additionally, the consultation group confirmed that they did not use or know of any comprehensive role analysis or standardised selection tool for support group leaders, a finding consistent with the literature review.

3.5 Consensus

Use of consensus methods has become increasingly evident as a tool to solve problems in health and medicine where definitive information from scientifically sound studies is not available (Fink, Kosecoff, Chassin, & Brook, 1984). Consensus methods provide a means of synthesising information and way of harnessing the insights of appropriate experts to enable decisions to be made (Jones & Hunter, 1995). The aim of consensus methods is to determine the extent to which experts agree on a given issue. The term agreement can take two forms: either the extent to which each respondent agrees with the issue under consideration, or the extent to which respondents agree with each other (Jones & Hunter, 1995).

When employed properly, consensus techniques create an environment in which experts are given the best available information to make decisions. This in turn, allows agreement of developed solutions to controversial subjects that are more justified, valid, and credible than they would otherwise be (Fink et al., 1984). These outcomes are considered especially relevant to the credibility of the community-based framework of peer support groups, given challenges reported by leaders regarding group credibility (Kirsten, Butow, et al., 2006). Importantly, many professional standards and guidelines have relied on consensus methods to help choose among the many areas that might be justifiable subjects for evaluation and to set standards for quality (Ferri et al., 2005; Fink et al., 1984). Fink et al. (1984) outline four major methods or models developed for consensus: Delphi, Nominal Group, National Institute of Health Consensus Development and Glaser's State-of-the-Art Approach.

Several themes emerged that guided the achievement of consensus for this project. First, consensus studies should focus on carefully defined problems that can be investigated in a timely and economical manner. Scoping for this project enabled a concise and manageable approach to determining which elements needed consensus. Namely, development of a structured interview and establishment of minimum standards. Second, decisions should be justified in light of available empirically derived data. Thus, there is a need to search all available information and synthesize it into a form that can be used. Current information obtained on cancer support group leaders was determined to be insufficient, not comprehensive, lacking synthesis, and not presented in a digestible form in order to make decisions. A systematic literature review was therefore more suitable for content analysis and thematic synthesis than the general literature overview outlined in Chapter Two of this thesis (Thomas & Harden, 2008). It is stated that in the absence of such a thorough synthesis, participants in a consensus study tend to rely solely on their own experience and reading (Fink et al., 1984). This was particularly important given the impact of participant biases identified in previous studies. Third, consensus participants should qualify for selection because they are representative of the subject matter or have power to implement findings. For example, given that cancer support group leaders operate within a community-based context, working with various stakeholders would broaden the knowledge base, perspectives, and credibility of decision making. In fact, Human Resources practices rely heavily on consensus of work analysis information in order to make reliable decisions, with trait descriptors derived from incumbents thought to lead to lower-quality decisions (Dierdorff & Morgeson, 2009). A consensus panel of diverse experts is a first in the

field, with previous studies providing perspectives and expertise limited to group members or group leaders.

Objectivity and skill in the administration of the consensus process is required. Given that previous research into support group leaders has been met with reported biases, objectivity needed to be maximised. For this reason, among others, the Delphi technique provided a way for us to remove ourselves as participants with our primary focus being coordinating the survey and interpreting results. This objectivity was also extended through peer review and thesis examination, with potential examiners removed from participating in the expert panel. Further, the level or type of consensus must be defined in advance; for this project, consensus was defined as 75% or more agreement (Diamond et al., 2014). Consensus findings should represent clear and specific guides to action. As such, this project aimed to identify the specific knowledge, skills, and attributes required of a support group leader and determine a practical way of assessing these. This would transform knowledge gathered to date from a random collection of desirable qualities or characteristics to a more structured, defined, and useable set of criteria.

Large-scale consensus studies are recommended to seek support by professionals and interested parties to help promote results. This project engaged a variety of experts for consensus in addition to consultation with cancer agency representatives and sponsorship through a relevant peak cancer body working with support groups. This study aimed to work with various cancer agencies, contribute to literature, and continue to share outputs with those who can benefit. A consensus-based approach was used for the first time to build specific knowledge on the role of the cancer support group leader and a standard by which to assess group leaders at a broad community level.

3.6 Clinical utility

Utility is associated with utilitarianism, a notion of trying to achieve the greatest good for the greatest number. More specifically, clinical utility literally means usefulness in clinical practice or as an intervention (Smart, 2006). The uptake of clinical utility as a concept has increased in the healthcare setting for studies of clinical effectiveness, economic evaluation, and everyday work practice. Smart (2006) argues that the concept of clinical utility must account for practitioners' perspectives about the usefulness, benefits, and drawbacks of an innovation for their working practice. As this project sought to introduce a novel selection and development approach for group leaders, the perspective of cancer agency workers as the 'user' was critical. Indeed, the contextual demands of users are influential (Van de Ven, 1986), with the needs of users central in decisions to adopt new techniques (Rich, 1997).

Clinical utility has been conceptualised as a multi-dimensional judgement that encompasses four components: appropriateness, accessibility, practicability, and acceptability (Smart, 2006). First, appropriateness refers to aspects of effectiveness and relevance. Issues such as importance of decision-making relating to selection of group leaders and how consistent decisions are across raters are covered under this component. Second, accessibility refers to aspects of resource implications and procurement, addressing issues relating to the limited resources available to cancer agency workers. Third, practicability covers aspects of functionality, suitability, and training. Issues considered for users covered completeness of materials and instructions, whether it performs the task it is designed for, and whether it can be adequately used by workers of varying experience levels. This point was relevant given that varying experience and high turnover of staff was identified during consultation. Finally, the component of acceptability covers aspects of how users

perceive the selection and development process to be acceptable to themselves and others such as support group leaders, the cancer organisation they work for, and the broader community.

To date, exploration of contextual demands on the cancer agencies who work with support group leaders has not been undertaken despite their central role in provision of support, resources, and training. This has ignored the important influence agencies have over the delivery of support provided by networks of affiliated support groups. Additionally, it has overlooked the potential capacity of cancer agencies to drive a collective standard for peer support groups, rather than the limited individualist approach of examining single support groups. It was proposed that examining the accumulated knowledge, views, and practices of cancer agency workers would help to address the shortfall and provide a stronger community-based framework.

However, in order to develop a reliable and practical solution to the problem of peer group leader selection, validity must also be considered. The contextual demands of a new selection and development tool can be addressed through a clinical utility, consultation, and consensus-based approach, but this must be coupled with the rigour of maximising components of structure to the interview.

3.7 A structured interview and the importance of a job analysis for assessing appropriateness to be a cancer support group leader

Consultation revealed many cancer agency workers engage in conversations with potential group leaders but are unsure what information or questions should be covered and how to assess the information that is gathered. A useful and common method of gaining information and insight is interviewing (Azarpazhooh, Ryding, & Leake, 2008). In essence, an interview would convert the informal conversation already being utilised into a more scientific assessment.

Interviews are the most widely used methods of assessing candidates in an employment setting (Campion, Palmer, & Campion, 1997; Huffcutt & Arthur, 1994; Macan, 2009; Pulakos & Schmitt, 1995; Van Iddekinge, McFarland, & Raymark, 2007), yet job interviews are fraught with potential for unreliable and inappropriate hiring (Graves & Karren, 1996). The psychometric properties of an unstructured interview have been determined to be deficient in predictability (Arvey & Campion, 1982; Huffcutt & Arthur, 1994; McDaniel, Whetzel, Schmidt, & Maurer, 1994). Additionally, inter-rater reliability has been found to be low due to a lack of established criteria and differences in interview approaches and evaluation (Campion, Pursell, & Brown, 1988; Graves & Karren, 1996).

There are various qualities that differentiate a structured interview from an unstructured interview. Huffcutt and Arthur (1994) define structure to be “the reduction in procedural variability across applicants, which can translate into the degree of discretion that an interviewer is allowed in conducting the interview” (p.186). However, the construct of structure is more complex than either being structured or not structured (Huffcutt & Arthur, 1994). Complexity occurs because

structure is conceptualised as a continuous and multi-dimensional construct. Huffcutt and Arthur argued that there are two dimensions of structure that relate to the degree of discretion permitted when conducting an interview: interview questions and response scoring. More recently, Dipboye et al. (2004) described a tighter conceptual framework corresponding to the life cycle of an interview, which includes interview development, conduct, and evaluation.

Previous research has provided the conclusion that structured interviews are more useful for predicting job performance (Arvey & Campion, 1982). Meta-analysis on validity has supported the dominant features and superiority of structured interviews (Huffcutt & Arthur, 1994; Hunter & Hunter, 1984; Wright, Lichtenfels, & Pursell, 1989). Structured interviews have also demonstrated criterion-related validity coefficients comparable to those of cognitive ability tests (Huffcutt & Arthur, 1994). Furthermore, structured interviews introduce less biases and discrimination (Bragger, Kutcher, Morgan, & Firth, 2002; Kutcher & Bragger, 2004; Reilly, Bocketti, Maser, & Wennet, 2006). Therefore, it is in the best interests of cancer agencies to use structured interviews rather than unstructured ones when making decisions regarding support group leader selection because of the psychometric properties inherent in the structure. Development of our structured interview specifically for cancer support group leaders will improve the probability that raters will consistently arrive at a decision that stems from consensus-based standards.

A job analysis is a systematic study of a job conducted by experts to discover the specifications and skill requirements for the job (Wagar, Schwind, Fassina, Uggerslav, & Bulmash, 2016). A job analysis is a basic requirement for the development of valid selection procedures for employment according to professional, legal, and testing guidelines. Job analysis can yield realistic job descriptions, which

act like road maps for recruitment, selection, and orientation (Pavur Jr, 2010). A job analysis should enhance the amount of job-relevant information brought to the interview. This can result in the identification of knowledge, skills, and abilities related to the job rather than personality traits (Harvey, 1991). Furthermore, undertaking a role analysis may allow for a more accurate prioritisation of skills, abilities, and competencies (Dierdorff, Rubin, & Morgeson, 2009). Importantly, leader performance is improved by attracting the appropriate applicant and preparing the new leader for the role. An accurate job analysis, therefore, can improve the success of the new leader (Pavur Jr, 2010) and is considered a vital component of structure for the development of an interview for cancer support group leaders.

3.8 A user manual to complement the structured interview

Dipboye (1992) states that training is probably the most common way to improve interviews. Campion et al. (1997) on the other hand, position training as a way of ensuring that other components are implemented correctly instead of being a component itself. A content analysis of training revealed the key content to be: 1) description of background and purpose of the interview (Walters, Miller, & Ree, 1993); 2) discussion of the interview itself (Pulakos & Schmitt, 1995; Walters et al., 1993); 3) how to write interview questions (Roth & Campion, 1992) or how to use questions already written. Training frequently discusses rapport building, job requirements or understanding of job-relatedness (Pursell, Campion, & Gaylord, 1980), evaluation of answers, use of rating scales and cut-off scores, and avoidance of discrimination and bias (Roth & Campion, 1992). Of interest, research has yet to demonstrate the unique effects of training of interviewers. Many challenges have been identified regarding proper implementation with such challenges as: scores not used as intended with decisions based on overall impressions (Latham & Saari,

1984); re-formatting questions and answers provided to interviewees (Weekley & Gier, 1987); or adding a personal touch and thereby increasing variations in structure (Dipboye & Gaugler, 1993).

Considering the pragmatic limitation of delivering training to all users of the structured interview, it was determined that for this project a user manual would provide the format for delivery of key information to assist consistency of interviews. All suggested training content outlined above was included in the format of a user manual. For example, the purpose of the user guide, explanation of a structured interview, understanding core elements of structure for the interview, how to score responses, and guidance on how to conduct the interview. The manual's clinical utility was then assessed by users during the pilot study and determined to be adequate for use (see Chapter 8).

3.9 Conclusions

Our study approach was novel, comprehensive, and robust in addressing the contextual demands for development of a structured interview and user manual for the selection and development for the cancer support group leader role. The specific components of structure for interview development and accompanying user manual is expanded upon in Chapter 7. The limitations of previous research have been noted with a pragmatic framework introduced to ensure the research design is applicable to the community-setting. Importantly, key stakeholder input has ensured the project meets the actual need, and is relevant and useful. No other study to date has tailored and combined these approaches to produce pragmatic and consensus-based minimum standards for cancer support group leaders. This study approach ensured a comprehensive role analysis was undertaken and provided a solid

foundation on which to apply mixed study methods, which will be described in the Chapter 4.

4 STUDY METHODS

4.1 Chapter overview

This chapter contains our protocol paper, published in BMJ Open in June 2017 (Volume 7, Issue 6). This chapter aims to provide a descriptive overview of the mixed-methods study used to generate pragmatic consensus-based minimum standards and structured interview for the selection and development of cancer support group leaders. This chapter clearly outlines the study objectives and accepted qualitative and quantitative methodologies used, which were: a systematic literature review and qualitative synthesis; online Delphi study; pilot and field testing. Details and results of each study will be expanded on in subsequent chapters of this thesis.

Given the project's strong need for outputs to be useful, acceptable, and accessible, it was determined that a protocol paper would be the most appropriate way to communicate this information. Previous research has suggested that there is a positive relationship between a research protocol and overall quality and acceptability of the resulting research study (Ott, 1991). Publishing a protocol allowed for the study documentation process to be disseminated to others working in the field to assist with the uptake of the structured interview and future development of the structured interview. Additionally, it was hoped that methods used for this study could be shared and applied more generally to non-cancer specific community-based support groups. Please refer to Appendix 28 for details on peer reviewer comments and responses.

BMJ Open

Pragmatic, consensus-based minimum standards and structured interview to guide the selection and development of cancer support group leaders: a protocol paper

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ABSTRACT

Introduction Across the globe, peer support groups have emerged as a community-led approach to accessing support and connecting with others with cancer experiences. Little is known about qualities required to lead a peer support group or how to determine suitability for the role. Organisations providing assistance to cancer support groups and their leaders are currently operating independently, without a standard national framework or published guidelines. This protocol describes the methods that will be used to generate pragmatic consensus-based minimum standards and an accessible structured interview with user manual to guide the selection and development of cancer support group leaders.

Methods and analysis We will: (A) identify and collate peer-reviewed literature that describes qualities of support group leaders through a systematic review; (B) content analyse eligible documents for information relevant to requisite knowledge, skills and attributes of group leaders generally and specifically to cancer support groups; (C) use an online reactive Delphi method with an interdisciplinary panel of experts to produce a clear, suitable, relevant and appropriate structured interview comprising a set of agreed questions with behaviourally anchored rating scales; (D) produce a user manual to facilitate standard delivery of the structured interview; (E) pilot the structured interview to improve clinical utility; and (F) field test the structured interview to develop a rational scoring model and provide a summary of existing group leader qualities.

Ethics and dissemination The study is approved by the Department Human Ethics Advisory Group of The University of Melbourne. The study is based on voluntary participation and informed written consent, with participants able to withdraw at any time. The results will be disseminated at research conferences and peer review journals. Presentations and free access to the developed structured interview and user manual will be available to cancer agencies.

Strengths and limitations of this study

- Novel and robust method for developing a structured interview using an interdisciplinary panel of experts.
- Protocol designed to be feasible, acceptable and valid in a community setting.
- Development of the first pragmatic and consensus-based minimum standards for the selection and development of cancer support group leaders.
- Studies described in the protocol will not ascertain competency level of the support group leader once in the role nor address cross-cultural adaptation of the structured interview.
- Self-reporting of knowledge, skills and attributes by potential group leaders is subjective and may be incorrect, incomplete or biased.

INTRODUCTION

The number of cancer cases across the globe has grown rapidly, along with improved survival due to increased rates of early detection and better access to effective treatment in developed countries.[1] With no centralised registry, the exact number of peer support groups for cancer survivors led by peers is unknown but thought to be considerable. Peak cancer agencies have established relationships with support groups in an effort to sustain and strengthen delivery of peer support. Agencies across the globe have extended funding, training, resources and support staff to independently run groups, with leaders being the primary point of contact. For those who either access support groups or recommend them as a low-cost psychosocial support, having a trained group leader is thought to be an important component to a group's effectiveness.[2] However, challenges have been reported in maintaining quality of life and burn out in group leaders who are mainly volunteers, often with a diagnosis of cancer themselves. The ability of the individual to function within the role and maintain this role over a period of time is important for group sustainability.[3] However, little is known about the essential qualities of

group leaders or how to determine a person's suitability for the role.[4]

Initial scoping revealed the lack of a relevant role analysis or, indeed, any detailed synopsis of the knowledge, skills and attributes required for the cancer support group leader role. It also failed to uncover published guidelines, standards or tools to guide the selection and development of leaders of cancer support groups, yet these are needed to inform policy and practice within and across organisations involved with these groups.[4] Given the very specific nature of the cancer support group leader role, a rigorous, robust and systematic approach to the development of minimum standards and a tool to assess suitability and readiness to undertake the support group leader role based on these standards is warranted. As a first step, *minimum* standards, rather than *best practice* standards, are needed to enrich the quality of support being delivered in the community by existing group leaders. Additionally, any tool to assess suitability and readiness will need to balance contextual demands (ie, the reality that most peers are volunteers and the fact that resourcing for selection and development are limited) against psychometric demands (ie, the validity and reliability of the interview). This protocol seeks to describe and justify the methods that will be used to develop pragmatic, consensus-based minimum standards and a structured interview with user manual to guide the selection and development of cancer support group leaders. Here, the intended aim of better selection and development is to enhance the experience of both group leaders and members and to maximise the sustainability of cancer support groups in the community.

In the absence of a single agreed approach to developing minimum standards, this study drew on methods used by the International Society for Quality of Life Research (ISOQOL) to develop minimum standards for the design and selection of patient-reported outcome measures for use in patient-centred outcomes and comparative effectiveness research.[5] These methods were considered appropriate for at least three reasons. First, the authors employed a compatible definition of a minimum standard, with a focus on the identification of critical attributes and judgements of suitability. Second, the approach described facilitated identification of *best practice* standards in addition to *minimum* standards. Third, many of the identified standards for patient-reported outcome measures are relevant to the design of structured interviews.[6] As such, these standards will be given consideration when developing the structured interview, for example, the knowledge, skills and attributes to be revealed by interview questions (content validity), the interpretability of scores and interviewer–interviewee burden.

A structured interview assessing role-related dimensions was considered the selection technique of choice for at least three reasons. First, interviews are a popular selection technique,[7] so most organisations likely to use this tool will be familiar with the interview process. Second, compared with other selection techniques, interviewees perceive interviews as fair.[8] Interviews are also seen as an expected part of the selection process.[9] Third, compared with 'unstructured' interviews, judgements based on more highly structured interviews are more predictive of job performance,[10] where structure refers to any enhancement that increases standardisation of the interview content and evaluation. According to Campion *et al*,[6] there are 15 components of structure that can be manipulated to increase the validity of interviewer evaluations. More recently, however, Dipboye *et al* in 2004[11] described a tighter conceptual framework corresponding to the life cycle of an interview, which includes interview development, conduct and evaluation. Validities can be maximised by enhancing: job-relatedness (or role-relatedness) in the development of the interview; standardisation of process in the conduct of the interview; and increasing structure in the use of the data for interviewee evaluation and decision making. Increasing structure in the use of data can be achieved by utilising behaviourally anchored rating scales, formal (or statistical) methods for combining ratings and consistently applied decision rules. In this study, we will aim to optimise all three dimensions in our structured interview.

Finally, the interview will incorporate assessment of both suitability and readiness; prior experience as a group leader is likely to be the exception rather than the rule, so it seems unreasonable to expect those who seek to undertake the group leader role to be ready at the outset (ie, have all requisite knowledge, skills and attributes).

To enable broad uptake and integration into routine practice, the minimum standards and structured interview need to be readily understood, appropriate and acceptable to end-users.[12 13] Aspects of clinical utility—including appropriateness, accessibility, practicability and acceptability[14] —will be considered and appraised at various stages throughout the project.

STUDY OBJECTIVES

This study aims to:

1. identify and summarise literature describing qualities of cancer support group leaders
2. identify minimum and best-practice standards for the role of a cancer support group leader
3. produce, in draft form, a structured interview designed to assess the knowledge, skills and attributes of individuals who seek to undertake the cancer support group leader role
4. produce, in draft form, a user manual to facilitate standard delivery of the structured interview
5. pilot test the structured interview to appraise aspects of clinical utility including usability and acceptability to end-users
6. field test the structured interview and use results to establish a rational scoring model and produce preliminary data on the knowledge, skills and attributes of current cancer support group leaders

7. disseminate guidelines and minimum standards to audiences in academia and cancer agencies for uptake.
8. have an accessible study protocol to facilitate knowledge transfer and assist others to further develop the structured interview.

STUDY OUTPUTS

We aim to generate three main outputs:

1. pragmatic, consensus-based minimum standards for the role of a cancer support group leader
2. a structured interview to guide cancer agencies involved in the selection and development of support group leaders
3. a user manual for cancer agency workers conducting the structured interview.

METHODS AND ANALYSIS

Study design

Systematic literature review, online reactive Delphi study, as well as a pilot and field test of the structured interview undertaken between 2014 and 2017 (figure 1).

Systematic literature review

Systematic reviews are routinely used in healthcare to ensure justification for further research and as a starting point for developing clinical practice guidelines.[15] In this study, we will undertake a systematic review as part of a job (or role) analysis, that is, 'a thorough and systematic analysis of the job for which the candidate is being considered' (ref 11, p. 300). Possible task dimensions and the knowledge, skills and attributes (or qualities) required to successfully undertake the role will be the focus of this review. A role analysis is crucial to the design of a structured interview, including its questions and rating scales. It provides an 'analysis of the fundamental behavioural dimensions underlying this content' (ref 11, p. 300) and, as stated above, the predictive validity of interviewer evaluations may be enhanced by ensuring the role-relatedness of interview content.[16 17]

Consultation will occur with a specialist librarian to identify appropriate electronic databases and publication dates and to generate combined subject heading and text word searches to maximise scope and increase relevancy. The PRISMA statement, checklist and flow diagram will be used to optimise the review. PROSPERO format will be followed for the systematic review; however, as the study is not intervention focused, it does not meet eligibility criteria and therefore will not be registered.

Inclusion and exclusion criteria will be set by the research team to ensure the content derived from the literature is relevant to adult peer support groups in health settings. All citations identified through database searches and reference lists will be reviewed by an author and screened for eligibility. Any uncertainty regarding eligibility will require review and discussion with a second coauthor. At a minimum, data extracted from eligible documents will include year of publication, country, study design, method, group type, sample description, group leadership and group leader qualities. Summarising content analysis will be used to analyse eligible documents for content relevant to qualities of support group leaders. All extracted data will be entered into an Excel spreadsheet, then imported into R (reference index V.3.1.3 or higher) for analysis and graphing; the R package 'ggplot2' will be used to prepare graphs.[18] Descriptive statistics will be used to summarise data from all eligible documents and by group type (cancer or non-cancer and mixed). The output of this phase will be a provisional list of requisite knowledge, skills and attributes that will feed into the next stage of the project—the online Delphi study.

To ensure the breadth of content relevant to and representative of knowledge, skills and attributes required by cancer support group leaders, the review will include a wide range of research studies (ie, qualitative, quantitative and mixed methods) and then be synthesised qualitatively. Thematic synthesis will be used to formalise the identification and development of themes. This method can be applied to systematic reviews that address questions about people's experiences and perspectives.[13]

Online Delphi study

The purpose of the Delphi technique is to enable reflection and discussion among a panel of experts with a view to getting as close as possible to consensus and documenting both the agreements reached and the nature and extent of alternative opinions.[19] In this study, an online reactive Delphi method will be used to obtain expert agreement on the minimum standards (or qualities considered essential to the role) and the content and structure of the structured interview. In the development of highly structured interviews, subject-matter experts are usually engaged to provide input into the analysis of the role for which candidates are being considered,[11] in this case, to judge the importance of putative task dimensions and the knowledge, skills and attributes required in the support group leader role. Their opinion is sought on the boundaries of the behavioural dimensions as well as the knowledge, skills and attributes crucial to performing well on each dimension.

Influential factors on the quality of the Delphi process include: composition (expertise, diversity) of the expert panel; selection of background literature and evidence to be discussed by the panel (validity, representativeness and completeness); adequacy of opportunities to read and reflect (balance between accommodating experts' time limitations and keeping the study to a timeframe); qualitative analysis of responses (depth of reflection and articulation of key issues); quantitative analysis of responses (accuracy and appropriateness of statistical analysis and clarity in feedback); and how difference and ambiguity are treated (avoidance of 'group thinking').[19 20]

Evidence suggests that an online medium is more likely to improve quality of the consensus development process.[20]

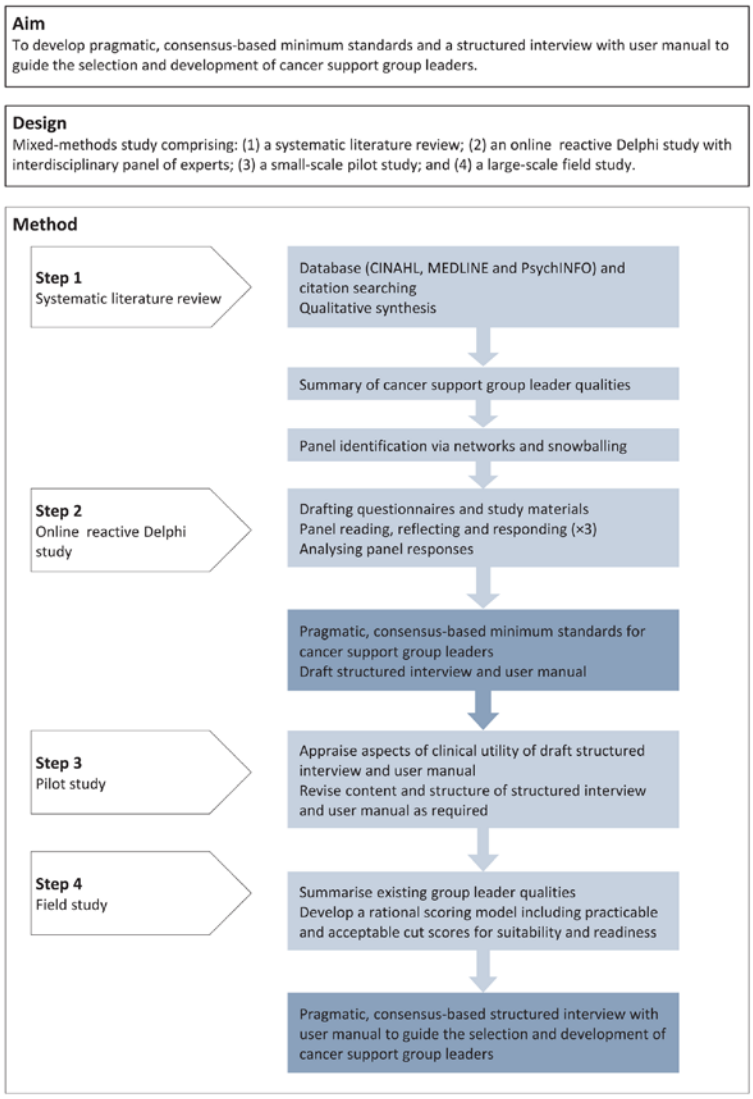

Figure 1 Overview of protocol study aim, design, methods and outputs. A flow chart outlining the four mixed-method study steps, to be undertaken from 2015 to 2017, to develop pragmatic consensus-based minimum standards and a structured interview to guide the selection and development of cancer support group leaders. Boxes coloured in dark steel blue represent these study outputs.

In addition, online communication has well-established benefits in promoting construction of knowledge and reflection.[21] There are also examples of successful online Delphi studies conducted across geographical locations of participants.[19 22] This is of particular importance for this study, as participants are likely to be dispersed across the country. Reported benefits also include no cost and flexibility for participants with scheduling completion of responses.[23]

Given the broad range of participant perspectives and likely large number of knowledge, skills and attributes to be considered in Delphi rounds, an acceptable range of consensus will be required. The definition of consensus for this study is 75% agreement.[24–26]

During the Delphi study, based on content from the systematic review and previous Delphi rounds, the research team will determine the appropriate presentation of data, estimate time needed to collect data, analyse and feedback the results to participants and how to enhance response rates.[19 27]

Panel participants

A key component of a successful Delphi process will be to include different perspectives by recruiting a wide range of experts involved in the research, referral, support and delivery of cancer support groups. Expert panel participants will be from Australia and purposely selected by the research team through professional networks and snowballing,[28] when participants suggest other potential participants. The Delphi panel will include experienced academics, health professionals, cancer agency workers and cancer support group leaders. Individuals also will be identified during the initial consultation phase of the project with various stakeholders relevant to the cancer support groups. Experienced support group leaders will be identified from current support group listings of three peak cancer agencies. A minimum of 10 is considered acceptable for a Delphi study.[29] To ensure equal representation across expert groups, this study aims to recruit around 30 participants.

Delphi rounds

The Delphi panel will be conducted anonymously and entirely via email. Sequential rounds of questionnaires will be developed, with set completion periods in order to allow for feedback integration and progression to the next round. Consent will be assumed if participants email completed questionnaires back, with responses to be saved electronically and coded and deidentified. In order to create a structured interview applicable across all cancer types, questions will not be specific to a particular cancer type. As required, participants' responses to each Delphi round will be entered into an Excel spreadsheet, then imported into R (reference index V.3.1.3 or higher) for analysis and graphing. Descriptive statistics will be used to summarise participants' responses. Summarised results will be returned to participants in the form of another questionnaire.

Round 1

Round 1 will consist of a questionnaire with an initial pool of requisite knowledge, skills and attributes of support group leaders deduced through the systematic literature review. Panel members will be asked to give their opinion about each quality, expand on the content and identify additional knowledge, skills and attributes to ensure the pool is relevant to and representative of qualities required in the cancer support group leader role. Second, experts will be asked to identify attributes or qualities that would automatically exclude someone from being a group leader. Responses will be summarised in a set of provisional statements, listed in a table and sent to participants for ranking (round 2).

Round 2

The second round will canvass opinions and reach consensus on key cancer support group leader qualities. This set of qualities will form the minimum standards; these will be used to develop the structured interview (described as part of round 3). Participants will be asked to confirm the relevance of listed knowledge, skills and attributes for the support group leader role. The purpose of this round will be for experts to determine what knowledge, skills and attributes of support group leaders are required or considered essential to undertake the role, compared with what qualities are ideal. An acceptable range of consensus will be based on 75% or more agreement by experts for each attribute (eg, individual knowledge, skills and attributes).

Round 3

A structured interview will be drafted by the research team with the aim of optimising the predictive validity and reliability of interviewer evaluations. We will do this by: ensuring good coverage of consensus qualities (or role-relatedness of the interview); ensuring a mix of questions (ie, situational, behavioural and experience), constraining phrasing of questions and limiting the use of follow-ups and probes (or standardisation of the interview process); and using behaviourally based rating scales (or structured use of data to evaluate candidates).[11] The draft structured interview will be distributed to the expert panel and will form the basis of a third Delphi round. This will include questions assessing: the technical quality of structured interview questions; the suitability of limited probes; proposed ratings for each answer; and the technical quality and appropriateness of behaviourally anchored rating scales. The panel will be asked to assess whether the interview is clear, suitable, relevant and appropriate. Separation and categorisation of knowledge, skills and attributes required for selection purposes compared with development needs will also be confirmed in this round.

Development of the user guide

Usability has the potential to impact on the usefulness, effectiveness, efficiency, learnability and satisfaction users can achieve with a particular product or service.[30] One objective of this study is to produce a publicly and freely accessible user manual to support the uptake and delivery of the interview by cancer agencies. Taking into account the format and orientation of other comparable materials, we will develop a user guide to increase ease of use and standardisation of the interview process. Development of a user guide is also intended to be a pragmatic way of providing interviewer training.

It is suggested that the rating scale used be as simple as possible, well defined and with the ability to identify development areas.[30] For example, a rating scale could be

an ordinal-level scale (eg, experienced, intermediate and not suitable) or as simple as acceptable or unacceptable. Therefore, an orientation or training for interviewers is highly recommended. Given the practical and time constraints on potential users to access training or support to learn and understand the structured interview, the research team decided to develop a user manual to accompany the structured interview employing usability methods to ensure optimum usability.[30]

A set of instructions will be developed on the use of the structured interview—its questions, probes and behaviourally anchored rating scales—consistent with Campion *et al* to reduce subjectivity and inconsistency. The background and purpose of the interview will be outlined, along with rapport-building techniques. How to ask questions and how to probe further will be explained. Instructions on how to record and evaluate answers will be given as well as how to use the rating scale. Interviewers will be directed to focus on descriptions rather than judgements and facts rather than opinions. The importance of note taking will be stressed to provide documented evidence of the interview and objective rating of responses. How to avoid potential rating errors will be outlined such as: first impressions, contrast effect and personal bias.

Development of effective instructions will increase consistent application of the interview and allow interviewers to evaluate potential group leaders from a common reference point. The structured interview and accompanying user guide have been developed as a stand-alone measure for selecting and developing group leaders, based on agreed minimum standards. However, we anticipate that these resources may need to be adapted and perhaps supplemented by cancer agencies based on their own organisational needs and requirements.

Pilot testing

A small-scale pilot study will be conducted to appraise aspects of clinical utility including usability and acceptability to end-users. Three cancer agency workers who have direct contact with cancer support groups will be recruited to conduct the interviews. Workers will be selected from different cancer agencies. Workers will be asked to read the user manual and familiarise themselves with the structured interview schedule and standard form for documenting interview responses. Cancer agency workers will record and rate support group leaders' responses using the standard form, with interviews audiotaped. A total of 12 current support group leaders will be recruited via three peak cancer agencies. Leaders will also be asked to take part in a telephone-based interview.

After conducting the newly developed structured interview, cancer agency workers will be asked to provide feedback on their experience through semistructured interviews with a member of the study team (AP). Feedback will be solicited on the ease of use, time involved, selection process, potential barriers to implementation and likelihood of using the structured interview in their current practice. Interviews will not be transcribed, but notes will be taken by the researcher during the interview. Responses will be synthesised and then used to review the tool to determine what components worked well and what should be further improved. Results obtained by the cancer agency worker regarding the participants' suitability and readiness for the group leader role will be cross-checked by the researcher. This will involve the researcher (AP) listening to the audio recording of each pilot interview and comparing scores with that of the pilot interviewer. Format, questions and instructions will be revised as required.

Field testing

A large-scale field test will be undertaken for two main purposes: to provide a summary of existing group leader qualities and to develop a rational scoring model. In more structured behavioural interviews, the interviewer provides numerical ratings on each of several dimensions and the interview is 'scored' by statistically combining the interviewer's ratings. Therefore, the use of statistical combinations of data, rather than clinical predications, to form judgements yield better results.[11] In this case, the knowledge, skills and attributes of current support group leaders will be used as a benchmark to appraise the reasonableness of behaviourally anchored rating scales to interview questions. They will also be used to establish appropriate and acceptable cut scores for suitability and readiness.

Current cancer support group leaders will be recruited through three peak cancer agencies that support cancer support groups and cancer support group leaders. A network of leaders from 170 prostate cancer support groups and over 300 breast cancer support groups will be invited to participate in the field testing. Structured interviews will be conducted over the phone by cancer agency workers from collaborating cancer agencies. Participation will be voluntary and anonymous. Interviewers will be asked to complete interviews, approximately 10 to 20 interviews each. Support group leaders will be asked a small number of questions for the purposes of characterising the study sample before taking part in the structured interview (eg, age, gender, support group type (breast, prostate) and time as support group leader).

Support group leaders' responses to demographic questions and interviewers' ratings to interview questions will be entered into an Excel spreadsheet, then imported into R (reference index V.3.1.3 or higher) for analysis and graphing. Descriptive statistics will be used to summarise sample characteristics and participants' responses to the structured interview questions. This will be done for the full sample and by support group type (breast and prostate). Interviewer ratings to interview questions along with interviewer ratings of suitability and readiness will be used to determine appropriate and acceptable cut scores.

DISCUSSION

Despite substantial numbers of peer-based cancer support groups being in operation, there are currently no existing guidelines or minimum standards relevant to the selection and development of group leaders. A pragmatic, consensus-based structured interview with user manual may help organisations rationalise the provision of support and assistance to cancer support group leaders. In addition, establishment of consensus-based minimum standards may help reduce concerns of clinicians and potential barriers in referral pathways.

The proposed study will use accepted qualitative and quantitative methodologies—a systematic review and qualitative synthesis, a Delphi study with an interdisciplinary panel (three rounds) along with pilot and field testing—to develop clinically relevant and acceptable minimum standards and a means to implement these standards in the selection and development of cancer support group leaders. We hope the use of these outputs will lead to greater consistency, equality and targeted use of limited cancer agency resources available to support cancer support groups. We also believe our approach and outputs (minimum standards and structured interview) could be used or adapted for other healthcare or community settings where peer support groups are in operation.

CONCLUSIONS

The development of pragmatic and consensus-based minimum standards is an important first step in building a framework for support group leader selection and development. The aim of this study is to assist cancer agencies in their selection and development of support group leaders and lead to greater consistency and equality across agencies. It is recognised that due to the varying types of support groups, along with different relationships and supports provided by cancer agencies to support groups, it would be detrimental to be overly prescriptive about what must be covered in the application of the standards. Instead, these standards are intended as a starting point with the need for ongoing review and development. It is also hoped that following field testing, further research is undertaken to determine the appropriateness of the content and structure in other countries. By contributing to the model of peer support in this way, it is hoped that we can optimise the value of the cancer support group experience for leaders and group members.

ETHICS AND DISSEMINATION

All procedures proposed in this study involving human participants are approved by the Department Human Ethics Advisory Group, Melbourne School of Psychological Sciences, The University of Melbourne, Victoria, Australia (Minimal Risk application 1443027.1). Informed consent to participate in the study to be obtained from participants as outlined in approved application. The three main study outputs will be reported in publications and conference presentations, with final versions of the structured interview and user manual freely accessible to cancer agencies. Consideration will be given to transferability of outputs to different cancer groups (eg, different disease types and stages, and different genders).

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Competing interests None declared.

Patient consent Ongoing protocol study with data collection yet to be obtained from participants. The University of Melbourne consent form template will be used in accordance with ethics approval.

Ethics approval Department Human Ethics Advisory Group, Melbourne School of Psychological Sciences, The University of Melbourne.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement As this protocol study is ongoing, data from the study is not currently available. Once study has been undertaken, any additional unpublished data can be accessed from the corresponding author.

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5 SYSTEMATIC REVIEW AND QUALITATIVE SYNTHESIS OF SUPPORT GROUP LEADER QUALITIES

5.1 Chapter overview

Chapter 4 introduced the use of a systematic literature review as a study method for this project, as contained within the protocol paper. This chapter will focus on the first stage of the project, being the systematic literature review and qualitative synthesis. The chapter will consist of a systematic review paper published in *Patient Education and Counseling* in May 2016 (Volume 99, Issue 5). The aim of the systematic review was to identify and collate peer-reviewed literature describing qualities of support group leaders as part of a role analysis.

To understand what would make someone suitable for the role, we looked for three types of basic competency categories relevant to and representative of the support group leader role. The three categories were knowledge, skills, and attributes. The category of ‘knowledge’ refers to particular knowledge that can be applied to support group activities undertaken by the leader, for example understanding confidentiality. The category of ‘skills’ refers to abilities needed to execute role duties, such as listening. The category of ‘attributes’ refers to characteristics that a group leader must display in the role, such as being warm. Knowledge, skills, and attributes needed to undertake the role were then able to be separated into two areas: selection of peer group leaders, and development of peer group leaders already in the role. Overarching themes across the three categories are referred to as ‘qualities’. Information gleaned from this literature review was crucial for collating role-specific content to assist the expert panel in the online

Delphi study outlined in Chapter 6. Please refer to Appendix 29 for details on peer reviewer comments and responses.

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Review article

Skills, knowledge and attributes of support group leaders: A systematic review

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ABSTRACT

Objectives: A systematic review and qualitative synthesis was undertaken to deduce requisite knowledge, skills and attributes of cancer support group leaders.
Methods: Medline, CINAHL, and PsychINFO databases were used to identify relevant literature. Inclusion criteria were made deliberately broad after pilot searches produced too few documents and included: adult group leaders who were volunteers, peers or professionals; published in English from database inception to February 2014. Data was extracted on: year of publication; country of authors' origin; study design (if relevant) and methods; group type and group leadership; sample description; and leader qualities.
Results: Forty-nine documents met inclusion criteria. Fourteen reported on cancer groups, 31 on non-cancer groups (including four mixed groups) and four did not specify group type. Seven qualities were deduced including group management, group process, role modelling, awareness, willingness, agreeableness, and openness. These were consistent across group type and group leadership.
Conclusions: Findings may be relevant to a general model of peer group support and can inform the development of a practical and realistic minimum standard for support group leadership in healthcare.
Practice implications: Results can be used to help cancer agencies manage relationships with group leaders. Knowledge of requisite qualities may inform selection, training and support.

Contents

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1. Introduction

Cancer is set to become the major cause of morbidity and mortality in the next few decades in every region of the world [1]. With population growth and aging, new cancer cases are expected to reach 22 million in 2030. Survival rates have improved due to increased rates of early detection and better access to effective treatment in high-income countries. The experience of a cancer diagnosis and treatment is also changing; consideration needs to be given to reproductive factors, regional and economic diversity, psychosocial care and management of long-term effects. Around the world, health care systems are struggling with rising costs, and unsatisfactory and uneven quality of care [2]. There is a clear need for improved outcomes that matter to patients and survivors relative to the cost of achieving those outcomes [2]. The focus is moving towards meeting the psychosocial care needs of patients and families across the health trajectory [3]. Significant and swift action is required to develop or adapt solution-based approaches that engage those impacted by cancer with community-based supportive care.

In the 1960s, descriptive case studies of peer support first emerged in the literature. Chambers et al. [4] identified six theoretical approaches (or models) that are specifically relevant to how peer support is expressed and consumed: social support, the helper-therapy principle, experiential knowledge, social learning theory, social comparison theory and social identity theory [4]. The essence of peer support is people seeking out interactions with others who have a similar experience, often as a way of comparison to establish a sense of normalcy (social comparison theory) [5]. Social support theory can further be used to explain how peer support encompasses emotional, practical and informational support in a way that facilitates adjustment and engagement in active coping strategies [6]. Peers with shared experience are perceived as more credible role models (social learning theory) [7], with specialised information and perspectives (experiential knowledge) [8]. With significant life experiences, such as cancer, disruption of one's identity can occur and therefore the groups in which individuals perceive membership to can be derived from these experiences. Part of an individual's self-concept can therefore be derived from membership of a particular peer group [9], with peer support offering a real sense of belonging and identity (social identity theory). Additionally, many who engage in peer support express their desire to help others (the helper-theory principle) and satisfaction with developing interpersonal relationships [10]. However, as yet there is not a specific or all-encompassing model developed for peer support.

Effectiveness of peer support in the context of cancer has begun to be explored through literature reviews. Peer support programs have been found to provide informational and emotional support benefits [11,12], improved wellbeing [13] and high level of satisfaction [14]. Evidence for effectiveness, however, is limited, with challenges in isolating dynamics and other sources of variation. It could be argued that the context in which peer support operates and how it works is not easily defined or measured. In addition, effectiveness of peer support has focused on delivery of programs or one-to-one support, which is different to peer support groups.

The evolution of group work spans several behavioural science disciplines, with most theory grounded in professional delivery of psychotherapeutic and educational programs. In response to the need for support during the lived experience of cancer, support groups have developed somewhat organically over time and make up part of the broader category of self-help groups.

Theme-centred groups, such as cancer support groups, are considered to be a particularly useful intervention; groups may complement individual treatment and are a cost effective means of delivering support within the broader health care system. General cancer support groups are the most common type of support group, followed by breast and prostate cancer support groups [15]. The purpose of a peer-based support group is to allow a safe place to connect and share with others who have been or are going through a similar experience [16]. Peer groups adopt certain aspects of psychotherapeutic and education programs, but should not provide therapy or education. Members of cancer support groups seek to help themselves and each other to reduce the negative or disabling effect that cancer may have on general health, relationships, coping abilities and daily functioning. More often than not, group leadership is provided voluntarily, mostly by those with a personal experience of cancer.

Group leaders are typically self-selected, and motivated by the desire to help others, while at the same time placing themselves into a role they may know very little about [17]. Within the group, leaders have a considerable amount of power, prestige, responsibility and status, with many not able to manage or even recognise these factors [18]. Not surprisingly, alongside the many benefits, leaders have reported a range of difficulties associated with cancer support group leadership. For example, some struggle to deal with issues like difficult and demanding personalities, maintaining adequate group numbers, disease progression, and death [19,20]. Challenges in maintaining their own quality of life and avoiding burnout are not uncommon, and these issues can contribute to the termination of groups [17]. Difficulties, however, are often outweighed by the rewards. Rewards include feeling part of members' lives, own self-development, and being part of the process that helps members' adjustment and empowerment following a cancer diagnosis [20]. Arguably, the experiences of group leaders, both positive and negative, may be related to some or all of the qualities group leaders bring to the role. But, to date, there has been little focus on the nature of the role itself and who is best suited to it.

