The role of support groups and ConnectGroups in ameliorating psychological distress

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Background

The purpose of this project is to provide current evidence on the value and effectiveness of support groups, and how ConnectGroups, as a leading peak body for self-help and peer support groups, compares to the activities and work of other domestic and international organisations. It is expected that by providing this information to ConnectGroups the organisation will be able to focus their activities on promoting and advocating for its members within the community and among funding bodies, further publicising/marketing its services, making informed decisions, sharing relevant knowledge, providing appropriate support and services, and educating its membership and external stakeholders. Therefore, this project was to conduct a review of literature relating to the:

1. benefits of self-help and peer support groups as a way to ameliorate and control stress-related health conditions
2. work and scope of activities of ConnectGroups as a peak body supporting and facilitating self help and support groups.

To complete this work this report is divided into three sections. Section 1 provides a theoretical understanding of support groups which includes professionally-led and volunteer groups, the latter including peer support and self-help groups. Section 2 is a systematic literature review to critically analyse national and international evidence for the efficacy of peer support and self-help groups to improve mental health for people with chronic obstructive pulmonary disease and cardiovascular disease. For the purpose of this review professionally-led support groups were not assessed as they are not aligned with ConnectGroups current model of support groups. For section 3, a systematic internet search was completed using Google search engine to identify local, national and international organisations which were similar to ConnectGroups, with comparisons made between organisations. Finally, recommendations are provided based on the findings of this report.
Defining support groups

Introduction
There has been considerable attention given to support groups within the literature, with evidence to suggest that support groups increase availability and access to health services, and are both an effective and economical method of treatment (Bottomley, 1997; Humphreys & Ribisl, 1999). As the number and availability of support groups is growing, both in Australia and internationally, it is becoming increasingly important to clarify the role of such groups, particularly in health care. Since 2004, there has only been ad hoc academic interest in support groups, despite it being such an area of growth (Munn-Giddings & McVicar, 2007).

Although there are numerous types of support groups, distinguishing between the different types of groups has become a challenge and remains largely unclear. This is predominantly due to the independent and non-standardised nature of support groups (Jackson, Gregory, & McKinstry, 2009). As Pistrang, Barker, and Humphreys (2008) explain, the term ‘support groups’ often incorporates a range of group types and functions which leads to misunderstanding. This is illustrated through authors using terms such as mutual aid groups or peer support services to encompass all group types (Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011; Solomon, 2004), whilst others terms such as mutual support groups, self-help groups, peer support programs, and consumer-run services are used interchangeably (Hildingh & Fridlund, 2001b; Munn-Giddings & McVicar, 2007). It is uncommon for studies to make clear distinctions between self-help groups, peer support groups and other ‘mutual aid’ programs. Thus, it is difficult to determine from the terms alone which type of group is being referred to in the literature. Indeed this lack of clarity is well supported (Jackson et al., 2009; Munn-Giddings & McVicar, 2007). As such the first section of this report will endeavour to make clear distinctions between professionally-led support groups, peer support groups and self-help groups, in order to clarify the nature of such programs and define their role within the health care context.

Background and theoretical models of support groups
Since the 1970s support groups have been emerging as a valuable component of health care, and have been found to help improve health outcomes and reduce mortality rates (Munn-Giddings & McVicar, 2007; Pfeiffer et al., 2011). The social movements of the 1970s which bolstered equal rights for minority groups, including people with disabilities and mental health problems (notably the women’s health movement), also led to a distrust of governments and well-established institutions, and hence community run health clinics were developed to enable autonomy over one’s own health care. These clinics and community-run groups are what we now recognise as support groups (Borkman & Munn-Giddings, 2008).
Support groups are founded on the premise that supportive interactions with people who have experienced similar problems can give individuals a sense of empowerment, increase self-efficacy, and enhance coping skills (Pistrang et al., 2008). According to Helgeson and Gottlieb (2000) support groups are rarely theory driven, but are guided by the notion that people facing similar problems have a shared understanding and can offer mutual, empathic support that naturally occurring social supports may not. A person’s own support network may lack experience, be consumed by their own stressors or feel uncomfortable responding to the issue (Helgeson & Gottlieb, 2000). Peers are therefore able to validate and normalise the problem, thereby reducing isolation and fostering a sense of belonging. Pistrang et al. (2008) describes this principle as ‘socially supportive interactions,’ in which the empathy derived from ones peer group can compensate for the absences in peoples natural support networks. This is supported by Bryan (2013) who suggests that peers who experience similar stressors have an exclusive capacity to respond empathically, due to a shared understanding of the issue.