While unknown, the total number of support groups in operation globally is thought to be considerable. For example, Macmillian Cancer Support in the UK is linked to over 900 support groups. And, the American Cancer Society is currently developing cancer support networks to provide support to face-to-face, phone and online communities. Many groups, however, operate without formalised structures, policies and procedures. Currently, then, support groups may be an under-acknowledged and under-developed resource in public health. Within Australia, peak cancer agencies have been working to establish relationships with independently run support groups. In recent times, funding, training, resources and support staff have been made available to group leaders as a way of strengthening the delivery of support provided by groups. If support groups are to be formally recognised as one of many solution-based approaches to the delivery of cancer care, further investigation is needed to address the question: who should lead support groups? More specifically, what are the requisite knowledge, skills and attributes of leaders of cancer support groups? There is a clear need to establish an evidence-based framework to inform the selection process of group leaders seeking legitimacy, funding or support from external agencies, regardless of whether the role is undertaken in a paid or volunteer

Table 1
Summary of papers and theses meeting eligibility criteria for inclusion in the review.

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
Butow 2005 Australia [25]	Mixed	Qualitative: observation and focus groups Quantitative: cross-sectional survey via phone interview or self-report survey	Cancer	Peer, professional and mixed	Leaders (n = 176 of 184 groups in New South Wales, Australia) and group members (n = 416) from 47 of 50 randomly selected groups in quantitative component; and members of 9 groups in qualitative component	GM	Organisation
						GP	Giving enough opportunity for members to talk; welcoming new members & helping them settle in
						A	Understanding of how things have been for members
						W	Availability outside of group
						Agree	Caring; charisma; humour
						O	Enthusiasm
Butow 2007* Australia [26]	Quantitative	Cross-sectional survey	Cancer	Peer, professional and mixed	Group members (n = 417) from 47 of 50 groups randomly selected from 176 groups in New South Wales, Australia	GP	Leader allowing people enough time to talk
						RM	Provision for ethnic or cultural diversity
						A	Understanding
						Agree	Empathy
Cella 1993 USA [27]		Narrative review	Cancer	NA	NA	GM	Use consensus decision making; be well informed to help guide exploration of ideas
						GP	Guide others with constructive processes
						RM	Offer reinforcement, guide others with realistic optimism
						Agree	Non-authoritarian; humour to balance the seriousness
Fobair 1997 USA [28]		Theoretical exposition	Cancer	Professional and mixed	NA	GM	Intervene with community agencies on the group's behalf; number of leaders, knowledge & experience; review work accomplished; seek feedback
						GP	Offer supportive responses; reduce anxiety and regression; help members understand and master material; focus on the needs of the group as a whole; encourage self-disclosure, validate and get members to talk; intervention approach; launch meeting & orient new members; define group task; guide group as it addresses & feelings;
						A	Not become over identified with individual group members
						W	Willing to talk about themselves & discuss personal issues openly; have the time required;
						Agree	Attentive; warm; respectful; human; empathy; genuineness, sympathetic; non-judgemental
Galinsky 2008 USA [29]	Quantitative	Narrative review Cross-sectional survey	Cancer	Professional	Leaders (n = 20) in a state-wide sample of members of a community organisation	GM	Medical knowledge or accessibility to medical professionals; provide structured exercises/activities;
						GP	Provide direction, deal with problems & negative effects; utilise group problem-solving; group work; understanding support group and its group process; deal with effects of group issues
						A	Emotional distance to maintain balanced perspective; individual

Table 1 (*Continued*)

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
							member contact; assess constructive/deconstructive potential of group issues
Kirsten 2006 Australia [30]	Qualitative	Focus groups and interviews	Cancer	Peer or professional	Leaders from 27 of 34 groups out of 173 groups in New South Wales, Australia	GM	Administrating & facilitating tasks
						GP	Actively intervene in group interactions using summarising, refocusing and re-framing skills
Matsunanga 2004 USA [31]	Qualitative	Interviews	Prostate cancer	Peer	Group members (n = 24; 17 of whom were of Asian or Pacific Islander ancestry)	GM	Extensive social networks in community; involve people; attention to details & follow through;
						A	Recognise the various ways members can participate; identify commonalities/difference amongst members
						W	Having the time to dedicate
						Agree	Charismatic; genuine; caring; informal; personal approach
Noeres 2013 Germany [32]	Quantitative	Cross-sectional survey	Breast cancer	Peer	Leaders (n = 390) and group members/women with breast cancer (n = 337)	GM	Organising the knowledge transfer; sourcing information from other support groups/ patients/specialists/print media; administration
						RM	Motivate learning through experience
						W	High level of commitment
Oliffe 2008 Canada [33]	Qualitative	Ethnographic fieldwork and participant observation	Prostate cancer	Not specified	Meetings of 15 groups in 2005–2006	GM	Manage organisation and promotion of group; recruit guest speakers; provision of information; cohesive and shared leadership
						GP	Meeting diverse individual needs at meetings; establish rapport and camaraderie; facilitator strategies
						W	Commitment to the group for define term
						Agree	Engaging
Owen 2009 USA and Canada [34]	Mixed	Qualitative: thematic analysis of supervision transcripts Quantitative: cross-sectional survey	Cancer survivor and family	Professional	Leaders of face-to-face groups (n = 29) and leaders of online groups (n = 11)	GP	Promote & pace discussion; ethical concerns
						O	Adapt to uncertainty & environment; creativity
Price 2006 Australia [35]		Narrative review	Cancer		Eight articles focused on small groups meeting for health related education, support and/or improving coping skills	GM	Understanding of what group members are experiencing; provide information; gain consensus from group; executive management; managing group tasks
						GP	Ensuring that everyone has opportunity to talk; encouraging group cohesion & structure; moderate potential difficulties; nurturing positive group environment & managing interactions and group focus; evoke participation; meaning, structure, focus of interaction; summarising, refocusing and providing a framework for concepts to understand dilemmas; actively intervene in group in group interactions; establish clear & compelling

Table 1 (*Continued*)

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
							goals; engaging members; recognising all members have needs to be met
						A	Uses self to reveal own feelings & beliefs; not dominating the group; being able to self-monitor; communication behaviours
						Agree	Personality of leader; nurturing; supportive; inspiring confidence
						O	Flexible
Stevinson 2010 UK [36]	Quantitative	Cross-sectional survey	Cancer (mainly breast and prostate)	Peer or professional	Leaders (n = 315) recruited via cancer organisation, representing all regions of the UK		
Stevinson 2011 UK* [37]	Quantitative	Cross-sectional survey	Cancer (mainly breast and prostate)	Peer or professional	Leaders (n = 315) comprising 264 of 443 groups, and group members (n = 841) of 172 groups	Agree	Loving; charismatic
Ussher 2006 Australia [38]	Qualitative	Interviews, observations	General cancer and cancer-specific	Peer or professional	Group members (n = 93; female = 73 male = 18) from 9 representative groups in New South Wales, Australia	GM	Sense of community through role
						GP	Facilitating open & caring atmosphere; sense of belong from group; allowing group to meet perceived needs of members
						Agree	Supportive
Calderone 1992 USA [39]	Quantitative	Cross-sectional survey	Bereaved parents		Leaders (n = 119) and group members (n = 642) from 79 groups affiliated with community organisations	GM	Affiliated with community support network; fit between member and group
						GP	Developmental phases of group; cooperation
						A	Unresolved anger of leader may affect group
						Agree	Friendliness; warmth; interest
Cerel 2009 USA [40]	Quantitative	Cross-sectional survey	Suicide survivors	Peer and unspecified	Leaders (n = 100; 78% survivors from publicly listed support groups)	GM	Suicidal members & follow up with members
						W	Undertake training in group skills
						Agree	Empathy
						O	Objectivity
Davis 1995 USA [41]	Qualitative	Narrative review Case study	Multiracial	Professional	NA	GM	Familiar with community resources
						RM	Cultural appropriateness and problem solving; care and respect
						A	Aware of racial tension in broader community/discrimination & individual concerns about difference; recognise critical racial, ethnic and cultural differences; group dynamics
Finger 1987 USA [42]	Qualitative	Case study	Families of people with amyotrophic lateral sclerosis	Professional	One group observed over 20 meetings (participant numbers ranged from 6 to 21)	GM	Provide information; juggling and redefining of roles within the group; knowledge/information on area of expertise; timing
						GP	Maintain safe environment; facilitate discussion& group interaction
						A	Group dynamics; self- knowledge
						Agree	Honesty; integrity; patience; courage; warmth; empathy
						O	Flexibility; intelligence
	Qualitative	Case study	AIDS			GP	

Table 1 (*Continued*)

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
Getzel 1993 USA [43]				Peer or professional	Leaders (n = 3) and group members (n = 27) of a single group observed across 2 1/2 years		Understanding group dynamics; provide safe environment; management of issues; helping members find solutions
Gonyea 1989 USA [44]	Quantitative	Cross-sectional survey	Alzheimer's	Peer, professional and mixed	Leaders (n = 47) and group members (n = 301)	GP	Permitting & enabling members to express emotions and explore the impact of the disease
Greif 2014 USA [45]		Theoretical exposition	Caregivers of people with Alzheimer's	Peer or professional	NA	GM	Refer to professional therapist; ask group members for suggestions; seek evaluation from members
						GP	Feelings of members carefully elicited & handled empathically; help people enter the group; introduce the purpose of the group; discuss confidentiality; work with group to help support each other
						RM	Normalise experiences
						A	Step back & allow the group to flow when functioning well
						Agree	Provide support in a kindly, non-confrontational and transparent manner
Halm 1991 USA [46]		Theoretical exposition	Family's of adults in ICU	Professional	NA	GM	Appropriately refer to professionals; identify topics for discussion
						GP	Awareness of group process; confidentiality; monitor & direct active involvement of members; encourage expression; sharing & mutual aid; foster process of effective help seeking & giving; intervene when members dominate discussions
Hepburn 1986 USA [47]		Theoretical exposition	Family caregivers of people with dementia	Not specified	NA	GM	Knowledge on topic & community resources
						A	Group dynamics; not assuming their way of thinking is best
						Agree	Warm; sensitive; caring
						O	Intelligence
Jackson 2002 USA [48]	Mixed	Qualitative: observation and interviews Quantitative: cross-sectional survey	Caregivers of people with dementia	Professional	Leaders (n = 102) interviewed, of which 66 of 77 groups were observed in qualitative component and group members (n = 296) in quantitative component	GM	Accurate information & practical strategies; co-facilitation; organisation; utilise resources; rotate leadership duties
						GP	Protect group members; balance needs of the individual members within the group; establishing a trusting caring environment; provide emotional support
						RM	Emphasizing strengths & coping mechanisms; effective interpersonal behaviours
						A	Separate own needs from the needs of the groups; knowledge of group behaviour
						W	Commitment to the self-help model
						O	Initiative
LaMore 2001 USA [49]	Qualitative	Case study	Alzheimer's	Professional	Not specified	GM	Co-leader; provide information; connect group to facilitate mutual aid

Table 1 (*Continued*)

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
						RM	Provide support
						A	Understand communication & interaction that occurs between individuals; be familiar with group's structure, function & processes
Lemberg 1984 USA [50]		Theoretical exposition	Self-help groups		NA	GM	Share responsibilities for maintaining the group; rotate leadership
						GP	Foster communication between members
						W	Allow own needs as leader to be met
						Agree	Honest & transparent
Lorenz 1998 USA [51]		Theoretical exposition	Bereavement	Professional	NA	GM	Providing information; screen participants for readiness & appropriateness; refer
						GP	Promote a sense of cohesion and safe climate; help members support one another; help members understand what to expect with ground rules
						A	Self-awareness, personal impact of loss; co-facilitation for mentoring & debriefing
						W	Ongoing commitment; contact individuals between meetings
						Agree	Empathy; sensitive;
Lund 1992 USA [52]	Quantitative	Longitudinal survey	Bereavement	Peer or professional	Group members who attended 8 weekly meeting ($n = 82$) and members who attended 10 monthly meetings in addition to the 8 weekly meetings ($n = 52$)	GP	Clarify purpose of the group; establishing norms; harnessing group pressure; guide and promote interactions; manage monopolising & silent members; create climate of safety; linking member communication; assist members explore personal goals; allow members opportunity to offer help
						RM	Leader modelling; listen and encourage; effective communication; praise
						A	Manage own contributions and not dominate; appropriate self-disclosure
						Agree	Empathic; authentic;
McFarland 2000 USA [53]	Qualitative	Narrative review Focus groups	Educational support group for male caregivers of people with Alzheimer's disease	Professional	Group members ($n = 11$)	GM	Knowledgeable about community resources; male & female differences;
						RM	Empowerment; same gender role model to provide hope
						A	Group dynamics
Monahan 1994 USA [54]		Theoretical exposition	Bereavement (AIDS)	Not specified	NA	GM	Knowledge/understanding of group issue; prepare a topic to focus discussion
						GP	Meet the needs of the group, general group skills; help bereaved understand what they are going through; discover options
						A	Awareness to flow with group's need's
Mowdy 1998		Theoretical exposition	Ostomy	Professional	NA	GM	Maintaining current knowledge; organising; evaluation of group

Table 1 (*Continued*)

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
USA [55]							effectiveness; practical consideration of physical accommodation, refreshments, meeting times
						GP	Facilitating the process of shared aid; promoting group cohesion; foster a safe climate; respect confidentiality and mutual respect; providing group structure
						Agree	Avoid assuming an authoritarian/ territorial/competitive position
Perraud 2004 USA [56]	Qualitative	Thematic analysis of group leader summaries of group sessions	Family caregivers of people with dementia		Group members (n = 177)	GM	Managing time
						GP	Promoting group connectedness; include less talkative members; covering missed information; encouraging activities such as sharing; providing structure & direction; managing negative behaviours; giving direction; establishing goals & purpose
						RM	Helping members to listen; providing emotional support; sense of belonging; reinforcing positive norm development; listens; commitment to the group
						W	Commitment to the group
						Agree	Supportive
Redburn 1989 USA [57]	Quantitative	Longitudinal survey and open-ended evaluations of training sessions	Bereaved widows	Peer	Leaders (n = 8), all female, recruited from a larger study	A	Physical health; variations in personal reactions & expressions; unresolved personal issues
Revenson 1991 USA and Canada [58]	Quantitative		Scoliosis self-help groups	Peer or professional	Leaders (n = 45)	GP	Group process skills to maintain & strengthen group
						W	Provide & receive support
Schwab 1986 USA [59]		Theoretical exposition	Bereavement	Professional	NA	GM	Referral; alert to potentially suicidal members
						GP	Facilitate process of interaction; allow opportunity to talk; identify member needs beyond what group offers
						A	Play secondary role; re-evaluate own practice & assumptions; gain deeper understanding of others & self
						W	Provide additional support to members outside of group
Steffen 2012 USA [60]	Mixed	Qualitative: observation and interviews Quantitative	Alzheimer's family support groups	Peer or professional	Leaders (n = 66) in qualitative component and group members (n = 296) in observation and quantitative component	GM	Proving issue specific information; arrive on time; set up room; provide printed material; refer to associating body; referral
						GP	Remind participants of group rules & guidelines; keep discussions focused
Stewart 2001 Canada [61]	Qualitative	Observation and interviews	Seniors with disabilities (telephone)	Peer or professional	Group members (n = 23) of four groups	GM	Communicating with participants before group is launched
						GP	

Table 1 (*Continued*)

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
							Process and facilitation; clarify who was speaking during discussions; guide group; encourage process; introduce & encourage others to identify topics; create comfortable environment
						A	Leadership balance
						Agree	Supportive
Terry 2006 UK [62]		Theoretical exposition	Breast-feeding support and postnatal depression	Professional	NA	GM	Obtain feedback; publicise group, network
						GP	Varied involvement in group dynamics; keep focus of the group; group work skills
						RM	Interpersonal skills
						A	Member interactions and behaviour; be non-intrusive
						W	Undertake training or support
						Agree	Supportive
						O	Enthusiasm; creativity
Thuen 1995 Norway [63]	Quantitative	Cross-sectional survey	Bereavement	Peer or professional	Group members (n = 164) recruited via community organisation	GP	Concerned about the group as a whole & social atmosphere; emotional support; group cohesiveness
						Agree	Caring; empathic
Toseland 1989 USA [64]	Mixed	Qualitative: interviews Quantitative: longitudinal survey	Female caregivers of a frail parent	Peer or professional	Group members who were adult daughters or daughters-in-law randomly assigned to one of three conditions: a professionally-led group (n = 18); a peer-led group (n = 18); and a respite only control (n = 20)	GP	Supportive interventions; encouraging ventilation of stressful experiences
						RM	Validation & confirmation of similar caregiving experiences; affirmation of members coping; praise for providing care, support & understanding for those struggling
						Agree	Supportive
Tregea 2013 Australia [65]	Qualitative	Ethnographic participant observations, focus group discussions and interviews, as well as written artefacts analysis	Aphasia	Peer	Leaders (n = 3) and group members (n = 23) from 4 groups	GM	Informational & practical support; organisation; interact & negotiate with people in the community
						GP	Facilitating equal inclusion of members
						W	Time commitment; motivated
						Agree	Confidence; warm; friendly
						O	Flexible
Manton 1988 USA [66]	Quantitative	Cross-sectional survey	Mixed	Not specified	Group members (n = 144) from 3 types of self-help groups; members selected randomly to ensure equal numbers from each type of group	GM	Effective utilisation of resources
						GP	Develop a positive & supportive group climate
						A	Emotionally & socially aware
						W	Both receive & provide support
Schopler 1993 USA [67]	Qualitative	Narrative review Interviews	Mixed	Professional	Leaders (n = 12) in qualitative component, selected based on experience from a variety of agencies	GM	Information about problem/ condition; planning & maintaining the group; arrange guest speakers; topics for discussion
						GP	

Table 1 (*Continued*)

Author	Study		Group type	Group leadership	Sample description		
	Design	Method				Theme	Codes
							Knowledge on group work practice; deal with emotions; reflective listening; guiding;
						A	Group dynamics; sense emotions
Wituk 2002 USA [68]	Mixed	Qualitative: interviews Quantitative: analysis of themes developed from interview data	Mixed	Peer	Representatives from 245 active and 94 recently disbanded groups from Self-Help Network database of Kansas	GM	Diversify leadership responsibilities among members
Zordan 2010 Australia [17]	Quantitative	Cross-sectional survey	Mixed	Peer or professional	Leaders ($n = 358$) who had lead or were currently leading a support group		
Macgowan 2003 USA [69]		Theoretical exposition	Not specified	Not specified	NA		
Maram 2002 USA [70]	Quantitative	Narrative review Cross-sectional survey	Not specified	Professional	Leaders ($n = 67$) many ($n = 32$) of whom shared same issue/ diagnosis as group members	GP	Focus on member sharing
						RM	Role and responsibilities to members
						A	Self-knowledge to deal with transference/ countertransference; appropriate disclosure; not talking too much to meet own needs; balance own needs
Heiney 1989 USA [71]		Theoretical exposition	Not specified	Professional	NA	GM	Interview potential members; obtaining consensus; organising the group; maintaining records; evaluations & peer review; leadership team & support; backup plan
						GP	Understand members reason for participation; orientate people to the group, help members to know each other; maintain consistent environment & format; intervene when members monopolise the group; defining group's focus
						A	Undertake periodic self-appraisal
						RM	Modelling of appropriate group behaviour; sharing of reactions & feelings; fostering sense of trust & belonging
Rosenberg 1984 USA [72]		Theoretical exposition	Not specified	Professional	NA	GM	Provide appropriate information
						GP	Question behaviour; building trust, support & communication amongst members; group cohesion; reasoning or interpreting group discussion; provide guidance
						RM	Active role modelling, demonstrate positive supportive attitudes; provide examples of personal positive coping pattern; interpersonal positive reinforcement
						A	Not use the group for own purposes; step aside when group is functioning
						Agree	Transparency; sharing; empathy; non punitive/confrontational
						O	Objective

Notes. GM: group management, GP: group process, RM: role modelling, A: awareness, W: willingness, Agree: agreeableness, O: openness.

capacity. Additionally, knowledge of leader qualities requiring development should allow for more targeted and cost effective delivery of support. Above all, a realistic, respectful and practical approach is required in order for it to be incorporated successfully into a community health setting. The aim of this paper is to report on a systematic review and qualitative synthesise of the literature designed to shed light on the requisite knowledge, skills and attributes of cancer support group leaders.

2. Methods

A systematic search of the published literature was undertaken using electronic databases, including CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE and PsychINFO. There was no restriction on date of publication, being from inception to the date the searches were run (February 2014). Pilot searches were conducted using the key terms: leaders, support groups, peer and/or volunteer support and cancer. Pilot searches produced too few documents to map the content domain, so the key term cancer was removed and the definition of group was broadened to include self-help.

The PRISMA statement, checklist and flow diagram were utilized to optimize reporting of the review [21]. The review strategy was developed based on the PROSPERO registration format for systematic reviews; however, as the review did not focus on the effects of an intervention or strategy, the project did not meet the inclusion criteria for registration purposes.

In all three databases, subject heading searches were combined with various text word searches. The search contained subject headings: "peer group" or "self-help groups", and "leadership". Text words used were: "peer support", "peer group", "peer led", "peer leader", "support group", "support leader", "leader", "characteristics", "qualities", "skills", "experience", "qualifications", "strengths", "effective", "successful" or "identify" or "knowledge" or "attributes" and all their word variations. All citations identified through database searches and reference lists therein were reviewed by author AP. Duplicate citations were identified and deleted and the remaining documents screened for eligibility.

Inclusion criteria were: written in English; any setting or study design; adult support group leaders who were volunteers, peers, or professionals; support groups that primarily focus on providing peer support for a shared experience; and make up part of the broader category of health. Papers and theses meeting any of the following criteria were excluded: children and adolescents under 18 years of age; educational or therapeutic support groups; and/or groups not primarily focused on peer support. After excluding clearly non-relevant documents based on titles and abstracts, author AP retrieved the remaining potentially relevant full-text articles and theses. These were read in full and assessed for eligibility. Any uncertainty regarding eligibility was resolved through review and discussion with co-author KG.

Next, author AP extracted data from eligible documents on: year of publication; country of authors' origin; study design (qualitative, quantitative or mixed methods), if relevant, and method (this included theoretical exposition, narrative review and case study); sample description; group type (cancer, non-cancer or mixed); group leadership (peer, professional or mixed); and group leader qualities. No attempt was made to filter or prioritise eligible documents or qualities reported therein, as the intent was to provide an exhaustive summary of all knowledge, skills and attributes bearing on the selection of support group leaders.

Summarising content analysis was used to analyse eligible documents for content relevant to the requisite knowledge, skills and attributes of support group leaders by author AP. For theoretical expositions, narrative reviews and case studies, the whole document was the subject of analysis; for qualitative, quantitative and mixed methods studies, only the results and discussion were the subject of analysis. First, a line-by-line coding of the text from each document was conducted and reviewed in relation to the research question (Table 1). Examples of coding include: referral, suicidal members, social networking and obtaining feedback. Next, initial codes were grouped and collapsed into themes (or qualities) reflective of the collected data; for example, group management. More exploratory and analytical themes were generated for some of the codes [22]. Qualities included those borrowed from personality theory. While some knowledge, skills and attributes could be relevant to more than one quality, allocation was based on what was interpreted to be the predominate theme. Any uncertainly regarding interpretation or allocation of themes was resolved through review and discussions with co-author KG.

All data extracted from eligible papers and theses was entered into Excel, then imported into R (reference index version 3.1.3 "Smooth Sidewalk") [23] for analysis and graphing; the latter was done using the "ggplot2" package [24]. Descriptive statistics were used to summarise characteristics of papers and theses, including group leader qualities identified through summarising content analysis. Descriptive statistics were calculated for all eligible documents and by group type (cancer or non-cancer and mixed).

3. Results

3.1. Search results

The search identified 769 records (Fig. 1). After removal of duplicates, titles and abstracts of 584 records were screened; 482 were identified as clearly non-relevant and excluded. For example, the paper or thesis focused on executive leadership in workplaces, community health education programs or staff debriefing and supervision.

In total, 95 full-text articles and five theses were assessed for eligibility; two theses were unable to be retrieved. Fifty-one documents were excluded (Appendix A), because they did not meet eligibility criteria. For example, the paper or thesis focused on physical activity-based groups, therapy intervention groups or did not actually deal with support group leaders. Full-text articles and theses meeting study eligibility criteria totalled 49.

3.2. Description of eligible papers and theses

A summary of eligible papers and theses is provided in Table 1.

The earliest publication was 1984, the latest 2014. Authors originated from seven countries, but most were from the United States ($n=33$) and Australia ($n=6$). Most (69%, $n=34$) documents reported on quantitative ($n=15$), qualitative ($n=13$) or mixed methods studies ($n=6$). Note, however, the two papers by Butow and colleagues [25,26] reported on data from a single sample, as did the two papers by Stevinson and colleagues [36,37]. The remaining documents (31% $n=15$) contained theoretical expositions ($n=13$) or narrative reviews ($n=2$).

Most (63%, $n=31$) documents reported on non-cancer groups (this included samples comprising a mixture of group types). Group type was not specified in four documents and the remaining documents (29%, $n=14$) reported on cancer groups. A graphical representation of year of publication by group type is provided in Fig. 2. The overwhelming majority of documents reporting on

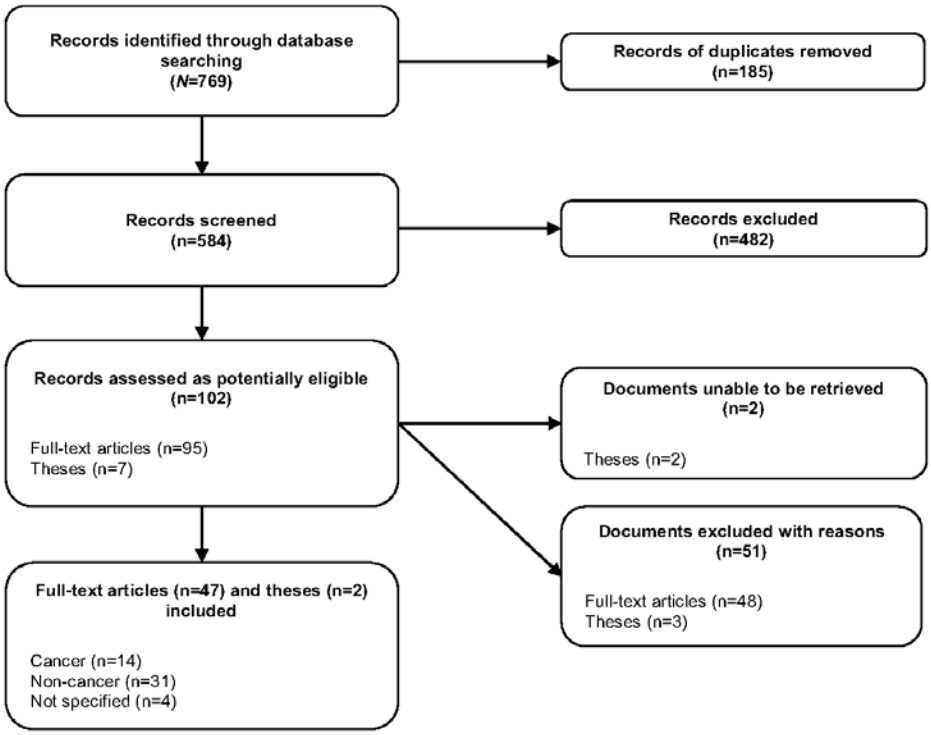

Fig. 1. Document selection.

cancer groups were published this century. In contrast, documents reporting on non-cancer groups spanned all three decades from 1984 to 2014.

3.3. Qualitative, quantitative and mixed methods studies of cancer groups

Studies of cancer groups included breast, prostate and non-tumour-specific cancer support groups (Table 1). In total, there were five separate quantitative studies; five sampled leaders (median = 176 leaders; range = 20 – 390 leaders) and two sampled group members (n = 417 members and n = 841 members). In total, there were six separate qualitative studies; two provided no details on numbers sampled, two sampled leaders (n = 27 leaders and n = 40 leaders) and two sampled group members (n = 24 members and n = 93 members).

3.4. Qualitative, quantitative and mixed methods studies of non-cancer groups

Studies of non-cancer groups were incredibly varied and included shared issues relating to: bereavement, AIDS, Alzheimer's, dementia, suicide, amyotrophic lateral sclerosis, ostomy, scoliosis, aphasia, multiple sclerosis, chronic disabilities, carer perspective, family of adults in ICU, and breast feeding and post natal depression (Table 1).

In total, there were 13 separate quantitative studies; six sampled leaders (median = 74 leaders; range = 8–358 leaders) and nine sampled group members (median = 296 members; range = 5 – 642 members). In total, there were 13 separate qualitative studies; three provided no details on numbers sampled, five sampled leaders (median = 12 leaders; range = 3 – 102 leaders) and eight sampled group members (median = 42 members; range = 11 – 339 members).

3.5. Group leader qualities

Results of the thematic analysis are provided in Table 2. Specific knowledge, skills and attributes were grouped into seven major themes reflecting qualities identified in eligible papers and theses. Qualities included: group management, group process, role modelling, awareness, willingness, agreeableness, and openness.

Group management is defined as the tasks and activities performed by the group leader to ensure the continuity of the group (e.g., organising practical tasks, administration, group referrals). *Group process* relates to how the leader facilitates the group (e.g., confidentiality, cohesion, safe environment). *Role modelling* is defined as the leader's ability to demonstrate or provide a practical example of desirable qualities to other group members (e.g., positive reinforcement, acceptance of difference, commitment to the group). *Awareness* relates to the leader's consciousness of the needs of themselves, individual members and

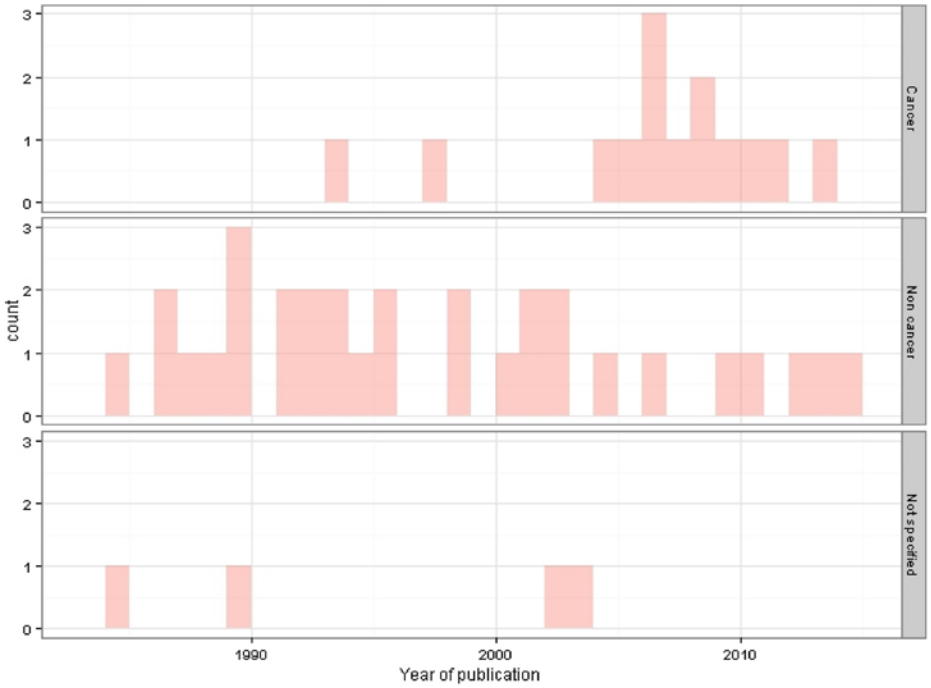

Fig. 2. Year of publication by group type.

the group as a whole and how these interact with one another (e.g., group dynamics, having minimal involvement in group discussion, own physical health). *Willingness* is defined as the leader's ability to give of themselves to the group (e.g., availability of time, to give and receive support, follow up outside of group). *Agreeableness* relates to how likeable and engaging the leader is (e.g., supportive, warm, empathic). Finally, *Openness* is defined as the leader's ability to be mentally open with a positive or solution-based approach (e.g., flexible, creative, enthusiastic).

3.6. Cancer groups

All seven qualities were identified in documents reporting on cancer groups (Table 1). The most frequently identified qualities related to Group management ($n = 10$), Group process ($n = 8$), and Agreeableness ($n = 8$). Knowledge, skills and attributes relevant to Awareness, Willingness, Modelling and Openness were identified in five, five, four and three documents, respectively.

3.7. Non-cancer groups

Similarly, all seven qualities were identified in documents reporting on non-cancer or mixed groups (Table 1). Again, the most frequently identified qualities related to Group management ($n = 22$) and Group process ($n = 22$) and Agreeableness ($n = 15$). Knowledge, skills and attributes relevant to Awareness, Willingness, Modelling and Openness were identified in 14, 10, seven and six documents, respectively. In this case, the order of frequency of qualities was consistent across group type.

4. Discussion and conclusion

4.1. Discussion

Peer support groups are an important support mechanism for many people impacted by cancer. In recognition of this fact, organisations across the globe have started to provide assistance to support groups and their leaders. This assistance can take many forms, ranging from the provision of printed materials and the listing of groups on agency websites through to the provision of staff, training and funding to support group activities. To ensure the judicious use of limited resources, organisations could benefit from an evidence-based framework to guide the selection of leaders and identification of their development needs. To this end, we undertook a systematic review and qualitative synthesis of peer-reviewed literature to identify the requisite knowledge, skills and attributes of support group leaders. Our search identified 49 eligible documents, 31 reported on non-cancer groups and 14 on cancer groups. Group type was not specified in four documents. Across all eligible documents, seven main qualities were identified including group management, group process, role modelling, awareness, willingness, agreeableness, and openness. These were consistent across group type. Findings may provide the foundations for a practical and realistic minimum standard for support group leadership in healthcare. They may also be relevant to a general model of peer group support.

Notably, qualities could be readily sub-divided into those more relevant to selection (i.e., awareness, willingness, agreeableness and openness) and those more relevant to knowledge and skills

Table 2
Thematic analysis results.

Quality	Knowledge, skills and attributes
Group management	Referral
	Suicidal members
	Community resources
	Social networking
	Administration
	Screening of members
	Organisation of practical tasks (e.g., refreshments, venue)
	Obtaining feedback
	Shared responsibility
	Knowledge/information on central topic of group
Group process	Maintaining group focus
	Identification of members' needs
	Opportunity for members to talk
	Confidentiality
	Intervene with management of issues/challenging members
	Encourage member sharing, involvement and support
	Facilitating, guiding and summarising discussion
	Safe environment
	Cohesion
Role modelling	Positive reinforcement and reframing
	Listening
	Support
	Foster sense of belonging
	Problem solving
	Interpersonal skills
	Normalise experiences of members
	Acceptance of difference
	Commitment to the group
Awareness	Separate own needs from the groups
	Sense of balance to life
	Minimal involvement in group discussion
	Group dynamics
	Member interactions
	Own physical health
Willingness	Give and receive support
	Availability of time to give
	Contact and follow up with members outside of group
	Commitment to the group
Agreeableness	Sensitive
	Supportive
	Positive
	Honest
	Integrity
	Warm
	Empathic
	Non-authoritarian
	Sense of humour
	Charismatic
	Caring
	Attentive
	Authentic
	Confident
Openness	Intelligent
	Flexible
	Objective
	Creative
	Initiative
	Enthusiastic
	Energetic

development (i.e., group management, group process and role modelling). Within a community-based setting where most group leaders are volunteers, it is not practical or reasonable to expect potential group leaders to have all the requisite knowledge and skills prior to undertaking the role. Identifying requisite qualities that can be developed or refined allows for more targeted support and delivery of training by cancer agencies. At the same time, this affords group leaders many opportunities to check-in with staff who can identify changing circumstances and ongoing support needs. This is crucial given that most leaders are living with cancer

and some may be at risk of burnout. On the other hand, it is recognised that certain qualities may not be able to be taught. In practice this means that some people may be unsuited to the role regardless of their intention, background or access to training and support.

Importantly, from the clinician's perspective, there appear to be gaps in the content identified from the literature. For example, selection criteria for other peer support roles often consider length of time since diagnosis and treatment. This allows some consideration of a person's current physical and psychological state, and how this may impact on their ability to support others. Further, while qualities identified in this review may be relevant to the cancer support group leader role, it is not clear how these would be used to make selection decisions or to identify development needs in a standard and unbiased manner. Implementation in practice would also require the identification of a practical and realistic minimum standard for cancer support group leaders.

5. Conclusion

Like all other forms of support in healthcare, peer support models need to be supported and guided by evidence. Leadership inconsistences may result in inequities between support groups and access to quality support by the community. Identification of requisite group leader qualities means that we no longer have to operate from unsubstantiated assumptions or beliefs about what is important to the group leader role. However, given the limitations outlined above, additional steps are required to determine what skills, knowledge and attributes are the most relevant and important aspects of support group leadership in the cancer context [73]. Furthermore, appropriate and novel strategies are needed to apply these knowledge, skills and attributes to the selection and development of cancer support group leaders.

By increasing knowledge of leader qualities we can begin to clearly define the role and establish a leader selection and development process. Such evidence-based approaches would: minimise potential risk to those who take up leadership roles, consistently guide cancer agency workers in their delivery of support and training to group leaders, and provide funding bodies with measured outcomes to assist with cost effective investment. Development of the support group model also leads to strengthening the broader delivery of supportive care in the community. The benefits are multi-layered but at its core is maximising value for those people who choose to utilise groups for support during the cancer experience.

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Appendix A

Summary of excluded papers and theses including reasons for exclusion.

Year	Author	Literature source	Reason for exclusion
2008	Arrington Grant & Vanderford	J Psychosoc Oncol	Not related to support group leader charactertics
2001	Barlow & Hainsworth	Ageing Soc	Intervention program, not focused on support group leader characteristics
1985	Baron	Pratt Institute Creative Arts Therapy Review	Not focused on support group leader characteristics, therapeutic intervention
2008	Becker, Bull, Smith, et al.	Eating Disorders	Eating Disorder prevention program
1976	Bednarek, Benson & Mustafa	Small Group Behav	Work based support group
2010	Boothroyd & Fisher	Family Pract	Not related to support group leaders
2004	Boyce	Dissertation (George Mason University)	Not focused on support group leaders
1993	Brunner	Orthop Nurs	Not focused on support group leaders
1993	Byers-Lang & McCall	RE:view: Rehab Educ Blind Vis Impair	Not focused on support group leaders
2011	Caperchione, Mummery & Duncan	J Sci Med Sport	Physical activity group based program
1993	Clark, Jones, Quinn, et al.	Crisis	Not focused on support group leaders
1995	Cope	Cancer Nurs	Not focused on support group leaders
2013	Dunlop & Beauchamp	J Aging Phys Act	Physical activity group based program
1994	Farran & Keane-Hagerty	Appl Nurs Res	Not focused on support group leaders
2002	Fung & Chien	Arch Psychiatr Nurs	Not focused on support group leaders
1999	Gray, Carroll, Fitch, et al.	Cancer Pract	Not focused on support group leaders
2009	Gurr	Int J Ther Rehabil	Therapeutic intervention
2012	Haberstroh & Moyer	J Specialists Group Work	Moderated on-line support group (users did not hold real time conversations)
1982	Hartford & Parsons	Soc Work Groups	Therapeutic intervention
1997	Heller, Roccoforte, & Cook	Family Relations	Not focused on support group leaders
1989	Hunsberger	Am J Hosp Care	Work based support group
2008	Janson	Leadership	Not related to support group leader charactertics
1999	Karp, Brown, Sullivan, et al.	J Genet Couns	Psychoeducational group intervention
1993	Kostyk, Fuchs, Tabisz, et al.	Soc Work Groups	Therapy intervention program
2002	Lieberman & Golant	Group Dyn	Therapeutic intervention
2004	Lieberman, Golant & Altman	Group Dyn	Not focused on support group leader characteristics
2013	McCreary, Kaponda, Davis, et al.	J Nurs Scholarsh	Community peer health education program
2012	McHugh, Wherton, Prendergast, et al.	Am J Alzheimers Dis Other Demen	Not focused in support group leaders
2005	Milberg, Rydstrand, Helander, et al.	J Pallat Care	Therapeutic intervention
2012	Mosack, Wendorf, Brouwer, et al.	Chronic Illn	Intervention program
2008	Page, Delmonico, Walsh, et al.	J Spec Group Work	Therapeutic support group
2013	Patterson	Dissertation (Walden University)	Peer behavioural intervention programs
2010	Pavur	Psychol Manag J	Not focused on support group leader characteristics
1980	Pilisuk & Parks	J Psychol	Not focused on support group leader characteristics
2004	Pitkala, Blomquist,	Educ Gerontol	Intervention programs

(*Continued*)

Year	Author	Literature source	Reason for exclusion
	Routasalo, et al.		
1997	Reiter-Lavery	Dissertation (The Catholic University of America)	Not focused on support group leader characteristics
2011	Rogers & Mapp	J HIV AIDS Soc Serv	Not focused on support group leaders
2003	Rosenbaum, Gautier, Fobair, et al.	Support Care Cancer	Hospital based supportive care program, not focused on support group leaders
2009	Salzer, Katz, Kidwell, et al.	Psychiatr Rehab J	Not focused on support group leaders, specialist training for employment
2011	Schimmel & Jacobs	J Spec Group Work	Therapeutic intervention
1997	Shaw	Group	Therapeutic (psychoanalytic) based support group
2013	Simmons	Eur Diabetes Nurs	Not related to support group leaders
2008	Stang & Mittelmark	Int J Mental Health Promot	Not focused on support group leaders
2011a	Tang, Funnell, Gillard, et al.	Diabetes Educ	Intervention program
2011b	Tang, Funnell, Gillard, et al.	Patient Educ Couns	Peer intervention programs
1990	Toseland, Rossiter, Peak, et al.	Int J Group Psychother	Therapeutic support
1989	Tracey & Toro	Am J Community Psychol	Group issues (marital problems) not related to health and/or cancer
1986	Wasow	Social Work	Not focused on support group leaders
2000	Wituk, Shepard, Slavich, et al.	Social Work	Not focused on support group leaders
2003	Yaskowich & Stam	J Health Psychol	Not focused on support group leaders
2013	Young, Zhao, Tieu, et al	J Consum Health Internet	Community peer health education program

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*denotes paper included in systematic review.

6 EXPERT AGREED STANDARDS FOR THE SELECTION AND DEVELOPMENT OF CANCER SUPPORT GROUP LEADERS

6.1 Chapter overview

In the previous chapter, a description was provided of how knowledge, skills, and attributes of cancer support group leaders were deduced through a systematic literature review. The next step of the role analysis required identification of the necessary or requisite knowledge, skills, and attributes for the cancer support group leader role by an expert panel. This chapter reports on the methods and outcomes of the online reactive Delphi study. This study utilised a consensus-based approach to ensure input from multidisciplinary experts. The consensus of many experts facilitated the production of a thorough role analysis and worked to ensure that the developed standards were timely in completion and relevant to support groups that serve diverse communities and varied structures.

Chapter 6 of this thesis consists of an online reactive Delphi study paper published in *Supportive Care in Cancer* in January 2018 (Volume 26). As described in the protocol in Chapter 4 of this thesis, the first aim of this Delphi study was to develop pragmatic, consensus-based minimum standards for the cancer support group leader role. The second aim was to produce, in draft form, a structured interview designed to assess the knowledge, skills, and attributes of individuals who seek to undertake the role. The objective was to systematically appraise the deduced knowledge, skills, and attributes from the systematic literature review and combine the evidence with expert opinion to derive both evidence- and consensus-based minimum standards for the selection and development of cancer support group leaders. Experts confirmed 52 knowledge, skills, and attributes as minimum

standards for support group leaders along with aspects of content and structure of the structured interview. Expert feedback provided further refinement of wording, reordering of questions, and improvement of probing questions.

6.2 Appendices for this chapter

A number of appendices relating to the Delphi study have been included with this thesis. Participants of the Delphi study were provided with a plain language statement (Appendix 3), received an email inviting them to take part in the study with instructions on how to complete the questionnaire for Round 1 (Appendix 4) along with the Delphi study questionnaire for Round 1 (Appendix 5). For Round 2 of the Delphi study, participants were provided with emailed instructions (Appendix 6) and the Round 2 questionnaire (Appendix 7). For the final Round 3, participants were again emailed instructions (Appendix 8) and provided with Round 3 questionnaire (Appendix 9). Collated information from previous rounds was presented in accompanying attachments, being the table of determined knowledge, skills, and attributes for cancer support group leaders (Appendix 10) and drafted structured interview (Appendix 11). Please also refer to Appendix 30 for details on peer reviewer comments and responses relating to the Delphi study paper.

Expert agreed standards for the selection and development of cancer support group leaders: an online reactive Delphi study

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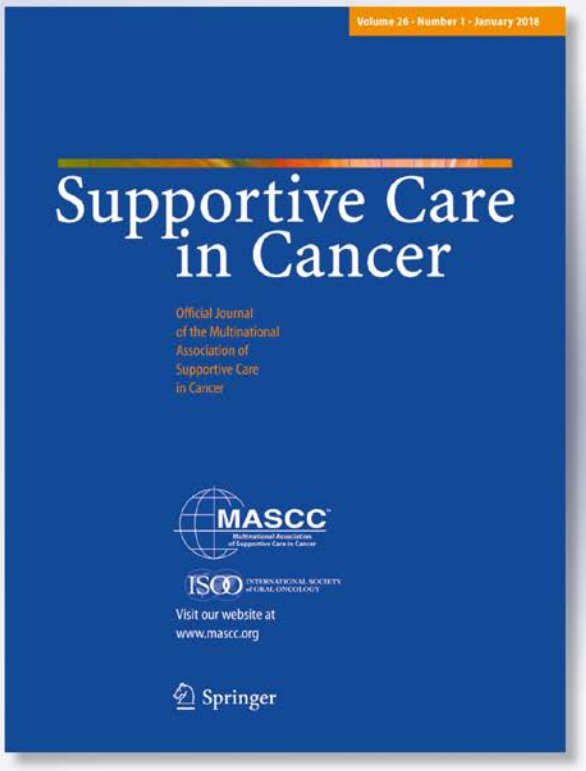

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ORIGINAL ARTICLE

Expert agreed standards for the selection and development of cancer support group leaders: an online reactive Delphi study

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Abstract
Purpose The aim of this study was to develop pragmatic, consensus-based minimum standards for the role of a cancer support group leader. Secondly, to produce a structured interview designed to assess the knowledge, skills and attributes of the individuals who seek to undertake the role.
Methods An expert panel of 73 academics, health professionals, cancer agency workers and cancer support group leaders were invited to participate in a reactive online Delphi study involving three online questionnaire rounds. Participants determined and ranked requisite knowledge, skills and attributes (KSA) for cancer support group leaders, differentiated ideal from required KSA to establish minimum standards, and agreed on a method of rating KSA to determine suitability and readiness.
Results Forty-five experts (62%) participated in round 1, 36 (49%) in round 2 and 23 (31%) in round 3. In round 1, experts confirmed 59 KSA identified via a systemic review and identified a further 55 KSA. In round 2, using agreement ≥75%, 52 KSA emerged as minimum standards for support group leaders. In round 3, consensus was reached on almost every aspect of the content and structure of a structured interview. Panel member comments guided refinement of wording, reordering of questions and improvement of probing questions.
Conclusions Alongside a novel structured interview, the first consensus-based minimum standards have been developed for cancer support group leaders, incorporating expert consensus and pragmatic considerations. Pilot and field testing will be used to appraise aspects of clinical utility and establish a rational scoring model for the structured interview.

Keywords Online Delphi method · Cancer survivors · Support groups · Peer leadership · Evidence-based standards

Background

Cancer presents many people with a major life stress, with an estimated one-third of people diagnosed going on to experience psychological difficulties and need for supportive care

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[1–4]. In an effort to reduce the psychosocial burden, peer support groups have emerged around the globe, frequently initiated by cancer patients themselves, to provide community-based support [5]. A number of studies have assessed the benefits of social support through groups, including cancer support groups, to contribute to general well-being [6–8].

Group leaders are the primary point of contact for the group and often underpin the group's success and sustainability [9]. The role of the group leader comes with challenges that can be detrimental to the individual such as dealing with disease, maintaining boundaries and burnout [10]. Agencies have introduced group leader training, funding, resources and staff in order to support the provision of group-based peer support in the community [11]. However, with a limited body of knowledge on the preferred or required characteristics of group leaders [10, 12, 13], there are currently no standards to guide agencies on how best to select and support group leaders in their role. Specifically, there are no established guidelines on the knowledge, skills and attributes (i.e. quality indicators) required to lead a cancer support group. Agencies that work with group leaders require a universal bench mark for selection to ensure adequate and reasonable standards are met in the community. In addition, consistent and objective measures of group leader qualities are needed to promote fairness and optimise collaboration and share resources across agencies.

Overall, there is insufficient information available at present to define realistic standards for group leaders or to determine how best to identify suitable group leaders and recommendations for support and training. Answers to these questions are essential to advance the model of peer support groups and the development of a structured, *consensus*-based approach to leader selection and development. Furthermore, a systematic approach combined with expert opinion would work to address limitations in research to date [14, 15]. Importantly, in order for standards to be introduced into practice, they must be considered reasonable for peer volunteers and practical to implement in the real world [16]. A transfer of knowledge into guidelines grounded in evidence have the potential to benefit a large number of cancer agencies working with support groups, group leaders and their members, along with the broader community of stakeholders invested in the delivery of peer-based group support.

Aims

The purpose of this study was to develop pragmatic, consensus-based minimum standards for the role of a cancer support group leader. A structured interview will then be produced for cancer agency workers to assess the knowledge, skills and attributes (KSA) of individuals who seek to undertake the cancer support group leader role.

Methods

A three-round, online reactive Delphi [17] was used to identify minimum standards and develop the draft structured interview. Ethics approval was granted by the Psychological Sciences Human Ethics Advisory Group of University of Melbourne (ID:1443027).

Panel

Experts were defined as individuals involved in the analysis, referral, support and/or delivery of cancer support groups. Expert panel participants were geographically diverse and included academics, health professionals, agency workers and support group leaders.

Recruitment process

For a Delphi study, a minimum of 10 or more participants in total is considered acceptable [18]. This study aimed to recruit approximately 30 participants. Experts were purposively selected from a list of individuals identified through professional networks and a person-to-person cascade approach (i.e. snowballing) [19]. Support group leaders were identified from current support group listings of cancer agencies. Invitation and participation in the Delphi study was completed via email.

The recruitment email included an overview of the project and aims, a statement indicating the invitee had been identified as an expert who could make a valuable contribution to the project, estimated time to complete questionnaires and the total number of rounds to be completed. A Plain Language Statement was also attached to the email in a separate document. In order to improve recruitment and retention over the Delphi rounds, the purpose and practical application of the Delphi results were outlined in participant information [19]. Consent was assumed if participants returned completed questionnaires. For all rounds, participants were given 4 to 6 weeks to complete questionnaires. Reminder emails for each round were sent to participants who had not yet responded, at both 2 weeks and 1 week before the closing date [20]. Experts who declined to participate were not contacted in subsequent rounds. Each round was emailed to all participants irrespective of participation or non-participation in previous rounds.

Procedure

Round 1

The aims of the first round were confirmation of key qualities and expansion of content identified via a systematic review and qualitative synthesis of the relevant literature. Here, content refers to the specific KSA needed to undertake the cancer support group leader role. Panel members were asked to

respond to statements contained in a word document, then save and return via email. Panellists were asked to reflect on the role of the group leader within a cancer support group and the KSA they would consider important to that role. The provision of medical/counselling knowledge or advice was not considered to be part of the group leader role. As a starting point, the panel were asked to react to a list of key qualities deduced from a systematic review and qualitative synthesis of the literature [21]. Specifically, the panel were asked the following questions:

- *Please list any additional knowledge, skills or attributes you think are relevant to each quality listed.*
- *Do you think there are other qualities important to being a peer group leader that are not listed? If yes, please provide examples of relevant knowledge, skills and/or attributes.*
- *Is there any characteristic or circumstance that would automatically preclude an individual from being a support group leader?*

First round analysis Responses were collated in an Excel spreadsheet. Responses were then assigned to a quality under the framework of headings developed for this Delphi study; specifically: (a) quality descriptor; (b) knowledge, skill or attribute; (c) comments; and (d) combined responses. Similar terms or wording of participant responses were combined and repeated responses were removed or reallocated to a more relevant quality. All non-discriminatory responses generated by the experts were included [22]. See Appendix A for list of excluded responses deemed discriminatory. A list of KSA for each key quality was prepared based on combined responses and sent to participants for ranking (round 2).

Round 2

The aim of this round was to identify minimum standards for the selection of cancer support group leaders. Expert consensus on requisite qualities provided the framework for establishing minimum standards for the role. An acceptable range of consensus was based on 75% or more agreement by experts for each attribute (e.g. individual knowledge, skills and attributes) [23, 24]. Seeking input from the panel of experts in the second round, a final list of 114 KSA based on responses to the first round was presented. The concept of work readiness was adapted to recognise when an individual is adequately prepared or 'ready' to take on the role [25].

In this Delphi round, we would like you to indicate (by placing an X in the appropriate column) whether the knowledge, skills and attributes listed are:

1) *required to be ready to undertake the cancer support group leader role;*
2) *desirable but not required;*
3) *not required to be ready;*
4) you are unsure; or
5) *you have no opinion.*

The panel was instructed to reflect on the role of the group leader within the context of a cancer support group. The fact that many groups operate independently in the community, at minimal cost, and in a limited peer, volunteer capacity was highlighted. It was also noted that the provision of medical/counselling knowledge or advice was not considered to be part of the role of the cancer support group leader. As per the first round, panel members were asked to save responses in the word document and return via email.

Second round analysis Responses were entered into an Excel spreadsheet. Descriptive statistics (counts and percentages) were used to summarise participant responses. KSA identified as being *required to be ready to undertake the cancer support group leader role* by at least 75% of experts were accepted as minimum standards. A total of 52 KSA met the study's consensus criterion.

Structured interview development A structured interview to be used by cancer agency workers when assessing prospective group leader candidates was drafted with the aim of optimising the predictive validity and reliability of interviewer evaluations. In this case, role-relatedness was maximised by ensuring good coverage of consensus qualities, interview conduct was standardised wherever possible and a highly structured use of data in candidate evaluations was adopted [26]. Specifically, questions, scenarios and probing questions were drafted by researcher AP and confirmed by all researchers, with the aim of eliciting responses relevant to and representative of requisite KSA identified from round 2. Where possible questions were developed to combine assessment of KSA and reduce the total number of questions generated in order to minimise interviewer and interviewee burden [27]. The format included questions and scenarios focusing on past behaviours as well as expected behaviours in hypothetical situations to measure different aspects of performance [28, 29]. Development of questions and scenarios was underpinned by the following criteria: open ended, use of concise and clear language, realistic of the responsibilities of the role, reflective of required competences, appropriate to all educational levels, non-threating and non-discriminatory. Drafted questions and scenarios were assigned to one of two categories (or domains): suitability or readiness. Suitability included KSA that could not be developed through additional support and/

or training (e.g. availability of time to give to the group). Readiness included KSA that could be developed through additional support and/or training (e.g. knowledge on how to foster a welcoming space for group members). An evaluative rating scale anchored by examples of responses (or expected behaviours) was developed for each question and scenario. Suggested responses or expected behaviours were grouped into an ordinal rating scale ranging from 0 to 2. A score of 2 indicated the interviewee demonstrated awareness, provided examples and described expected behaviours relevant to the KSA question. A score of 1 indicated adequate but not comprehensive examples and behavioural responses. A score of 0 indicated that the interviewee was unable to provide examples, convey awareness, or describe expected behaviours. Evidence suggests this standardised approach improves the accuracy of judgments made by interviewers and helps in later comparisons among applicants [29].

Round 3

The aim of the final round was to confirm the content and structure of the proposed structured interview, referred to as 'a structured conversation'. Three separate word documents were provided: (1) a confirmed list of requisite KSA meeting expert consensus; (2) a provisional structured interview with description of its genesis and intended use; and (3) a response table to evaluate the content and structure of the provisional structured interview. More specifically:

As part of Delphi Round 3, you will need to complete the table below. For each question and scenario, you will be asked to assess whether:

Does the structured conversation as a whole provide an adequate assessment of the KSA needed to be ready to undertake the role of a cancer support group leader?

1) *the wording is clear and understandable*
2) *it is likely to elicit information relevant of the specified KSA*
3) *the specified KSA have been assigned to the appropriate category (suitability, readiness)*
4) *suggested probing questions are suitable (i.e. it is likely to elicit more information relevant to the question)*
5) *the examples of responses (or expected behaviours) are appropriate indicators of the KSA being assessed*
6) *you believe the evaluative rating scale is reasonable given the relevant population (i.e. community volunteers)*

Response options for each question were *Yes* or *No*, with recommendations requested for those questions which a *No* response was provided. The panel was also provided the opportunity for further comments or recommendations.

Third round analysis Responses were entered into an Excel spreadsheet then imported into R (reference index version 3.3.0) for graphing; the R package 'ggplot2' was used to prepare graphs [30].

Results

An overview of study results is provided in Fig. 1.

Study profile

Of 73 purposively selected experts, two declined to participate. These experts were not included in subsequent Delphi rounds. Forty-five of the remaining 71 experts participated in round 1, 36 in round 2 and 23 in round 3. Table 1 provides an overview of participation for all three rounds.

Round 1

Table 2 provides as overview of all identified KSA relevant to and representative of the cancer support group leader role. No new qualities were identified in round 1, but the pool of KSA was expanded from 59 KSA to 114 KSA. Feedback from experts was also used to refine, modify, or re-assign KSA accordingly.

Round 2

Minimum standards for selection and development of cancer support group leaders were determined in this round. Fifty-two KSA were determined by the expert panel to be required to undertake the cancer support group leader role. Table 2 outlines agreed minimum KSA in bold.

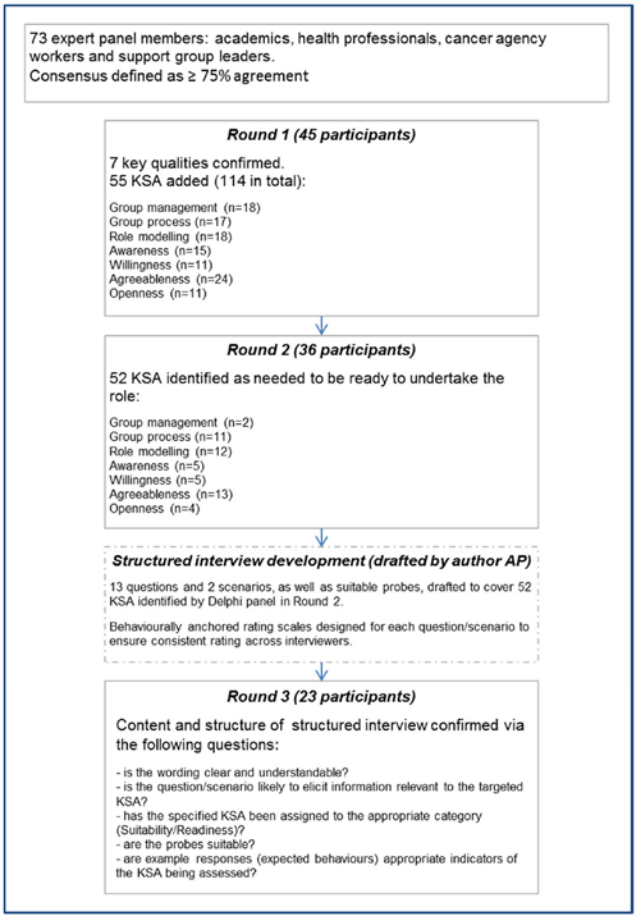
Round 3

Round 3 results are summarised in Fig. 2. For all questions and scenarios, panel members agreed that the wording was clear and understandable, that it was likely to elicit information relevant to the specified KSA, that examples of responses were appropriate indicators of KSA being assessed and that the evaluative rating scale was reasonable. The single item that did not reach a satisfactory level of agreement was the suitability of probing questions for question 1. Although adequate consensus was reached for suitability of all other probing questions, it was identified as the area of least agreement.

Discussion

As better group outcomes are associated with leader behaviour [31], a more focused examination of group leaders and their

Fig. 1 Overview of study results



role in the group setting may lead to a more comprehensive assessment of potential strengths and limitations to support group interventions [32]. Specifically, Zordan et al. [33] highlighted that development of a set of minimum standards or process of accreditation for support group leaders would be appropriate to ensure that leaders are properly equipped to facilitate support groups. A systematic approach was taken to facilitate the development of quality indicators for cancer support group leaders where there was insufficient evidence previously.

We have produced expert-derived consensus on requisite KSA to provide the first minimum standards for cancer support group leaders. A reactive Delphi approach [17] maximised study efficiency, eased participant burden, as well as optimised content relevance and representativeness. The seven key qualities identified through the systematic review were confirmed by expert panel members. Consensus was reached on 52 KSA required to be ready to undertake the role of a cancer

Table 1 Delphi panel responses

Expert type	Invited	Respondents		
		Round 1	Round 2	Round 3
Academic/health professional	28	15	8	6
Cancer agency worker	23	13	13	9
Cancer support group leader	22	13	13	7
Snowballing		4	2	1
Total	73	45	36	23

Table 2 Round 1 and round 2 results

	Knowledge, skills and attributes	
Quality	From systematic review	Identified in round 1
Group management	Referring to supports external to the group	Succession planning
	Knowledge of community resources and support networks	*Capacity to be primary point of contact*[a]
	Social networking	Time management
	Administration	*Planning of group meeting*[a]
	Screening of members	Financial management
	Organisation of practical tasks (e.g. refreshments and venue)	Promotion of the group
	Obtaining feedback from the group	Facilitating group's relationship with external bodies/stakeholders
	Sharing responsibilities	Computer skills
	Knowledgeable on central topic of group	
	Awareness of psychologically unwell or vulnerable members	
Group process	Maintain group focus	*Work effectively with co-leader/s*[a]
	Identify group needs[a]	*Maintain respectful dialogue and interaction with/about others*[a]
	Maintain confidentiality[a]	Engage group in establishing and reviewing group purpose and structure
	Intervene with management of issues/challenging members[a]	*Manage alternative opinions/views/beliefs*[a]
	Encourage member sharing, involvement and support[a]	Lead group in alignment with group membership, context and culture
	Facilitate, guide and summarise discussion	Facilitate closure
	Foster a welcoming space[a]	Acknowledge own limitations of knowledge or boundaries
	Promote group cohesion and trust[a]	*Welcome and introduce new members*[a]
		Clarify their leader role with/to group members[a]
Role modelling	Positive reinforcement and reframing	*Empathy*[a]
	Listening[a]	Flexibility
	Supportive[a]	*Acknowledge limitation of self and the group*[a]
	Foster sense of belonging	*Respect for others*[a]
	Problem solving	*Operate within standards set by the group*[a]
	Communication skills[a]	*Self-care and care of other members*[a]
	Acknowledge and validate experiences of members	Empowering mutual aid of group members
	Acceptance of difference[a]	*Maintaining boundaries*[a]
	Commitment to the group[a]	*Remain calm*[a]
Awareness	*Separate own needs from the group's*[a]	Reflective of own experience, emotions, values
	Balance personal life and leadership responsibilities	Undertake role for agreed period of time with group
	Maintaining minimal involvement in group discussion	*Being mentally present*[a]
	Group dynamics	*Recognise when support/de-briefing is needed*[a]
	Maintaining own mental and physical health[a]	*Own self-care*[a]
	Context and culture of the group	Own development in the role
		Altruistic motivation
		Appropriate sharing of own story
		Manage own and group's expectations
Willingness	*Give and receive support*[a]	Be an advocate for the group
	Availability of time to give[a]	*Receive and manage feedback/criticism/complaints*[a]
	Contact and follow-up of tasks outside of group	Enable succession and step down from the role
	Commitment to the group[a]	Promote empowerment of members not reliance
		Maintain boundaries[a]
		Share leadership duties
		Undertake learning and development in the role

Table 2 (continued)

	Knowledge, skills and attributes	
Quality	From systematic review	Identified in round 1
Agreeableness	*Sensitive*[a]	*Approachable*[a]
	Supportive	Calm
	Positive	*Trustworthy*[a]
	Honest[a]	Intuitive
	Warm	*Inclusive*[a]
	Empathic[a]	Resilient
	Non-authoritarian[a]	*Responsive*[a]
	Appropriate sense of humour	*Respectful*[a]
	Charismatic	Assertive
	Attentive	*Ethical*[a]
	Authentic	*Patient*[a]
	Confident	*Genuine*[a]
		Diplomatic
Openness	*Capable*[a]	*Motivated*[a]
	Flexible	*Accepting*[a]
	Objective[a]	Thoughtful
	Creative	Persistent
	Intuitive	Resourceful
	Energetic	

[a] KSA was refined, modified or re-assigned

KSA reaching expert consensus as being required italicized

support group leader. There was also high agreement on the content and structure of the proposed structured interview.

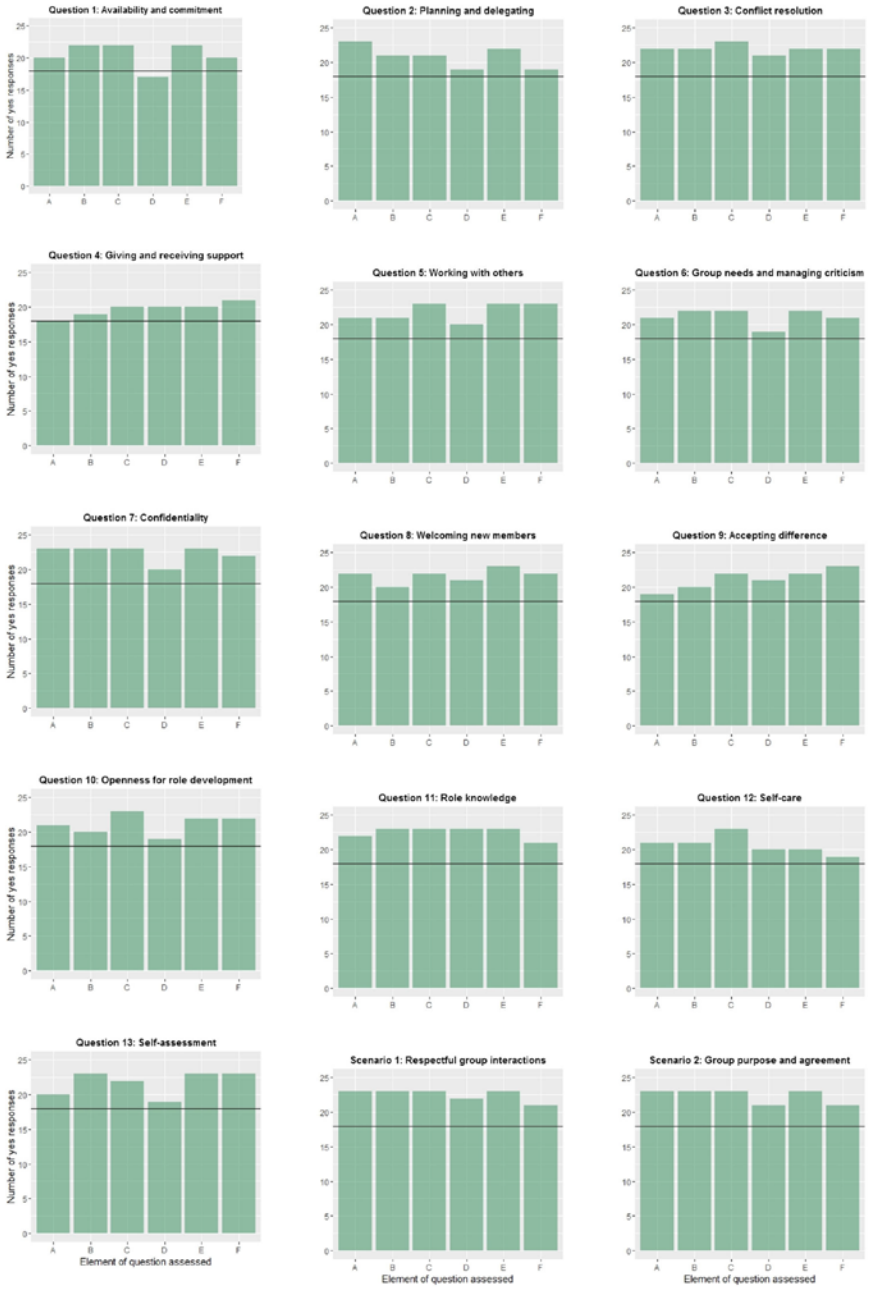
Group Process, Role Modelling and Agreeableness were the key qualities with the largest number of requisite KSA receiving consensus. Given that the majority of potential peer leaders are not professional group facilitators [34, 35], KSA relating to Group Process and Role Modelling could present the greatest learning curve for leaders and the highest needs for training and support. This would support the recommendations in the existing literature for training, support and supervision of peer leaders to prepare them for the role and overcome difficulties [10, 12, 36, 37].

The KSA determined to be most important were Maintaining Confidentiality, Listening and Respect for Others. These KSA are consistent with patient narratives that support groups provide a safe place for those who may experience social marginalisation due to a cancer experience [6] and opportunity to have a positive experience of supportive care [38].

On the other hand, the large number of KSA identified for Agreeableness indicates the importance of innate personal attributes required for the role that are not amenable to training. The person's natural fit or suitability for the role regardless of their peer experience of cancer or how much training and support is offered is an important consideration in light of limited resources.

Given the large number of requisite KSA overall, an ongoing approach to learning is needed for the role. Additionally, transparent disclosure of role requirements and necessary preparation to potential group leaders can also assist with self-selection and provide insight into the dynamic aspect of the leadership role [39]. This is likely to increase the probability of success for the leader and, ultimately, sustainability of the group. Given potential challenges of leader burnout and sustainability of the group [10], placing people into roles that they are both suitable and prepared for is a necessary next step to improve the existing model of peer support. Central to the matter is the needs of the support group member and how agencies can communicate to the community that support groups are led in a safe and supportive manner. Although it is understood that group ownership is largely independent of cancer agencies, the community looks to auspicing and referring bodies to provide support and structure to groups.

Of note, the total pool of KSA expanded from 55 to 114 during round one, along with additional content deemed discriminatory and excluded. The large number of KSA initially outlined raised questions as to what is considered reasonable to require of a community volunteer. For cancer agencies, knowing what level of personal disclosure is acceptable to ask in an interview reduces legal vulnerability [22, 29]. Additionally, identifying which KSA are measurable and trainable and which are not is likely to facilitate better use of training support provided by cancer agencies. The varied backgrounds of the expert panel also conveyed how support groups interact with multiple stakeholders across the



◀ **Fig. 2** Delphi round 3 results. *A* Is the wording of this question clear and understandable? *B* Is this question or scenario likely to elicit information relevant to the specified KSA? *C* Do you think the specified KSA have been assigned to the appropriate category (suitability, readiness)? *D* Do you think the probe is suitable (i.e. it is likely to elicit more information relevant to the question)? *E* Are the examples of responses appropriate indicators of the KSA being assessed? *F* Do you think the evaluative rating scale is reasonable?

community. Together, these circumstances place considerable demands on peer volunteers who undertake the role for the first time, free of charge, with minimal or no support.

Constraining unrealistic and perhaps unnecessary expectations was a pragmatic approach to developing minimum standards. There is strength and value to peer support without the need to 'professionalise' the role and turn leaders into counsellors. Given that groups operate independently, questions are raised as to the practicality and acceptability of assessing leader performance or competency. Most cancer agencies have limited time, staff resources and budget for the provision of support to a considerable number of support groups across the country. For those who work directly with groups and their leaders, a structured interview reduces the possibility for personal bias or perceived judgement [29]. Additionally, it supports workers with varying levels of experience in the role by clearly outlining requirements and guiding the conversation with potential group leaders. A structured process helps to aid consistency both within and across agencies.

Limitations

Despite attempts to minimise attrition, as expected participant numbers dropped at each stage of the study. Nonetheless, rounds included similar numbers from each expert group.

As yet, the newly developed structured interview has not been assessed for clinical utility to determine practicality and acceptability by cancer agencies. Additionally, incorporation of a scoring range for the categories of suitability and readiness [25] is yet to be determined or to what degree this may improve delivery of training based on individual development needs. Although the Delphi method has been used for quality-indicator development in healthcare, it relies on the available evidence and is complemented by expert opinion [14]. As yet, there is no assessment of effectiveness of leaders, once in the role, linked to the requisite KSA outlined. Accumulation of evidence to inform the implementation and evaluation of the appropriateness of the minimum standards is therefore needed. Future piloting to optimise clinical utility and field testing of the newly developed structured interview is also needed to establish a rational scoring model.

Conclusions

We described a consensus study using a reactive online Delphi with an expert panel, to develop a novel structured interview to guide the selection and development of cancer support group leaders. Importantly, 52 requisite KSA were determined to be required, introducing the first expert agreed minimum standards. These minimum standards were created to reflect an acceptable judgement on what makes someone suitable to lead a cancer support group and do not reflect "ideal standards" or "best practice". Pragmatic considerations were paramount in the development of the standards and work to facilitate a more effective, consensus-based process for cancer agencies and better support those seeking to undertake the cancer support group leader role. This is an important step to directing future practice and research in cancer support groups and broader health-focused support groups.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest. The authors had full control over all primary data and will allow the journal to review the data if requested.

Appendix A: Precluded items deemed discriminatory

Diagnosed less than 2 years
Undergoing treatment/active disease/physically very ill
Serious mental illness/personality disorder
End-of-life stage illness
Recently bereaved or dealing with complicated grief issues
Bias or strong beliefs related to treatment (alternative therapies)
Criminal history
Highly anxious/acute distress
Cognitive impairment
Inappropriate match for group membership (e.g. age and gender)

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7 THE STRUCTURED INTERVIEW and USER MANUAL

7.1 Chapter overview

The aim of this PhD study was to develop a structured interview for cancer agencies to use for the selection and development of cancer support group leaders. To do this, the literature on structured interview development was reviewed. This chapter defines the different components of structure for the development of the structured interview. Components are divided into two categories: components that influence content structure of the interview, and components that influence the evaluation process.

7.2 Appendices for this chapter

A number of appendices relate to the development and refinement of the structured interview and user manual throughout the entire project. In this Chapter, we refer to the drafted structured interview and user manual that was developed as an output from the Delphi study (Appendix 15 and Appendix 16). This version of the structured interview was also used for piloting purposes to determine clinical utility and reported in Chapter 8. Please note, ongoing refinement and revisions to the structured interview and user manual occurred at various stages of the entire project, with the final version of the structured interview contained in Appendix 22 and final version of the user manual in Appendix 23.

7.3 Addressing Elements of Structure in Interview Development

Campion et al. (1997) undertook a thorough review of the literature and determined there to be 15 components of structure. These components were divided into two categories: components that influence the content of the interview or “the nature of the information elicited” (p.656) and components that influence the evaluation

process or “the judgement of the information elicited” (p.656). Seven components influence the content of the interview: a job analysis; using the exact same questions; limit prompting and follow-up questions; using better types of questions; using a longer interview or larger number of questions; controlling ancillary information; and not allowing questions from candidates during the interview. Eight components influence the evaluation of responses: rating each answer or using multiple scales; using detailed anchored rating scales; taking detailed notes during the interview; employing multiple interviewers; using the same interviewers for all candidates; not discussing candidates or answers between interviews; providing training; and using statistical prediction to combine interview data rather than clinical prediction. Each component has unique impact on the reliability, validity, and user reactions, as outlined in Table 1 reproduced from Campion et al. (1997).

Table 1: Effects of Interview Structure on Reliability, Validity and User Reactions

	Reliability						Validity			User reactions		
	Test-retest	Inter-rater	Candid. consist.	Inter-cand. interaction	Internal consist.	Interrater agreement	Job-relatedness	Reduced deficiency	Reduced contam.	Reduced EEO bias	Candidate reactions	Interviewer reactions
Content												
1. Job analysis							+	+	+	+	+	+
2. Same questions	+	+	+	+				+	+	+		
3. Limit prompting	+	+	+	+				-	+	+	-	-
4. Better questions			+		+		+		+	+		+
5. Longer interview	+	+			+			+			-	-
6. Control ancillary information	+	+						-	+	+	-	-
7. No questions from candidate	+	+	+	+				-	+		-	-
Evaluation												
8. Rate each answer or use multiple scales	+	+			+			+	+			
9. Anchored rating scales	+	+				+	+	+	+	+		+
10. Detailed notes	+	+				+	+	+	+	+		-
11. Multiple interviewers	+	+		+	+	+		+	+	+	-	
12. Same interviewer(s)	+			+					+	-		
13. No discussion between interviews	+	-				-			+	+		-
14. Training	+	+	+	+	-	+	+	+	+	+	+	+
15. Statistical prediction	+	+			+			+	+	+		

Note: “+” means positive effect and “-” means negative effect.

Note. Reproduced with author’s permission from “A review of structure in the selection interview” by M.A. Campion, D.K. Palmer and J.E. Campion, 1997, Personnel Psychology, 50, p. 657.

This study aimed to optimise all 15 components of structure in development of our structured interview. A description of each component is provided below along with an explanation of how these components were addressed in the development of the structured interview and user manual.

7.3.1 Base questions on a job analysis

Two levels of structure relate to the component of base questions, either a job analysis can inform the development of questions or there are at least three unstructured alternatives. These alternatives include: 1) interviews being conducted by psychologists focusing on personality traits; 2) traditional unstructured questions not based on job analysis; 3) interviewers ask questions based on an intuitive approach. This study achieved the highest level of structure through a comprehensive job analysis. A variety of job analysis methods can be used to develop a structured interview as long as it includes a determination of knowledge, skills, and attributes upon which to base interview questions. The knowledge, skills, and attributes found to be 'critical' at the start of the role or job are the aspects that should be discovered during this job analysis and covered by the structured interview questions. Critical incidents are actual job situations that show how effective or ineffective an individual is in a specific aspect of work. The critical incident method is a procedure used to develop questions from knowledge, skills, and attributes (Outerbridge, 1994). A systematic literature review was undertaken to identify the initial pool of knowledge, skills, and attributes from the existing body of knowledge. However, Weekley and Gier (1987) suggests meeting with subject-matter experts as a common method to collect incidents and undertake a job analysis. An expert panel was established for this study, specific to the cancer support group leader role, with consensus established for requisite knowledge, skills, and attributes.

Development of job-related questions from critical incidents has been described as "an art requiring some literary licence" (Latham & Saari, 1984). This task was undertaken by the PhD student researcher through combining her experience and knowledge as a psychologist, a cancer agency worker, and

researcher. Once drafted, all job-related questions where subsequently reviewed by the expert panel to determine suitability, with consensus established on all questions.

To maximise results, a contextual job analysis was undertaken to make the job realistic and relevant to a community-based environment (Pavur Jr, 2010). For example, Delphi questionnaire instructions provided to the expert panel positioned the role realistically in the community, "*Before providing responses, please consider the role of the group leader within the context of a cancer support group. Please note that many groups operate independently in the community, at minimal cost, and in a limited peer volunteer capacity. The provision of medical/counselling knowledge or advice is not considered to be part of the role of the cancer support group leader."* The structured interview questions developed have a direct link to the critical and necessary knowledge, skills, and attributes required for the cancer support group leader role. Additionally involving the expert panel in the job analysis has increased their acceptance and confirmed agreement of the analysis to be appropriate and valid (Campion et al., 1997).

7.3.2 Ask Exact Same Questions

A basic component of structure is the standardisation of questions, with the highest level of structure achieved through the exact same questions being asked of each candidate in the same order. This component converts the interview from a conversation into a scientific assessment. It may reduce contamination by preventing discussion of unrelated topics and other biasing influences, a situation often reported anecdotally by cancer agency workers. Additionally, this component may increase reliability between interviewers as well as interviews conducted with different

candidates. Importantly, by asking the same questions it limits sources of bias in the interview and provides fairness by way of asking the same questions of each candidate.

7.3.3 Limit Prompting, Follow-up Questions and Elaboration

Several levels exist to the component of prompts, with the highest level prohibiting any prompting, follow-up questioning or elaboration. Reliability may increase by decreasing variation on the types and extent of prompts used. To provide an environment in which to elicit enough relevant information from the candidate, the second, less stringent, level was applied to the development of the interview for support group leaders. By which, suggested probes were provided and revised to meet expert consensus requirements and enhance the conversational style deemed important by users. The intention of prompting was to clarify answers and seek information from interviewees. For example, "*Can you tell me more? Can you give me some examples?"* The follow-up questions or probes were standardised for each question to guide interviewers to maintain consistency. Probes were also kept neutral to provide equal encouragement and opportunity to elaborate on answers for all interviewees.

7.3.4 Use Better Types of Questions

Interview questions should be developed from behaviours determined during the job analysis to be critical to the performance of the job. There are four types of interview questions: situational, past behaviour, background, and job knowledge. A variety of types of questions was used for this structured interview and was consistent with psychologists' recommendations (Campion et al., 1997). However, certain types of questions are more structured than others, with enhancement of validity occurring

when questions relate to the role. Researchers have found that the most predictive questions are behavioural or situational in nature (Campion et al., 1997). First, situational questions are highly structured due to their specific nature. These questions pose hypothetical situations that could occur in the role and interviewees are asked what they would do in this circumstance (Latham, Saari, D. Pursell, & A. Campion, 1980). For example, a question relevant to the role may be, *"In a group meeting, how would you show support to someone who has received some bad news?"* Second, past behaviour questions ask interviewees to describe what they did in past jobs relevant to requirements of the current role being sought (Janz, 1982). Past behaviour questions were important given that many group leaders volunteer and do not have previous experience in the role but can build on transferable skills from other roles. For example, "*Can you give me an example of planning and organising a group activity, either in a work, volunteer, or social capacity? What did you do and what was the outcome?"*

Third, background questions typically focus on work experience, education and other qualifications. This was systematically achieved through demographic questions prior to the interview, with data collected used to provide a summary. Questions were developed from previous research on group leader demographics to ensure adequate coverage of relevant information (Kirsten, Butow, et al., 2006; Stevinson et al., 2010; Zordan et al., 2010). Fourth is role knowledge questions, where interviewees are asked to describe or demonstrate their role knowledge. A pertinent example of a role knowledge question developed to address the requisite of confidentiality was "*What is your understanding of confidentiality as it relates to a support group?"* Another question deemed relevant was willingness questions based on the role mainly being undertaken in a volunteer capacity and previous

issues of engagement with training identified in the literature (Kirsten, Butow, et al., 2006; Zordan et al., 2015). For example, *"If assistance for the role were available would you be willing and available to access support either now or in the future?"*

Outerbridge (1994) also described six important characteristics of questions considered important for question development. Specifically, questions should be: 1) realistic; 2) to the point, brief, and unambiguous; 3) complex enough to allow adequate demonstration of the ability being rated; 5) tried out on job incumbents to check for clarity, precision of wording, and appropriateness; and 6) not dependent upon skills or policy that will be learned once in the job. These characteristics were important to address in question development for this structured interview given the pragmatic framework of the project. All questions were worded so that potential group leaders would clearly understand what was being asked. The use of acronyms, terminology, or jargon was avoided with the intention of making it as easy as possible for interviewees to understand the question. Open-ended questions were also developed to allow the candidates to reveal more about themselves and gather more information (Outerbridge, 1994).

Finally, all questions developed related specifically to the job analysis and the knowledge, skills, and attributes determined by the expert panel to be required for the cancer support group leader role. Therefore, no questions contained inquiry that could be biased or discriminatory in nature, thus increasing fairness of the interview (Kutcher & Bragger, 2004). For example, no questions were asked relating to mental health, disability, criminal record, or religious views.

7.3.5 Use Longer Interview or Larger Number of Questions

Within reasonable limits, longer interviews are considered more structured as they obtain a larger amount of information. Reporting on the time taken can also assist with internal consistency, allowing equal time to interviewees. Length can be reflected in either the amount of questions or time involved in its administration. Campion et al. (1997) found that two-thirds of interviews in the literature were between 30 and 60 minutes, with half between 15 and 20 minutes. The number of questions suggested was eight to fifteen to keep within a reasonable timeframe. These previous indications for timeframe and number of questions were used as an initial guide in the development of the structured interview. However, consideration of interview length relating to contextual demands was achieved though expert consensus and assessed through clinical utility.

7.3.6 Control Ancillary Information

A threat to structure is the uncontrolled use of ancillary information such as resumes, awards, personal recommendations, and so forth. Two problems occur when ancillary information is reviewed: 1) it confounds the interpretation of the value of the interview with validity possibly attributed to things other than the interview itself and 2) it creates unreliability if not available equally to all candidates. It is therefore suggested that ancillary information be withheld. Although not a circumstance deemed as highly likely to the selection process of the cancer support group leader role, the concept of determining suitability based on the interview conducted rather than other potentially biased information is an important one. It was considered a point of guidance for interviewers and was emphasised in the user manual.

7.3.7 Do Not Allow Questions from Candidates until After the Interview

Responding to questions from interviewees can change the interview content in unpredictable ways. Therefore, structure can be enhanced by not allowing questions, but instead allowing time outside the interview. It was considered a point of guidance for the interviewee and interviewer via the user manual.

7.3.8 Components of Evaluation

7.3.8.1 Rate Each Answer or Use Multiple Scales

There are two elements to this component, with three common levels. First, ratings can be made on each answer or on the entire interview. Second, multiple ratings or only a single rating can be made. However, higher levels of structure are achieved through rating each answer with scales tailored to each question. This is due to judgements made on specific responses are considered less cognitively complex, compared to multiple ratings. Therefore, individual ratings were developed for all questions. A simple 0-2 point-based rating scale was used. The rating scale was kept to a minimum to ensure levels could be defined, meaningful, and consistently assessed (Valadez, 1987). For example, a score of ‘0’ indicated the interviewee was unable to provide examples of knowledge, skills, and attributes, a score of ‘1’ indicated some aspects of the knowledge, skills, and attributes were reflected in the response, score of ‘2’ indicated the interviewee demonstrated most or all aspects of the knowledge, skills, and attributes. The exception was interviewer observations questions which were rated as either Observed or Not Observed. This was due to interviewers’ likely limited observations of the interviewee during the selection process and assumed difficulty of rating degree.

The second level of structure was applied to make multiple ratings at the end. The third level is to make one overall judgement at the end. In this instance, an overall judgement was established based on an ordinal scale for categories of suitability (i.e. Highly Suitable, Suitable) and Readiness (i.e. Ready, Ready with Support, Not Yet Ready). An overall judgement based on statistical procedures that combined data from structured components was deemed a useful measure to guide decision-making until an appropriate scoring matrix is developed.

Dimension scores are desired to match attributes to job requirements, provide feedback to candidates, or understand results in detail. For example, we wanted to determine separately: 1) the suitability of the potential group leader and 2) the readiness of the potential group leader. Therefore, as suggested, each question was rated and then questions that had bearing on either the suitability or readiness dimension were summed separately to produce two scores, one for suitability and one for readiness.

7.3.8.2 Use Detailed Anchored Rating Scales

Anchored rating scales use behavioural examples to illustrate scale points and work to reduce ambiguity and difference. Anchored rating scales enhance objectivity and reliability and should therefore reduce biases. On a practical level it also eases the difficulty of judging answers, considered important given variations in experience and knowledge reported by cancer agency workers during consultation. To develop such scales involved generation of example answers based on the researcher's clinical experience and then selecting answers that were unambiguous. Then the 'goodness' of those answers was judged by experts as part of the Delphi study and achieved consensus. There are at least four types of anchors that can be used: example

answers or illustrations; descriptions or definitions of answers; evaluations of the answer; and relative comparison. As it was deemed impractical to provide all possible responses or answers given the variable structures of the support groups, a pool of example answers was provided. Campion, Pursell, and Brown (1991) state that it is not essential to describe all level answers as long as the other levels provide adequate anchor points for making a rating decision on any of the levels. For example, for a score of '1' the interviewee displayed an adequate though not comprehensive number of responses listed for a score of '2' (e.g. two to three of the responses listed for a score of '2').

7.3.8.3 Take Detailed Notes

Structure can be further enhanced through note taking as it increases memory recall and requires justifying the ratings. Additionally, it can assist the interviewer to focus on the answers rather than recording judgements, thus increasing accuracy. More structure is given when note taking occurs for each answer. To cover this component, the user manual directs interviewers to take notes throughout. In addition, space was allocated under each question or scenario in the structured interview form for the purpose of note taking.

7.3.8.4 Use Multiple Interviewers

The use of multiple interviewers is favourable as it helps to reduce the impact of biases and cancels out random error when judgements are aggregated. Recall of information is thought to be better with multiple interviewers, with the range of information and perspectives likely to increase accuracy. The higher level of structure is a panel interview and a lower level is one interviewer. However, there is inconclusive evidence for the validity benefits of multiple interviewers particularly

when structure on other components is high. Therefore a pragmatic approach was taken in response to this component. First, a panel of interviewers may place undue stress on interviewees. Second, the limited staffing resources mean that many cancer agencies do not have the resources available to provide a panel for interview purposes. Guidance on additional interviewers was included in the user guide, with the suggestion for a second interviewer to be an experienced peer support group leader.

7.3.8.5 Use Same Interviewer across All Candidates

Use of the same interviewer is important when other elements of the interview are unstructured given that different questions can be asked, information elicited varies, and evaluated using different methods. The range of structure for this component is for one person to conduct all interviews to different people conducting each interview. However, using one interviewer for all candidate interviews may be impractical for some organisations. Instead, recommendations of interviewer training through a detailed user guide and increasing structure on other components were included in the user manual.

7.3.8.6 Do Not Discuss Candidates or Answers between Interviews

Irrelevant information may enter the evaluation process, resulting in contamination and reduced validity, if candidates are discussed. Reliability effects, may also be mixed. For example, reduction in interrater reliability and agreement can occur due to differences in evaluations not being identified or corrected. It is stated that all predictive effects need to be tested and this component may not matter if other components of structure are covered. Should multiple interviewers be involved,

some general guidelines have been included in the user manual with a potential need for review.

7.3.8.7 Use Statistical Rather than Clinical Prediction

The use of statistical procedures to combine data rather than interviewer judgements is a final way to enhance structure (Dipboye, 1992). This component focuses on the statistical prediction based on the measurements. Three situations are deemed relevant with no hierarchy assigned. First, ratings are combined from different questions or dimensions to make predictions with a statistical approach using a formula (Walters et al., 1993). Formulas can use differential unit weight (i.e. different rating based on judgement or relationship criteria) or equal unit weight (i.e. each rating given the same weight). However, ratings based on equal unit weight do not require cross-validation and are considered to be more robust with equally high validity (Wainer, 1976). This component was achieved for our structured interview by taking the most common approach of a simple average or sum across all questions and dimensions (Arvey, Miller, Gould, & Burch, 1987; Campion, Campion, & Hudson, 1994; Campion et al., 1988; Pulakos & Schmitt, 1995). The second situation described by Campion et al. (1997) relates to interviews conducted by multiple interviewers whereby data is combined. Again, the most structured approach for this is to use a formula of averaging or summing. The third less structured but more common approach is to have interviewers discuss differences to achieve consensus. It is thought that conversation might lead to more accurate consensus ratings. Discussion may identify errors in perception, clarify incorrect interpretations, and confront biases (Sackett & Wilson, 1982). A recommended compromise is to average across interviewers and discuss large differences (Campion et al., 1988). Given the contextual demands and pragmatic approach taken for the project, a

consensus rating approach was adopted and outlined in the user manual. This situation component was covered as an instruction in the user manual, *"If ratings vary between panel members, discuss reasons with the aim of reaching agreement to make the overall final decision. If this is not possible then average the scores and determine the outcome based on combined results".*

7.4 Conclusions

This chapter has presented an overview of the components of structure for development of our structured interview. Components covered those that influenced the content of the interview and those that influenced the evaluation process. The development of a structured interview is complex, continuous and multi-dimensional. A pilot study to improve clinical utility was required before field testing could occur, to develop a rational scoring model and provide a summary of existing group leader qualities. Chapter 8 will report on methods used and results for piloting and field testing of the structured interview.

8 PILOT STUDY AND FIELD TEST RESULTS

8.1 Chapter overview

With the structured interview development process detailed in the previous chapters, this chapter reports on the testing phase. The methods and results of two separate studies are outlined, being a pilot study and a field test. As described in the protocol paper contained in Chapter 4, the aim of the pilot study was to appraise aspects of clinical utility of the newly developed structured interview and user manual. Aspects included: appropriateness, accessibility, practicability, and acceptability. The aim of the field test was to test the structured interview and use results to establish a rational scoring model and produce preliminary data on the knowledge, skills, and attributes of current cancer support group leaders.

Chapter 8 of this thesis consists of a results paper submitted to *European Journal of Cancer Care* on 23rd September 2017 which is currently under peer review. The results of this pilot study determined the newly developed tool for selection and development of cancer support group leaders to be appropriate, accessible, practical, and acceptable for users. The field test provided a summary of current support group leaders' qualities and characteristics, and provided a cut-off score for suitability. However, a more comprehensive pool of participants and scores is needed to determine reasonable cut off scores for readiness. Findings in the context of previous literature, limitations, and recommendations for future research identified in field test are expanded on in the next discussion chapter.

8.2 Appendices for this chapter

A number of appendices relate to the pilot study and field test of this project and are therefore relevant to this chapter. As mentioned previously in Chapter 7, outputs from the Delphi study resulted in the proposed structured interview and user manual used for this pilot study (see Appendix 15 for structured interview and Appendix 16 for user manual as used in the pilot study). In addition, interviewers were provided with an interview script to maximise consistency across interviewers (Appendix 17). After interviews had been conducted, interviewers were asked to provide feedback on the clinical utility of the structured interview and user manual (Appendix 18 and Appendix 19).

For the field test, current support group leaders from Prostate Cancer Foundation of Australia and Breast Cancer Network of Australia were invited to participate in the field test. Documents provided to participants for this field test included a plain language statement (Appendix 20) and consent form (Appendix 21). The field test interview document incorporated the interview script, demographic questionnaire, and structured interview (Appendix 22). Interviewers were provided with supporting documents for the field test to including: the user manual (Appendix 23), field test criteria (Appendix 24), participant contact script (Appendix 25), overview of the field test process (Appendix 26), and participant invitation letter (Appendix 27).

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Structured interview and user manual for the selection and development of cancer support group leaders: pilot and field test results

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Introduction

Cancer support groups have emerged in the community and sometimes represent the only psychosocial care available through community advocacy organisations and treatment centres (Owen, Goldstein, Lee, Breen, & Rowland, 2007). Although au spicing organisations provide varying levels of training, funding and support to cancer support groups, they mainly operate independently, are volunteer lead and peer focused. The nature of the cancer support group leader role therefore is very specific. Until recently, little was known about qualities required to lead a peer cancer support group or how to determine suitability for the role. To this end, we undertook an initial scoping exercise that revealed the lack of a role analysis, published guidelines or standards specific to cancer support group leaders (Pomery, Schofield, Xhilaga, & Gough, 2017b).

A structured interview was considered the selection technique of choice for assessing role-related dimensions. Reasons for the use of a structured interview included; 1) familiar to users (Wilk & Cappelli, 2003), 2) perceived as fair and expected process for selection (Hausknecht, Day, & Thomas, 2004; Lievens, De Corte, & Brysse, 2003), and 3) predictive of job performance (Macan, 2009). Importantly, validities of an interview can be maximised by enhancing its structure through: job-relatedness in the development; standardisation of process in how the interview is conducted; and increasing structure in the use of data for evaluation and decision-making of the interviewee (Dipboye, 2004). We therefore designed a program of work to develop a structured interview to guide the selection and development of cancer support group leaders (Pomery et al., 2017b). This program included a systematic literature review, an online reactive Delphi study, which focused on the development and appraisal of a structured interview and user manual, a pilot study and a field test.

The systematic review identified and collated peer reviewed literature that described qualities of support group leaders. Forty-nine eligible full-text articles and theses were identified via a systematic search of Medline, CINAHL, and PsychINFO abstract databases (refer to Pomery et al (Pomery, Schofield, Xhilaga, & Gough, 2016) for more detail). Fifty-nine specific knowledge, skills and attributes were identified from these articles and theses using summarising content analysis (Flick, 2014). Knowledge, skills and attributes (KSA) were then grouped into seven major themes (or qualities) including group management, group process, role modelling, awareness, willingness, agreeableness, and openness. Qualities were then readily classified into those relevant to selection and those relevant to development.

A reactive online-Delphi study with an interdisciplinary panel was then undertaken to obtain expert agreement on essential qualities for the role (minimum standards) and the content for the structured interview (refer to Pomery et al (Pomery, Schofield, Xhilaga, & Gough, 2017a) for more detail). Results informed a provisional set of two scenarios and 11 questions to elicit information on KSA. The interview incorporated categorisation of questions assessing KSA relating to suitability and readiness of interviewees to undertake the group leader role. To increase the structure in the use of data, a behaviourally anchored rating scale with potential responses was developed for each question. The scale provides a formal method of rating behaviours and consistent application of decision rules. Consensus based on >75% agreement was reached on all elements (content, structure and format) of the interview. A pilot study and field test will mark the final phase of the study.

When introducing a novel instrument into community-based health care, it is important to ensure its usefulness, benefits and drawbacks (Smart, 2006). Of particular importance, is the need for the minimum standards and structured interview to be easily adopted and used by cancer agency workers (Peters, Adam, Alonge, Agyepong, & Tran, 2013; Reeve, 2012). Clinical utility (Smart, 2006), is a multi-dimensional model that outlines four factors in user judgements: 1) appropriateness, 2) accessibility, 3) practicality, and 4) acceptability. All these components are considered to ensure the structured interview and user guide are

readily understood, appropriate and able to be incorporated into practice. Issues and aspects of clinical utility to be considered will draw on relevant design considerations for structured interviews. For example: standards for patient reported outcome measures (Reeve, 2012), Dipboye et al. 2004's conceptual framework on interview development, and 15 components of structure (Campion, Palmer, & Campion, 1997). To determine a candidate's overall suitability, we also included acceptability of proposed cut off scores based on field test results.

Study Aims

This study aims to:

1. Pilot the newly developed structured interview and user manual, appraising aspects of clinical utility including usability and acceptability.
2. Field test the structured interview and describe the knowledge, skills and attributes of current cancer support group leaders and establish a rational scoring model.

Methods

Participants and recruitment

Pilot study. There were two groups of participants in the pilot study: three cancer agency workers (referred to hereon as interviewers) and twelve cancer support group leaders (referred to hereon as interviewees). Interviewers were identified and invited to participate in the pilot study by researcher AP. All were directly engaged with cancer support group leaders as part of their current role and would be reasonably expected to use the structured interview as part of this role. Interviewers were advised that the structured interview and user manual would be freely available and readily accessible to all cancer agencies, including the agency for which they worked.

Interviewees were identified by interviewers. Eligibility criteria for interviewees included: current cancer support group leader of a face-to-face group focused on peer support for a shared experience—meeting structure could be formal or informal; aged 18 years or older; and proficient in English. Interviewees could be volunteers, peers or professionals.

Field test. As per the pilot study, there were two groups of participants in the field test: four cancer agency workers (referred to hereon as interviewers); and 63 current support group leaders (referred to hereon as interviewees). Again, interviewer participants were directly engaged with cancer support group leaders and would be reasonably expected to administer the structured interview in their cancer agency role. The number of interviewers recruited was based on staff availability (e.g. their work commitments, whether they worked full-time or part-time). One interviewer was recruited to undertake structured interviews with prostate cancer support group leaders, whereas three interviewers were recruited to undertake structured interviews with breast cancer support group leaders.

Eligibility criteria for field test interviewees were the same as the pilot study criteria. Two national cancer agencies reviewed current support group leader listings to identify eligible participants/interviewees; in total, 277 eligible interviewees were identified including 143 prostate and 134 breast cancer support group leaders. Invitations were sent to all eligible participants via electronic and traditional mail. Invitations were endorsed by the relevant cancer agency and signed by the relevant cancer support group services manager.

Procedure

Ethics. Ethical approval was granted by the Psychological Sciences Human Ethics Advisory Group of University of Melbourne (ID:1443027.2). Participants provided written

informed consent before taking part in the pilot study and the field test. Participants involved in the pilot study also provided verbal consent to having the structured interview audiotaped.

Pilot study. First, interviewers were given a detailed document outlining how to prepare for and conduct the structured interview, along with how to provide feedback to interviewees. Interviewers were also given drafted email invitations, as well as consent forms and plain language statements to be sent to interviewees. Further, interviewers were given an interview script to help them introduce the study to interviewees before beginning the structured interview. Each interviewer was asked to identify and invite four support group leaders from their agency's network to participate in the pilot study. Participation was voluntary. Interviewee participants were told that the pilot study was designed to evaluate aspects of the structured interview rather than the qualities of interviewees.

Structured interviews were conducted via phone, consistent with its likely administration in practice. Interviews were audio-taped; responses were also noted by the interviewer. Interviewers were asked to rate interviewees' responses using the standard form provided. Pre- and post-interview briefings were provided to all interviewer participants.

Using the audio-taped structured interviews, interviewee responses were independently rated by researcher AP; the researcher was blinded to interviewer participant ratings. Then, ratings by interviewer participants and researcher AP were entered into an Excel spreadsheet and cross-checked by researcher KG to assess the consistency of ratings between agency workers and researcher AP.

Once interviewers had completed all four interviews, they completed a customised, self-report questionnaire and participated in a brief, semi-structured interview to appraise multiple aspects of clinical utility. Semi-structured interviews were conducted by researcher AP. Together, the semi-structured interview and questionnaire took approximately 40 minutes to complete. Aspects of clinical utility assessed, issues considered and methods of assessment are described in Table 1.

[INSERT TABLE 1 HERE]

Feedback from the semi-structured interviews was entered into an Excel spreadsheet. Responses were aggregated and assessed against aspects of clinical utility (i.e., appropriateness, accessibility, practicality, and acceptability); the aim was to determine what components of the structured interview and user manual worked well and what should be further improved. Consultation among the researchers determined integration of feedback and associated changes to instructions, format and/or questions.

Field test. Individual interviewer briefings (process overview and answering specific questions) were provided by researcher AP. Interviewers were given an administrative pack consisting of: an interview script, a customised interviewee characteristics questionnaire, a copy of the structured interview and scoring sheet (see supplementary online Appendix 1), as well as the user manual (see supplemental online Appendix 2). Invitations to participate were sent to potential interviewees by the relevant cancer agency, along with a reply paid envelope. A reminder email was sent three months after the initial mail out to boost participation.

Once consent forms had been received, mutually suitable interview times were coordinated by interviewers. Again, structured interviews were conducted over the phone. The time taken to complete each interview was recorded by interviewers. Interviewers were asked to rate interviewees on all structured interview questions using the behaviourally anchored rating scales (all scales are detailed in supplementary online Appendix 1) as soon as they had completed the interview. The ordinal rating scale ranged from 0 to 2; score of '0' indicated the interviewee was unable to provide examples of the KSA, a score of '1'indicated some aspects of the KSA were reflected in the response, score of '2' indicated the interviewee demonstrated most or all aspects of the KSA. They were also asked to rate the interviewees'

overall level of suitability (highly suitable, suitable, not currently suitable) and readiness (ready, ready with support, not yet ready) for the support group leader role. Interviewers were asked to record their ratings for each question and opinions regarding total scores for suitability and readiness on the scoring sheet.

Interviewee responses to demographic questions and interviewers' rating to individual interview questions were entered into an Excel spreadsheet, then imported into R (reference index V.3.1.3 or higher) for analysis and graphing. Descriptive statistics were used to summarise participant characteristics and responses to structured interview questions for the full sample and by support group type (prostate and breast). The R package 'ggplot2' (Wickham, 2016) was used to prepare graphs of suitability and readiness total scores by current level of suitability and readiness ratings, respectively.

Results

Pilot study

Appropriateness.

Effective. Ratings of interviewees by cancer agency workers and author AP were fairly consistent. Fifty-six of 60 ratings on suitability questions were concordant (93%). For nine interviews, all five ratings on suitability questions were concordant. For the remaining interviews, two had four concordant ratings and one had three concordant ratings. One-hundred and thirty-nine of 156 ratings on readiness questions were concordant (89%). For three interviews, all 13 ratings on readiness questions were concordant, for four 12 ratings were concordant, for two 11 were concordant and for three 10 were concordant.

Relevant. Overall, responses to the self-report questionnaire indicated that the structured interview was useful for decision-making: it helped determine candidate's suitability and readiness (ratings: strongly agree, n=2; undecided, n=1); and it helps standardised the selection and development of support group leaders (ratings: strongly agree, n=3).

Accessibility.

Resource implications. All three interviewers thought the time taken to complete the structured interview was manageable (ratings: strong agree, n=2; agree, n=1). One interviewer commented that "It takes time but it normally takes time with new groups anyway".

Procurement. Again, all three interviewers thought the structured interview would be adequately supported by current resources (ratings: strongly agree, n=2; agree, n=1) and could be easily integrated into their current role's procedures and practices (ratings: strongly agree, n=3).One interviewer commented, "The more familiar I was with it the better and increased my confidence. I'm feeling comfortable to prompt (interviewees) further now as I was unsure in the beginning".

Practicability.

Functional and suitable. Overall, responses to the self-report questionnaire indicated that the structured interview and user guide were complete and workable without the need for additional training. There was strong agreement that: the user guide supports the use of the structured interview (ratings: strongly agree, n=3); and the structured interview is sensible and workable (ratings: strongly agree, n=3). There was agreement that; the scoring table is suitable and easy to use (ratings: strongly agree, n=1; agree, n=2) and the structured interview was appropriately pitched for my level of experience and knowledge (ratings: strongly agree, n=2; agree, n=1).

Acceptability.

Acceptable to users and the community. All three interviewers thought that the structured interview was a reasonable selection process with likely uptake; would use the structured interview in their current role (ratings: strongly agree, n=3): would recommend the structured interview to another cancer agency worker (ratings: strong agree, n=3): the language and questions were comprehensible to the candidates (ratings: agree, n=3): the structure and format of the interview was acceptable to the candidate (ratings: strongly agree, n=2; agree, n=1): and the use of the structured interview would be acceptable to the various stakeholders relevant to their role (ratings: strongly agree, n=3). One interviewer commented that "It takes time but it normally does with new groups anyway".

Very few changes to the interview and user manual were required based on feedback provided as part of the semi-structured interviews. Minor changes included; adding a probe, providing a clearer explanation that interview is not a test, using additional probes as required, directing interviewers to offer a follow up call when closing the structured interview and highlighting the need for cancer agencies to be clear about what support they can offer in the user manual. Further, interviewers noted an obvious practice effect, so recommended the user manual include instructions for potential users to conduct a mock interview prior to conducting their first structured interview. Proposed changes were reviewed by the research team and incorporated into associated documents.

Field test

Study profile. Sixty-two cancer support group leaders participated in the field test: 24 leaders of breast cancer support groups (consent rate: 18%) and 38 leaders of prostate cancer support groups (consent rate: 27%). Interviews with prostate cancer support group leaders took longer on average than interviews with breast cancer support group leaders (median=60 minutes, inter-quartile range= 52 to 74 minutes; and median=46 minutes, inter-quartile range=42 to 43 minutes, respectively). Characteristics of cancer support group leaders are summarised in Table 2.

[INSERT TABLE 2 HERE]

The median age of support group leaders was 68 years (inter-quartile range= 61 to 73 years). All breast cancer support group leaders were female and six of 38 (16%) prostate cancer support group leaders were female. A majority of leaders (n=49, 79%) indicated that they had been diagnosed with cancer or were cancer survivors. The median length of time in the support group leader roles was 5.5 years (inter-quartile range= 3 to 9 years), with a substantial proportion of leaders having undertaken 1-2 day training (n=29, 47%) or having accredited qualifications (n=11, 18%).

When asked if they were interested in ongoing support for the group leader role, 69% agreed (n=25, 40%) or strongly agreed (n=18, 29%); ten leaders were neutral (16%) and nine disagreed or strongly disagreed (14%). Similarly, when asked about their likelihood of accessing support, 70% indicated they were likely (n=29, 47%) or extremely likely (n=14, 23%); eight leaders were neutral (13%) and 11 indicated they were unlikely to access support (18%).

Interview results. Table 3 provides a summary of interviewer ratings on suitability questions. All interviewees obtained a maximum rating of '2' for observations on desirable *Personal attributes*, indicated interviewers observed more than two listed attributes (e.g., respectful, listened, patient) at any time throughout the interaction. Overall, ratings on question 2: *Availability and commitment to the role* and question 13: *Self-assessment* were also high, with 85% and 90% of all interviewees, respectively, receiving a rating of '2'. Indicating that interviewees reflected on the conversation and overall perceived themselves as capable and ready to undertake the role. The lowest ratings were given for question 11: *Openness for role development* and question 12: *Self-care*. On *Openness for role*

development, four leaders (6%) received a rating of '0' and 21 (34%) received a rating of '1'. Similarly, for *Self-care*, three leaders (5%) received a rating of '0' and 25 (40%) received a rating of '1'.

[INSERT TABLE 3 HERE]

Table 4 provides a summary of interviewer ratings on readiness questions. The highest percentage of '0' ratings were recorded on question 4: *Conflict resolution*. Eight leaders (13%) received a rating of '0' and a further 21 (34%) received a rating of '1'. Notably, prostate cancer support group leaders were more likely to receive a rating of '0' on this question. Also of note, very few leaders received ratings of '2' for scenarios 1: *Respectful group interaction* and 2: *Group purpose and agreement* (27% and 34%, respectively). On questions 3: *Planning and delegating*, 5(b): *Receiving support*, 6: *Working with others*, 7(b): *Managing criticism* and 9: *Welcoming new members* approximately two-thirds or more leaders received a rating of '2'. A very high percentage of breast cancer support group leaders received a rating of '2' on question 5(a): *Giving support*. In contrast, for prostate cancer support group leaders the highest percentage of ratings of '2' was given for question 5(b): *Receiving support*.

[INSERT TABLE 4 HERE]

Suitability total scores by level of suitability ratings (not currently suitable, suitable and highly suitable) are shown in Figure 1. Readiness total scores by level of readiness ratings (not yet ready, ready with support and ready) are shown in Figure 2.

Only one interviewee was regarded as 'not currently suitable'. That interviewee obtained a suitability total score of '6'. Those regarded as 'suitable' (n=15) obtained total scores ranging from '7' to '10' (median=8, interquartile range=7 to 9). Those deemed 'highly suitable' (n=46) obtained total scores ranging from '7' to '10' (median=9, inter-quartile range=9 to 10).

Three interviewees were regarded as 'not currently ready' to lead a cancer support group. These interviewees received readiness total scores of '10', '13' and '22'. Those regarded as ready with support (n=31) obtained total scores ranging from '13' to '23' (median=18, inter-quartile range=16 to 20). Those deemed 'ready' (n=28) obtained readiness total scores ranging from '17' to '26' (median=23, inter-quartile range=22 to 24).

A follow-up interview was conducted to determine an acceptable scoring model based on field test scores. Specifically, what cut off scores would be considered reasonable by users, to determine a candidates suitability and readiness for the role. Interviewers were presented with field test total scores for suitability (Figure 1) and readiness (Figure 2) All interviewers indicated strong agreement with a suitability cut score of 5 out of a possible total score of 10 (rating: strongly agree, n=3). In contrast, interviewers believed that a cut score for readiness could not be determined as an outcome of the field test results and limited sample of participants. All interviewers were concordant with the decision to not set a cut score for readiness. Interviewers commented that assignment of a 'reasonable' readiness score would depend on candidate's access to support and training in order to assist in developing the necessary KSA.

[INSERT FIGURES 1 & 2 HERE]

Discussion

Limited research has been undertaken to investigate the required qualities of support group leaders or develop the model of peer support groups in line with current evidence-based practice. The aim of this study was to pilot the structured interview and user manual to appraise aspects of clinical utility and then field test the structured interview to establish a

rational scoring model and provide a summary of current support group leader demographics and qualities.

Firstly, the pilot study demonstrated strong agreement on clinical utility of the structured interview and user manual. All aspects assessed were acceptable to participants with only minor edits to wording or instructions contained in the user manual. Interviewers determined the tool to be easily incorporated into practice, considering practical constraints such as time and resources. Importantly, the interviewers found the tool to be of value to their role and respective cancer agency. In an interviewer's own words, "Knowing that I don't have to work out what to ask beforehand and that there is consistency across staff and organisations is reassuring". We believe that these results are indicative of the highly consultative approach to the project overall, from its conception, job analysis and drafting of the interview (Dipboye, 2004). Moreover, given the community-based setting support groups operate within, the mixed method approach and incorporation of consensus-based standards was crucial. This serves to balance the needs of various stakeholders and strengthen the credibility of peer support groups as part of a tiered psychosocial support option offered to cancer patients at a basic universal care level (Hutchison, Steginga, & Dunn, 2006). Endorsement of the tool by national and international cancer agents (e.g. Cancer Australia, Union for International Cancer Control) was suggested by participants to assist with distribution and uptake by individual agencies.

The majority of current support group leaders participating in the field test primarily identified themselves as; 1) having an experience of cancer themselves; 2) of retirement age; and 3) having a commitment to the role extending across several years. This was consistent with participants' high scores for availability and commitment to the role (Q2). Given the time invested by these leaders, it further strengthens the rationale for supporting people in the role with adequate resources and training.

Training undertaken by participants was varied, with the majority completing a 1 - 2 day workshop and 18% never engaging in any formal training. Most participants scored low on openness for role development, receiving support themselves and accepting criticism. This may indicate potential challenges for cancer agencies to engage peer group leaders in training and ongoing support for the role. Importantly, the implementation of a structured selection and development process needs to be related to the established consensus-based minimum standards (Pomery et al., 2017b). Similar to clinical adoption issues, evidence alone may not be perceived as a strong argument for change (Fitzgerald, Ferlie, & Hawkins, 2003). However, combining both evidence and consensus approaches works to bridge the gap in establishing creditability and by-in.

Interestingly, in reviewing all suitability question responses, participants scored lowest on openness for role development. Anecdotally, some participants perceived experience relating to time in the role rather than level or amount of training completed. However, there were low participant scores on (Q.1) relating to role knowledge despite the average length of time participants had spent in the role.

Not surprisingly, overall, participants scored lowest for both scenario questions based on hypothetical situations. We suspect that the highly structured and specific nature of these questions is one of the major contributing factors for these scores (Campion et al. 1997). Interestingly, scenario 2 focused on knowledge, skills and attributes relevant to group purpose and agreement, key content covered in basic support group leader training (Zordan et al). In addition to ensuring that all group leaders receive training in these basic skill areas, it is recommended that scenario questions would be ideal in assessing participants learning outcomes from training attendance or ongoing development in the role.

It was interesting to note that despite participants being active in the role, there was variation in readiness scores for participants. It is hoped this may reflect the usefulness of the structured interview as an effective tool to identify ongoing development needs. In particular, results of this study highlight potential training areas to strengthen the knowledge, skills and

abilities of group leaders in meeting the challenges of group dynamics and interpersonal skills. For example, conflict resolution, giving support appropriate to the role and accepting difference need to be covered or expanded on further in training and ongoing support. There are potential challenges for cancer agencies in how best to deliver this support given those participants also scored low on receiving support themselves and accepting criticism.

The degree to which requisite knowledge, skills, and attributes are developed in potential support group leaders prior to them taking on the role strongly relates to the capacity of the individual cancer agency. Realistic and informed consideration needs to be given to what organisational support each agency can or is prepared to provide. It is surmised that adequate support to develop requisite qualities would help to strengthen support provided by the group leader and reduce the potential for burnout in the role.

It is suggested that instead of a cut off total score, the individual readiness question ratings be used as a guide to focus and prioritise allocation of support, resources and training available to candidates. In addition, when organisations incorporate support groups into cancer program services, the level of competency expected of group leaders needs to be reflected in recognition agreements entered into with support groups and communication out to the broader community.

Participant scores for Role knowledge (Q.1) were varied despite the median length of time in the role. Given that lack of role clarity can be a contributing factor to burn out and potential inconsistencies in leader support across groups (Kirsten, 2006), cancer agencies need to consider how best to keep leaders informed of the role and the importance of the implementation of the newly established minimum standards for selection and development.

Limitations

Participant sample. To obtain an adequate number of participants and determine a feasible benchmark for leader qualities, current leaders actively in the role were recruited. Of the leaders recruited, experience in the role was high with the average time in the role being between 5 to 10 years. It could be assumed that given participants were already in the role, they would likely have the attributes required to be a suitable leader. This could explain why there was only one participant determined to not be currently suitable. Additionally the length of time in the role may assist participants to develop responses to interview questions by drawing on previous experiences. It is still yet to be determined how those candidates with no prior experience of leading a group would go in undertaking the structured interview.

In addition, participation in the study was optional, with only 27% of prostate and 18% of breast cancer leaders invited from the network of support groups participating. We suspect interviewees that opted into the study may be; 1) more engaged with the cancer agency that sent the invitation; 2) more comfortable in responding to questions relating to their role; and/or 3) feel more confident in their abilities as a support group leader. Therefore, the interview scores and leader characteristics (e.g. exposure to training) may be different to those group leaders who did not participate in the study. Due to the limitations outlined, the participant sample of this study was not suitable for setting cut scores. Although interviewers involved in field test agreed with the proposed minimum total score of 5 for suitability, no reasonable minimum score for readiness was able to be determined.

Evidence of competency. This study recognises that cancer support groups mainly operate independently in the community and are not managed by cancer agencies. Therefore, competency-based evaluation of group leaders is not able to be conducted. Instead, it is suggested that cancer agencies engage support group leaders in an ongoing consultative process (Maram & Rice, 2002; Noeres et al., 2013). Specifically, a self-directed inquiry as to how they function in the role, using Malcom Knowles (Knowles, 1980) adult learning principles. The six main learning characteristics to foster being; 1) self-directed and autonomous; 2) utilization of knowledge and life experiences; 3) goal-oriented; 4) relevancy-

orientated; 5) highlights practicality; and 6) encourages collaboration. Further research could be conducted as to development of a standardised or tailored adult learning approach specific to cancer support group leaders.

Adaption of tool. Although study participants covered the two largest cancer tumour streams to access cancer support groups (Herron, 2005; Stevinson, Lydon, & Amir, 2010), generalizability of results to other health-focused peer support groups is still yet to be determine. Additionally, cross cultural adaption of the structured interview and proposed scoring range could not be covered in this study, and therefore would need further investigation if applied to other cultures and countries.

Conclusion

This study is the first to investigate the newly developed structured interview and user manual for selection and development of cancer support group leaders. The pilot study determined the tool to be appropriate, accessible, practical and acceptable for users. Ongoing data collection of scores for future interviews conducted with both potential and established group leaders is necessary. As part of accessing this free tool, it is proposed that terms of use incorporate submission of de-identified data online to develop a more comprehensive pool of participants and result scores in which to determine reasonable cut off scores for selection.

Conflict of Interest

The authors declare that they have no conflict of interest. The authors had full control over all primary data and will allow the journal to review the data if requested.

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Illustrations

Figure 1: Suitability total scores by suitability rating

Describes participant total score results from field test of the structured interview that relate to how suitable the interviewee is overall for the role of support group leader. Suitability total scores of participants counted and described by level of suitability rating being; Not currently suitable, Suitable and Highly suitable.

Figure 2: Readiness total scores by readiness rating

Describes participant total score results from field test of the structured interview that relate to how ready the interviewee is overall for the role of support group leader. Readiness total scores of participants counted and described by level of readiness rating being; Not yet ready, Ready with support, Ready.

Tables

Table 1: Aspects of clinical utility assessed, issues considered and method of assessment

Table 2: Summary of support group leader characteristics for all leaders and by support group type (prostate or breast)

Table 3: Summary of ratings on suitability questions for all leaders and by support group type (prostate or breast)

Table 4: Summary of ratings on readiness questions for all leaders and by support group type (prostate or breast)

Online Supplementary Appendices

Appendix 1: Field test structured interview

Appendix 2: Field test user guide

Figure 1: Suitability total scores by suitability rating

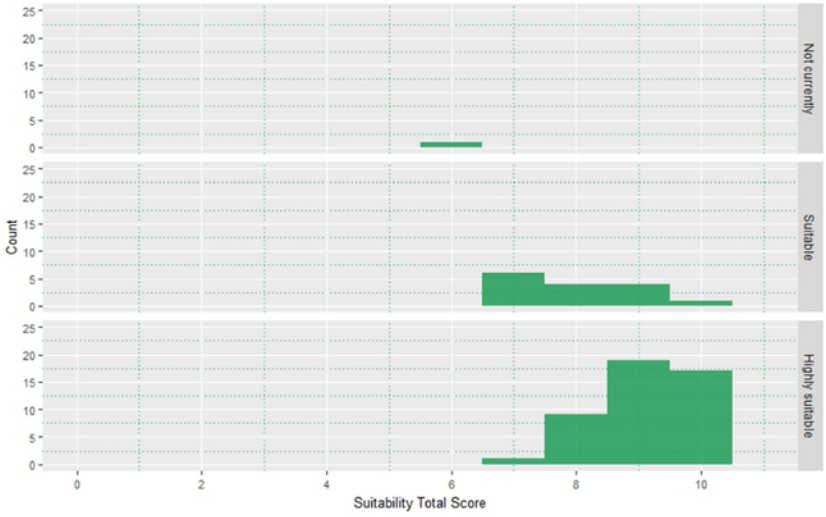

Figure 2: Readiness total scores by readiness rating

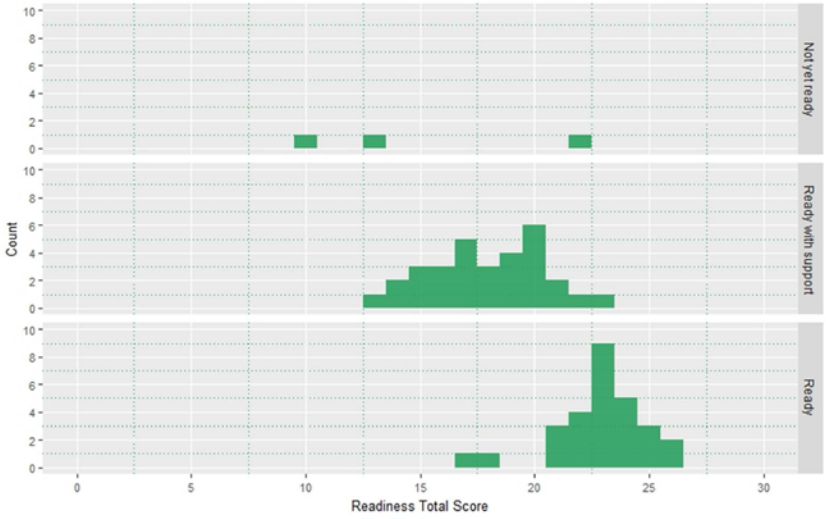

Table 1: Aspects of clinical utility assessed, issues considered and method of assessment

Component	Aspect	Issue considered	Methods of Assessment	Question
Appropriate	Effective	Evidence of score consistency	Cross-check by interview developer	NA
	Relevant	Useful for decision-making	Questionnaire	The structured interview and user guide helped me to determine the candidates suitability for the role
			Questionnaire	Using A Planned Conversation and User Guide enables me to determine the candidate's readiness to undertake the role
		Supports consistency of decision-making	Questionnaire	The structured interview and user guide will help standardise the selection and development of support group leaders
			Semi-structured interview	Any further comments, suggestions or feedback you want to share?
Accessible	Resource implications	Time requirements	Questionnaire	The time taken to conduct the structured interview was manageable
	Procurement	Integration with agencies internal processes and practices	Questionnaire	Current resources area adequate to fully support the use of A Planned Conversation within my agency
			Questionnaire	A Planned Conversation can be integrated into my role's procedures and practices
		Need for additional information, support or resourcing	Semi-structured interview	What (if any) additional information, support or resources would be helpful for those conducting A Planned Conversation?
Practical	Functional and suitable	Completeness and workability of materials, methods and instructions without the need for prior user experience or	Questionnaire	The user guide supports the use of A Planned Conversation

Component	Aspect	Issue considered	Methods of Assessment	Question
		additional training	Semi-structured interview	How did you find the structured interview (A Planned Conversation)? What worked well? What didn't work well?
			Questionnaire	The structure of A Planned Conversation is sensible and workable
			Questionnaire	The scoring table is suitable and easy to use
			Questionnaire	A Planned Conversation was appropriately pitched for my level of experience and knowledge
			Semi-structured interview	How did you find the User Guide? What worked well? What didn't work well?
			Semi-structured interview	Are there any aspects you were confused or uncertain about?
			Semi-structured interview	How could A Planned Conversation be improved?
Acceptable	To cancer agency workers, potential group leaders and the community more broadly	Likely uptake	Questionnaire	I would use A Planned Conversation in my current role
		Reasonable selection process	Semi-structured interview	What might be some challenges (or barriers) to using A Planned Conversation in your role?
			Questionnaire	I would recommend A Planned Conversation to another cancer agency worker
			Questionnaire	The language and questions were comprehensible to the candidates

Component	Aspect	Issue considered	Methods of Assessment	Question
			Questionnaire	The structure and format of the interview was acceptable to the candidates
			Questionnaire	The use of A Planned Conversation would be acceptable to the various stakeholders relevant to my role
			Semi-structured interview	From your perspective how did the support group leader find a Planned Conversation?
			Semi-structured interview	From your perspective what possible benefits are there to using A Planned Conversation?

Table 2: Summary of support group leader characteristics for all leaders and by support group type (prostate or breast)

Characteristic	All interviewees		Prostate cancer support group leaders		Breast cancer support group leaders	
	n	%	n	%	n	%
Sex						
Female	30	48	6	16	24	100
Male	32	52	32	84	0	0
Age (in years)						
Median	68		69		61	
Interquartile range	61 to 73		66 to 74		55 to 71	
Employment status						
Employed	26	42	14	37	12	50
Retired	35	56	24	63	11	46
Unemployed	1	2	0	0	1	4
Education level completed						
Primary	4	6	3	8	1	4
Secondary	13	21	5	13	8	33
Tertiary	33	53	19	50	14	58
Trade/TAFE	12	19	11	29	1	4
Residential location						
Major city	25	40	16	42	9	38
Inner regional	23	37	14	37	9	38
Outer regional	12	19	8	21	4	17
Remote	1	2	0	0	1	4
Very remote	1	2	0	0	1	4
English as first language						
Yes	61	98	37	97	24	100
No	1	2	1	3	0	0
Background						
Diagnosed/survivor	49	79	26	68	23	96
Partner/carer/family member	4	6	1	3	3	13
Allied health professional	11	18	6	16	5	21
Volunteer	11	18	7	18	4	17
Other	3	5	3	8	0	0
Years in role						
Median	5.5		5		8	
Interquartile range	3 to 9		3 to 8		5 to 10	

Characteristic	All interviewees		Prostate cancer support group leaders		Breast cancer support group leaders	
	n	%	n	%	n	%
Training						
No formal training	9	15	7	18	2	8
Training session (4hrs or less)	4	6	3	8	1	4
1-2 day training	29	47	20	53	9	38
2-5 day training	9	15	2	5	7	29
Accredited qualifications	11	18	6	16	5	21
Co-leader, leader support						
No	17	27	10	26	7	29
Yes	45	73	28	74	17	71

Table 3: Summary of ratings on suitability questions for all leaders and by support group type (prostate or breast)

Question			All support group leaders		Prostate cancer support group leaders		Breast cancer support group leaders	
Number	Knowledge, skill and/or attribute	Rating*	n	%	n	%	n	%
2	Availability and commitment	0	0	0	0	0	0	0
		1	9	15	3	8	6	25
		2	53	85	35	92	18	75
11	Openness for role development	0	4	6	4	11	0	0
		1	21	34	14	37	7	29
		2	37	60	20	53	17	71
12	Self-care	0	3	5	3	8	0	0
		1	25	40	17	45	8	33
		2	34	55	18	47	16	67
13	Self-assessment	0	0	0	0	0	0	0
		1	6	10	3	8	3	13
		2	56	90	35	92	21	88
Observations	Personal attributes	0	0	0	0	0	0	0
		1	0	0	0	0	0	0
		2	62	100	38	100	24	100

Notes. Rating scale*; '0' = no aspects of KSA provided; '1' = some aspects of the KSA provided; '2' =most or all aspects of KSA provided

Table 4: Summary of ratings on readiness questions for all leaders and by support group type (prostate or breast)

Question			All support group leaders		Prostate cancer support group leaders		Breast cancer support group leaders	
Number	Knowledge, skill and/or attribute	Rating*	n	%	n	%	n	%
1	Role knowledge	0	1	2	1	3	0	0
		1	26	42	18	47	8	33
		2	35	56	19	50	16	67
3	Planning and delegating	0	1	2	1	3	0	0
		1	12	19	8	21	4	17
		2	49	79	19	50	20	83
4	Conflict resolution	0	8	13	7	18	1	4
		1	21	34	10	26	11	46
		2	33	53	21	55	12	50
5(a)	Giving support	0	1	2	1	3	0	0
		1	32	52	31	82	1	4
		2	29	47	6	16	23	96
5(b)	Receiving support	0	2	3	1	3	1	4
		1	16	26	9	24	7	29
		2	44	71	28	74	16	67
6	Working with others	0	1	2	0	0	1	4
		1	20	32	15	39	5	21
		2	41	66	23	61	18	75
7(a)	Group needs	0	2	3	1	3	1	4
		1	23	37	17	45	6	25
		2	37	60	20	53	17	71
7(b)	Managing criticism	0	1	2	1	3	0	0
		1	19	31	13	34	6	25

Question			All support group leaders		Prostate cancer support group leaders		Breast cancer support group leaders	
Number	Knowledge, skill and/or attribute	Rating*	n	%	n	%	n	%
		2	42	68	24	63	18	75
8	Confidentiality	0	1	2	1	3	0	0
		1	22	35	12	32	10	42
		2	39	63	25	66	14	58
9	Welcoming new members	0	0	0	0	0	0	0
		1	22	35	17	45	5	21
		2	40	65	21	55	19	79
10	Accepting difference	0	2	3	2	5	0	0
		1	27	44	20	53	7	29
		2	33	53	16	42	17	71
Scenario 1	Respectful group interaction	0	2	3	1	3	1	4
		1	43	69	30	79	13	54
		2	17	27	7	18	10	42
Scenario 2	Group purpose and agreement	0	3	5	3	8	0	0
		1	38	61	17	45	11	46
		2	21	34	8	21	13	54

Notes. Rating scale*; '0' = no aspects of KSA provided; '1' = some aspects of the KSA provided; '2' =most or all aspects of KSA provided

9 DISCUSSION

9.1 Chapter overview

Peer support groups have emerged as a community-led approach to accessing support and connecting with others going through a cancer experience. There is value in support groups for those who choose to access them as a low-cost psychosocial support. Cancer agencies are working to maximise the support offered in the community by strengthening and sustaining the delivery of peer support. However, cancer agencies are operating without expert agreement, guidelines, or standards to guide program delivery. Challenges have also been reported in relation to the role of peer group leaders, with most being volunteers with a diagnosis themselves. Several investigations have focused on development of support group leader training. However, none have provided a robust or meaningful synopsis of the qualities needed to lead a cancer support group. Before developing training content, we need to take a rigorous and systematic approach to go back to first principles and understand the unique role of the group leader.

This PhD posed a practical and unexplored research question to address this real-world issue. What are the essential qualities of cancer support group leaders and how is a person's suitability for the role determined? We aimed to establish pragmatic consensus-based standards and a structured interview with user manual to guide cancer agencies with selection and development of cancer support group leaders. This thesis has outlined the mixed-methods used to meet project aims (Chapter 4). We have described in this thesis each study undertaken: a systematic literature review (Chapter 5); an online reactive Delphi study with interdisciplinary

panel of experts (Chapter 6); a small-scale pilot study and a large scale field test (Chapter 8).

In this final chapter of the thesis, the results of each study for the entire project are summarised and discussed. Findings are explored in the context of previous research; specifically, the prevalence of cancer support groups, cancer support group leader qualities, and role specific knowledge, skills, and attributes. The limitations of the study are outlined along with recommendations for implementation and future research.

9.2 Overview of important contribution to knowledge

This PhD provides a significant and original contribution to the field; it is the first study to investigate cancer support group leader qualities in order to inform the development of a structured interview and consensus-based minimum standards for selection and development of group leaders. Accepted qualitative and quantitative methodologies were combined to develop a novel protocol relevant to the field of peer support. The result was development of relevant and consensus-based minimum standards and the means to implement these standards through a structured interview. We believe the study was innovative and addresses a practical need. The study protocol ensured that the methods were adhered to, transparent, feasible, acceptable, and valid in a community setting. The development of a clear protocol provides potential for the methods or outputs of our study to be used or adapted for other healthcare or community settings where peer support groups are in operation.

To our knowledge, this is the first study to focus on cancer agencies as a key stakeholder and to use their unique position within the community to apply a

consistent and standard framework. The study outputs (i.e. the structured interview and user manual) have been deemed by experts to be fit for purpose, and they also provide a cost effective and solution-focused approach for cancer agencies to use. Finally, we contributed to the peer-reviewed literature in the field. Thus, published study results may provide worthy evidence to policy makers, supportive care program managers, and cancer agencies of the need for minimum standards for the group leader role and structured process for selection and development.

9.3 Findings from the systematic literature review

We undertook the first systematic literature review on cancer support group leader qualities (see Chapter 5 of this thesis). Given the paucity of literature specific to the role, too few documents were found to map content domains and so the search term ‘cancer’ was removed in order to broaden the search. It was therefore no surprise that, of the 49 documents that met inclusion criteria, 31 reported on non-cancer support groups and only 14 reported on cancer groups. Interestingly, the review identified that cancer support group literature has grown considerably in this century (Pomery, Schofield, Xhilaga, & Gough, 2016b).

The systematic literature review provided the initial step in conducting a role analysis. A total of 59 knowledge, skills, and attributes and seven main overarching qualities were identified across all eligible documents reviewed. This was considered a large pool of potential content for one role, especially given those currently in the role are non-professional volunteers. Thematic analysis of content provided an appropriate method and detailed account of the data (Braun & Clarke, 2006; Thomas & Harden, 2008) and identified seven main overarching qualities relevant to the group leader role: Group Management, Group Process, Role Modelling, Awareness,

Willingness, Agreeableness, and Openness. Role qualities were sub-divided into those more relevant to selection (i.e., Awareness, Willingness, Agreeableness, and Openness) and those more relevant to knowledge and skill development (i.e., Group Management, Group Process, and Role Modelling). Grouping attributes based on functional leadership performance requirements has precedent in the literature (Antonakis & Day, 2017; Zaccaro et al., 2013).

9.4 Findings from the Delphi study

The first consensus-based minimum standards have been developed for cancer support group leaders (see Chapter 6 of this thesis). A panel of 73 experts was carefully selected and invited to participate. The panel included: academics, health professionals, cancer agency workers, and cancer support group leaders. The number of participants in the online-reactive Delphi study exceeded the minimum number of 10 or more participants (Murphy et al., 1998) and covered a diversity of expertise including individuals involved in the analysis, referral, support, and/or delivery of cancer support groups. It was also hoped that engagement of experts would help to provide credibility of findings for the various stakeholders and assist knowledge translation (Fink et al., 1984; Patton, 1999).

Experts determined and ranked the most relevant or necessary knowledge, skills, and attributes for the group leader role. Fifty-two knowledge, skills, and attributes were determined by experts to be required for the role of cancer support group leader. The knowledge, skills, and attributes that reached the highest level of consensus were Maintaining Confidentiality, Listening, and Respect for Others. The sheer amount of requisite knowledge, skills, and attributes was surprising given this role does not require professional qualifications. Of interest, the overarching qualities

with the largest number of requisite knowledge, skills, and attributes, related to Group Process, Role Modelling and Agreeableness. Given that the majority of potential leaders are not professional counsellors or facilitators (Herron, 2005), the development of Group Process and Role Modelling knowledge, skills, and attributes presents the greatest learning challenge for group leaders.

A proposed structured interview was developed consisting of 13 questions, 2 scenarios, probes, behaviourally anchored rating scales for each question/scenario, and suggested responses. Consensus on content and structure of the proposed structured interview was confirmed among the expert panel. Panel member comments guided refinement of wording and re-ordering of questions, and improvement of probing questions.

9.5 Findings from the Pilot Study

A customised, self-report questionnaire and semi-structured interview were developed to assess aspects of clinical utility (see Chapter 8 of this thesis). Cross-checked scores for 12 cancer support group leader interviews were concordant for suitability questions (56 of 60 ratings) and readiness questions (139 of 156). Experts determined the structured interview and user manual to be appropriate, accessible, practical, and acceptable. This means that the newly developed tool has been considered to be fit for purpose. Strong agreement across all interviewers was established for: the tool to help standardise the selection and development of support group leaders; to be easily integrated into their current practices and procedures; the user guide supports the use of the structured interview; and that the structured interview is sensible and workable. Additionally, all interviewers strongly agreed they would use the structured interview in their role and recommend it to

other cancer agency workers. Participants reported that the structured interview provided a useful way to aid communication and guide their conversation with the support group leader. Furthermore, feedback highlighted that the process and language should remain informal and supportive without feeling like an assessment. Given that applicant anxiety may bias the predictive validity of interviews (McCarthy & Goffin, 2004), the language used was considered important. For example, minor amendments to the user manual instructions directed interviewers to inform interviewees that there are no right or wrong answers. Reference to the tool being referred to as a “structured conversation” instead of a “structured interview” was preferred and agreed to be more acceptable.

Positive feedback was received from cancer agency workers regarding their interaction with support group leaders whilst undertaking the structured interview. Some expressed that the structured interview created a space to open up a process of self-reflection and self-awareness for the group leader. This is consistent with findings from recruitment practice, that accurate job descriptions can improve chances of success, assist with self-selection, and provide insights for the candidate (Pavur Jr, 2010). At other times, responses developed by participants helped to boost their confidence in their own abilities and understanding the role. This is consistent with the benefits of adult learning theory of Knowles (1990), with greater understanding of the role leading to a possible reduction in potential burnout (Zordan et al., 2010).

Cancer agencies required a selection tool that was robust and addressed the structured requirement of an interview. This was important given that previous studies involving support group leaders and members have identified potential for subjectivity and bias reporting (Schopler & Galinsky, 1993). Our study aimed to

develop a highly structured interview for cancer agencies to maximise validity and evaluation, in accordance with the 15 components outlined by Campion et al.(1997). The structured interview incorporated role-related questions for each candidate, behaviourally-anchored rating scales, with every potential group leader to receive the same questions. The challenging task of evaluating potential group leaders is made easier because questions and responses are prepared in advance. This means that regardless of cancer agency workers' experience in working with support group leaders, they can be confident they have applied a standardised and agreed process. Although we are yet to determine outcomes of implementation, structured interviews have been proven to be predictive of candidate job performance in the workplace and are likely to yield similar results in the community setting. Community members can also be assured that support groups connected under the umbrella of cancer agencies have followed an interview process that is fair and reasonable for placing a group leader into the role (Hausknecht, Day, & Thomas, 2004).

9.6 Findings from the Field Test

A total of 63 interviews were conducted with current breast and prostate cancer support group leaders (see Chapter 8 of this thesis). A summary of support group specific leader characteristics and responses to questions was completed. A cut-off score of 5 out of 10 for suitability was agreed by experts, with cut off scores for readiness unable to be determined. This research is a first in its field and offers several contributions in the context of previous findings which are outlined below.

9.7 Findings in the Context of Previous Research

9.7.1 Cancer support groups

This PhD study contributes new knowledge about cancer support groups. This includes insights regarding the prevalence and type of cancer support groups reported in the literature.

9.7.1.1 The prevalence of cancer support groups reported in the literature

The findings from the systematic literature review presented in Chapter 5 are consistent with more recent studies which suggest that cancer survivors make greater use of community-based support groups than survivors of other chronic health conditions (Owen et al., 2007). Our systematic literature review highlighted the global use of cancer support groups, with seven countries producing literature on group leaders.

These findings reinforce the important support mechanism that support groups offer for many people impacted by cancer. Although peer support groups cannot meet all the supportive care issues in the cancer experience, when provided within a broad framework they can complement professional service models (Dunn et al., 2003). It is interesting to note, the United States and Australia lead the majority of the research in the area. At a basic universal level, peer cancer support groups offer a cost effective model of support delivery which can be utilised for high to low income countries. It is suspected that the amount of literature from high income countries is due to higher income countries' capacity to provide access to cancer diagnosis, treatment, and subsequent improved survivorship outcomes. In addition, funding for research into survivorship programs is likely more accessible in high income countries resulting in disparities in published literature from country to

country. For this PhD, inequities in access to psychosocial supports and economic burden in delivery of care has been a consideration in the development of a cost effective and accessible tool, with the potential for further development. It is assumed that reasons relating to global variations of cancer support groups are multifaceted and not yet understood. In addition, the motivations and experiences of survivors driving the formation of community-based cancer support groups may be different across cancer types, genders, and cultures (Brown et al., 2004; Dunn et al., 2017; Oliffe et al., 2010). How these motivations may change or evolve over time therefore remains unknown but of interest.

9.7.1.2 The types of cancer groups reported in the literature

The question of whether the model of cancer support groups is suited equally to both genders has been previously raised in the literature (Grande et al., 2006; Krizek, Roberts, Ragan, Ferrara, & Lord, 1999). One study reported that the primary type of cancer support groups were: 1) mixed cancer 2) breast cancer and 3) prostate cancer (Herron, 2015). Based on the cancer type reported, it is believed that the peer led support groups reflect cancer types that are both commonly diagnosed and have increased survivorship rates. Expert consultation and support group leader recruitment for this PhD therefore focused on the primary cancer agencies in Australia with the largest number of affiliated support groups; in this case, Cancer Councils, Breast Cancer Network Australia and Prostate Cancer Foundation of Australia. Nonetheless, the possibility that models of support may differ by genders is an important question that warrants further investigation. It was, however, a question that was beyond the scope of the current PhD study.

9.7.2 Significance of findings relating to cancer support group leader role

This PhD study contributes new knowledge about the cancer support group leader role. This includes insights and expert agreement on group leader qualities and specific knowledge, skills, and attributes for the role.

9.7.2.1 Cancer support group leader qualities

A systematic and pragmatic approach was taken to facilitate the development of quality indicators for cancer support group leaders where there was insufficient evidence previously. When compared to a therapeutic context, the general qualities and specific knowledge, skills, and attributes identified in the literature review are consistent with discrete group therapy leader behaviour relating to support (behaviours associated with group positive affective gestures), management (behaviours associated with group interactions and overall group functioning), and use of self (behaviour involved with modelling or demonstrating). However, other leader behaviours identified for a therapeutic group model were not, such as evocative or coherence-making behaviours (Lieberman et al., 1973). Similarly, it was interesting to compare identified qualities for the role with those of the Big Five personality traits referred to in the literature overview in Chapter 2 of this thesis. Two of the five personality factors, Agreeableness and Openness to Experience, were consistent with requisite qualities for the role of cancer support group leader. The personality trait of Agreeableness is consistent with the helper theory principle (Riessman, 1965) and with previous studies that have found group leaders to be motivated by altruism and wanting to give back to the community (Wiggins, 1996; Zordan et al., 2015). These traits, however, are not consistent with those that generally yield higher correlations with leader outcomes. This suggests that different

knowledge, skills, and attributes may apply in different workplace cultures or industries. This is consistent with the House and Aditya (1997) statement that leadership theory is contextual and not readily applied to other working cultures. However, the methods used in this body of work could be applied to other contexts to determine exactly what the appropriate knowledge, skills, and attributes are for that context.

9.7.3 Expert agreed standards on knowledge, skills, and attributes required for the role

Zordan et al. (2010) highlighted that development of a set of minimum standards or process of accreditation for support group leaders would be appropriate to ensure that leaders are properly equipped to facilitate groups. Our study has provided an original contribution to the field and responded to this recommendation, with the establishment of pragmatic and consensus-based minimum standards specific to the cancer support group leader role. Additionally, the multiple partnerships between community groups and relevant institutions were recognised through broadening the type of experts on the panel (Dunn et al., 2017). Our consensus-based approach offered varied expert insights and agreement beyond the narrowly experimental paradigm of the randomised controlled trial (Rycroft-Malone et al., 2012; Shepperd et al., 2009). Our Delphi study design (Chapter 6) addressed both the limitations of available literature (Boulkedid, Abdoul, Loustau, Sibony, & Alberti, 2011; Greenhalgh, Wong, Westhorp, & Pawson, 2011; Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013) and the contextual demands of using expert consensus.

The large number of knowledge, skills, and attributes initially outlined in the Delphi study raised questions about what was considered reasonable to require of a community volunteer. With the need to contain expectations to real-world applications (Celermajer, 2001) establishment of *minimum* standards for the role rather than *best practice* standards was justified. This approach was cognisant of the dearth of standards in the field, and inability to apply a “gold standard” or an “ideal” model to support groups (Bell et al., 2010; Fobair, 1997a). These standards represent a compromise between the contextual demands of meeting community need, the practical reality of working with predominately peer volunteers, and the demands to maximise validities and consistency. However, the degree to which requisite knowledge, skills, and attributes are developed in potential support group leaders prior to them taking on the role strongly relates to the capacity and expectations of the individual cancer agency.

9.7.4 Significance of findings relating to establishment of standards for selection and development of cancer support group leaders role

This PhD study has developed the first structured interview and user guide in the field of peer cancer support groups for the selection and development of group leaders. The establishment of a selection and development process is discussed in terms of how it relates to: potential for bias and discrimination in the recruitment process, key stakeholders such as cancer agencies, group leaders, and community members.

9.7.4.1 Reducing potential for bias and discrimination in the selection process

Lack of a selection process and assessment tools for the appointment of cancer support group leaders was identified by our study as a gap in practice. By not having

a standardised process, particular concerns were raised regarding the risk of bias or discrimination in appointment of group leaders. Informal conversations between cancer agency workers and potential group leaders provides an arena where negative stereotypes regarding characteristics such as gender, disability, race, or age could lead to biased evaluations (Brecher, Bragger, & Kutcher, 2006). Such negative biases and discrimination often result in unfavourable recruitment decisions based on irrelevant characteristics rather than role-relevant knowledge, skills, and attributes (Brecher et al., 2006). At the very least, initial impressions have a bearing on evaluations and ultimately impact impartial decision-making (Parsons, Liden, & Bauer, 2001). Most research on bias associated with disability in employment interviews deals with persons who currently have a disability where the disability itself is overt. Little research could be found related to biases of having a past record of disability, where an individual may no longer suffer from or be impaired by a condition (Bordieri & Drehmer, 1986; Reilly, Wennet, Murphy, & Thierauf, 1998). The relevant and obvious example for this study is a cancer diagnosis, but other chronic illnesses such as addiction or major depression would also fall under this category.

Reducing bias and likelihood of discriminatory questions was important in the development of the structured interview. This was addressed through applying multiple components of structure to maximise validities, especially predictive validity (Campion et al., 1997). However, the potential risk to cancer agencies and relevance of addressing the issue was only identified during the Delphi process. In gathering potential knowledge, skills, and attributes relevant to the cancer support group leader role, expert panel members initially provided some responses deemed to be discriminatory (please refer to the list of precluded items in Appendix A in the published manuscript in Chapter 5). Of most relevance to cancer support group

leaders is bias related cancer stage or hidden disabilities such as current mental illness or cognitive impairments (Czajka & DeNisi, 1988; Stone & Sawatzki, 1980). It was interesting to note that despite the fact that potential employers are prohibited from enquiring about disabilities of employees, many of the precluded items generated by experts for cancer support group leaders directly related to this line of enquiry. Consideration by management needs to be given regarding the potential for unwanted situations to arise that may even result in litigation. As leaders in the community, it is important for cancer agencies to ensure that an appropriate and fair process is followed by which to identify and prepare people to lead a support group.

The solution our study provides was the development of clear, job-specific performance standards to reduce or eliminate such biases in appraisal (Czajka & DeNisi, 1988). Research has shown that structured interviews can effectively mitigate the effects of stereotypes and biases and reduce their discriminatory impact on selection (Bragger et al., 2002; Kutcher & Bragger, 2004). Such findings support the notion that structure of interviews enhances objectivity and fairness, by reducing intrusive biases and irrelevant information (Brecher et al., 2006). Developed questions were based on clear role-related specific situations and objectives with behaviourally-anchored answers to standardise appraisal of qualities and minimise unnecessary or unfair variation. Addressing Campions et al.'s (1997) components of structure in the development of our structured interview reduced the potential for bias and discrimination to occur in the selection process. By using this structured interview cancer agencies are therefore safeguarding internal processes so that potential group leaders receive full and equal consideration.

9.7.4.2 Benefits of minimum standards for cancer agencies

The minimum standards aim to guide cancer agency workers in applying greater consistency and rigour to the process of selection within their individual organisation. It works to address the inconsistencies across agencies, and workers, and begins to create a structured framework for the delivery of peer group support. Given that cancer agency workers may come from varied professional backgrounds or experience levels, standardisation of process greatly assists those new to the field.

Through establishing consistency across agencies, use of the structured interview and user manual also works to establish a professional practice. This begins to position cancer agencies as leaders in delivery of minimum standards in the peer support field. Implementation of minimum standards by cancer agencies may add perceived value or credibility to the agencies' recognition or affiliation status. This in turn may assist referrals through to support groups and sustainability of the broader network of peer support groups.

Consensus-based minimum standards provide the evidence often sought by funders, referring bodies, and professionals needed to support and sustain program delivery. Demonstrating the requirements of consensus-based minimum standards by cancer agencies may help support rationale for the resourcing required to adequately deliver cancer support group programs.

9.7.4.3 Benefits of minimum standards for group leaders

The minimum standards set a benchmark considered reasonable for the community setting and act to provide key stakeholders with a clear and realistic defined role (Rush et al., 1977). Importantly, potential group leaders can better understand requirements of the role. Such reduction of role ambiguity works to decrease

potential burnout for volunteers (Paradis, Miller, & Runnion, 1987), an issue reported by leaders in the field (Kirsten, Butow, et al., 2006). Additionally, determining someone's suitability and readiness before placing them in the role acts to protect leaders from being exposed to potential challenges that they may be ill equipped or unprepared for. It is hoped that the standard recruitment process also reduces the likelihood of group leaders doing harm to themselves or to other group members.

9.7.4.4 Benefits of minimum standards for the community

Previous studies with health professionals suggested that they view support groups with either benign indifference or concern about the potential for misinformation or generation of psychosocial harm (Carroll et al., 2000). Other studies have shown that despite generally positive attitudes, referral to support groups is low (Steginga et al., 2007). Additionally, those who participated in support groups were more likely to believe that their significant others were favourable towards their participation (Grande et al., 2006). Based on these studies, the opinions of others relevant to the person with cancer have an impact on whether they may or may not access a support group. Therefore, it is hoped that establishment of consensus-based minimum standards may help to reduce concerns of referring parties. Having greater consistency and role-specific selection and development can work to standardise the level of leadership offered across cancer support groups. Minimum standards for group leaders may help to reassure people of the level of potential support offered in the group and to reduce the likelihood of potential harm to vulnerable group members. It is thought that in order to fully utilise support groups as a potential low-cost psychosocial support throughout the cancer trajectory, expert consensus and standards are necessary into order to link community-based support groups into a health system driven by evidence.

9.7.5 Significance of findings for future practice

This PhD project contributes new knowledge targeted to cancer agencies' capacity to leverage support group leaders as a community resource. This includes insights into sustaining cancer support groups, need for support and development for group leaders, and training development.

9.7.5.1 Sustainability of the cancer support groups

Many group leaders who participated in the field test were volunteers of retirement age who had been committed to the role over an extended period. It is believed that many may be on the cusp of stepping down from the role. Studies have shown that how groups transition during role succession does impact on the sustainability of the group (Oliffe et al., 2008). Difficulties finding back-ups or replacements have also been previously reported in the literature (Butow et al., 2006; Kirsten, Butow, et al., 2006; Zordan et al., 2010). However, it is proposed that leader succession is a larger issue with the potential to impact on sustainability of the model itself. In fact, volunteer participation on an ongoing and regular basis will be vital to sustain the broader network of support groups in the community and the non-profit organisations they are connected to (Snyder & Omoto, 2008).

Volunteering in general is widespread with a considerable percentage of people participating to volunteer their time. Across the top ten countries by participation rates, 55-40% of people were reported to volunteer their time (Charities Aid Foundation, 2017). Within Australia, 5.2 million people volunteered in 2006 with a staggering contribution of 623 million hours to the non-profit sector with a wage equivalent value of AUD $15 billion (Fitzgerald, Trewin, Gordon, & McGregor-Lowndes, 2010). However, the nature of volunteering is changing with volunteers

facing time constraints, limiting their participation in the traditional forms of volunteering (Merrill, 2006). Of concern is the evidence of declining average number of hours volunteered (Australian Bureau of Statistics, 2006).

Given the time requirements and regularity of meetings for the group leader role, it is anticipated that current and future challenges will relate to availability of volunteers to service existing groups. Our study works to address some of the future recruitment challenges through the development of a contextual job description and a standardised process of selection and development. Study outputs can then be used as a roadmap for recruitment purposes, in addition to the selection and development of group leaders (Pavur Jr, 2010). Furthermore, early application of requisite knowledge, skills, and attributes for the role would improve the quality of every phase of selection and development.

9.7.6 The need for support and development in the support group leader role

Our finding that there are a total of 52 knowledge, skills, and attributes required to undertake the role validate the need for training or support to maintain adequate learning and development for support group leaders (Butow et al., 2006; Kirsten, Butow, et al., 2006; Zordan et al., 2010). Notably, this is consistent with recommendations from Martin and Smith (1996) for continuous assessment and awareness of facilitators' needs to ensure productivity of group meetings for those who attend.

On the other hand, the large number of knowledge, skills, and attributes identified for Agreeableness indicated the importance of innate personal attributes required for the role that are not considered amenable to training. Consensus on the overarching quality of Agreeableness was a new and interesting finding. Although

not referenced in the existing literature, this was consistent with consultation with cancer agency workers who stated that some group leaders remain unsuited to the role regardless of training or support provided. Given that some people do not possess the necessary qualities they are unlikely to benefit from training. As there is a significant personal investment of time and energy for group leaders while in the role, it is important that a conversation about suitability occurs earlier rather than later.

9.7.7 An understanding of the requirements of the group leader role may facilitate training

Our Delphi study confirmed expert consensus on qualities of Willingness and Openness required for the role. These two qualities align with two of the Big Five personality traits which have been found to display high corrected correlations with leader emergence and leader effectiveness (McCrae & Costa, 1987). Of relevance, the construct of Openness to Experience, has been found to be a valid predictor of training proficiency. Those individuals who score high on this dimension are more likely to have positive attitudes to learning experiences in general. Research has shown that the attitude of the individual who enters the training program is a key component in the success of such programs (Goldstein & Ford, 2002; Ryman & Biersner, 1975) and whether learning is likely to occur (Sanders, 1983). Those who accept personal responsibility for the learning process, are willing to participate, and engage in self-assessment are more likely to benefit from training programs (Ryman & Biersner, 1975). Incorporating qualities of Openness and Willingness into the selection process may help to identify those potential group leaders most likely to benefit from training offered and thereby maximise training outcomes for cancer agencies. By identifying the specific knowledge, skills, and attributes required for the

role and assessing these via the structured interview, we provide a standardised means of determining what the development needs of the individual are and so enable more targeted and effective delivery.

Such evidence can potentially be used by cancer agencies as a spring board (or basis) upon which to tailor and target training that in turn is more effective and efficient. Additionally, highlighting specific learning needs to group leaders could improve uptake or engagement with the training and support that is offered. Implementation of a selection process prevents the allocation of time and resources to those individuals who are unsuited to the role. It is hoped that a systematic approach will aid in the equitable allocation of resources across support group leaders and improve training outcomes. Moreover, this PhD study provides a rationale for the provision of agency resources to maximise the knowledge, skills, and attributes of cancer support group leaders and increase the quality of peer group support offered in the community.

Our field test results found low scores on openness for role development, receiving support, and accepting criticism for the majority of participants. Other research has suggested that there are methodological challenges when investigating the experience of cancer support group leaders. Namely, group leaders seem to be reluctant to report aspects of the support group or the leadership experience that are perceived as negative (Schopler & Galinsky, 1993). It is suggested that there may be a strong response bias relating to having development needs due to their personal investment and perhaps the established status of being a group leader. This indicates the importance of non-biased assessment of potential learning and development needs, in addition to normalising the concept of ongoing training and development for group leaders.

One explanation for this could be the length of time in the role, with some staying in the role for decades. A surprising finding was that some cancer support group leaders were determined to ‘not be ready’ to undertake the role despite having been in the role for several years. Indeed, after completing the interview and reflecting upon their responses, some of the cancer support group leaders identified themselves as having underdeveloped knowledge, skills, and attributes essential to the role. This knowledge gap was evident to both the current support group leaders and the cancer agency workers. Feedback from cancer agency workers (i.e. the interviewers) revealed that this perception of readiness was re-defined after undertaking the structured interview providing opportunity for self-reflection and self-awareness by the interviewee. Additionally, by following a structured process cancer agency workers were able to evaluate through a non-biased lens, with many surprised by the variation in performance compared to their pre-conceived ideas of the competency levels of the support group leader. This is consistent with literature on the use of job analysis and panel interviews to form questions to improve the reliability and validity of recruitment (Arvey & Campion, 1982).

9.7.8 Relevance of leader qualities to other types of support groups

The findings from the systematic literature review identified seven group leader qualities that were important regardless of the group type. This indicates that the general pool of knowledge, skills, and attributes identified in this study may be relevant to other support group leader roles beyond cancer. Although role-specific expert consensus may confirm different requisite knowledge, skills, and attributes or standards, methods outlined in the published protocol paper could be applied to other community-based support groups or broader health care settings.

9.8 Limitations

The sixty-three field test participants in this study were all current support group leaders. This was a limitation because the structured interview has been developed for potential support group leaders who had no prior experience in the role, not experienced group leaders. A summary of the demographics of the existing support group leaders who participated in the field test was provided in Chapter 8. The majority of the participants identified themselves as having an experience of cancer themselves, being of retirement age and having a commitment to the role that extended over several years. These participant characteristics are consistent with leader characteristics found in other studies (Oliffe et al., 2008; Stevinson et al., 2010). Overall there was a high level of education, with 53% obtaining a tertiary education. There was a good spread of residential locations across Australia, with 40% from major city, 37% inner regional and 19% outer regional. The majority had a co-leader (73%), which is consistent with recommendations found in the literature (Price et al., 2006).

Field test participants, however, may not be representative of the broader support group leader network. With participation in the study being optional, it is suspected that those who choose to opt into the study may be: 1) more engaged with the cancer agency; 2) more confident in their abilities as a support group leader; or 3) more comfortable in responding to questions. Therefore, it is possible, if not likely, that field test participants and their qualities are different from those of the network of cancer support group leaders. In this case, results from a pool of participants wanting to undertake the cancer support group leader role is required.

A second limitation of this study was that cut-off scores have been provided at a very basic level, mainly consensus determined ratings for individual responses and general categorisation of total scores (e.g. highly suitable, suitable, not currently suitable). In Chapter 7, we referred to addressing elements of structure in interview development. Campion et al. (1997), determined there to be 15 components of structure, with one of these components relating to the use of statistical procedures to make selection decisions rather than interviewer judgements. As there are no established reasonable cut-off scores for the rating scales (being overall suitability and readiness of candidate) interviewers still have to make judgements based on individual ratings for each question. Furthermore, the accuracy of predictions based on scores is yet to be determined.

Ideally, we wanted to increase structure in the use of data for decision making on candidates' suitability and readiness; stated another way, establishing standard decision rules was an objective of this study. A preliminary cut-off score was identified for suitability but not for readiness. However, learnings from the project highlighted that different cancer agencies differed in their capacity to train and develop group leaders. We would also expect some variation between high and low income countries. This variability of access to resources could influence assessments of the utility and 'reasonableness' of any pre-specified cut-off scores. For example, if the demand to fill the role exceeds the availability of potential leaders, there may be a greater desire to work more closely with those people determined to be suitable but with lower scores on readiness. This may be particularly relevant when assessing the need for ongoing development of co-leaders for the purposes of succession planning. Therefore, some flexibility is required in determining level of readiness.

In the absence of a decision rule for readiness, using an average rating of ‘1’ for each of the readiness questions seems reasonable; this goes some way towards fulfilling the minimum standards identified by Delphi participants. Cancer agencies also need to establish realistic expectations with potential group leaders regarding their development needs; the aim should be minimising potential stress or uncertainty when ‘deficits’ are uncovered by the interview. Within limits, such interviewees can be assured of their ability to function in the role; ratings for almost half the leaders who participated in the field test indicated the need for further support or training. Cancer agencies may also wish to prioritise certain aspects of knowledge and skill development before others, with the expectation of ongoing development so that they acquire all the requisite knowledge, skills, and attributes identified by experts. All these decisions should be made *a priori* and be consistently applied to ensure fairness to individual candidates.

9.9 Implementation into practice

A major focus of this project has been the real-world application of the structured interview and establishment of minimum standards for selection and development of cancer support group leaders. Strategic consultation and engagement with stakeholders occurred throughout the entire project. This approach was crucial as it informed the choice of methodology, assisted recruitment and provided ongoing feedback to ensure an academically robust tool that was fit for purpose.

A systematic approach to knowledge translation will be required to move this research into the hands of those who can put it to practical use. I have been awarded a mentorship grant through the NHMRC Centre of Research Excellence in Prostate Cancer Survivorship to undertake an internationally recognised knowledge

translation course. Knowledge and skills acquired will be used to develop a knowledge translation plan, build partnerships and create supportive communication strategies to achieve this aim.

Indeed, development and dissemination of the structured interview will continue into the future. Consultation has begun with the Australian Cancer Councils, Breast Cancer Network Australia and Prostate Cancer Foundation of Australia around use of the structured interview for the selection of new leaders and the development of existing group leaders. Discussion has also centred on amending affiliation and recognition requirements, to include the newly developed minimum standards and the investigation of existing online platforms to determine how the tool could be adapted to an online format. This could facilitate ongoing use and data collection to maximise the validity of interview-based decisions.

It is also intended that findings from the study will be used to develop resources and training for support group leaders across various Australia-based cancer agencies. Specifically, study results will inform the development of Cancer Council Victoria's *Keeping Things on Track* education resources for support group leaders, as part of the 2017 Cancer Australia Supporting People with Cancer grant initiative. I will also be working with the Union of International Cancer Control (UICC) to include learning objectives based on study results as part of the 2018 Peer Group Masters Course. The UICC has also sought permission to upload the interview and user manual to their website as a resource for UICC members.

Four published papers (contained within this thesis) and conference presentations (Pomery, Schofield, Xhilaga, & Gough, 2016a, 2016c) have assisted in the translation of findings internationally. Importantly, lay summaries of the study will

be written and incorporated into various Prostate Cancer Foundation of Australia publications, consumer presentations and Research Blogs. The completed structured interview and user manual will be made freely available to all cancer agencies with the intention of creating collaborative organisational partnership both within Australia and internationally.

9.10 Further research

9.10.1 Cross-cultural adaptation of structured interview

Cross-cultural adaptation of the structured interview was considered important but beyond the scope of this study. There are significant variations in cultural context for cancer support group leaders globally. Adequate investigation of the cultural diversity of leaders and/or development of a reliable or valid cultural translation of the structured interview is therefore needed.

9.10.2 Ascertaining competency of group leaders

Competency levels of cancer support group leaders once in the role could be investigated. For example, future studies could investigate whether leaders' self-reported knowledge, skills, and attributes were evident in actual leader behaviour observed in a cancer support group meeting. The prediction of structured interview assessments could be researched to determine group leader suitability. This line of investigation seemed premature given the paucity of literature and evidence on requisite qualities for the role. Additionally, there were concerns regarding how competency-based approach would be appropriately applied to community support groups that rely on effective partnerships to maximise mutual benefit. Further research could be undertaken with caution to determine validity of reported attributes compared to actual performance.

9.10.3 Emergence of online cancer support groups

With the advancement and accessibility of the internet, online support has begun to emerge as an alternative mode of delivery (Klemm et al., 2003). Support group members no longer have to meet face-to-face in order to benefit from support groups, with studies documenting the effectiveness of online support groups (Im, Chee, Tsai, Lin, & Cheng, 2005; Lieberman, 2007). There has been organic growth in peers connecting and supporting one another informally (e.g. Facebook) and formally (e.g. online communities). Anecdotal reports indicate that online membership numbers are increasing, with cancer agencies across the globe investing more resources in online platforms. As the next evolutionary step for peer support, there is potential to apply learnings and research methods employed from this study to investigate online support. How can we understand the benefits to those experiencing cancer and maximise support offered via online modes? How does online support integrate into psychosocial supports currently offered? Are there differences between those who access face-to-face peer support and those who engage with online support? Future research investigating how peers lead in the online space, associated challenges, and specific knowledge, skills, and attributes required may help to maximise its delivery.

For the numerous people impacted by cancer in our global community, many will continue to seek support and improve their experience. For those who choose to utilise peer groups for support, this study has provided an agreed minimum standard by which to select and develop group leaders. It is hoped that this approach will contribute to maximising peer group support and sustaining community-based delivery both now and into the future.

9.11 Conclusions

The model of community-based and led cancer support groups offers a flexible and cost effective way to respond to some survivorship needs and is worthy of investigation. Emergence of cancer support groups has been driven largely by patient preference and they are likely to continue to exist as long as there is benefit for those who choose to attend. Cancer support group leaders take on an extensive role and are vital in the provision of support offered to those impacted by cancer who choose to access peer support groups. With this role comes the need for specific knowledge, skills, and attributes to maximise the support provided and equip leaders to manage the many and varied challenges of group work. There was a lack of role analysis, agreed standards, and tools to assist with the selection and development of cancer support group leaders. This study has addressed this gap with the development of pragmatic, consensus-based minimum standards, and a structured interview with user manual. The development phase consisted of a systematic review and analysis of the literature, expert consensus on requisite qualities, content, and structure of the structured interview, pilot study on clinical utility of the provisional tool, and field testing on scoring for decision making. The final product was a robust structured interview and user guide which the pilot and field testing determined to be fit for purpose. This original tool is based on the agreed minimum requirements for the group leader role, and has been designed to guide cancer agencies in determining a person's suitability and readiness for the role. This PhD has addressed an important gap in the literature as well as providing a solution to a practical, real world issue. Further research can now allow for ongoing data collection to establish effective cut-off scores and to explore its capacity to be

adapted to online peer support, cross-culturally, and across the diverse number of health related community support groups.

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Zordan, R. D., Juraskova, I., Butow, P. N., Jolan, A., Kirsten, L., Chapman, J., . . . Sundquist, K. (2010). Exploring the impact of training on the experience of Australian support group leaders: Current practices and implications for research. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy, 13*(4), 427-440.

Appendix 1 Minimal Risk Ethics Approval

THE UNIVERSITY OF MELBOURNE

31 October 2014

A/Prof Penelope Schofield
Melbourne School of Psychological Sciences
The University of Melbourne

Dear Penelope

I am pleased to advise that the Department Human Ethics Advisory Group has approved the following Minimal Risk application:

Title of project:	*Improving the quality of care provided to people affected by cancer via support groups, by establishing evidence-based practice through the development of a structured interview on the selection and development of group leaders*
Themis No.	1443027.1
Other investigators:	Amanda Pomery, Dr Karla Gough, A/Prof Miranda Xhilaga

The application has been approved for the period of 31/10/2014 to 31/12/2015.

It is potentially renewable annually for a maximum of 3 years, depending on program approval.

Please note:

a. **Limit of approval:** *Approval is limited strictly to the research project as submitted in your application.*
b. **Variation to project within program application:** *Any subsequent variation or modifications you might wish to make to your project must be notified formally to the Department Human Ethics Advisory Group for further consideration and approval before the modified study is commenced. If the Department Human Ethics Advisory Group considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised project.*
c. **Annual report:** *An annual report is to be completed at the end of each year.*

On behalf of the Department Human Ethics Advisory Group I wish you well in your research.

Yours sincerely

David Castle
Research Programs Officer

Melbourne School of Psychological Sciences
The University of Melbourne, Victoria 3010 Australia
(Ph) +613 8344 6346 (E) rhd-psych@unimelb.edu.au (W) www.psych.unimelb.edu.au

Appendix 2 Approved Amendment to Minimal Risk Ethics Application

15 August 2016

Assoc. Prof Penelope Schofield
Melbourne School of Psychological Sciences
The University of Melbourne

THE UNIVERSITY OF MELBOURNE

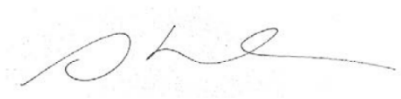
Dear Assoc. Prof Schofield,

Project title:	**Improving the quality of care provided to people affected by cancer.**
Other Researchers:	Ms Amanda Pomay, Dr Karla Gough, Assoc. Prof Miranda Xhilaga.
Ethics ID:	**1443027.2**

I am pleased to advise that the amendment to this Minimal Risk ethics application was approved by Melbourne School of Psychological Sciences HEAG on 15 August 2016.

Please note it is your responsibility to ensure that all people associated with the Project are made aware of the amendment.

Yours sincerely,



Dr Simon Laham
Chair of Psychological Sciences Human Ethics Advisory Group

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W: http://psychologicalsciences.unimelb.edu.au/

Appendix 3 Delphi Study Participant Plain Language Statement

Prostate Cancer Foundation of Australia

THE UNIVERSITY OF MELBOURNE

Melbourne School of Psychological Sciences

Delphi Study Plain Language Statement (Expert)

Project: Improving the quality of care provided to people with cancer via support groups: establishing evidence-based practice for group leaders.

A/Prof Penelope Schofield (Principle Researcher/Supervisor)
Tel: 03 9656 3560; email: penelope.schofield@petermac.org.au
Ms Amanda Pomery (PhD student)
Tel: 03 9948 2078; email: amanda.pomery@pcfa.org.au
Dr Karla Gough (Co-Researcher/Supervisor)
Tel: 03 9656 5205; email: karla.gough@petermac.org.au
A/Prof Miranda Xhilaga (Co-Researcher/Supervisor)
Tel: 03 9948 2072; email: miranda.xhilaga@pcfa.org.au

You are being invited to take part in a research study. Before you decide, it is important for you to know why the research is being done and what it will involve. Please read the following information carefully and feel free to ask questions if anything is not clear to you or if you would like any further information to decide if you wish to take part in this study.

1. What is the purpose of the project?

The study is about developing a practical and consistent way for group leaders to be chosen, and to work out areas of opportunity for development in leading a support group. A structured interview will be developed for this purpose, by integrating peer-reviewed literature, expert opinion and user feedback before undertaking a snap shot of existing support group leaders. The structured interview will be developed to establish a minimum standard for group leaders, as a way of guiding the delivery of support provided in the community to those affected by cancer.

2. Why have I been chosen?

You have been asked to take part because **you have been identified as an expert in this area**. This Delphi study will be used to establish consensus amongst experts in the field to develop a structured interview for selection and development of support group leaders. We will make every effort to ensure representation of multiple perspectives including academia, health agencies, health professionals, direct support providers, group leaders.

3. Can I suggest other potential participants to the study?

Please advise of any other experts in the field whose experience and input would be of benefit to the study via email to Amanda Pomery amanda.pomery@pcfa.org.au or phone 03 9948 2078. Potential participants will be sent an invitation for their consideration.

HREC Number: 1443027.1
Version Number:1 Date: 8 October 2014

4. Do I have to take part?

Being in this study is completely voluntary – you are not under any obligation to consent and – if you do consent – you can withdraw at any time without affecting your relationship with the researcher(s), The University of Melbourne, or the Prostate Cancer Foundation of Australia (PCFA), Breast Cancer Network of Australia (BCNA) or Cancer Council.

Return email will be notification of your consent to participate. If you wish to withdraw at any stage, please notify the researcher, Amanda Pomery.

5. Will my taking part in the study be kept confidential?

If you consent to take part in this study, your name will not be disclosed and would not be revealed in any reports or publications resulting from this study. Each expert will be allocated a code, and you will remain anonymous to the other participants (or experts) throughout and only the researcher will be able to identify your specific answers. All information will be handled and stored in accordance with the requirements of University of Melbourne Policy on the Management of Research Data and Records is available at: http://www.unimelb.edu.au/records/research.html. All information will be destroyed after 5 years of the research being conducted as stated in the University Of Melbourne Code Of *Conduct for Research*.

6. What happens when the research study stops?

The results of this study will be used to develop a structured interview for the selection and development of support group leaders. The structured interview will then be piloted before undertaking a main study with prostate cancer and breast cancer support group leaders to determine validity. Write up of results will be submitted to journals for publication and part of a PhD thesis. Where possible, presentations on the project will be delivered to key stakeholders and at professional conferences.

7. Who is conducting the research?

The study is being conducted by Amanda Pomery, PhD student at The University of Melbourne and in association with the Prostate Cancer Foundation of Australia (PCFA), Breast Cancer Network of Australia (BCNA), and Cancer Councils. The research is sponsored by PCFA. Supervisors and co-researchers are listed below.

Associate Professor Penelope Schofield, Principal Researcher, Director of Department of Cancer Experiences Research, Peter MacCallum Cancer Centre;

Dr Karla Gough, Co-Researcher, Head of Applied Statistics Cancer Experiences Research, Peter MacCallum Cancer Centre;

Associate Professor Miranda Xhilaga, Co-Researcher, Director of Research Programs, Prostate Cancer Foundation of Australia.

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http://www.psych.unimelb.edu.au

8. Who has reviewed this study?

The study has been approved by the Psychological Sciences Human Research Ethics Committee (HREC Number 1443027.1). If you have any concerns about this project please contact the Executive Officer, Human Research Ethics, The University of Melbourne (ph: 03 8344 2073; fax: 03 9347 6739).

9. Further information

If you wish to contact someone for further information regarding this study or your involvement please contact; Amanda Pomery on amanda.pomery@pcfa.org.au or 03 9948 2078.

THANK YOU

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Appendix 4 Delphi Study Round 1 Emailed Participant Instructions

Dear Participant,

This project aims to develop an evidence-based, standardised, practical method to guide the selection of cancer support group leaders, and to identify any areas that may require further development.

A structured interview will be designed for this purpose, by integrating peer-reviewed literature, expert opinion and user feedback. Once finalised, the structured interview will be used to capture a snap-shot of the knowledge, skills and attributes of existing cancer support group leaders.

You have been asked to take part in this study because **you have been identified as an expert who could make a meaningful contribution to this work**.

Three rounds of Delphi questionnaires delivered via email will be used to establish consensus amongst experts in the field. **The first questionnaire will take approximately 5 to 10 minutes to complete and is provided in the attached word document *Delphi Round 1*. Your consent will be assumed if you return completed responses to amanda.pomery@pcfa.org.au**.

For further information please refer to the attached *Delphi Study Plain Language Statement*. Also, please feel free to contact me on 03 9948 2078, if you have any questions.

Thanks in advance for your time and contributions.

Kind regards,

Amanda Pomery

Appendix 5 Delphi Study Round 1 Questionnaire

DELPHI ROUND 1

Please respond to action statements within this document; then save and return via email.

Please reflect on the role of the group leader within a cancer support group, and the knowledge, skills, and attributes that you would consider important to that role. Please note that the provision of medical/counselling knowledge or advice is not considered to be part of the role of the cancer peer group leader.

Action: Is there any characteristic or circumstance that would automatically preclude an individual from being a support group leader?

-

In recent months, we undertook a systematic review and qualitative synthesis of the peer-reviewed literature to compile a list of the requisite knowledge, skills and attributes of support group leaders. Identified knowledge, skills and attributes were collapsed into seven major themes, or qualities. Each of these qualities is presented below, as is a definition of each quality and key examples of relevant knowledge, skills and attributes identified in the peer-reviewed literature. Please examine each quality, including its definition and examples, then add any knowledge, skills and/or attributes you think are missing.

Quality 1: Group Management

Definition: tasks and activities performed by the group leader to ensure the continuity of the group.

- referral
- community resources
- social networking
- administration
- screening of members
- organisation of practical tasks (eg refreshments, venue)
- obtaining feedback
- shared responsibility
- knowledge/information on central topic of group
- suicidal members

Action: Please list any additional knowledge, skills or attributes you think are relevant to this quality.

-

Quality 2: Group Process

Definition: how the leader facilitates the group.

- maintaining group focus
- identification of members' needs

- opportunity for members to talk
- confidentiality
- intervene with management of issues/challenging members
- encourage member sharing, involvement & support
- facilitating, guiding and summarising discussion
- safe environment
- cohesion

Action: Please list any additional knowledge, skills or attributes you think are relevant to this quality.

-

Quality 3: Role Modelling

Definition: ability to demonstrate or provide a practical example of desirable qualities to other group members.

- positive reinforcement & reframing
- listening
- support
- foster sense of belonging
- problem solving
- interpersonal skills
- normalise experiences of members
- acceptance of difference
- commitment to the group

Action: Please list any additional knowledge, skills or attributes you think are relevant to this quality.

-

Quality 4: Awareness

Definition: the leader's consciousness of the needs of themselves, individual members and the group as a whole and how these interact.

- separate own needs from the groups
- sense of balance to life
- minimal involvement in group discussion
- group dynamics
- member interactions
- own physical health

Action: Please list any additional knowledge, skills or attributes you think are relevant to this quality.

-

Quality 5: Willingness

Definition: ability to give of themselves to the group.

- give and receive support
- availability of time to give
- contact and follow up with members outside of group
- commitment to the group

Action: Please list any additional knowledge, skills or attributes you think are relevant to this quality.

-

Quality 6: Agreeableness

Definition: how likeable and engaging the person is to others.

- sensitive
- supportive
- positive
- honest
- integrity
- warm
- empathic
- non-authoritarian
- sense of humour
- charismatic
- caring
- attentive
- authentic
- confident

Action: Please list any additional knowledge, skills or attributes you think are relevant to this quality.

-

Quality 7: Openness

Definition: ability to be mentally open with a positive or solution based approach.

- intelligent
- flexible
- objective

- creative
- initiative
- enthusiastic
- energetic

Action: Please list any additional knowledge, skills or attributes you think are relevant to this quality.

-

Additional qualities

Action: Do you think there are other qualities important to being a peer group leader that are not listed above? If yes, please type them below and provide example of relevant knowledge, skills and/or attributes.

-

Please be sure to save your responses before closing this document.

THANK-YOU FOR YOUR TIME.

Appendix 6 Delphi Study Round 2 Emailed Participant Instructions

Dear Participant,

Last month you were invited to participate as an expert in a research project to develop an evidence-based, standardised, practical method to guide the selection of cancer support group leaders, and to identify any areas that may require further development.

Thank you to those who participated in the first round; in total, 45 individuals completed the first questionnaire. Responses were analysed and combined to create a manageable list of qualities for review. Every attempt was made to incorporate the essence of participants' contributions to the first round.

Together, qualities identified in the systematic review and first Delphi round form the basis of this second round, which focuses on identifying qualities associated with readiness to undertake the cancer support group leader role.

The second questionnaire will take approximately 10 to 15 minutes to complete and is provided in the attached word document *Delphi Round 2*. Again your consent will be assumed if you return completed responses to amanda.pomery@pcfa.org.au.

For further information please refer to the attached *Delphi Study Plain Language Statement*. Also, please feel free to contact me on 03 9948 2078, if you have any questions.

Thanks in advance for your time and contributions.

Kind regards,

Amanda Pomery

Appendix 7 Delphi Study Round 2 Questionnaire

DELPHI ROUND 2

Qualities associated with readiness to undertake the cancer support group leader role

In this Delphi round, we would like you to indicate (by placing an X in the appropriate column) whether the knowledge, skills and attributes listed are:

1) required to be ready to undertake the cancer support group leader role;
2) desirable but not required;
3) not required to be ready;
4) you are unsure; or
5) you have no opinion.

Again, knowledge, skills and attributes are presented under the seven major qualities described in the first Delphi round. A definition of each quality is provided for your convenience. Please note that this document is eight pages in total; however, it is only expected to take around 10 to 15 minutes to complete.

Before providing responses, please reflect on the role of the group leader within the context of a cancer support group. Please note that many groups operate independently in the community, at minimal cost, and in a limited peer volunteer capacity. The provision of medical/counselling knowledge or advice is not considered to be part of the role of the cancer support group leader.

Please save your responses and return via email.

Quality 1: Group management

Tasks and activities performed by the group leader to ensure the continuity and functioning of the group.

Knowledge, Skills & Attributes	Required to be ready	Desirable but not required to be ready	Not required to be ready	Not sure	No opinion
Referring to supports external to the group					
Knowledge of community resources & support networks					
Social networking					
Administration					
Screening of members					
Organisation of practical tasks (eg. refreshments, venue)					
Obtaining feedback from the group					
Sharing responsibilities					
Knowledgeable on central topic of group					
Awareness of psychologically unwell or vulnerable members					
Succession planning					
Capacity to be primary point of contact					
Time management					
Planning of group meeting					
Financial management					
Promotion of the group					
Facilitating group's relationship with external bodies/stakeholders					
Computer skills					

Quality 2: Group Process

How the leader facilitates the group.

Knowledge, Skills & Attributes	Required to be ready	Desirable but not required to be ready	Not required to be ready	Not sure	No opinion
Maintain group focus					
Identify group needs					
Maintain confidentiality					
Intervene with management of issues/challenging members					
Encourage member sharing, involvement & support					
Facilitate, guide and summarise discussion					
Foster a welcoming space					
Promote group cohesion & trust					
Work effectively with co-leader/s					
Maintain respectful dialogue & interaction with/about others					
Engage group in establishing & reviewing group purpose & structure					
Manage alternative opinions/view/beliefs					
Lead group in alignment with group membership, context & culture					
Facilitate closure					
Acknowledge own limitations of knowledge or boundaries					
Welcome & introduce new members					
Clarify their leader role with/to group members					

Quality 3: Role Modelling

Ability to demonstrate or provide a practical example of desirable qualities to other group members.

Knowledge, Skills & Attributes	Required to be ready	Desirable but not required to be ready	Not required to be ready	Not sure	No opinion
Positive reinforcement & reframing					
Listening					
Supportive					
Foster sense of belonging					
Problem solving					
Communication skills					
Acknowledge & validate experiences of members					
Acceptance of difference					
Commitment to the group					
Empathy					
Flexibility					
Acknowledge limitation of self & the group					
Respect for others					
Operate within standards set by the group					
Self-care and care of other members					
Empowering mutual aid of group members					
Maintaining boundaries					
Remain calm					

Quality 4: Awareness

Leader's consciousness of the needs of themselves, individual members and the group as a whole and how these interact.

Knowledge, Skills & Attributes	Required to be ready	Desirable but not required to be ready	Not required to be ready	Not sure	No opinion
Separate own needs from the group's					
Balance personal life & leadership responsibilities					
Maintaining minimal involvement in group discussion					
Group dynamics					
Maintaining own mental & physical health					
Context & culture of the group					
Reflective of own experience, emotions, values					
Undertake role for agreed period of time with group					
Being mentally present					
Recognise when support/de-briefing is needed					
Own self-care					
Own development in the role					
Altruistic motivation					
Appropriate sharing of own story					
Manage own & group's expectations					

Quality 5: Willingness

Ability to give of themselves to the group.

Knowledge, Skills & Attributes	Required to be ready	Desirable but not required to be ready	Not required to be ready	Not sure	No opinion
Give and receive support					
Availability of time to give					
Contact and follow up of tasks outside of group					
Commitment to the group					
Be an advocate for the group					
Receive and manage feedback/criticism/complaints					
Enable succession & step down from the role					
Promote empowerment of members not reliance					
Maintain boundaries					
Share leadership duties					
Undertake learning & development in the role					

Quality 6: Agreeableness

How likeable and engaging the person is to others.

Knowledge, Skills & Attributes	Required to be ready	Desirable but not required to be ready	Not required to be ready	Not sure	No opinion
Sensitive					
Supportive					
Positive					
Honest					
Warm					
Empathic					
Non-authoritarian					
Appropriate sense of humour					
Charismatic					
Attentive					
Confident					
Approachable					
Calm					
Trustworthy					
Intuitive					
Inclusive					
Resilient					
Responsive					
Respectful					
Assertive					
Ethical					
Patient					
Genuine					
Diplomatic					

Quality 7: Openness

Ability to be mentally open and enabling the group to reach its aims and purpose.

Knowledge, Skills & Attributes	Required to be ready	Desirable but not required to be ready	Not required to be ready	Not sure	No opinion
Capable					
Flexible					
Objective					
Creative					
Intuitive					
Energetic					
Motivated					
Accepting					
Thoughtful					
Persistent					
Resourceful					

Please be sure to save your responses before closing this document.

THANK-YOU FOR YOUR TIME.

Appendix 8 Delphi Study Round 3 Emailed Participant Instructions

Dear Participant,

Previously you were invited to participate as an expert in a research project to develop an evidence-based, standardised, practical method to guide the selection of cancer support group leaders, and to identify any areas that may require further development.

Thank-you to those who participated in the second Delphi round. In total, 36 individuals completed the second questionnaire. Responses were used to determine the knowledge, skills and attributes (KSA) needed to be ready to undertake the role of a cancer support group leader. In this case, specific KSA were retained if *at least 75% of respondents* indicated that the knowledge, skill or attribute was *required to be ready to undertake the cancer support group leader role.*

A structured conversation with questions, scenarios and an evaluative rating scale anchored by examples of responses has been developed to determine a potential group leader's readiness to undertake the role. Based on agreed qualities and associated KSA, this developed structured conversation forms the basis of the third and final Delphi round, where you are asked to rate the format, questions and evaluative rating scales.

The third questionnaire will take approximately 20-30 minutes to complete and is provided in the attached word document *Delphi Round 3*. If you intend to participate, please sent the completed questionnaire back by Friday 15th January 2016. Again, your consent will be assumed if you return completed responses to amanda.pomery@pcfa.org.au.

For further information please refer to the attached *Delphi Study Plain Language Statement*. Also, please feel free to contact me on 03 9948 2078, if you have any questions.

Thanks in advance for your time and contributions.

Kind regards,

Amanda Pomery

Appendix 9 Delphi Study Round 3 Questionnaire

DELPHI ROUND 3

You will need to refer to *Attachment 1: KSA table* and *Attachment 2: Structured conversation* in this final delphi round. *Attachment 1* contains a list of knowledge, skills and attributes (KSA) needed to be ready to undertake the role of a cancer support group leader. KSA were determined based on the systematic review and previous delphi rounds. *Attachment 2* contains a structured conversation with questions, scenarios, probing questions, and an evaluative rating scale anchored by examples of responses or expected behaviours. This structured conversation will be used to determine a potential group leader's readiness to undertake the role and is based on the KSA outlined in the attachment.

Questions and scenarios comprising the structured conversation have been grouped into one of two categories: *Suitability for the role* and *Knowledge and skill development for the role*. KSA that **cannot** be developed through additional support and/or training have been assigned to the category *Suitability for the role*; for example, availability of time to give to the group. KSA that **can** be developed through additional support and/or training have been assigned to the category *Knowledge & skill development for the role*; for example, foster a welcoming space.

As part of Delphi Round 3, you will need to complete the table below. For each question and scenario, you will be asked to assess whether:

1) the wording is clear and understandable
2) it is likely to elicit information relevant of the specified KSA
3) the specified KSA have been assigned to the appropriate category
4) suggested probing questions are suitable
5) the examples of responses (or expected behaviours) are appropriate indicators of the KSA being assessed
6) you believe the evaluative rating scale is reasonable given the relevant population (i.e., community volunteers)

In some instances, you will be asked to provide additional information dependent on your answer.

Please note that this document is seven pages in total; however, it should only take around 20-30 minutes to complete.

Before providing responses, please again consider the role of the group leader within the context of a cancer support group. Please note that many groups operate independently in the community, at minimal cost, and in a limited peer volunteer capacity. The provision of medical/counselling knowledge or advice is <u>not</u> considered to be part of the role of the cancer support group leader.

Please save your responses and return via email.

Question Number	Is the wording of this question or scenario clear and understandable?	Is this question or scenario likely to elicit information relevant to the specified KSA?	Do you think the specified KSA have been assigned to the appropriate category?	Do you think the probe is suitable (i.e., it is likely to elicit more information relevant to the question)?	Are the examples of responses appropriate indicators of the KSA being assessed?	Do you think the evaluative rating scale is reasonable?
1	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
2	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
3	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?

Question Number	Is the wording of this question or scenario clear and understandable?	Is this question or scenario likely to elicit information relevant to the specified KSA?	Do you think the specified KSA have been assigned to the appropriate category?	Do you think the probe is suitable (i.e., it is likely to elicit more information relevant to the question)?	Are the examples of responses appropriate indicators of the KSA being assessed?	Do you think the evaluative rating scale is reasonable?
4	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
5	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
6	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?

Question Number	Is the wording of this question or scenario clear and understandable?	Is this question or scenario likely to elicit information relevant to the specified KSA?	Do you think the specified KSA have been assigned to the appropriate category?	Do you think the probe is suitable (i.e., it is likely to elicit more information relevant to the question or scenario)?	Are the examples of responses appropriate indicators of the KSA being assessed?	Do you think the evaluative rating scale is reasonable?
7	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
8	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
9	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?

Question Number	Is the wording of this question or scenario clear and understandable?	Is this question or scenario likely to elicit information relevant to the specified KSA?	Do you think the specified KSA have been assigned to the appropriate category?	Do you think the probe is suitable (i.e., it is likely to elicit more information relevant to the question or scenario)?	Are the examples of responses appropriate indicators of the KSA being assessed?	Do you think the evaluative rating scale is reasonable?
10	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
Scenario 1	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
Scenario 2	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?

Question Number	Is the wording of this question or scenario clear and understandable?	Is this question or scenario likely to elicit information relevant to the specified KSA?	Do you think the specified KSA have been assigned to the appropriate category?	Do you think the probe is suitable (i.e., it is likely to elicit more information relevant to the question or scenario)?	Are the examples of responses appropriate indicators of the KSA being assessed?	Do you think the evaluative rating scale is reasonable?
11	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
12	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, what suggestions would you recommend?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?
13	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
		If no, which KSA was not identified?		If no, what probe(s) would you recommend?	If no, what suggestions would you recommend?	If no, how would you improve the scale?

Interviewer observations	**Responses**
Is the wording of the interviewer observations clear and understandable?	Yes/No
Do you think the specified KSA have been assigned to the appropriate category?	Yes/No
Do you think that the evaluation of these KSA is suitable?	Yes/No If no, please provide further comments.
Summary Questions	**Responses**
Does the structured conversation as a whole provide an adequate assessment of the KSA needed to be ready to undertake the role of a cancer support group leader?	Yes/No If no, please provide further comments.
Do you have any further comments or recommendations?	

Appendix 10 Delphi Study Round 3 Attachment 1 KSA Table

Attachment 1: KSA table

Knowledge, skills and attributes generally considered by experts as required to be ready to undertake the role of cancer support group leader

Quality	Knowledge, skills and attributes
Group Management	Capacity to be primary point of contact Planning of group meeting
Group Process	Identify group needs Maintain confidentiality Intervene with management of issues/challenging members Foster a welcoming space Encourage member sharing, involvement and support Facilitating, guiding and summarising discussion Work effectively with co-leader/s Maintain respectful dialogue & interaction with/about others Promote group cohesion& trust Manage alternative views/beliefs/opinions Welcome & introduce new members Clarify their leader role with/to group members
Role Modelling	Listening Support Communication skills Acceptance of difference Commitment to the group Empathy Acknowledging limitations of self & the group Respect for others Operate within standards set by the group Self-care & care of other members Maintaining boundaries Remaining calm
Awareness	Separate own needs from the groups Maintaining own mental & physical health Being mentally present Own self-care Recognise when support/de-briefing is needed
Willingness	Give and receive support Availability of time to give Commitment to the group Receive and manage criticism/complaints Maintain boundaries

Quality	Knowledge, skills and attributes
Agreeableness	Sensitive
	Supportive
	Honest
	Integrity
	Empathic
	Non-authoritarian
	Approachable
	Trustworthy
	Inclusive
	Responsive
	Respectful
	Ethical
	Patient
	Genuine
Openness	Capable
	Objective
	Motivated
	Accepting

Appendix 11 Delphi Study Round 3 Attachment 2 Drafted Structured Interview

Attachment 2: Structured conversation

Developed questions, scenarios, responses and evaluative rating scale relating to knowledge, skills and attributes generally considered required to be ready to undertake the cancer support group leader role.

Question 1: The role of a cancer support group leader requires a commitment of your time and capacity to be the primary point of contact for the group. Can you explain how you will fit this in with your other activities and responsibilities?	
Specific knowledge, skills and attributes covered by question: Capacity to be primary point of contact; Availability of time to give; Commitment to the group; Motivated	
Category: Suitability for the role	
Probe	Can you give me an example?
Scale	Examples of Responses
2	• Reflective and give examples of other personal, work or volunteer commitments • Explains how they will be available and willing to give sufficient time to the role • Confirms being committed to undertaking the role on an ongoing basis
1	• Indicates availability to give time to the role but provides no examples of current commitments or explains how they will be available • Indicates willingness but limited commitment or time to undertaking the role
0	• Current commitments mean insufficient time to give to the role • Unable to commit to the role and group
Question 2: Can you give an example of having to plan and organise a group activity (either in a work, volunteer or social capacity)?	
Specific knowledge, skills and attributes covered by question: Planning of group meeting	
Category: Knowledge & skill development for the role	
Probe	Can you tell me more about that?
Scale	Examples of Responses
2	• Provides an example of a group activity they were responsible for planning & organising. Describes how the activity was accomplished and the outcome
1	• Provides an example of an activity they were involved with planning or organising
0	• Unable to give an example of an activity involving planning or organising

Question 3: Describe a time when you experienced a conflict or difference of opinion amongst a group of people. How did you react to the situation? How was the situation resolved?	
Specific knowledge, skills and attributes covered by question: Intervene with management of issues/challenging group members; Manage alternative opinions/views/ beliefs	
Category: Knowledge & skill development for the role	
Probes	Can you tell me more about that? What do you mean by that?
Scale	Examples of Responses
2	• Provides an example of a group conflict, conveying awareness of people's alternative opinions/beliefs/views • Describes reacting to the situation where they intervened • Attempted to calm others • Describes resolution to the situation that was supportive and respectful to all parties
1	• Provides an example of group conflict • Describes reacting to the situation with a desire/intention to intervene • Describes partial resolution to the situation
0	• Unable to give an example of a group conflict • Unable to convey ability or awareness to intervene • Conflict was not handled well • Little or no flexibility in approaching situation
Question 4: In a group meeting, how would you show support to someone who has received some bad news? And how would you go receiving support from others during difficult times?	
Specific knowledge, skills and attributes covered by question: Empathy; Support; Self-care & care of others ; Empathic; Sensitive; Supportive; Give and receive support	
Category: Knowledge & skill development for the role	
Probes	Can you give me some more examples?
Scale	Examples of Responses
2	• Demonstrate awareness and ability to be empathic, sensitive to other's needs, and supportive in approach • Demonstrate awareness of own need for support and willingness to receive support from others
1	• Conveys ability to be empathic, sensitive or supportive in their approach • Conveys willingness to receive support from others
0	• Unable to give an example of how they would support others or provides examples that would be unhelpful

	• Unaware of own potential need for support and unwilling to receive support from others
Question 5: Can you explain how you prefer to get tasks done when working with others? What approach do you take?	
Specific knowledge, skills and attributes covered by question: Encouraging member sharing, involvement and support; Work effectively with group leaders	
Category: Knowledge & skill development for the role	
Probe	Can you give me some examples?
Scale	Examples of Responses
2	• Provides opportunity and encourages others to be involved • Shares responsibility with key individual if relevant (e.g. co-leader, 2nd in charge, nominated support person) • Awareness of people's interests and strengths in delegation of tasks • Takes a lead role in organisation of practical tasks
1	• Capacity to take a lead role in organisation of practical tasks • Encourages others to be involved, but may not provide opportunity • Desire to delegate tasks and responsibilities but unsure how to go about it
0	• Unaware of involving others in completing tasks • Unable to explain how they would approach task completion
Question 6: How would you find out what the needs of the group are? How would you react if group members asked for something different to what was being provided?	
Specific knowledge, skills and attributes covered by question: Identification group needs; Encourage member sharing, involvement & support; Maintaining group focus; Listening ; Receive and manage criticism/complaints; Non-authoritarian	
Category: Knowledge & skill development for the role	
Probe	Can you give me some examples?
Scale	Examples of Responses
2	• Provide opportunity for members to talk about their needs • Encourage member sharing & involvement with how the group is run • Provides examples of how to obtain feedback • Listening to members of the group • Awareness to separate out own needs and maintain a group focus • Open to receiving criticism/complaints
1	• Obtains feedback through listening to members talk about their needs • Encourages members sharing

	• Willing to receive criticism/complaints
0	• Unable to explain how they would find out about the needs of the group • Assumes or dictates what the needs are without seeking further clarification or information • Unwilling to receive criticism/complaints
Question 7: What is your understanding of confidentiality as it relates to a support group?	
Specific knowledge, skills and attributes covered by question: Maintain confidentiality	
Category: Knowledge & skill development for the role	
Probes	What do you mean by that? Can you tell me more?
Scale	Examples of Responses
2	• Demonstrates clear understanding regarding the importance of confidentiality in a group setting • Awareness of the sensitive content or nature of the support group • Refers to the group's rules/code of conduct/agreement • Recognises discussions held in the group meeting are private • Considers confidentiality of group members beyond the group meeting itself (e.g. newsletters, website/Facebook, conversations with others outside of group)
1	• Conveys understanding regarding the importance of confidentiality in a group setting • Recognises discussions held in the group meeting are private, but unable to provide examples of how confidentiality is maintained beyond the meeting
0	• Unable to demonstrate importance of confidentiality • Unable to provide examples of how confidentiality may be maintained
Question 8: If you were to attend a support group meeting, what do you think or believe would make it a welcoming space? What could a group leader do to assist?	
Specific knowledge, skills and attributes covered by question: Foster a welcoming space; Welcome & introduce new members	
Category: Knowledge & skill development for the role	
Probe	Can you give me some examples?
Scale	Examples of Responses
2	• Safe & confidential environment • Fostered sense of belonging • Opportunity for members to talk & listen to others

	• Able to receive support • Being welcomed and accepted into the group • Being introduced to others • Welcoming of members included in group process/management
1	• Understood basic concept of welcoming & introducing others to the group • Coveys sense of group being a safe space • Able to provide some examples of a welcoming space but limited knowledge of strategies group leaders could take
0	• Unable to provide examples of a welcoming space or approaches a group leader could take • Places responsibility onto the new member to fit in with the group
Question 9: Members of a support group can have varying backgrounds, needs, beliefs, and views. How might you go about supporting those members that might be different to you?	
Specific knowledge, skills and attributes covered by question: Acceptance of difference; Respect for others; Inclusive; Accepting	
Category: Knowledge & skill development for the role	
Probe	Can you give me some examples?
Scale	Examples of Responses
2	• Demonstrates awareness of how members can be different to themselves &/or other members • Provides examples of how members can be different (e.g. culture, age, gender, financial backgrounds, support needs, stage of illness, beliefs, values, views) • Awareness not to assume, but identifying member's needs as they relate to their personal circumstances • Separate own needs from others • Role models respect for others • Role models acceptance of difference to others • Mindful of spending time welcoming, fostering sense of belonging and listening
1	• As an individual demonstrates respect for others • Coveys acceptance of difference to others • Willingness to support those different to themselves
0	• Unable to acknowledge potential differences amongst group members • Unwilling to support those different to themselves • Places responsibility onto the member to conform or restrict support offered in the group to align with their own needs

Question 10: We (e.g. specific organisation) provide assistance (such as training, resources) to get you ready for the role and develop your skills and knowledge to support you along the way. Would you be willing and available to access such support either now or into the future?	
Specific knowledge, skills and attributes covered by question: Recognise when support/de-briefing is needed; Give & receive support; Availability of time to give	
Category: Suitability for the role	
Probe	Can you confirm that you're willing and able to do this?
Scale	Examples of Responses
2	• Recognises the importance of continuous learning and accessing support when needed • Confirms willingness to undertake assistance provided by organisation • Confirms commitment to ongoing development • Confirms availability to access support
1	• Conveys willingness to undertake assistance provided by the organisation • Expresses limited availability to access support
0	• Has the view they have nothing more to learn • Unwilling to undertake assistance either now or into the future • Unable to commit time to accessing support
Scenario 1: Suppose in a group meeting, a member starts complaining about a health professional. The member becomes quite angry, states the doctor's name, how they believe they are no good, and tells everyone that they shouldn't see them for treatment. The group has a standing agreement that everyone is respectful of one another. Describe how you would handle the situation.	
Specific knowledge, skills and attributes covered by scenario: Maintaining respectful dialogue & interactions with/about others; Intervene with management of issues/challenging members; Facilitating, guiding and summarising discussion; Operate within the standards of the group; Remain calm	
Category: Knowledge & skill development for the role	
Probe	Can you give me some more examples?
Scale	Examples of Responses
2	• Awareness of group dynamics and reactions of members • Intervene to maintain respectful dialogue about others • Listen to and acknowledge member's experience, views and beliefs • Look for opportunity to positively reframe & guide discussion • Maintain group focus, reinforce what the purpose of the group is and what support is possible • Refer to group agreement or standards • Demonstrate empathy, genuine care, and sensitivity

	• Remain calm • Positively reinforce respect to others includes doctors • Provide opportunity for other members to talk and share • Identify member's support needs and possible referral to assistance outside of group
1	• Display an adequate though not comprehensive number of the above or other effective responses
0	• Unable to provide a basic effective response
Scenario 2: Suppose in a meeting, a member wants to talk about his daughter's mental health and financial problems. The member explains how it's been really hard on the family and asks if the group could host a fundraiser to help. The support group is specifically for people impacted by cancer, with the main focus on providing support to each other and sharing information about cancer. The group has not been involved in other events or fundraisers. Describe how you would handle the situation.	
Specific knowledge, skills and attributes covered by scenario: Group cohesion & trust; confidentiality; Facilitating, guiding and summarising discussion; Operate within the standards of the group; Acknowledge limitations of self & group	
Category: Knowledge & skill development for the role	
Probe	Can you give me some more examples?
Scale	Examples of Responses
2	• Listen to and acknowledge member's experience & request • Maintain group focus, reinforce what the purpose of the group is and what support is possible • Role model respect and confidentiality towards member's situation • Facilitate, guide and summarise discussion for members • Refer to group agreement or standards • Acknowledge limitations of the group and unable to provide support to all people for all things • Maintain group cohesion • Obtain feedback from the group • Problem solve, provide opportunity for individuals to assist if they choose rather than have the group as a whole commit • Refer to other more appropriate community supports • Demonstrate empathy, genuine care, and sensitivity
1	• Display an adequate though not comprehensive number of the above or other effective responses
0	• Unable to provide a basic effective response

Question 11: I'm interested to hear what you think a support group leader does? Are there any limits to the support given in the role?	
Specific knowledge, skills and attributes covered by question: Clarify their role with/to group members; Maintaining boundaries	
Category: Knowledge & skill development for the role	
Probes	Can you tell me more? Can you give me some examples?
Scale	Examples of Responses
2	• Able to describe and explain the role of a support group leader • Provides examples relating to group management & group process • Demonstrates awareness of key elements of the role such as being empathic, supportive, respectful • Understands the importance of confidentiality • Confirms there are limits to support given, with awareness of maintaining boundaries • Provides examples of when they would say no to giving support due to it being outside the role
1	• Display an adequate though not comprehensive number of the above or other appropriate responses • Understands there are limits to support given, with awareness of maintaining boundaries`
0	• Unable to provide a basic effective response • Unable to understand there are limits to the role, or unwilling to maintain personal boundaries
Question 12: In order to support others, group leaders generally have to look after themselves mentally and physically. Is there anything you need to consider that would impact on your ability to undertake the role? Do you have any strategies for looking after yourself?	
Specific knowledge, skills and attributes covered by question: Maintaining own mental & physical health; Own self-care	
Category: Suitability for the role	
Probes	Can you tell me more about that? Can you give some examples?
Scale	Examples of Responses
2	• Reflective and articulates awareness of own circumstances, physical health and wellbeing • Sense of balance to their life • Established own personal support network

	• Being organised, planning ahead, prioritise commitments • Taking time out • Diet, exercise, and relaxation strategies
1	• Disclosed personal physical or mental health issues that are currently being managed • Display an adequate though not comprehensive number of the above self-care strategies or other appropriate responses
0	• Disclosed physical or mental health issues that would significantly impact on their ability to function in the role • Unable to identify any self-care strategies
Question 13: Reflecting on our conversation, overall do you think you are capable and ready to undertake the role of group leader?	
Specific knowledge, skills and attributes covered by question: Separate own needs from the group's; Capable	
Category: Suitability for the role	
Probe	Would you like some more time to think about your response and get back to me?
Scale	Examples of Responses
2	• Demonstrates awareness of the role and knowledge, skills & attributes required of them to undertake role • Awareness to separate own personal desire or needs to be a group leader in order for the group to be led by a suitable person • Objectively determines (based on previous responses or experience) they are capable and ready to undertake role
1	• Determines they are capable to undertake role with assistance to support them become ready
0	• Determines they are currently not ready to undertake the role • Determines the role does not suit them or their circumstances

Interviewer observations: Indicate if any of the following attributes were observed at any time throughout the interaction with the candidate.		
Specific attributes covered by observations: Being mentally present; Respectful; Listening; Communication skills; Trustworthy/Ethical; Responsive; Patient; Genuine; Calm; Non-authoritarian; Approachable; Honest/Integrity; Objective		
Category: Suitability for the role		
Attribute	Observed	Not observed
Respectful of the process, your role, &/or the organisation you represent		
Listened		
Patient		
Followed through on what they said they would do (before/during/after conversation)		
Provided objective responses		
Mentally present		
Approachable manner		
Calm		
Non-authoritarian approach		
Genuineness		

Appendix 12 Pilot Study Participant Plain Language Statement

Prostate Cancer Foundation of Australia

THE UNIVERSITY OF MELBOURNE

Melbourne School of Psychological Sciences
Pilot Study
Plain Language Statement

Project: Improving the quality of care provided to people with cancer via support groups: establishing evidence-based practice for group leaders.

A/Prof Penelope Schofield (Principle Researcher/Supervisor)
Tel: 03 9656 3560; email: penelope.schofield@petermac.org.au
Ms Amanda Pomery (PhD student)
Tel: 03 9948 2078; email: amanda.pomery@pcfa.org.au
Dr Karla Gough (Co-Researcher/Supervisor)
Tel: 03 9656 5205; email: karla.gough@petermac.org.au
A/Prof Miranda Xhilaga (Co-Researcher/Supervisor)
Tel: 03 9948 2072; email: miranda.xhilaga@pcfa.org.au

You are being invited to take part in a research study. Before you decide, it is important for you to know why the research is being done and what it will involve. Please read the following information carefully and feel free to ask if anything is not clear to you or if you would like any further information to decide if you wish to join this study.

1. What is the study about?

The study is about developing a practical and consistent way for group leaders to be chosen, and to work out areas of opportunity for development in leading a support group. The aim of this study is to test out a newly developed structured interview and obtain feedback on your experience (for example, if you think the interview questions make sense). Feedback from support group leaders and cancer agency workers will be used to improve the user manual for the structured interview, the structured interview itself and the standard form used to record and rate interview responses. These updated resources will then be used in a larger study, which will help us to better understand the attributes and training needs of existing prostate and breast cancer support group leaders.

2. What does the study involve?

If you are a support group leader, you will take part in a telephone interview. During this interview you will be asked set questions about your role as a support group leader, and areas for development in leading a support group you may have. The interview will take about 30 minutes. It will be audio-taped and your responses will be noted by the interviewer.

If you are a cancer agency worker, you will be asked to read a brief user manual for the newly developed structured interview and familiarise yourself with the interview schedule and standard form for documenting interview responses. You will then phone one support group leader at a pre-arranged time to conduct the structured interview. You will need to record and rate the support group leader's responses to interview questions using the standard form. Interviews will also be audio-taped.

HREC Number: 1443027.1
Version Number:1 Date: 8 October 2014

After conducting or participating in the newly developed structured interview, you will also take part in a brief interview with the student researcher. During this interview, you will be asked to provide feedback on the structure, content and acceptability of the structured interview. This interview will take about 15 minutes. It will be audio-taped and your responses will be noted by the student researcher.

If you decide you would like to participate, please complete, sign and return the consent form. Enclosed reply paid forms are to be sent Attention: Amanda Pomery Prostate Cancer Foundation of Australia Level 5, 437 St Kilda Road, Melbourne VIC 3004 or scanned and emailed to amanda.pomery@pcfa.org.au.

Once the consent form has been received, we can then arrange a interview times. Interviews will be done over the phone, on a day and at a time that mutually suits both the interviewer and interviewee.

3. Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with the researcher(s), The University of Melbourne, or the Prostate Cancer Foundation of Australia (PCFA), Breast Cancer Network of Australia (BCNA) or Cancer Council.

You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study. If you wish to withdraw, please notify the researcher, Amanda Pomery.

4. Will anyone else know the results?

The information you provide will be strictly confidential but subject to legal limitations, and only the named researchers will have access to your information. Information you provide will be coded and kept in a locked filling cabinet. Any stored electronic data files will be protected by password. Write up of results will be submitted to journals for publication and part of a PhD thesis. Where possible, presentations on the project will be delivered to key stakeholders and at professional conferences. As a part of publication and presentations, no identifying information will be presented.

All information will be handled and stored in accordance with the requirements of University of Melbourne Policy on the Management of Research Data and Records is available at: http://www.unimelb.edu.au/records/research.html. All information will be destroyed after 5 years of the research being conducted as stated in the University Of Melbourne Code Of *Conduct for Research*.

5. Will I be able to access the information obtained about me?

In accordance with relevant Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform Amanda Pomery if you would like to access your information.

Psychological Sciences
The University of Melbourne Victoria 3010 Australia
Telephone: +61 3 8344 6377
Fax: +61 3 9347 6618
http://www.psych.unimelb.edu.au

6. Will the study benefit me?

We hope to use the information from this study to develop a practical and consistent way to guide group leadership into the future, with the focus on building quality supportive care to those people affected by cancer. We cannot and do not guarantee or promise that you will receive any benefits from the study.

7. What are the risks?

With any research project, it is highly unlikely that there are no known risks. You may possibly feel that some of the questions in the discussion are stressful or upsetting. If you become upset or distressed, please let a member of the research team know. If a member of the research team is worried about you, they may put you in contact with a health professional. Alternatively you can also contact counselling services such as LifeLine (13 11 14), beyondblue (1300 22 4636) or Cancer Council Helpline (13 11 20). You may also experience inconvenience due to the time it takes to complete the telephone interviews as outlined above in point 2.

8. Can I tell other people about the study?

You can tell other people about your participation in this study and are free to pass on the contact details for Amanda Pomery (amanda.pomery@pcfa.org.au or 03 9948 2078) should others want to know more about the study.

9. Who is conducting the research?

The study is being conducted by Amanda Pomery, PhD student at The University of Melbourne and in association with the Prostate Cancer Foundation of Australia (PCFA), Breast Cancer Network of Australia (BCNA), and Cancer Councils. The research is sponsored by PCFA. Supervisors and co-researchers are listed below.

Associate Professor Penelope Schofield, Principal Researcher, Director of Department of Cancer Experiences Research, Peter MacCallum Cancer Centre;

Dr Karla Gough, Co-Researcher, Head of Applied Statistics, Cancer Experiences Research, Peter MacCallum Cancer Centre;

Associate Professor Miranda Xhilaga, Co-Researcher, Director of Research Programs, Prostate Cancer Foundation of Australia.

10. Who has reviewed this study?

The study has been approved by the Psychological Sciences Human Research Ethics Committee (HREC 1443027.1). If you have any concerns about this project please contact the Executive Officer, Human Research Ethics, The University of Melbourne (ph: 03 8344 2073; fax: 03 9347 6739).

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11. Further information

If you wish to contact someone for further information regarding this study or your involvement please contact; Amanda Pomery on amanda.pomery@pcfa.org.au or 03 9948 2078.

THANK YOU

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Appendix 13 Pilot Study Participant Consent Form

Prostate Cancer Foundation of Australia

THE UNIVERSITY OF MELBOURNE

Melbourne School of Psychological Sciences
Pilot Study
Consent form for persons participating in a research project

Project Title: Improving the quality of care provided to people with cancer via support groups: establishing evidence-based practice for group leaders.

Name of Participant:

Name of Primary Researcher: A/Prof Penelope Schofield
Name of Additional Researchers: Ms. Amanda Pomery (PhD student), Dr Karla Gough (Co-Researcher/Supervisor), A/Prof Miranda Xhilaga (Co-Research/Supervisor)
Sponsor: Prostate Cancer Foundation of Australia

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.

2. I understand that the project is for the purpose of research.

3. I understand that my participation will involve interviews and I agree that the researcher may use the results as described in the plain language statement;

   a) Cancer agency workers will be conducting the structured interview and will be required to familiarise themselves with the resource, conduct one interview with a support group leader, and participate in an interview with the student for feedback purposes,

   b) Support group leaders will be asked to be interviewed by a cancer agency worker and participate in an interview with the student researcher for feedback purposes.

4. I understand that my participation is voluntary and that I am free to withdraw from the study at anytime without explanation or prejudice and to withdraw any unprocessed data I have provided. Withdrawing from the study will not affect my relationship with the researcher(s), or the University of Melbourne, or the Prostate Cancer Foundation of Australia/Breast Cancer Network of Australia/Cancer Council now or in the future.

5. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published however no information about me will be used in any way that is identifiable.

6. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.

7. I acknowledge that I have been informed that with my consent the ***interviews will be audio-taped and I understand that audio-tapes*** will be stored at University of Melbourne department and will be destroyed after five years;

PID: XXX
HREC Number: 1443027.1
Consent Form Version 1, 8 October 2014

8. I understand that after I sign and return this consent form it will be retained by the researcher.

Participant signature: _____ Date: _____

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http://www.psych.unimelb.edu.au

Appendix 14 Pilot Study Emailed Participant Instructions

Dear Participant,

Thanks again for agreeing to participate in a research project to develop an evidence-based, standardised, practical method to guide the selection of cancer support group leaders, and identify any areas that may require further development.

A Planned Conversation has been developed based on content identified through a systematic literature review and Delphi study. The purpose of this pilot study is to determine how potential users (e.g. cancer agency workers) judge the usefulness, benefits and drawbacks of a newly developed structured interview, referred to as *A Planned Conversation*. Feedback obtained will be used to refine and improve *A Planned Conversation* before conducting the main pilot study to develop the scoring matrix.

Please refer to the attached document "Piloting study: clinical utility feedback" for instructions. You are asked to identify four current support group leaders to conduct the structured interview with. Pilot Study Pain Language Statement and Pilot Consent Form are to be provided to participants.

Before conducting *A Planned Conversation* please familiarise yourself with the content in conjunction with the User Guide. The Interview sheet will help you introduce the study to participants before conducting the interview.

Interview documentation and candidate rating is to be completed during or shortly after each interview. **Please email the interview audio-recording and corresponding documentation as you complete each interview to amanda.pomery@pcfa.org.au.**

Once you have **completed a total of four interviews** with support group leaders, **please complete and return the feedback questionnaire to amanda.pomery@pcfa.org.au**.

In order for your valuable feedback to be used for the main piloting study, it would be really appreciated if you could complete all interviews and feedback by **Tuesday 31st May 2016**.

Please feel free to contact me on 03 9948 2078, if you have any questions.

Thanks again in advance for your time and contributions.

Kind regards,

Appendix 15 Pilot Study Proposed Structured Interview

Question 1: I'm interested to hear what you think a support group leader does? Are there any limits to the support given in the role?	
Suggested probes	Can you think of some activities that would be outside the scope of a group leader? Can you tell me more? Can you give me some examples?
Score	**Examples of responses**
2	• Able to describe and explain the role of a support group leader • Provides examples relating to group management and group process • Demonstrates awareness of key elements of the role such as being empathic, supportive, respectful • Understands the importance of confidentiality • Confirms there are limits to support given, with awareness of maintaining boundaries • Provides examples of when they would say no to giving support due to it being outside the role
1	• Displays an adequate though not comprehensive number of the above or other appropriate responses (e.g. two to three of the responses listed for a score of '2') • Understands there are limits to support given, with awareness of maintaining boundaries
0	• Unable to provide a basic effective response (e.g. one or none of the responses listed for a score of '2') • Unable to understand there are limits to the role or unwilling to maintain personal boundaries

Notes:

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Score:.....

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Question 2: The role of a cancer support group leader requires a time commitment and the capacity to be the primary point of contact for the group. Can you explain how you will fit the role in around your other commitments?	
Suggested probes	Can you give me an example? Can you give me an example of how you manage your time? How will your other activities be affected by this role?
Score	**Examples of responses**
2	• Reflective and give examples of other personal, work or volunteer commitments • Explains how they will be available and willing to give sufficient time to the role • Confirms being committed to undertaking the role on an ongoing basis • Provides examples of how they will fit the role in around other commitments
1	• Indicates availability to allocate time to the role but provides no examples of current commitments or explains how they will be available • Indicates willingness but limited commitment or time to undertake the role • Acknowledges time required for the role and indicates desire to reflect on ability to meet this commitment
0	• Current commitments mean insufficient time to allocate to the role • Unable to commit to the role and group

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Question 3: Can you give an example of planning and organising a group activity (either in a work, volunteer or social capacity)? What did you do and what was the outcome?	
Suggested probes	What was your experience of planning the event like? Can you tell me more about this and what you liked and didn't like about it?
Score	**Examples of responses**
2	• Provides an example of a group activity they were responsible for planning and organising • Describes how the activity was accomplished with a positive outcome
1	• Provides an example of an activity they helped plan or organised that had mixed outcome
0	• Unable to give an example of an activity involving planning or organising

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Question 4: Describe a time when you were responsible for resolving a conflict or difference of opinion amongst a group of people. How did you react to the situation? Was the situation resolved and if so how?	
Suggested probes	What did you do? Can you tell me more about that? How did you feel during the event?
Score	**Examples of responses**
2	• Provides an example of a group conflict, conveying awareness of people's alternative opinions, beliefs and/or views • Describes reacting to the situation in which they intervened • Describes attempting to calm others • Describes a resolution (where possible) to the situation that was supportive and respectful to all parties
1	• Provides an example of group conflict • Describes reacting to the situation with a desire or intention to intervene • Describes partial resolution to the situation
0	• Unable to give an example of a group conflict • Unable to convey ability or awareness to intervene • Conflict was not handled well • Conveys little or no flexibility in approaching situation

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Question 5(a): In a group meeting, how would you show support to someone who has received some bad news?	
Suggested probes	Can you give me some more examples? What do you think is the most important thing to do to support someone who has received some bad news?
Score	**Examples of responses**
2	• Demonstrate awareness and ability to be empathic, sensitive to others' needs, and supportive in approach • Awareness of the impact one member's distress may have on other group members and looks to support the group as a whole
1	• Conveys ability to be empathic, sensitive or supportive in their approach • Understands the impact one member's distress may have on other group members
0	• Unable to give an example of how they would support others or provides examples that would be unhelpful • Unaware of possible impact on the group as a whole

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Question 5(b): How comfortable would you be receiving support from others? How would you seek support from others during difficult times?	
Suggested probes	Can you give me some more examples?
Score	**Examples of responses**
2	• Demonstrates awareness of their own need for support and willingness to receive support from others
1	• Conveys willingness to receive support from others
0	• Unaware of own potential need for support and unwilling to receive support from others

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Question 6: Can you explain how you prefer to get tasks done when working with others? What approach do you take?	
Suggested probes	Can you give me some examples? How would you describe your leadership style?
Score	**Examples of responses**
2	• Provides opportunity and encourages others to be involved • Shares responsibility with key individual, if relevant (e.g. co-leader, second in charge, nominated support person) • Awareness of people's interests, abilities and strengths in delegation of tasks • Takes a lead role in organising practical tasks
1	• Demonstrates capacity to take a lead role in organising practical tasks • Encourages others to be involved, but may not provide opportunity • Conveys desire to delegate tasks and responsibilities but unsure how to go about it
0	• Unaware of involving others in completing tasks • Unable to explain how they would approach task completion

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Question 7(a): How would you find out what the needs of the group are?	
Suggested probes	Can you give me some examples?
Score	**Examples of responses**
2	• Provides opportunity for members to talk about their needs • Encourages member sharing and involvement with how the group is run • Provides examples of how to obtain feedback • Describes listening to members of the group • Awareness to separate out own needs and maintain a group focus
1	• Obtains feedback by listening to members talk about their needs • Encourages members sharing
0	• Unable to explain how they would find out about the needs of the group

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Question 7(b): How would you react if group members asked for something different to what was being provided?	
Suggested probes	Can you give me some examples?
Score	**Examples of responses**
2	• Actively facilitates opportunities to receiving feedback, criticism and/or complaints • Responsive to the feedback of the group
1	• Willing to receive criticism and/or complaints • Acknowledges feedback from the group
0	• Unwilling to receive criticism and/or complaints • Assumes or dictates what the needs are without seeking further clarification or information

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Question 8: What is your understanding of confidentiality as it relates to a support group?	
Suggested probes	Why do you think confidentiality is important? What do you think that means for you personally and for the group members?
Score	**Examples of responses**
2	• Demonstrates clear understanding regarding the importance of confidentiality in a group setting and its members • Awareness of the sensitive content or nature of the support group • Refers to the group's rules/code of conduct/agreement • Recognises discussions held in the group meeting are private • Considers confidentiality of group members beyond the group meeting itself (e.g. newsletters, website, Facebook, conversations with others outside of group)
1	• Conveys understanding regarding the importance of confidentiality in a group setting • Recognises discussions held in the group meeting are private, but unable to provide examples of how confidentiality is maintained beyond the meeting
0	• Unable to demonstrate importance of confidentiality • Unable to provide examples of how confidentiality may be maintained

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Question 9: If you were to attend a support group meeting for the first time, what do you think or believe would make it a welcoming space? What could a group leader do to assist?	
Suggested probes	What practical or emotionally supportive examples can you give?
Score	**Examples of responses**
2	• Provide a safe and confidential environment • Foster a sense of belonging • Provide opportunities for members to talk and listen to others • Able to receive support • Welcome and accept new members into the group • Assist in the introduction of members • Include the welcome of members in the group process/management
1	• Understands basic concept of welcoming and introducing others to the group • Conveys sense of group being a safe space • Able to provide some examples of a welcoming space but limited knowledge of strategies group leaders could take
0	• Unable to provide examples of a welcoming space or approaches a group leader could take • Places responsibility onto the new member to fit in with the group

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Question 10: Members of a support group can have varying backgrounds, needs, beliefs and views. How might you go about supporting members that are different to you?	
Suggested probes	What types of things do you think will vary between members?
Score	**Examples of responses**
2	• Demonstrates awareness of how members can be different to themselves and/or other members • Provides examples of how members can be different (e.g. culture, age, gender, financial backgrounds, sexuality, support needs, stage of illness, beliefs, values, views) • Conveys awareness to not assume the needs of members, but identify member's needs as they relate to their individual circumstances • Able to separate own needs from those of others • Role models respect for others • Role models acceptance of difference to others • Mindful to spend time welcoming, fostering sense of belonging and listening to others
1	• As an individual demonstrates respect for others • Conveys acceptance of difference to others • Willingness to support those different to themselves
0	• Unable to acknowledge potential differences amongst group members • Unwilling to support those different to themselves • Places responsibility onto the member to conform or restrict support offered in the group to align with their own needs

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Question 11: If assistance for the role were available, would you be willing and available to access support either now or into the future?	
Suggested probes	How would you describe the value, if any, of ongoing support and training for people leading groups?
Score	**Examples of responses**
2	• Recognises the importance of continuous learning and accessing assistance when needed • Confirms willingness to undertake assistance available • Confirms commitment to ongoing development • Confirms availability to access assistance
1	• Understands benefits to additional skill or knowledge development • Conveys willingness to undertake assistance available • Expresses limited availability to access assistance
0	• Has the view they have nothing more to learn • Unwilling to undertake assistance either now or into the future • Unable to commit time to accessing assistance

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Scenario 1: Suppose in a group meeting, a member starts complaining about a health professional. The member becomes quite angry, states the doctor's name, how they believe they are no good, and tells everyone that they shouldn't see them for treatment. The group has a standing agreement that everyone is respectful of one another. Describe how you would handle the situation.	
Suggested probes	What kind of actions or strategies do you think would be helpful in this situation?"
Score	**Examples of responses**
2	• Awareness of group dynamics and reactions of members • Intervene to maintain respectful dialogue about others • Listen to and acknowledge member's experience, views and beliefs • Look for opportunity to positively reframe and guide discussion • Maintain group focus, reinforce what the purpose of the group is and what support is possible • Refer to group agreement or standards • Demonstrate empathy, genuine care, and sensitivity • Remain calm • Positively reinforce respect to others includes doctors • Provide opportunity for other members to talk and share • Identify member's support needs and possible referral to assistance outside of group • Check in with person separately afterwards to clarify or reinforce any strategies applied
1	• Display an adequate though not comprehensive number of the above or other effective responses (e.g. two to six of the responses listed for a score of '2')
0	• Unable to provide a basic effective response (e.g. one or none of the responses listed for a score of '2')

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Scenario 2: Suppose in a meeting, a member wants to talk about his daughter's mental health and financial problems. The member explains how it's been really hard on the family and asks if the group could host a fundraiser to help. The support group is specifically for people impacted by cancer, with the main focus on providing support to each other and sharing information about cancer. The group has not been involved in other events or fundraisers. Describe how you would handle the situation.	
Suggested probes	What kind of actions or strategies do you think would be helpful in this situation?
Score	**Examples of responses**
2	• Listen to and acknowledge member's experience and request for help • Maintain group focus, reinforce what the purpose of the group is and what support is possible • Role model respect and confidentiality towards member's situation • Facilitate, guide and summarise discussion for members • Refer to group agreement or standards • Acknowledge limitations of the group and how the group is unable to provide support to all people for all things • Maintain group cohesion • Obtain feedback from the group • Problem solve, provide opportunity for individuals to assist if they choose rather than have the group as a whole commit • Refer members to other more appropriate community supports • Demonstrate empathy, genuine care and sensitivity
1	• Display an adequate though not comprehensive number of the above or other effective responses (e.g. two to five of the responses listed for a score of '2')
0	• Unable to provide a basic effective response (e.g. one or none of the responses listed for a score of '2')

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Question 12: In order to support others, it can be helpful for group leaders to look after themselves mentally and physically. Is there anything you need to consider that would impact on your ability to undertake the role?	
Suggested probes	Do you have any strategies for looking after yourself? Can you tell me more about that? Can you give some examples?
Score	**Examples of responses**
2	• Reflective and articulates awareness of own circumstances, physical health and wellbeing • Conveys a sense of balance to their life • Has established own personal support network • Able to be organised, planning ahead or prioritise commitments • Takes time out • Diet, exercise and relaxation strategies • Back up plans and/or co-leaders to assist with coverage
1	• Disclosed personal physical or mental health issues that are currently being managed • Display an adequate though not comprehensive number of the above self-care strategies or other appropriate responses (e.g. two to three of the responses listed for a score of '2')
0	• Disclosed physical or mental health issues that would significantly impact on their ability to function in the role • Unable to identify any self-care strategies

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Question 13: Reflecting on our conversation, overall do you think you are capable and ready to undertake the role of group leader?	
Suggested probes	What knowledge or skills do you think you might need to develop further in order to be ready for the role? Would you like some more time to think about your response and get back to me?
Score	**Examples of responses**
2	• Demonstrates awareness of the role and knowledge, skills and attributes required of them to undertake role • Awareness to separate own personal desire or needs to be a group leader in order for the group to be led by a suitable person • Objectively determines (based on previous responses or experience) they are capable and ready to undertake role • Acknowledges own capacity for growth and development
1	• Determines they are capable to undertake role with assistance to support them become ready
0	• Determines they are currently not ready to undertake the role • Determines the role does not suit them or their circumstances

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Interviewer observations: Indicate if any of the following attributes were observed at any time throughout the interaction with the candidate.		
Attribute	**Observed**	**Not observed**
Respectful of the process, your role, and/or the organisation you represent		
Listened		
Patient		
Followed through on what they said they would do (before, during and/or after conversation)		
Provided objective responses		
Mentally present		
Approachable manner		
Calm		
Non-authoritarian approach		
Genuineness		

Score	Interviewer observations
2	Observed more than two attributes listed above
1	Observed two attributes listed above
0	Did not observe any of the attributes listed above

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Scoring Table

Category	Question or Scenario	Knowledge, skill and/or attribute development area(s) assessed	Scores
Suitability	2	Availability and commitment	
	11	Openness for role development	
	12	Self-care	
	13	Self-assessment	
	Interviewer observations	Personal attributes	
		Total score	
Readiness	1	Role knowledge	
	3	Planning and delegating	
	4	Conflict resolution	
	5(a)	Giving support	
	5(b)	Receiving support	
	6	Working with others	
	7(a)	Group needs	
	7(b)	Managing criticism	
	8	Confidentiality	
	9	Welcoming new members	
	10	Accepting difference	
	Scenario 1	Respectful group interactions	
	Scenario 2	Group purpose and agreement	
		Total score	

Rating Table

Category	Rating	Definition
Suitability	Highly Suitable	Candidate has the desirable knowledge, skills and attributes to be a suitable fit for the group leader role
	Suitable	Candidate has the required knowledge, skills and attributes to be a suitable fit for the group leader role
	Not Currently Suitable	Candidate does not currently have the required knowledge, skills and attributes to be a suitable fit for the group leader role
	Candidate determined to be	
Readiness	Ready	Candidate is ready to undertake the role of support group leader independently
	Ready with Support	Candidate is ready to undertake the role of support group leader but requires some support to develop certain knowledge, skills and attributes
	Not yet Ready	Candidate is not yet ready to undertake the role without support
	Candidate determined to be	

Appendix 16 Pilot Study Proposed User Manual

Prostate Cancer Foundation of Australia

THE UNIVERSITY OF MELBOURNE

A Planned Conversation

User Guide

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Overview

Cancer support groups are considered to be a valuable and cost-effective means of delivering support in the community. Leadership of these groups is often voluntary and mostly delivered by people with a lived experience of cancer. The role of the group leader, however, requires commitment and comes with responsibilities and challenges; these may include possible risks to group members or the leaders themselves. Guided selection and development of group leaders, therefore, is needed to ensure the sustainability of groups and the quality of support received by group members.

An evidence-based and pragmatic approach was used to develop minimum standards for selection and development of cancer support group leaders. The standards provide a consistent framework for agencies who work with groups seeking legitimacy, funding or support. They reflect the complexity of the role and the diverse knowledge, skills and attributes that leaders may require. Critically, the standards can help identify development and support needs of current and prospective group leaders, so that they may receive targeted and individualised assistance as required. The standards were used to create a structured interview called *A Planned Conversation* for this purpose.

Purpose of this User Guide

This user guide provides practical information relevant to *A Planned Conversation*; this will optimise clear and consistent application of the standards. The guide outlines: why interviews should have structure; the structure and content of *A Planned Conversation;* how to conduct the interview; and how to score responses to the questions comprising *A Planned Conversation*. Please note, this guide and interview was designed to promote minimum standards in support group leadership. Therefore, it is important to consider any additional or specific requirements relevant to your agency.

Why Use an Interview?

Agencies assisting in the selection of group leaders need to identify people possessing characteristics required for the role. Interviews are an effective way of determining who has these attributes and, therefore, who is suitable and ready for the role. The approach of an interview is preferred, as it is more personal than traditional selection procedures (e.g., written tests) and because it can be used to evaluate characteristics like interpersonal skills that are not easily assessed using other approaches. This is particularly important when dealing with a population with varied education and literacy levels.

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Structured versus Unstructured

Interviews can be structured or unstructured. A structured interview uses multiple elements to facilitate the process of recruiting candidates that is systematic and role-related. Structured interviews are twice as effective as unstructured interviews in predicting job performance (Wiesner & Cronshaw, 1988). Structured interviews ensure that each candidate has an equal opportunity to provide information and be assessed in an accurate, consistent and fair manner. Unstructured interviews, where interviewers rely on unaided judgement, are subject to bias and may expose both parties to future complaints or challenges. The benefits of consistently selecting quality candidates and reducing the risk of complaints far outweigh any costs of adding structure (e.g., additional time and expertise needed to assess potential candidates).

A Planned Conversation

As support groups often are independent, community-based and volunteer-led, the language used throughout is less formal, non-authoritative or non-intimidating, the intent being to encourage positive engagement. Further, the term structured interview has been replaced with the phrase *A Planned Conversation*. While the conversation may be conducted by a single interviewer over the phone, a face-to-face meeting is preferred, as is a two-person panel. A two-person panel provides a useful means of cross-checking responses and observations. Ideally, the panel should include an agency representative who has a direct role with the group. An experienced support group leader may also serve as a member of the two-person panel.

The elements of *A Planned Conversation* include:

1. Core questions relevant to role (ensures evidence-based framework)
2. Effective questions and prompts (evokes responses that aid decision-making)
3. Standardised questions (ensures fairness and impartiality)
4. Anchored rating scale (helps quantify subjective data)
5. User Guide to support interviewers (ensures consistency is maintained across staff and organisations)
6. Where possible utilisation of a panel of two interviewers (provides checks and balances to ensure fairness and impartiality)
7. Note taking (increase accuracy of recall and provide a record)
8. Objective assessment of responses (de-personalises decision outcomes)

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Role Analysis

Knowledge, skills and attributes (KSA) for the role of a support group leader were identified and analysed through a systematic review of the literature (Pomery et al, 2015). Consultation with experts in the field provided agreement on requisite qualities for the role and are outlined in Appendix 1. The questions contained in *A Planned Conversation* are designed to indicate if a candidate has the qualities required for the role. Past performance is one of the best predictors of future performance. As many candidates would not have led a cancer support group before, behavioural-based questions have been developed, where possible, to a apply candidate's life experiences to the role.

Anchored Responses

An interdisciplinary panel of experts helped develop a pragmatic method for scoring interviewer observations. In this case, experts helped to determine examples of responses indicative of comprehensive, adequate and insufficient responses to each question and scenario comprising *A Planned Conversation*. In every case, responses reflect knowledge, skills and attributes to be assessed by each question and scenario. Interviewees need not use exactly the same words provided in the examples of responses; examples should simply act as a guide for scoring interviewee responses. Additionally, candidates are not required to provide all examples of responses listed in order to obtain a score of '2'.

Rating Scale

A simple 3-point rating scale ranging from 0 to 2 is used to evaluate candidates' responses. Ratings are interpreted as follows:

0 = Insufficient response

1= Adequate response

2= Comprehensive response

A rating scale for each attribute listed under 'Interviewer observations' was not developed. Instead candidate attributes are recorded as either observed or not observed during the interview process.

Scoring Responses

Evaluate and score questions, scenarios and interviewer observations against available benchmarks; once complete, transfer scores to the scoring table. The Scoring Table was designed to simplify the process of calculating scores on two scales: *Suitability for role* and *Readiness for role*. Scoring is best done immediately after the conversation, when the details

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are fresh in your mind; allow an additional 15 minutes at the end of each conversation for this purpose.

If applicable complete the Scoring Table and discuss with the other panel member; the aim is to reach consensus on *Suitability* and *Readiness* ratings as described in the following sections. If ratings vary between panel members, discuss reasons with the aim of reaching agreement to make the overall final decision. If this is not possible then average the scores and determine the outcome based on combined results.

Category 1: Suitability

Note: a scoring matrix will be developed based on results from the second stage of piloting. For this first stage, please indicate the rating you think best describes the candidate's suitability.

The Suitability scale indicates the level of suitability the candidate has for the role of support group.

Circumstances that render the person not suitable, may not be permanent or ongoing. In such cases, an invitation may be extended to re-discuss the role at a later or more suitable stage.

Rating	Definition
Highly Suitable	Candidate has the desirable knowledge, skills and attributes to be a suitable fit for the group leader role
Suitable	Candidate has the required knowledge, skills and attributes to be a suitable fit for the group leader role
Not Currently Suitable	Candidate does not currently have the required knowledge, skills and attributes to be a suitable fit for the group leader role

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Category 2: Readiness

Please note the second phase of piloting will determine the score ranges for each rating. For this first stage, please indicate the rating you think best describes the candidate's readiness.

The Readiness scale indicates the level of skill, knowledge and attribute (KSA) development the candidate has for the role currently. This category reflects the expectation that those presenting for the role are most likely volunteering and may not necessary have direct previous experience.

Rating	Definition
Ready	Candidate is ready to undertake the role of support group leader independently
Ready with Support	Candidate is ready to undertake the role of support group leader but requires some support to develop certain knowledge, skills and attributes *
Not yet Ready	Candidate is not yet ready to undertake the role without support **

*It is recommended that support be targeted to areas identified in the scoring table. Consider what support your agency can offer to assist, such as training modules, resources or peer mentoring.

** Circumstances that render the person not ready may not be permanent or ongoing. In such cases, an invitation may be extended to re-discuss the role at a later or more suitable stage or to undertake minimum training and support prior to beginning the role.

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During A Planned Conversation

Provide background

Try to create a relaxed atmosphere and build rapport with the person as much as possible. Start with breaking the ice over general conversation about the weather etc. If conducting the conversation in person offer them a glass of water/tea/coffee. Begin the Planned Conversation with a brief description of the role of support group leader, the cancer agency and its relationship to the support group, along with information about the group if known.

Provide the person with an overview of the conversation format. For instance, tell the person that a series of questions will be asked in order to open up the conversation and explore together whether the role is a good fit for them. The process is designed to; clarify any questions, identify the knowledge, skills and attributes they have relevant to the role, if they are ready to undertake the role, along with what supports might be of benefit to decrease the risk of the role impacting negatively on them. The aim is also to allow the person to reflect for themselves if this is a role they want and are able to take on. Explain to the candidate that notes will be taken during the conversation, with it normally taking up to an hour.

Interview Do's

Show respect for the candidate at all times, particular as they may be volunteering their time. Many undertake the role in their own time and have a strong personal interest or experience that has lead them to becoming involved in a support group. Ask open-ended questions and allow the candidate to do most of the talking (don't talk more than 20% of the time). Listen carefully to what the candidate says, respond when necessary, and maintain control of the interview.

Use probes

Probes are phrases used to follow-up open-ended questions that encourage a person to reveal more information. Examples include: *What did you do? What did you think about or want? Can you tell me more? Who was involved and how did you contribute? What was the outcome?* Suggested probes have been provided for each question for the interviewer to use at their own discretion and as required.

Take Notes

Notes serve two purposes. Firstly, they help you capture the content of the conversation rather than relying on memory. Secondly, notes help to create a record which may be helpful for delivery of support services to the leader and checking-in with them regarding their development in the role. Notes should reflect content of what was said and observations. For

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convenience and completeness of records, space has been provided for taking notes after each question.

Closing the interview

Give the person time at the end of the conversation to ask you/or the panel questions and reflect on the information exchanged. Let them know what the next steps in the process will be and your expected timeframe. Importantly thank them for their time and interest.

Training and Development

In the scoring table, questions and corresponding key KSAs have been specifically outlined to identify target areas for development that may be provided to the candidate. Training and support may be provided to the candidate before proceeding in order for them to be ready for the role, or accessed on an ongoing basis whilst undertaking the role. For example, a score of 0 for Question 9 would indicate a need for accessing information, support or training on welcoming new members to the group. It will therefore be important to identify what assistance and access to resources can be offered by the organisation.

The Planned Conversation can be undertaken again as a way of checking in with the group leader, consolidating learning for the leader and assisting the organisation in delivery of tailored support where required.

Important reminder

Australian Commonwealth Government and the state and territory governments have introduced laws to help protect people from discrimination and harassment. Please refer to https://www.humanrights.gov.au/employers/good-practice-good-business-factsheets/quick-guide-australian-discrimination-laws for further information. All questions contained in the Planned Conversation comply with the current obligations to prevent discrimination in the selection process. Interviewers are asked to;

1. Educate those involved in the recruitment process about the obligations,
2. Cast the net as wide as possible to attract a diverse pool of people,
3. Be consistent and fair in the way you treat people,
4. Accommodate people who require adjustments,
5. Do not seek irrelevant personal information,
6. Focus on the essential requirements for the role,
7. Set aside personal bias/myths and stereotypes,
8. Keep records of your decisions.

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Appendix 1

Knowledge, skills and attributes identified as required to be ready to undertake the role of a cancer support group leader

Quality	Knowledge, skills and attributes
Group Management	Capacity to be primary point of contact Planning of group meeting
Group Process	Identify group needs Maintain confidentiality Intervene with management of issues/challenging members Foster a welcoming space Encourage member sharing, involvement and support Facilitating, guiding and summarising discussion Work effectively with co-leader/s Maintain respectful dialogue and interaction with/about others Promote group cohesion and trust Manage alternative views/beliefs/opinions Welcome and introduce new members Clarify their leader role with/to group members
Role Modelling	Listening Support Communication skills Acceptance of difference Commitment to the group Empathy Acknowledging limitations of self and the group Respect for others Operate within standards set by the group Self-care and care of other members Maintaining boundaries Remaining calm
Awareness	Separate own needs from the groups Maintaining own mental and physical health Being mentally present Own self-care Recognise when support/de-briefing is needed
Willingness	Give and receive support Availability of time to give Commitment to the group Receive and manage criticism/complaints Maintain boundaries

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Quality	Knowledge, skills and attributes
Agreeableness	Sensitive
	Supportive
	Honest
	Integrity
	Empathic
	Non-authoritarian
	Approachable
	Trustworthy
	Inclusive
	Responsive
	Respectful
	Ethical
	Patient
	Genuine
Openness	Capable
	Objective
	Motivated
	Accepting

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Appendix 17 Pilot Study Interview Script

Pilot study: Usability and acceptability
Interview Script

Date:
Interviewer:
PID:
Time taken to complete interview:

Introduce self and role.

Thank you for agreeing to participate in this project "Improving the quality of care provided to people with cancer via support groups: establishing evidence-based practice for group leaders". The information gathered in this pilot study will be used to check the usability and acceptability of the newly developed structured interview. The interview has been developed to guide the selection and development of future group leaders.

Just a reminder, this project is being conducted by Amanda Pomery, a PhD student through Sir Peter MacCallum Department of Oncology, at the University of Melbourne. Results will be shared with others at conferences and via peer-reviewed papers. They will also be published as part of Amanda's PhD thesis. All information will be de-identified and your anonymity/confidentiality will be protected.

Also, I need to remind you that participation in the study is not mandatory and whether or not you choose to participate is entirely voluntary and will in no way affect your relationship with PCFA/BCNA/Cancer Council or how we work with you. Also, it will not affect your relationship with the University of Melbourne. Through the course of our discussion, if any key discussion points come up, I'll ask that we make a note of them and hold off discussing them until after we complete the questionnaire. Once completed, we can take the time needed, or schedule another time to talk through any issues.

Do you have any questions? (Note these questions)

_____

_____

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_____

Can I switch on the recording device? Yes No (If no, please note why not)

_____

_____

_____

_____

Any additional comments about the interview?

_____

_____

_____

_____

Appendix 18 Pilot Study Clinical Utility Feedback

Pilot study: Usability and acceptability feedback

The purpose of this pilot study is to determine how potential users (e.g. cancer agency workers) judge the usefulness, benefits and drawbacks of a newly developed structured interview, referred to as *A Planned Conversation*. Feedback will be used to refine and improve *A Planned Conversation* before embarking on the main study to finalise the scoring model.

1) Conducting the Structured Interviews

You will need to identify and invite four current support group leaders from your agency's support group network to take part in a telephone interview. If possible, choose leaders with different skill sets/levels and be sure to emphasise the fact that their participation is voluntary. Before participating, please give leaders an opportunity to read the *Plain Language Statement* in full and have them sign the *Consent Form*. *A Planned Conversation* consists of 13 questions and 2 scenarios designed to elicit information bearing on a candidate's suitability and readiness for the support group leader role. The interview will take approximately 45 minutes to complete.

Please read the *User Guide* and familiarise yourself with *A Planned Conversation* interview schedule and the standard form for documenting the interview. The interview is to be audio-taped and responses noted by you the interviewer. Please refer to the Interview Sheet to begin each interview. Document and rate the support group leader's responses using the standard form.

2) Providing your feedback

You will be asked to provide feedback on the structured interviews. Feedback on all four interviews will be obtained through a brief questionnaire and a semi-structured interview.

- The **questionnaire** consists of 15 questions covering four components of clinical utility as defined by Smart (2006). You will need to respond to these questions using a 5 point Likert-type scale ranging from strongly agree to strongly disagree. Please indicate your response by placing an X in the appropriate column, with there being no right or wrong answers. The questionnaire is expected to take approximately 5 minutes to complete.
- The **semi-structured interview** consists of open-ended questions on your experience of using the structured interview, in order to provide more detailed or specific feedback. Again there are no right or wrong answers, with your honest feedback welcomed. The semi-structured interview is expected to take approximately 15 minutes to complete.

Component	Statement	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
Appropriate	The structured interview and user guide helped me determine the candidates suitability for the role					
	Using *A Planned Conversation* and User Guide enabled me to determine the candidates' readiness to undertake the role					
	The structured interview and user guide will help standardise the selection and development of support group leaders					
Accessible	The time taken to conduct the structured interview was manageable					
	Current resources are adequate to fully support the use of *A Planned Conversation* within my agency					
	A Planned Conversation can be integrated into my role's procedures and practices					
Practicable	The user guide supports the use of *A Planned Conversation*					
	The structure of *A Planned Conversation* is sensible and workable					
	The scoring table is suitable and easy to use					
	A Planned Conversation was appropriately pitched for my level of experience and knowledge					
Acceptable	I would use *A Planned Conversation* in my current role					
	I would recommend *A Planned Conversation* to another cancer agency worker					
	The language and questions were comprehensible to the candidates					
	The structure and format of the interview was acceptable to the candidates					
	The use of *A Planned Conversation* would be acceptable to the various stakeholders relevant to my role					

Appendix 19 Pilot Study Clinical Utility Semi-structured Interview

Pilot study: Usability and acceptability feedback

Semi-structured interview

Participant background

- Can you tell me a bit about your professional background?
- What is the highest degree or qualification you have completed?
- How long have you been working with support group leaders?
- How is your current role involved in the selection &/or development of group leaders?

Feedback

- How did you find the structured interview (A Planned Conversation)?
    - What worked well? What didn't work well?
- How did you find the *User Guide*?
    - What worked well? What didn't work well?
- Are there any aspects you were confused or uncertain about?
- From your perspective how did the support group leaders find *A Planned Conversation*?
- From your perspective what possible benefits are there to using *A Planned Conversation*?
- What might be some challenges (or barriers) to using *A Planned Conversation* in your role?
- How could *A Planned Conversation* be improved?
- What (if any) additional information, support or resources would be helpful for those conducting *A Planned Conversation*?
- Any further comments, suggestions or feedback you want to share?

Appendix 20 Field Test Participant Plain Language Statement

Prostate Cancer Foundation of Australia

THE UNIVERSITY OF MELBOURNE

Melbourne School of Psychological Sciences

Plain Language Statement

Project: Improving the quality of care provided to people with cancer via support groups: Establishing evidence-based practice for group leaders.

A/Prof Penelope Schofield (Principle Researcher/Supervisor)
Tel: 03 9656 3560; email: penelope.schofield@petermac.org.au
Ms Amanda Pomery (PhD student)
Tel: 03 9948 2078; email: amanda.pomery@pcfa.org.au
Dr Karla Gough (Co-Researcher/Supervisor)
Tel: 03 9656 5205; email: karla.gough@petermac.org.au
A/Prof Miranda Xhilaga (Co-Researcher/Supervisor)
Tel: 03 9948 2072; email: miranda.xhilaga@pcfa.org.au

You are being invited to take part in a research study. Before you decide, it is important for you to know why the research is being done and what it will involve. Please read the following information carefully and feel free to ask if anything is not clear to you or if you would like any further information to decide if you wish to join this study.

1. What is the study about?

The study is about developing a practical and consistent way for group leaders to be chosen, and to work out areas of opportunity for development in leading a support group. The aim of this study is to work out if a newly developed structured interview is a good tool to use, and provide a snapshot of current leaders of prostate and breast cancer support groups. Ultimately, it is hoped this research will positively contribute to the quality of group support provided to those affected by cancer.

2. What does the study involve?

During the phone interview you will be asked set questions about your role as a support group leader and any needs you may have. Your responses will be noted by the interviewer. Over 300 prostate and breast cancer support group leaders across Australia have been invited to participate in this study.

If you decide you would like to participate, please complete, sign and return the consent form. Enclosed reply paid forms are to be sent Attention: Amanda Pomery Prostate Cancer Foundation of Australia Level 5, 437 St Kilda Road, Melbourne VIC 3004 or scanned and emailed to amanda.pomery@pcfa.org.au.

Once the consent form has been received, we can then arrange an interview time for you. Interviews will be done over the phone, on a day and at a time that suits you. The telephone interview will take about 30 minutes of your time.

HREC Number: 1443027.2
Version Number:2 Date:4 August 2016

3. Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with the researcher(s), The University of Melbourne, or the Prostate Cancer Foundation of Australia (PCFA), Breast Cancer Network of Australia (BCNA) or Cancer Council.

You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study. If you wish to withdraw, please notify the researcher, Amanda Pomery.

4. Will anyone else know the results?

The information you provide will be strictly confidential but subject to legal limitations, and only the named researchers will have access to your information. Information you provide will be coded and kept in a locked filling cabinet. Any stored electronic data files will be protected by password. Write up of results will be submitted to journals for publication and part of a PhD thesis. Where possible, presentations on the project will be delivered to key stakeholders and at professional conferences. As a part of publication and presentations, no identifying information will be presented.

All information will be handled and stored in accordance with the requirements of University of Melbourne Policy on the Management of Research Data and Records is available at: http://www.unimelb.edu.au/records/research.html. All information will be destroyed after 5 years of the research being conducted as stated in the University Of Melbourne Code Of *Conduct for Research*.

5. Will I be able to access the information obtained about me?

In accordance with relevant Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform Amanda Pomery if you would like to access your information.

6. Will the study benefit me?

We hope to use the information from this study to develop a practical and consistent way to guide group leadership into the future, with the focus on building quality supportive care to those people affected by cancer. We cannot and do not guarantee or promise that you will receive any benefits from the study.

7. What are the risks?

With any research project, it is highly unlikely that there are no known risks. You may possibly feel that some of the questions in the discussion are stressful or upsetting. If you become upset or distressed, please let a member of the research team know. If a member of the research team is worried about you, they may put you in contact with a health professional. Alternatively you can also contact counselling services such as LifeLine (13 11

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14), beyondblue (1300 22 4636) or Cancer Council Helpline (13 11 20). You may also experience inconvenience due to the time it takes to complete the telephone (approximately 30 minutes).

8. Can I tell other people about the study?

You can tell other people about your participation in this study and are free to pass on the contact details for Amanda Pomery (amanda.pomery@pcfa.org.au or 03 9948 2078) should other group leaders want to know more about the study. Potential participants who are current group leaders can then be sent an invitation for their consideration.

9. Who is conducting the research?

The study is being conducted by Amanda Pomery, PhD student at The University of Melbourne and in association with the Prostate Cancer Foundation of Australia (PCFA), Breast Cancer Network of Australia (BCNA), and Cancer Councils. The research is sponsored by PCFA. Supervisors and co-researchers are listed below.

Associate Professor Penelope Schofield, Principal Researcher, Director of Department of Cancer Experiences Research, Peter MacCallum Cancer Centre;

Dr Karla Gough, Co-Researcher, Head of Applied Statistics Cancer Experiences Research, Peter MacCallum Cancer Centre;

Associate Professor Miranda Xhilaga, Co-Researcher, Director of Research Programs, Prostate Cancer Foundation of Australia.

10. Who has reviewed this study?

The study has been approved by the Psychological Sciences Human Research Ethics Committee (HREC 1443027.1). If you have any concerns about this project please contact the Executive Officer, Human Research Ethics, The University of Melbourne (ph: 03 8344 2073; fax: 03 9347 6739).

11. Further information

If you wish to contact someone for further information regarding this study or your involvement please contact; Amanda Pomery on amanda.pomery@pcfa.org.au or 03 9948 2078.

THANK YOU

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Appendix 21 Field Test Participant Consent Form

Prostate Cancer Foundation of Australia

THE UNIVERSITY OF MELBOURNE

Melbourne School of Psychological Sciences

Consent form for persons participating in a research project

Project Title: Improving the quality of care provided to people with cancer via support groups: establishing evidence-based practice for group leaders.

Name of Participant:

Name of Primary Researcher: A/Prof Penelope Schofield
Name of Additional Researchers: Ms. Amanda Pomery (PhD student), Dr Karla Gough (Co-Researcher/Supervisor), A/Prof Miranda Xhilaga (Co-Research/Supervisor).
Sponsor: Prostate Cancer Foundation of Australia

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.
2. I understand that the project is for the purpose of research.
3. I understand that my participation will involve an ***interview*** and I agree that the researcher may use the results as described in the plain language statement.
4. I understand that my participation is voluntary and that I am free to withdraw from the study at anytime without explanation or prejudice and to withdraw any unprocessed data I have provided. Withdrawing from the study will not affect my relationship with the researcher(s), or the University of Melbourne, or the Prostate Cancer Foundation of Australia/Breast Cancer Network of Australia/Cancer Council now or in the future.
5. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published however no information about me will be used in any way that is identifiable.
6. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.
7. I acknowledge that I have been informed that with my consent ***my responses will be noted and I understand that interview notes will be stored*** at University of Melbourne department and will be destroyed after five years;
8. I understand that after I sign and return this consent form it will be retained by the researcher.

Participant signature: Date:

PID:
HREC Number: 1443027.2
Consent Form Version 2, 4 August 2016

Appendix 22 Field Test Interview Script, Demographic Questionnaire, Structured Interview

Field testing: Interview Script

Introduce self and role.

Thank you for agreeing to participate in this project "Improving the quality of care provided to people with cancer via support groups: establishing evidence-based practice for group leaders". The information gathered will be used to provide a snap shot of existing support group leaders across breast and prostate cancer support groups in Australia, and help to validate the newly developed Structured Interview to guide the selection and development of future group leaders.

Just a reminder that this project is being conducted by Amanda Pomery, a PhD student through Sir Peter MacCallum Department of Oncology, at the University of Melbourne, to help build a strong body of evidence that can possibly be shared with the rest of the Australia and internationally through presentations and publications. The results from this project will also be published as part of a PhD thesis. All information will be de-identified and your anonymity/confidentiality will be protected.

Also, I need to remind you that participation in the study is not mandatory and whether or not you choose to participate is entirely voluntary and will in no way affect your relationship with PCFA/BCNA/Cancer Council or how we work with you and it will not affect your relationship with the University of Melbourne. Through the course of our discussion, if any key discussion points come up, I'll ask that we make a note of them and hold off discussing them until after we complete the questionnaire. Once completed, we can take the time needed, or schedule another time to talk through whatever is needed.
Have you any questions? (Note these questions)

_____
_____
_____
_____
_____

Do you have any questions or comments? (Note these questions)

_____
_____
_____
_____
_____

Office use only	*Participant ID:*	*Date received:*

Field testing: Baseline Demographics Questionnaire

Interview completed on

D	**D**	**/**	**M**	**M**	**/**	**Y**	**Y**

Interviewer:

.....

Cancer agency: .....

Total time taken for interview: .....hours/minutes

Name of group leader:

.....

Name of support group:

.....

Location of support group

Suburb: .....

State/ Territory:.....

Postcode:.....

1.	What is your sex?	☐ 0 Male ☐ 1 Female ☐ 2 Other, *please specify:* _____
2.	What is your date of birth?	☐☐ / ☐☐ / ☐☐ D D / M M / Y Y
3.	What is your postcode?	☐☐☐☐
4.	What is your country of birth?	☐ 0 Australia ☐ 1 Other, *please specify:* _____
5.	Is English your first language?	☐ 0 Yes ☐ 1 No, *please specify:* _____
6.	What is your current marital status?	☐ 0 Single / never married ☐ 1 Married / de facto ☐ 2 Separated / divorced ☐ 3 Widowed
7.	What is your current employment situation?	☐ 0 Employed *(fulltime or part time)* ☐ 1 Unemployed *(including studying, home duties)* ☐ 2 Retired
8.	What is / was your main occupation?	*Please specify:* _____

9.	What is the highest level of formal education you completed?	☐ 0 No formal schooling ☐ 1 Primary schooling ☐ 2 Secondary schooling ☐ 3 Trade / TAFE college ☐ 4 Tertiary schooling
10.	Do you have any dependants?	☐ 0 No ☐ 1 Yes *If yes, specify ages:* _____
11.	Do you feel that you have adequate social support?	☐ 0 No ☐ 1 Yes
12.	What best describes your background?	☐ 0 Diagnosed with cancer/survivor ☐ 1 Partner/carer/family member of someone diagnosed ☐ 2 Allied health professional ☐ 3 Volunteer ☐ 4 Other *Please specify:* _____
13.	How long have you been leading a support group?	*Please specify:* _____ _____ years/months approximate number of group meetings _____

14. How would you describe your training level as a group leader?	☐ 0 No formal training ☐ 1 Training session (4hrs or less) ☐ 2 1-2 day workshop ☐ 3 2-5 day training program ☐ 4 Accredited qualifications in group work or counselling ☐ 5 Other, *please specify:* _____
15. Do you have a co-leader or other members to support you in your role?	☐ 0 No ☐ 1 Yes
16. Please rate how much you agree with the statement: I am interested in accessing support for the leader role (e.g. training, on-line resources, one-to-one support)?	☐ 0 Strongly disagree ☐ 1 Disagree ☐ 2 Neither agree or disagree ☐ 3 Agree ☐ 4 Strongly agree
17. Please rate how likely you are to access support for your leader role (e.g. training, on-line resources, one-to-one support)?	☐ 0 Extremely unlikely ☐ 1 Unlikely ☐ 2 Neutral ☐ 3 Likely ☐ 4 Extremely likely

Field testing: Structured Interview

Question 1: I'm interested to hear what you think a support group leader does? Are there any limits to the support given in the role?	
Suggested probes	Can you think of some activities that would be outside the scope of a group leader? Can you tell me more? Can you give me some examples?
Score	**Examples of responses**
2	• Able to describe and explain the role of a support group leader • Provides examples relating to group management and group process • Demonstrates awareness of key elements of the role such as being empathic, supportive, respectful • Understands the importance of confidentiality • Confirms there are limits to support given, with awareness of maintaining boundaries • Provides examples of when they would say no to giving support due to it being outside the role
1	• Displays an adequate though not comprehensive number of the above or other appropriate responses (e.g. two to three of the responses listed for a score of '2') • Understands there are limits to support given, with awareness of maintaining boundaries
0	• Unable to provide a basic effective response (e.g. one or none of the responses listed for a score of '2') • Unable to understand there are limits to the role or unwilling to maintain personal boundaries

Notes:

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Score:.....

Question 2: The role of a cancer support group leader requires a time commitment and the capacity to be the primary point of contact for the group. Can you explain how you will fit the role in around your other commitments?	
Suggested probes	Can you give me an example? Can you give me an example of how you manage your time? How will your other activities be affected by this role?
Score	**Examples of responses**
2	• Reflective and give examples of other personal, work or volunteer commitments • Explains how they will be available and willing to give sufficient time to the role • Confirms being committed to undertaking the role on an ongoing basis • Provides examples of how they will fit the role in around other commitments
1	• Indicates availability to allocate time to the role but provides no examples of current commitments or explains how they will be available • Indicates willingness but limited commitment or time to undertake the role • Acknowledges time required for the role and indicates desire to reflect on ability to meet this commitment
0	• Current commitments mean insufficient time to allocate to the role • Unable to commit to the role and group

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Score:.....

Question 3: Can you give an example of planning and organising a group activity (either in a work, volunteer or social capacity)? What did you do and what was the outcome?	
Suggested probes	What was your experience of planning the event like? Can you tell me more about this and what you liked and didn't like about it?
Score	**Examples of responses**
2	• Provides an example of a group activity they were responsible for planning and organising • Describes how the activity was accomplished with a positive outcome
1	• Provides an example of an activity they helped plan or organised that had mixed outcome
0	• Unable to give an example of an activity involving planning or organising

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Score: .....

Question 4: Describe a time when you were responsible for resolving a conflict or difference of opinion amongst a group of people. How did you react to the situation? Was the situation resolved and if so how?	
Suggested probes	What did you do? Can you tell me more about that? How did you feel during the event?
Score	**Examples of responses**
2	• Provides an example of a group conflict, conveying awareness of people's alternative opinions, beliefs and/or views • Describes reacting to the situation in which they intervened • Describes attempting to calm others • Describes a resolution (where possible) to the situation that was supportive and respectful to all parties
1	• Provides an example of group conflict • Describes reacting to the situation with a desire or intention to intervene • Describes partial resolution to the situation
0	• Unable to give an example of a group conflict • Unable to convey ability or awareness to intervene • Conflict was not handled well • Conveys little or no flexibility in approaching situation

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Score: .....

Question 5(a): In a group meeting, how would you show support to someone who has received some bad news?	
Suggested probes	How would you handle the situation? Can you give me some more examples? What do you think is the most important thing to do to support someone who has received some bad news?
Score	**Examples of responses**
2	• Demonstrate awareness and ability to be empathic, sensitive to others' needs, and supportive in approach • Awareness of the impact one member's distress may have on other group members and looks to support the group as a whole
1	• Conveys ability to be empathic, sensitive or supportive in their approach • Understands the impact one member's distress may have on other group members
0	• Unable to give an example of how they would support others or provides examples that would be unhelpful • Unaware of possible impact on the group as a whole

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Score: .....

Question 5(b): How comfortable would you be receiving support from others? How would you seek support from others during difficult times?	
Suggested probes	Can you give me some more examples?
Score	**Examples of responses**
2	• Demonstrates awareness of their own need for support and willingness to receive support from others
1	• Conveys willingness to receive support from others
0	• Unaware of own potential need for support and unwilling to receive support from others

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Score:.....

Question 6: Can you explain how you prefer to get tasks done when working with others? What approach do you take?	
Suggested probes	Can you give me some examples? How would you describe your leadership style?
Score	**Examples of responses**
2	• Provides opportunity and encourages others to be involved • Shares responsibility with key individual, if relevant (e.g. co-leader, second in charge, nominated support person) • Awareness of people's interests, abilities and strengths in delegation of tasks • Takes a lead role in organising practical tasks
1	• Demonstrates capacity to take a lead role in organising practical tasks • Encourages others to be involved, but may not provide opportunity • Conveys desire to delegate tasks and responsibilities but unsure how to go about it
0	• Unaware of involving others in completing tasks • Unable to explain how they would approach task completion

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Score:.....

Question 7(a): How would you find out what the needs of the group are?	
Suggested probes	Can you give me some examples?
Score	**Examples of responses**
2	• Provides opportunity for members to talk about their needs • Encourages member sharing and involvement with how the group is run • Provides examples of how to obtain feedback • Describes listening to members of the group • Awareness to separate out own needs and maintain a group focus
1	• Obtains feedback by listening to members talk about their needs • Encourages members sharing
0	• Unable to explain how they would find out about the needs of the group

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Score: .....

Question 7(b): How would you react if group members asked for something different to what was being provided?	
Suggested probes	Can you give me some examples?
Score	**Examples of responses**
2	• Actively facilitates opportunities to receiving feedback, criticism and/or complaints • Responsive to the feedback of the group
1	• Willing to receive criticism and/or complaints • Acknowledges feedback from the group
0	• Unwilling to receive criticism and/or complaints • Assumes or dictates what the needs are without seeking further clarification or information

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Score:.....

Question 8: What is your understanding of confidentiality as it relates to a support group?	
Suggested probes	Why do you think confidentiality is important? What do you think that means for you personally and for the group members?
Score	**Examples of responses**
2	• Demonstrates clear understanding regarding the importance of confidentiality in a group setting and its members • Awareness of the sensitive content or nature of the support group • Refers to the group's rules/code of conduct/agreement • Recognises discussions held in the group meeting are private • Considers confidentiality of group members beyond the group meeting itself (e.g. newsletters, website, Facebook, conversations with others outside of group)
1	• Conveys understanding regarding the importance of confidentiality in a group setting • Recognises discussions held in the group meeting are private, but unable to provide examples of how confidentiality is maintained beyond the meeting
0	• Unable to demonstrate importance of confidentiality • Unable to provide examples of how confidentiality may be maintained

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Score:.....

Question 9: If you were to attend a support group meeting for the first time, what do you think or believe would make it a welcoming space? What could a group leader do to assist?	
Suggested probes	What practical or emotionally supportive examples can you give?
Score	**Examples of responses**
2	• Provide a safe and confidential environment • Foster a sense of belonging • Provide opportunities for members to talk and listen to others • Able to receive support • Welcome and accept new members into the group • Assist in the introduction of members • Include the welcome of members in the group process/management
1	• Understands basic concept of welcoming and introducing others to the group • Conveys sense of group being a safe space • Able to provide some examples of a welcoming space but limited knowledge of strategies group leaders could take
0	• Unable to provide examples of a welcoming space or approaches a group leader could take • Places responsibility onto the new member to fit in with the group

Notes:

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Score:.....

Question 10: Members of a support group can have varying backgrounds, needs, beliefs and views. How might you go about supporting members that are different to you?	
Suggested probes	What types of things do you think will vary between members?
Score	**Examples of responses**
2	• Demonstrates awareness of how members can be different to themselves and/or other members • Provides examples of how members can be different (e.g. culture, age, gender, financial backgrounds, sexuality, support needs, stage of illness, beliefs, values, views) • Conveys awareness to not assume the needs of members, but identify member's needs as they relate to their individual circumstances • Able to separate own needs from those of others • Role models respect for others • Role models acceptance of difference to others • Mindful to spend time welcoming, fostering sense of belonging and listening to others
1	• As an individual demonstrates respect for others • Conveys acceptance of difference to others • Willingness to support those different to themselves
0	• Unable to acknowledge potential differences amongst group members • Unwilling to support those different to themselves • Places responsibility onto the member to conform or restrict support offered in the group to align with their own needs

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Score: .....

Question 11: If assistance for the role were available, would you be willing and available to access support either now or into the future?	
Suggested probes	How would you describe the value, if any, of ongoing support and training for people leading groups?
Score	**Examples of responses**
2	• Recognises the importance of continuous learning and accessing assistance when needed • Confirms willingness to undertake assistance available • Confirms commitment to ongoing development • Confirms availability to access assistance
1	• Understands benefits to additional skill or knowledge development • Conveys willingness to undertake assistance available • Expresses limited availability to access assistance
0	• Has the view they have nothing more to learn • Unwilling to undertake assistance either now or into the future • Unable to commit time to accessing assistance

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Score:.....

Scenario 1: Suppose in a group meeting, a member starts complaining about a health professional. The member becomes quite angry, states the doctor's name, how they believe they are no good, and tells everyone that they shouldn't see them for treatment. The group has a standing agreement that everyone is respectful of one another. Describe how you would handle the situation.	
Suggested probes	What kind of actions or strategies do you think would be helpful in this situation?"
Score	**Examples of responses**
2	• Awareness of group dynamics and reactions of members • Intervene to maintain respectful dialogue about others • Listen to and acknowledge member's experience, views and beliefs • Look for opportunity to positively reframe and guide discussion • Maintain group focus, reinforce what the purpose of the group is and what support is possible • Refer to group agreement or standards • Demonstrate empathy, genuine care, and sensitivity • Remain calm • Positively reinforce respect to others includes doctors • Provide opportunity for other members to talk and share • Identify member's support needs and possible referral to assistance outside of group • Check in with person separately afterwards to clarify or reinforce any strategies applied
1	• Display an adequate though not comprehensive number of the above or other effective responses (e.g. two to six of the responses listed for a score of '2')
0	• Unable to provide a basic effective response (e.g. one or none of the responses listed for a score of '2')

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Score: .....

Scenario 2: Suppose in a meeting, a member wants to talk about his daughter's mental health and financial problems. The member explains how it's been really hard on the family and asks if the group could host a fundraiser to help. The support group is specifically for people impacted by cancer, with the main focus on providing support to each other and sharing information about cancer. The group has not been involved in other events or fundraisers. Describe how you would handle the situation.	
Suggested probes	What kind of actions or strategies do you think would be helpful in this situation?
Score	**Examples of responses**
2	• Listen to and acknowledge member's experience and request for help • Maintain group focus, reinforce what the purpose of the group is and what support is possible • Role model respect and confidentiality towards member's situation • Facilitate, guide and summarise discussion for members • Refer to group agreement or standards • Acknowledge limitations of the group and how the group is unable to provide support to all people for all things • Maintain group cohesion • Obtain feedback from the group • Problem solve, provide opportunity for individuals to assist if they choose rather than have the group as a whole commit • Refer members to other more appropriate community supports • Demonstrate empathy, genuine care and sensitivity
1	• Display an adequate though not comprehensive number of the above or other effective responses (e.g. two to five of the responses listed for a score of '2')
0	• Unable to provide a basic effective response (e.g. one or none of the responses listed for a score of '2')

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Score: .....

Question 12: In order to support others, it can be helpful for group leaders to look after themselves mentally and physically. Is there anything you need to consider that would impact on your ability to undertake the role?	
Suggested probes	Do you have any strategies for looking after yourself? Can you tell me more about that? Can you give some examples?
Score	**Examples of responses**
2	• Reflective and articulates awareness of own circumstances, physical health and wellbeing • Conveys a sense of balance to their life • Has established own personal support network • Able to be organised, planning ahead or prioritise commitments • Takes time out • Diet, exercise and relaxation strategies • Back up plans and/or co-leaders to assist with coverage
1	• Disclosed personal physical or mental health issues that are currently being managed • Display an adequate though not comprehensive number of the above self-care strategies or other appropriate responses (e.g. two to three of the responses listed for a score of '2')
0	• Disclosed physical or mental health issues that would significantly impact on their ability to function in the role • Unable to identify any self-care strategies

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Score: .....

Question 13: Reflecting on our conversation, overall do you think you are capable and ready to undertake the role of group leader?	
Suggested probes	What knowledge or skills do you think you might need to develop further in order to be ready for the role? Would you like some more time to think about your response and get back to me?
Score	**Examples of responses**
2	• Demonstrates awareness of the role and knowledge, skills and attributes required of them to undertake role • Awareness to separate own personal desire or needs to be a group leader in order for the group to be led by a suitable person • Objectively determines (based on previous responses or experience) they are capable and ready to undertake role • Acknowledges own capacity for growth and development
1	• Determines they are capable to undertake role with assistance to support them become ready
0	• Determines they are currently not ready to undertake the role • Determines the role does not suit them or their circumstances

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Score:.....

Interviewer observations: Indicate if any of the following attributes were observed at any time throughout the interaction with the candidate.		
Attribute	**Observed**	**Not observed**
Respectful of the process, your role, and/or the organisation you represent		
Listened		
Patient		
Followed through on what they said they would do (before, during and/or after conversation)		
Provided objective responses		
Mentally present		
Approachable manner		
Calm		
Non-authoritarian approach		
Genuineness		

Score	Interviewer observations
2	Observed more than two attributes listed above
1	Observed two attributes listed above
0	Did not observe any of the attributes listed above

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Score: .....

Scoring Table

Category	Question or Scenario	Knowledge, skill and/or attribute development area(s) assessed	Scores
Suitability	2	Availability and commitment	
	11	Openness for role development	
	12	Self-care	
	13	Self-assessment	
	Interviewer observations	Personal attributes	
		Total score	
Readiness	1	Role knowledge	
	3	Planning and delegating	
	4	Conflict resolution	
	5(a)	Giving support	
	5(b)	Receiving support	
	6	Working with others	
	7(a)	Group needs	
	7(b)	Managing criticism	
	8	Confidentiality	
	9	Welcoming new members	
	10	Accepting difference	
	Scenario 1	Respectful group interactions	
	Scenario 2	Group purpose and agreement	
		Total score	

Rating Table

Category	Rating	Definition
Suitability	Highly Suitable	Candidate has the desirable knowledge, skills and attributes to be a suitable fit for the group leader role
	Suitable	Candidate has the required knowledge, skills and attributes to be a suitable fit for the group leader role
	Not Currently Suitable	Candidate does not currently have the required knowledge, skills and attributes to be a suitable fit for the group leader role
	Candidate determined to be	
Readiness	Ready	Candidate is ready to undertake the role of support group leader independently
	Ready with Support	Candidate is ready to undertake the role of support group leader but requires some support to develop certain knowledge, skills and attributes
	Not yet Ready	Candidate is not yet ready to undertake the role without support
	Candidate determined to be	

Appendix 23 Field Test User Manual

Prostate Cancer Foundation of Australia

THE UNIVERSITY OF MELBOURNE

A Planned Conversation

User Guide

Author: AMANDA POMERY
Version: 2

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Overview

Cancer support groups are considered to be a valuable and cost-effective means of delivering support in the community. Leadership of these groups is often voluntary and mostly delivered by people with a lived experience of cancer. The role of the group leader, however, requires commitment and comes with responsibilities and challenges; these may include possible risks to group members or the leaders themselves. Guided selection and development of group leaders, therefore, is needed to ensure the sustainability of groups and the quality of support received by group members.

An evidence-based and pragmatic approach was used to develop minimum standards for selection and development of cancer support group leaders. The standards provide a consistent framework for agencies who work with groups seeking legitimacy, funding or support. They reflect the complexity of the role and the diverse knowledge, skills and attributes that leaders may require. Critically, the standards can help identify development and support needs of current and prospective group leaders, so that they may receive targeted and individualised assistance as required. The standards were used to create a structured interview called *A Planned Conversation* for this purpose.

Purpose of this User Guide

This user guide provides practical information relevant to *A Planned Conversation*; this will optimise clear and consistent application of the standards. The guide outlines: why interviews should have structure; the structure and content of *A Planned Conversation;* how to conduct the interview; and how to score responses to the questions comprising *A Planned Conversation*. Please note, this guide and interview was designed to promote minimum standards in support group leadership. Therefore, it is important to consider any additional or specific requirements relevant to your agency. *A Planned Conversation* is to be used as a guide in the selection and development process, so it is important that the interviewer uses their own judgement based on the individual circumstances. Please consider the person's education and background, and use language that the person is familiar with in order to elicit responses.

Why Use an Interview?

Agencies assisting in the selection of group leaders need to identify people possessing characteristics required for the role. Interviews are an effective way of determining who has these attributes and, therefore, who is suitable and ready for the role. The approach of an interview is preferred, as it is more personal than traditional selection procedures (e.g., written tests) and because it can be used to evaluate characteristics like interpersonal skills

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that are not easily assessed using other approaches. This is particularly important when dealing with a population with varied education and literacy levels.

Structured versus Unstructured

Interviews can be structured or unstructured. A structured interview uses multiple elements to facilitate the process of recruiting candidates that is systematic and role-related. Structured interviews are twice as effective as unstructured interviews in predicting job performance (Wiesner & Cronshaw, 1988). Structured interviews ensure that each candidate has an equal opportunity to provide information and be assessed in an accurate, consistent and fair manner. Unstructured interviews, where interviewers rely on unaided judgement, are subject to bias and may expose both parties to future complaints or challenges. The benefits of consistently selecting quality candidates and reducing the risk of complaints far outweigh any costs of adding structure (e.g., additional time and expertise needed to assess potential candidates).

A Planned Conversation

As support groups often are independent, community-based and volunteer-led, the language used throughout is less formal, non-authoritative or non-intimidating, the intent being to encourage positive engagement. Further, the term structured interview has been replaced with the phrase *A Planned Conversation*. While the conversation may be conducted by a single interviewer over the phone, a face-to-face meeting is preferred, as is a two-person panel. A two-person panel provides a useful means of cross-checking responses and observations. Ideally, the panel should include an agency representative who has a direct role with the group. An experienced support group leader may also serve as a member of the two-person panel.

The elements of *A Planned Conversation* include:

1. Core questions relevant to role (ensures evidence-based framework)
2. Effective questions and prompts (evokes responses that aid decision-making)
3. Standardised questions (ensures fairness and impartiality)
4. Anchored rating scale (helps quantify subjective data)
5. User Guide to support interviewers (ensures consistency is maintained across staff and organisations)
6. Where possible utilisation of a panel of two interviewers (provides checks and balances to ensure fairness and impartiality)
7. Note taking (increase accuracy of recall and provide a record)

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8. Objective assessment of responses (de-personalises decision outcomes)

Role Analysis

Knowledge, skills and attributes (KSA) for the role of a support group leader were identified and analysed through a systematic review of the literature (Pomery et al, 2015). Consultation with experts in the field provided agreement on requisite qualities for the role and are outlined in Appendix 1. The questions contained in *A Planned Conversation* are designed to indicate if a candidate has the qualities required for the role. Past performance is one of the best predictors of future performance. As many candidates would not have led a cancer support group before, behavioural-based questions have been developed, where possible, to a apply candidate's life experiences to the role.

Anchored Responses

An interdisciplinary panel of experts helped develop a pragmatic method for scoring interviewer observations. In this case, experts helped to determine examples of responses indicative of comprehensive, adequate and insufficient responses to each question and scenario comprising *A Planned Conversation*. In every case, responses reflect knowledge, skills and attributes to be assessed by each question and scenario. Interviewees need not use exactly the same words provided in the examples of responses; examples should simply act as a guide for scoring interviewee responses. Additionally, candidates are not required to provide all examples of responses listed in order to obtain a score of '2'.

Rating Scale

A simple 3-point rating scale ranging from 0 to 2 is used to evaluate candidates' responses. Ratings are interpreted as follows:

0 = Insufficient response

1= Adequate response

2= Comprehensive response

A rating scale for each attribute listed under 'Interviewer observations' was not developed. Instead candidate attributes are recorded as either observed or not observed during the interview process.

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Scoring Responses

Evaluate and score questions, scenarios and interviewer observations against available benchmarks; once complete, transfer scores to the scoring table. The Scoring Table was designed to simplify the process of calculating scores on two scales: *Suitability for role* and *Readiness for role*. Scoring is best done immediately after the conversation, when the details are fresh in your mind; allow an additional 15 minutes at the end of each conversation for this purpose.

If applicable complete the Scoring Table and discuss with the other panel member; the aim is to reach consensus on *Suitability* and *Readiness* ratings as described in the following sections. If ratings vary between panel members, discuss reasons with the aim of reaching agreement to make the overall final decision. If this is not possible then average the scores and determine the outcome based on combined results.

Category 1: Suitability

Note: a scoring matrix will be developed based on results from undertaking this field testing. For this stage, please indicate the rating you think best describes the candidate's suitability.

The Suitability scale indicates the level of suitability the candidate has for the role of support group.

Circumstances that render the person not suitable, may not be permanent or ongoing. In such cases, an invitation may be extended to re-discuss the role at a later or more suitable stage.

Rating	Definition
Highly Suitable	Candidate has the desirable knowledge, skills and attributes to be a suitable fit for the group leader role
Suitable	Candidate has the required knowledge, skills and attributes to be a suitable fit for the group leader role
Not Currently Suitable	Candidate does not currently have the required knowledge, skills and attributes to be a suitable fit for the group leader role

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Category 2: Readiness

Please note this field testing will determine the score ranges for each rating. For this stage, please indicate the rating you think best describes the candidate's readiness.

The Readiness scale indicates the level of skill, knowledge and attribute (KSA) development the candidate has for the role currently. This category reflects the expectation that those presenting for the role are most likely volunteering and may not necessary have direct previous experience.

Rating	Definition
Ready	Candidate is ready to undertake the role of support group leader independently
Ready with Support	Candidate is ready to undertake the role of support group leader but requires some support to develop certain knowledge, skills and attributes *
Not yet Ready	Candidate is not yet ready to undertake the role without support **

*It is recommended that support be targeted to areas identified in the scoring table. Consider what support your agency can offer to assist, such as training modules, resources or peer mentoring.

** Circumstances that render the person not ready may not be permanent or ongoing. In such cases, an invitation may be extended to re-discuss the role at a later or more suitable stage or to undertake minimum training and support prior to beginning the role.

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During A Planned Conversation

Practice beforehand

Cancer agency workers involved in the pilot study of *A Planned Conversation* reported a practice effect when undertaking interviews. For this reason it is strongly recommended that first time interviewers undertake a practice interview with another staff member prior to using it for the purpose of selection.

Provide background

Try to create a relaxed atmosphere and build rapport with the person as much as possible. Start with breaking the ice over general conversation about the weather etc. If conducting the conversation in person offer them a glass of water/tea/coffee. Begin *A Planned Conversation* with a brief description of the role of support group leader, the cancer agency and its relationship to the support group, along with information about the group if known.

Provide the person with an overview of the conversation format. For instance, tell the person that a series of questions will be asked in order to open up the conversation and explore together whether the role is a good fit for them. Reinforce this is not a test, with no right or wrong answers. Instead questions have been developed to get to know more about them, in a way that is relevant to the support group leader role.

The process is designed to; clarify any questions, identify the knowledge, skills and attributes they have relevant to the role, if they are ready to undertake the role, along with what supports might be of benefit to decrease the risk of the role impacting negatively on them. The aim is also to allow the person to reflect for themselves if this is a role they want and are able to take on. Explain to the candidate that notes will be taken during the conversation, with it normally taking up to an hour.

Interview Do's

Show respect for the candidate at all times, particular as they may be volunteering their time. Many undertake the role in their own time and have a strong personal interest or experience that has lead them to becoming involved in a support group. Ask open-ended questions and allow the candidate to do most of the talking (don't talk more than 20% of the time). Listen carefully to what the candidate says, respond when necessary, and maintain control of the interview.

Use probes

Probes are phrases used to follow-up open-ended questions that encourage a person to reveal more information. Examples include: *What did you do? What did you think about or want? Can you tell me more? Who was involved and how did you contribute? What was the*

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outcome? Suggested probes have been provided for each question for the interviewer to use at their own discretion and as required. Additionally, interviewers are free to use their own probes in order to elicit the required information.

Take Notes

Notes serve two purposes. Firstly, they help you capture the content of the conversation rather than relying on memory. Secondly, notes help to create a record which may be helpful for delivery of support services to the leader and checking-in with them regarding their development in the role. Notes should reflect content of what was said and observations. For convenience and completeness of records, space has been provided for taking notes after each question.

Closing the interview

Give the person time at the end of the conversation to ask you/or the panel questions and reflect on the information exchanged. Let them know what the next steps in the process will be and your expected timeframe. Importantly thank them for their time and interest. If necessary, provide opportunity for a follow up call to clarify if they wish to provide any further information or consider undertaking the role.

Training and Development

Investigate what supports, resources or training is provided by your organisation, or accessible through other agencies, to support group leaders in their role. During *A Planned Conversation* it is advised to clearly explain what supports are available and any expectations the organisation has for recognising the support group. Question 11 has been include to open up this conversation and for you to explain what assistance is available.

In the scoring table, questions and corresponding key KSAs have been specifically outlined to identify target areas for development that may be provided to the candidate. Training and support may be provided to the candidate before proceeding in order for them to be ready for the role, or accessed on an ongoing basis whilst undertaking the role. For example, a score of 0 for Question 9 would indicate a need for accessing information, support or training on welcoming new members to the group. It will therefore be important to identify what assistance and access to resources can be offered by the organisation.

The Planned Conversation can be undertaken again as a way of checking in with the group leader, consolidating learning for the leader and assisting the organisation in delivery of tailored support where required.

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Important reminder

Australian Commonwealth Government and the state and territory governments have introduced laws to help protect people from discrimination and harassment. Please refer to https://www.humanrights.gov.au/employers/good-practice-good-business-factsheets/quick-guide-australian-discrimination-laws for further information. All questions contained in the Planned Conversation comply with the current obligations to prevent discrimination in the selection process. Interviewers are asked to;

1. Educate those involved in the recruitment process about the obligations,
2. Cast the net as wide as possible to attract a diverse pool of people,
3. Be consistent and fair in the way you treat people,
4. Accommodate people who require adjustments,
5. Do not seek irrelevant personal information,
6. Focus on the essential requirements for the role,
7. Set aside personal bias/myths and stereotypes,
8. Keep records of your decisions.

References

Wiesner, W., Cronshaw, S. (1988) A meta-analytic investigation of the impact of interview format and degree of structure on the validity of the employment interview. Journal of Occupational Psychology, 61, 275-290.

Pomery, A., Schofield, P., Xhilaga, M., Gough, K. (2016) Skills, knowledge and attributes of support group leaders: A systematic review. Patient Education and Counseling, Volume 99, Issue 5:672-88.

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Appendix 1

Knowledge, skills and attributes identified as required to be ready to undertake the role of a cancer support group leader

Quality	Knowledge, skills and attributes
Group Management	Capacity to be primary point of contact Planning of group meeting
Group Process	Identify group needs Maintain confidentiality Intervene with management of issues/challenging members Foster a welcoming space Encourage member sharing, involvement and support Facilitating, guiding and summarising discussion Work effectively with co-leader/s Maintain respectful dialogue and interaction with/about others Promote group cohesion and trust Manage alternative views/beliefs/opinions Welcome and introduce new members Clarify their leader role with/to group members
Role Modelling	Listening Support Communication skills Acceptance of difference Commitment to the group Empathy Acknowledging limitations of self and the group Respect for others Operate within standards set by the group Self-care and care of other members Maintaining boundaries Remaining calm
Awareness	Separate own needs from the groups Maintaining own mental and physical health Being mentally present Own self-care Recognise when support/de-briefing is needed
Willingness	Give and receive support Availability of time to give Commitment to the group Receive and manage criticism/complaints Maintain boundaries

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Quality	Knowledge, skills and attributes
Agreeableness	Sensitive
	Supportive
	Honest
	Integrity
	Empathic
	Non-authoritarian
	Approachable
	Trustworthy
	Inclusive
	Responsive
	Respectful
	Ethical
	Patient
	Genuine
Openness	Capable
	Objective
	Motivated
	Accepting

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Appendix 24 Field Test Participant Criteria

Approved participant criteria for research study,

Improving the quality of cancer care via support groups: establishing evidence-based practice for support group leaders.

Inclusion Criteria

- ✓ adult 18+ years
- ✓ adequate level of English
- ✓ current support group leader or co-leader
- ✓ lead a prostate or breast cancer support group
- ✓ peer-based support group
- ✓ volunteer, peer or professional
- ✓ group meets face to face
- ✓ primarily group focus is on providing peer support for a shared experience
- ✓ meetings can be formal or informal in structure

Exclusion Criteria

- × children and adolescents under 18 years
- × requires an interpreter
- × lead an educational or therapeutic support group
- × not primarily focused on peer support (e.g. exercise, dragon-boat racing)
- × group is conducted over the telephone or online

If you are unsure whether someone meets the approved criteria, please feel free to email or contact Amanda Pomery on amanda.pomery@pcfa.org.au or 03 9948 2078.

Appendix 25 Field Test Participant Contact Script

Contact Script (1)

Thank you for returning the signed consent form to participate in the research study on improving the quality of cancer care via support groups and establishing evidence-based practice for support group leaders.

As we value your time, before proceeding in scheduling an interview, we want to check you understand the criteria for participating and make sure it's applicable to you. The inclusion criteria is;

- ✓ adult 18+ years
- ✓ adequate level of English
- ✓ current support group leader or co-leader
- ✓ lead a prostate or breast cancer support group
- ✓ peer-based support group
- ✓ volunteer, peer or professional
- ✓ group meets face to face
- ✓ primarily group focus is on providing peer support for a shared experience
- ✓ meetings can be formal or informal in structure

Can you confirm you meet the criteria?

If yes, proceed in scheduling a suitable time, advise the group leader who will be contacting them to conduct the interview and check what phone number is best to contact them on.

Allow 1 hour for the interview, but advise it is likely to take only 45 minutes. Explain that there is nothing they need to prepare for the interview.

Thank them for their time and agreeing to participate in the study.

If no, thank them for their offer to participate. Advise that all group leaders will be informed of study outcomes early next year.

Appendix 26 Field Test Overview of Process

Research study on

Improving the quality of cancer care via support groups: establishing evidence-based practice for support group leaders

Field Testing –ethics approved briefing

Step	Date	Action taken	Documents	Person responsible
Mail out	As soon as possible	Filter list of support group leaders to approach & remove those not meeting criteria	Refer to Approved participant criteria	
		Mail merge list of support group leader names with Consent Form (insert next to *Name of Participant)*	Consent form	
		Compile invitation package, include reply paid envelope addressed to BCNA appointed contact person	Invite Letter to SG Leaders, Consent Form, Plain Language Statement, reply paid envelope	
Email	12th August	Email invitation to support group leaders	Email invitation text, Plain Language Statement, Consent Form	
Collate consent forms	Until 11th November	Record return of consent. These can be returned by post or scanned and emailed.	Participant Recording Sheet	
		Contact SG leader and arrange interview time	Participant Recording Sheet, Contact Script (1)	
		Assign & advise interviewer of arranged time	Interviewer to note date/time in diary	
Follow up calls	15th August – 3rd September	Reminder provided to SG leaders and included in scheduled BCNA program contact phone calls	Reminder script	

Follow up email	3rd October	Email reminder sent to SG leaders	Email to be drafted based on response rates	
Briefing	TBC	Briefing session provided by Amanda to prepare interviewers and clarify any questions	User Guide, Background Questions and Structured interview	
Check in	Monthly, dates TBC	Monthly team sessions with Amanda to check in on progress, respond to questions or provide de-briefing as required (please note in addition Amanda is available via phone/email whenever required)		
Interviews	Until 11th November	Conduct interview, record responses and score	Structured Interview	
Storage	Until 11th November	Store consent forms and completed responses in secure cabinet until collected by Amanda		

Appendix 27 Field Test Participant Invitation Letter

<<Name>>
<<Address>>
<<Suburb State Postcode>>

Dear <<Support Group Leader Name>>,

We are writing to seek your assistance with a research project, **Improving the quality of cancer care via support groups: establishing evidence-based practice for support group leaders** (The University of Melbourne Ethics Approval No. 1443027). The study aims to determine what the key qualities of cancer support group leaders are and how this information can be used to establish a model of standard practice for selecting and supporting group leaders.

Support group leaders have a crucial role and are central to the success of the group. There are significant challenges associated with leading a group, such as keeping the group going, dealing with tough situations, and having to manage multiple tasks and responsibilities. We are wanting to better understand how we can serve and support group leaders better, particularly when people are undertaking the role for the first time.

To do this, the Prostate Cancer Foundation of Australia is working with The University of Melbourne, Breast Cancer Network Australia and Cancer Council Victoria to undertake telephone-based interviews with current support group leaders. During the interview set questions will be asked about the knowledge, skills and attributes you have developed for the role. All information will be de-identified and your anonymity/confidentiality will be protected.

To be eligible for this study you need to be a **current prostate or breast cancer support group leader or co-leader**, the group you lead **meets face-to-face**, and primarily focus on **providing peer support** for a shared experience either through structured/formal meetings or informal social catch ups.

The interview takes up to 45 minutes to complete. **If you can help,** we ask that you please read the Plain Language Statement**, sign the Consent Form and return it in the enclosed reply paid envelope.** Once received, you will be contacted to arrange a convenient time to undertake the interview.

Participation in the study is entirely voluntary and will in no way affect your relationship with PCFA/BCNA and how we work with you. Should you have any questions about the project, please contact Amanda Pomery via telephone: +61 (03) 9948 2078 or email: amanda.pomery@pcfa.org.au. We thank you very much in advance for your support.

Yours sincerely,

Amanda Pomery
National Manager, Support & Community Outreach
Prostate Cancer Foundation of Australia

Janelle Woods
Community Programs Coordinator
Breast Cancer Network Australia

Appendix 28 Protocol Paper - Response to Editor

Assistant Editor
Editorial Office
BMJ Open

Dear Emma Gray,

Ref.: revision bmjopen-2016-014408 entitled "Pragmatic, evidence-based minimum standards and structured interview to guide the selection and development of cancer support group leaders."

Thank you for your correspondence and invitation to submit a revised version of the manuscript. Consideration, time and comments from the Editor and reviewers are very much appreciated.

By undertaking the revisions as recommended, the authors believe the paper has been further improved to address an important topic for BMJ Open.

Please find below a summary of amendments to our manuscript in response to all reviewer comments. As requested, changes in the manuscript and other documents have been highlighted in bold.

We thank you for your re-evaluation of the manuscript and look forward to contributing to the journal.

Yours sincerely,

Amanda Pomery

Revision bmjopen-2016-014408

Editor

Comments: Please make clear in the title that this is a protocol.

The authors thank the Editor for this comment and agree this was an oversight. To clearly indicate to the reader that this is a protocol paper, the title has been changed to:

> Pragmatic, **consensus**-based minimum standards and a structured interview to guide the selection and development of cancer support group leaders: **a study protocol**.

We have also modified the Abstract Introduction paragraph, line 5 on page 2 to make this clear:

> **This protocol describes the methods that will be used to generate pragmatic consensus-based minimum standards and an accessible structured interview with user manual to guide the selection and development of cancer support group leaders.**

Please note that reference to evidence-based minimum standards has also been changed to consensus-based minimum standards to more clearly reflect the method of evaluation.

Reviewer #1

Comments: This is an interesting study. The study would benefit from looking at cultural diversity in support group leaders. The study would also benefit from a global dimension to look at support group leaders in other countries.

We thank the reviewer for highlighting the importance of recognising cultural diversity in both support group leaders themselves and across countries. Cultural adaptation was identified as an area needing further investigation, particularly given the significant variations in cultural context from first to third world countries for example. Significant scoping of the study occurred in order to determine what could be reasonably and thoroughly covered in the initial development of the structured interview. Therefore such investigation was considered beyond the scope of this study, with it determined that we were unable to adequately investigate cultural diversity of leaders and/or develop a reliable or valid cultural translation of the structured interview. We have therefore highlighted this as a limitation of the study by adding reference to this in the Strengths and Limitations section, point 4 on page 3 to include:

- **Studies described in the** protocol will not ascertain competency level of the support group leader once in the role **nor address cross-cultural adaptation of the structured interview**

Additionally we have added to the Study Objectives, point 8 on page 6;

> **To have an accessible study protocol to facilitate knowledge transfer and assist others to further develop the structured interview.**

In the Conclusion section, lines 4-5 on page 16, we have added;

> **It is also hoped that following field testing, further research will be undertaken to determine the appropriateness of the content and structure in other countries.**

We would like to note that the systematic review of published literature that helped to inform initial content on qualities of support group leaders, included papers from USA, Australia, Germany, Canada, UK, and Norway. Criteria for literature was broadened to include group leaders of cancer and health-related support groups but was limited to papers written in English.

Reviewer #2

Comments: The findings from the proposed development of existing guidelines to help select and train cancer peer support leaders likely will be insightful and useful. The results from the proposed study could indeed by very useful and worthy of publication as well as an important guide to identifying, recruiting, and effectively training peer group leaders.

We thank Reviewer 2 for their comments. We agree that the proposed study "could indeed be very useful and worthy of publication as well as [be] an important guide to identifying, recruiting, and effectively training peer group leaders."

Comments: However, the description as written of the proposed procedures to develop these for this reviewer was not in and of itself very useful. The authors do not cite the current literature on characteristics of peer supporters/peer leaders who have been effective. While there may not yet be 'guidelines' for recruiting peer leaders, there is indeed a body of literature on qualities that effective peer leaders/coaches have.

Before embarking on this project, we carried out a thorough scoping exercise to ensure the utility and novelty of the project; in this case, a narrative review of the professional and grey literature was undertaken. This review uncovered remarkable variability across citations in terms of the delivery of peer support, group focus and leader characteristics. Further, and critically, no single manuscript or report provided a robust or meaningful synopsis of the qualities (knowledge, skills and attributes) needed to lead a peer cancer support group or how to determine a leader's suitability and readiness for the role. This is reflected in the following statement from the abstract of the original submission: "Little is known about qualities required to lead a peer support group or how to determine suitability for the role." Further information is outlined in the published paper by the authors titled *Skills, knowledge and attributes of support group leaders: A systematic literature review* as referenced in the submitted introduction section of the paper.

To address the reviewer's comments, we have added the following to the Introduction, paragraph 2, lines 1-5 on page 4:

> **Initial scoping revealed the lack of a relevant role analysis or, indeed, any detailed synopsis of the knowledge, skills and attributes required for the cancer support group leader role. It also failed to uncover** published guidelines, standards **or tools** to **guide** the selection and development of **leaders of cancer support groups; yet** these are needed to inform policy and practice within and across organisations involved with these groups [4].

Comments: Moreover, the authors do not cite or discuss other efforts to develop such guidelines in other relevant areas. How do the proposed methods build on or differ from other similar initiatives and why? The description of the process is vague and not grounded in evidence from other similar initiatives. As written the protocol does not contribute significantly to the literature as a description of work to be completed. The protocol in and of itself as currently described and justified in relation to other similar work is not innovative enough to be published as a protocol.

An essential element to maximising validities of an interview is enhancing the job-relatedness in development of the interview. More specifically, content needs to be based on a thorough and systematic analysis of the job for which the candidate is being considered (Dipboye et al., 2004). The specificity of the cancer support group leader role, which is predominately volunteer-based and focused on peer support in a group setting, does not allow for adequate comparisons with other role analysis. To the authors knowledge there are no other similar initiatives of relevance to draw from which is why we went to great lengths to describe and justify each of the study objectives.

The authors would therefore maintain that the outlined mixed study methods applied to this field of peer support is novel and innovative, whilst working to address a practical need. Consequently, we felt a rigorous, robust and systematic approach to the development of minimum standards and a tool to assess suitability and readiness to undertake the cancer support group leader role was warranted.

In addition to the dearth of literature on peer support group leader characteristics was a lack of published guidelines or standards specific to the selection and development of cancer support group leaders. In the absence of guidelines specific to the area of investigation, we used methods outlined for patient-reported outcomes (ISOQOL) as the most appropriate and useful approach to developing minimum standards.

In address the reviewer's comments, a significant revision of the Introduction and Methods and Analysis sections has been undertaken to provide further description, reference to evidence-based methods used and rationale for undertaking the study.

Specifically we wish to highlight to the following revisions &/or additions;

First, in the Introduction, paragraph 2, lines 5-8 on page 4:

> **Given the very specific nature of the cancer support group leader role, a rigorous, robust and systematic approach to the development of minimum standards and a tool to assess suitability and readiness to undertake the support group leader role based on these standards is warranted.**

Second, in the Introduction section, paragraph 3, pages 4-5:

> **In the absence of a single agreed approach to developing minimum standards, this study drew on methods** used by the International Society for Quality of Life Research (ISOQOL) to **develop** minimum standards for **the design and selection** of patient-reported outcome measures **for use** in patient-centred outcomes and comparative effectiveness research [5]. **These methods were considered appropriate for at least three reasons. First, the authors employed a compatible definition of a minimum standard, with a focus on the identification of critical attributes and judgments of suitability. Second, the approach described facilitated identification of *best practice* standards in addition to *minimum* standards. Third, many of the identified standards for patient-reported outcome measures are relevant to the design of structured interviews [6].**

Third, in the Introduction section, a fourth paragraph has been added on page 5.

Four, in the Methods and Analysis section, under Systematic Literature Review, paragraph 1 has been revised on page 7.

Five, in the Methods and Analysis section, under Online Delphi Study, paragraph 1 has been revised on page 9.

Comments: In what ways are the proposed procedures useful as a guide for similar efforts?

Although the study methods described in the protocol have been used for the specific purpose of selection and development of cancer support group leaders, we believe the approach and outputs could be used for other healthcare setting. We kindly refer the reviewer back to the following statement, which we have also added to, outlined in the Discussion section, lines 6-8 in paragraph 2, on page 15:

> We also believe our approach and outputs (minimum standards and structured interview) could be used or adapted for other healthcare settings or **community settings** where peer support groups are in operation.

Additionally, we have included the following statement in the Conclusion section on page 16:

> **It is also hoped that following field testing, further research will be undertaken to determine the appropriateness of the content and structure in other countries.**

Reviewer #3

Comments: With a major revision the paper would be suitable for a re-submission. However, the paper would need to be redesigned as a methods paper. The title is misleading and leads the reader to believe the paper includes results.

We thank the reviewer for their time and feedback. As previously outlined in response to the Editor, we have re-titled the paper to clearly indicate to the reader this is a protocol paper.

Comments: The aims of the study are articulated however the aims and justification of the paper are not.

We agree with the reviewer that inclusion of the aim and justification of the paper itself was required. In addition to the major revisions undertaken in the Introduction section as outlined in response to Reviewer 2, the following has been added;

First, in the Introduction section of the Abstract on page 2 we have added:

> **This protocol describes the methods that will be used to generate pragmatic consensus-based minimum standards and an accessible structured interview with user manual to guide the selection and development of cancer support group leaders.**

Second, the following has been added to Study Objectives on page 6:

(8) To have an accessible study protocol to facilitate knowledge transfer and assist others to further develop the structured interview.

Comments: In the discussion section the 'establishment of evidence-based minimum standards may help reduce concerns of clinicians and potential barriers in referral pathways.' Sections such as this need to be integrated earlier and in a clear and structured manner to justify the study, this leading to the main focus that should be a justification of the study design.

Considerable consultation and scoping for this project was undertaken to assist in the formation and justification of the study objectives. Although establishment of minimum standards may help reduce concerns of clinicians, the authors' consider this a potential by-product rather than justification for the study itself. Instead the authors' primary aim, as referred to in the introduction section, is to help guide cancer agencies with an consensus-based approach, similar to other forms of psychosocial support in healthcare, in the selection and development of group leaders. The driving factors for this study are to improve the preparation and on-going experience of group leaders in their role and maximise value for those people who choose to utilise groups for support during the cancer experience. It is critical that we take a patient-centred approach in justifying the study, which in this instance means placing those with a cancer experience who access peer support groups at the centre.

In response, we have elaborated further on the study aims and justifications in the Introduction paragraph 2 on page 4 to include the following:

Here, the intended aim of better selection and development is to enhance the experience of both group leaders and members and to maximise the sustainability of cancer support groups in the community.

Further justification of the study design has been added to the Introduction and Methods and Analysis sections as outlined in response to Reviewer 2.

Comments: As a methods paper the paper fails to outline and justify each stage, rather the paper is presented as a narrative of the study design. Sections of the design are not clear including the reference to 'structured interview' questioning is this a pro-forma?

We agree that the rationale for developing a structured interview needed to be justified, including a definition of a structured interview and referencing to evidence-based methods on developing structure in an interview.

First, we have therefore included this information in the Introduction, paragraph 2 on page 5.

Second, we have added details regarding the development of structured interviews in the Methods and Analysis section under Systematic Literature Review, paragraph 1 on page 7 and Online Delphi Study, paragraph 1 on page 9.

Comments: The paper requires a restructure to reduce the repetitive nature and improve the alignment between the methods, study design, objectives, outputs and the aims of the paper. Whilst the paper includes sections that provide an overview of the methodology including the online Delphi method, this needs to be integrated rather than being presented as separated and isolated background information.

We thank the reviewer for their comments and have revised the paper to reduce repetition and improve alignment by actioning the following; *(Please note that to ensure readability of the revised manuscript, deletions were not able to be retained in the track changes)*

First, we have removed from the original manuscript on page 5, the Study Objectives paragraph (totalling 14 lines) repeating details already provided.

Second, we have removed the Methods and Analysis synopsis paragraph (totalling 8 lines) on page 6 of the original manuscript.

Third, repetitive statements contained in Online Delphi Method paragraphs 1 and 2 on page 8 of the original manuscript have also been removed.

Fourth, Study Design has been repositioned under Methods and Analysis on page 7.

Five, expansions and integration of methodology has been included and outlined in response to Reviewer 2 and Reviewer 3.

Comments: The strengths and limitations of the study need to be justified and again there is a focus on the study and not the research design. The introduction of further literature would support the study design and provide clarity around participant numbers and in turn this would lead to support the strengths and limitations of the study.

We thank the reviewer for bringing these points to our attention. Considerable revision of the Introduction has been undertaken to support the study design to include reference to literature on developing minimum standards and structured interviews adapted for this study.

All additions to the Introduction have been bolded, with the majority of additions contained in pages 4-5.

Potential participant numbers based on identified recruitment channels for the study have been included in paragraph 2 of the Field Testing section on page 14 as outlined below:

> **A network of leaders from 170 prostate cancer support groups and over 300 breast cancer support groups will be invited to participate in the field testing.**

Reviewer #4

Comments: What about references are the sequences of study design and study objectives? Please describe the inclusive and exclusive of the current recruited support group leaders, such as pilot and field testing phase. Please describe the sample size of field testing and how many support group leaders was recruited. Please provide figure 1 more clearly .

We thank the reviewer for their time and further questions relating to the study. We are of the opinion that questions raised regarding the paper highlight the need to clarify, in the first instance, this is a study protocol.

In response, we have changed the title of the paper as previously outlined, to clearly indicate to the reader this is a protocol paper.

As outlined previously in response to Reviewer 3 we have also included a statement on potential participant numbers based on recruitment channels in the Field Testing section on page 14.

However, the addition of other specific information requested would be relevant to a methods paper, which is not the purpose or intention of this study. A follow up study detailing piloting and field testing outcomes is yet to be completed.

Comments: How long have been this study and each study stage?

We have included study timeframes as requested in the Study Design on page 7:

> Systematic literature review, online **reactive** Delphi study, **as well as** a pilot and field **test of the structured interview undertaken between 2014 and 2017**(Figure 1).

Comments: Please update reference 25

The authors recognise that reference 25 is long-standing, however content described in the referenced paper has great relevance to the development of the structured interview outlined in the study.

A further explanation of the structured interview and justification of approach used has been included in the introduction along with additional and/or more recent references outlined in the Reference List on pages18-19 to include;

6. Campion MA, Palmer DK, Campion JE: **A review of structure in the selection interview**. *Personnel Psychology* 1997, **50**(3):655-702.
7. Wilk SL, Cappelli P: **Understanding the determinants of employer use of selection methods**. *Personnel Psychology* 2003, **56**(1):103-124.
8. Hausknecht JP, Day DV, Thomas SC: **Applicant reactions to selection procedures: An updated model and meta-analysis**. *Personnel psychology* 2004, **57**(3):639-683.
9. Lievens F, De Corte W, Brysse K: **Applicant perceptions of selection procedures: The role of selection information, belief in tests, and comparative anxiety**. *International Journal of Selection and Assessment* 2003, **11**(1):67-77.
10. Macan T: **The employment interview: A review of current studies and directions for future research**. *Human Resource Management Review* 2009, **19**(3):203-218.
11. Dipboye RL, Wooten, K., & Halverson, S.K : **Behavioral and situational interviews**. In: *Comprehensive Handbook of Psychological Assessment, Industrial and Organizational Assessment. Volume 4*, edn. Edited by Thomas JC. Hoboken, NJ: John Wiley & Sons Inc.; 2004: 297-316.
16. Wiesner WH, Cronshaw SF: **A meta-analytic investigation of the impact of interview format and degree of structure on the validity of the employment interview**. *Journal of Occupational Psychology* 1988, **61**(4):275-290.
17. McDaniel MA, Schmidt FL, Hunter JE: **A meta-analysis of the validity of methods for rating training and experience in personnel selection**. *Personnel Psychology* 1988, **41**(2):283-309.

Appendix 29 Systematic Literature Review Paper - Response to Editor

Editor-in-Chief
Editorial Office
Patient Education and Counseling

Dear Dr Finset,

Ref.: major revision PEC-15-528, Title: Skills, Knowledge and Attributes of Support Group Leaders: A systematic review

Thank you for your correspondence and invitation to submit a revised version of the manuscript for re-evaluation. Consideration, time and comments from both yourself and the reviewers is very much appreciated.

By undertaking the major revisions as recommended, the authors believe the paper has been further improved to address an important topic for Patient Education and Counseling.

Please find below a summary of amendments to our manuscript in response to all reviewer comments. As requested, changes in the manuscript and other documents have been highlighted in bold.

We thank you for your re-evaluation of the manuscript and look forward to contributing to the journal.

Yours sincerely,

Amanda Pomery

Major Revisions PEC-15-528

Reviewer #1

Comment 1: Place the theme code on table at beginning, end, or in footnote of table so reader knows what these initials mean (GM GP RM A W Agree O).

As suggested, we have placed the theme code at the end of the table on page 19 to assist the reader.

Comment 2: State author/ co-author or PI/ co-PI within the text in regard to conducting analysis rather than initials of author - at first I did not understand what "AP" meant…?

As suggested, we have included author/ co-author before initials within the text to assist the reader.

Reviewer #2

Comment 1: Given the focus on peer support a clearer in depth discussion of peer support conceptually is needed. As well, unless the ideal leadership qualities are linked to effectiveness, these conclusions are conjecture. In the introduction there is no mention of the research showing the ideal skills, attributes and knowledge of peer support leaders specifically as opposed to health professionals and/or leadership theory which suggests the features of optimal leadership. The review would benefit from including this information.

We agree that discussion on the concept of peer support and its effectiveness was needed, and have included this on page 4 and 5 in the introduction.

We agree that this area is under researched, with no specific theoretical model or investigation into what the ideal knowledge, skills and attributes are for peer support group leadership. A number of theoretical perspectives are likely to be relevant, however have mainly been grounded in professional delivery of psychotherapeutic and educational programs as indicated on page 4, paragraph 3 in the introduction. It was the authors' intention to systematically review the available literature that refers to support group leader qualities in order for these to be identified.

Comment 2: In text (first section of the discussion) the authors make the statement "Across all eligible documents, seven main qualities were identified...These were consistent across group type and evident in literature reporting on peer, professional and mixed leadership". However there doesn't appear to be any evidence presented in the review to support this statement. In the results relating to leader qualities, sub-sections are needed which detail and compare the themes based on 1) group type (cancer vs. non-cancer) and 2) type of leadership (professional, peer, mixed).

We would like to highlight that comparisons based on group type appear on pages 13:

> ***Cancer groups.*** All seven qualities were identified in documents reporting on cancer groups (Table 1). The most frequently identified qualities related to Group Management (n=10), Group Process (n=8), and Agreeableness (n=8). Knowledge, skills and attributes relevant to Awareness, Willingness, Modelling and Openness were identified in five, five, four and three documents, respectively.

Non-cancer groups. Similarly, all seven qualities were identified in documents reporting on non-cancer or mixed groups (Table 1). Again, the most frequently identified qualities related to Group Management (n=22) and Group Process (n=22) and Agreeableness (n=15). Knowledge, skills and attributes relevant to Awareness, Willingness, Modelling and Openness were identified in 14, 10, seven and six documents, respectively. In this case, the order of frequency of qualities was consistent across group type.

No direct comparison for leadership was undertaken; this was a statement that the themes were evident (not necessarily consistently) by group leadership type. In this case, we have removed the latter part of this statement.

Comment 3: More description is needed on the results for qualitative studies, specifically the themes across studies and how these linked to the broader codes generated for the systematic review.

Comparing cancer and non-cancer support groups to ensure comparable themes across group type was the focus of this review; differences between qualitative and quantitative methodologies were not. Further, given the relatively small number of studies employing each methodology and the fact that some studies employed mixed methodologies, such a comparison was not practicable or translatable/interpretable. Nevertheless, the interested reader can glean this information from Table 1 now, because of the inclusion of raw codes.

Comment 4: The table while comprehensive would benefit from some re-organization to make it clearer for the reader. For instance, it would be useful to separate out by methodology (quantitative studies in one section, qualitative studies in a second section etc), and within this it would be helpful for results to be organized by group type (cancer vs. non-cancer) and/or leadership (professional, peer, mixed).

As suggested, Table 1 has been re-organised by group type (cancer, non-cancer, mixed, & unspecified) to make it easier for the reader. Organisation in this way also reflects the topic at hand and the question of whether leadership qualities are different across group type. We did attempt to re-organise by methodology and leadership as suggested. However, we found that the layering was overly complicated and would not be comprehensible or apparent to the reader. Reason for this is that leadership comprises of more than three categories, as combinations of leadership types reported are varied. Similarly, methodology comprised more than 2 categories to cover; qualitative, quantitative, mixed, narrative review, and theoretical exposition).

Comment 5: The table also should include actual results from each of the studies rather than solely the authors content analysis of these results. There needs to be a clear link, which currently is missing from the review, between what each study found and how this fits with the themes generated.

As suggested, Table 1 has been re-worked to include actual codes from each of the studies.

*Comment 6: The papers used in the systematic review should be designated in the reference list (e.g., by a * or similar).*

As suggested, papers used in the systematic review have been designated in the reference list by assigning * to each reference.

Comment 7: Quality of the research reviewed has not been assessed

The quality of the research was not assessed because piloting of search terms and the review itself indicated a very limited body of research. Moreover, the literature available was highly diverse – ranging from theoretical expositions to mixed methods cross-sectional studies – so there were no standard criteria that could be reasonably applied to all literature found. For this reason, we decided to undertake a thematic analysis that was more akin to a realist synthesis rather than a systematic review of Level 1 evidence.

We would like to highlight that rationale was outlined on page 9 as outlined below:

> No attempt was made to filter or prioritise eligible documents or qualities reported in therein, as the intent was to provide an exhaustive summary of all knowledge, skills and attributes bearing on the selection of support group leaders.

Appendix 30 Delphi Study Paper - Response to Editor

Editor-in-Chief
Editorial Office
Supportive Care in Cancer

Dear Fred Ashbury PhD,

Ref.: No. JSCC-D-17-00184 Supportive Care in Cancer
Expert agreed standards for the selection and development of cancer support group leaders: An online reactive Delphi study

Thank you for your correspondence and acceptance of the manuscript with requested revisions. Consideration, time and comments from the reviewers are very much appreciated.

By undertaking the revisions as recommended, the authors believe the paper has been further improved for publication with Supportive Care in Cancer.

Please find below a summary of amendments to our manuscript in response to reviewer comments, with changes in the manuscript highlighted in bold.

We thank you for your re-evaluation of the manuscript and look forward to contributing to the journal.

Yours sincerely,

Amanda Pomery

Ref.: No.JSCC-D-17-00184

Reviewer #2

Comments: Useful study which has produced expert consensus about the skills needed for cancer support group leaders, including peer support in the community. More explanation is needed to understand how the 114 KSA found after the first round had been narrowed down to only 52 during the round 2.

We thank the reviewer for their comments. We agree further explanation is needed to clarify the process of determining final list of KSA.

The following information has been added to the Methods section, Round 2, Second round analysis paragraph on page 4.

> **KSA identified as being *required to be ready to undertake the cancer support group leader role* by at least 75% of experts were accepted as minimum standards. A total of 52 KSA met the study's consensus criterion.**

Comments: Structured interview with 13 questions and 2 scenarios should be described in detail: who is leading the interview? How to use it for selecting cancer support group leaders?

We agree with the reviewer that a further description of the development and use of the structured interview would be beneficial. The actual structured interview has not been included as it is yet to be pilot and field tested. The full structured interview will be released once a rational scoring model has been established through this process. Only then can we make sound recommendation on how the interview can be used in decision-making. We kindly refer to reviewer back to the Limitations section on page 8, contained in the original manuscript, where this required step has been referred to.

In response, additional information has been added in bold to the Methods, Round 2, Structured interview development section, pages 4-5. Specifically we wish to highlight the following statements;

> **A structured interview to be used by cancer agency workers when assessing prospective group leader candidates was drafted with the aim of optimising the predictive validity and reliability of interviewer evaluations. In this case, role-relatedness was maximised by ensuring good coverage of consensus qualities, interview conduct was standardised wherever possible and a highly structured use of data in candidate evaluations was adopted (Dipboye et al., 2004).**

Please also note that in response to reviewer feedback on another project, reference to evidence-based minimum standards has been changed to consensus-based minimum standards to more clearly reflect the method of evaluation.