**Theoretical models**

Two theoretical models have been posited in the literature that solidify the benefit of support groups (M. J. Stewart, 1990). Support groups are said to have both a direct and indirect effect on physical and psychological health outcomes (Dennis, 2003; M. J. Stewart, 1990). The indirect ‘buffering’ model suggests that support groups act as protection against stressors and builds coping skills (Dennis, 2003). This model is founded in Lazarus and Folkman’s 1984 coping theory, in which in order to cope effectively with challenges, cognitive and behavioural change is required (Lazarus & Folkman, 1984). However as stated previously, support groups are rarely theory driven, and as such there are a number of concepts that endorse and build upon this indirect model, strengthening the role of support groups (Helgeson & Gottlieb, 2000). One of these concepts is vicarious learning. Originating from Bandura’s social cognitive theory, vicarious learning is the concept that people learn through observing others and the outcome of others behaviour (Bandura, 1998; Dennis, 2003; M. J. Stewart, 1990). These interpersonal relationships are considered important in moderating the way in which an individual interprets and responds to an event (Dennis, 2003). Another concept pertaining to Bandura’s theory, earlier established by Reissman’s 1965 helper therapy-principle, is self-efficacy (Bandura, 1998; Gartner & Riessman, 1982; Roberts et al., 1999). Self-efficacy is where individuals assess their own ability to perform certain tasks or behaviours, and this assessment determines whether they engage and persevere with behavioural change. The more attention given to successes or gains made the greater self-efficacy (Bandura, 1998; Dennis, 2003). By helping others group members can develop an insight into one’s own problems and develop self-confidence, which facilitates behavioural change (Gartner & Riessman, 1982; Roberts et al., 1999). Even if a group member does not receive help, the
giving of advice and assistance is thought to provide equal opportunity for personal growth. As such the indirect model considers support groups to be an avenue through which vicarious learning can occur, and in which individuals can receive feedback from peers which enhances self-efficacy. Dennis (2003) distinguishes these processes of vicarious learning and self-efficacy as a separate model, the mediating effect model, however other authors contend that this process is part of the indirect effect of support groups (Cohen & Wills, 1985; M. J. Stewart, 1990).

The direct effect model proposes that social support has explicit benefits on health and well-being through encouraging social integration, fostering self-esteem, positive emotion, and reducing isolation, all of which are essential social needs, and occur through the development of significant positive relationships (Dennis, 2003; Pfeiffer et al., 2011; M. J. Stewart, 1990). Social integration has been associated with increased life span and survival from various serious health conditions such as cancer and depression (Dennis, 2003). This model can be linked to the social-inoculation theory, which suggests that social support influences the susceptibility to some infections and to some aspects of the humoral and cell mediated immune response (Pfeiffer et al., 2011).

**Types of support groups**

Two types of support groups have been identified within the literature; professionally-led and volunteer support groups. The latter group has been further divided into peer support and self-help groups. Figure 3.1 provides an illustration and summary of the types of support groups.
Figure 3.1: Illustration and summary of types of support groups.

Professionally-led support groups

Professionally-led support groups are therapeutic in nature, and focus on developing treatment goals within a group setting (M. B. Cohen & Mullender, 2006). These groups provide the opportunity for both mutual and trained support, with psychoeducation and rehabilitation common aims, particularly within the health context (Bright, Baker, & Neimeyer, 1999). A major component of these groups is sharing experiences, and providing feedback and assistance to bring about greater insight, awareness and personal change through the facilitation of a trained worker (Mason, Clare, & Pistrang, 2005). For example professionally-led support groups for dementia encourage sharing emotions, fears and concerns, which can lead to a better understanding of and adjustment to difficulties and changes in role and identity (Mason et al., 2005). A review on the literature for cancer support groups identified two main categories of professionally-led groups; supportive groups and psychoeducational groups (Bottomley, 1997). Supportive groups were focused on mutual support, encouraging group members to share experiences, feelings, and concerns (Bottomley, 1997). Psychoeducational groups were
more structured and remedial in nature, and involved education and specific cognitive and behavioural techniques (Bottomley, 1997).

Another specific of professionally-led support groups includes being facilitated by a qualified individual who has extensive training in their field (Stevinson, Lydon, & Amir, 2010). Usually these individuals are involved in support groups as part of their work, or as a voluntary extension of their job. In a health care context professionally-led groups may be run by nurses, social workers, or mental health specialists (Stevinson et al., 2010). The degree to which a professional is involved in a group can be highly variable, from adopting a highly structured leadership role in which education and knowledge is dispersed, to a more nondirective approach, in which group members are encouraged to share experiences and provide mutual support to one another (Twehues, 2009). As Lennon-Dearing (2008) states, combing the capabilities of an expert facilitator with the experiential knowledge of group members can be highly valuable. The mutual support offered in a professionally-led group however, is highly reliant on group member’s engagement within the group.

Volunteer support groups

Peer support groups

Dennis (2003) defines peer support as “the provision of emotional, appraisal and informational assistance by a created social network member”. This social network member must be a person who has personal experience with the health-related concern, and hence be considered a peer who can offer reciprocal support (Dennis, 2003; Oades, Deane, & Anderson, 2012). In terms of health and well-being peer support groups have a variety of aims, including illness-prevention, disease management, and health promotion. Three distinct aims of peer support groups are (M. B. Cohen & Mullender, 2006; Oades et al., 2012):

- to offer a remedial function through focussing on recovery
- an interactional objective by centring on personal experiences and relationships
- a social function through encouraging personal growth and empowerment.

These aims are achieved through emotional, appraisal and informational assistance. Whereby, emotional assistance endeavours to build self-esteem through reassurance and advice giving. Appraisal support involves problem-solving, encouragement, and building motivation and resilience. Lastly, informational support helps guide individuals on the causes of their concerns, suitability of their actions, and availability and effectiveness of resources. Through these mechanisms peer support groups aim to provide a sense of community, building significant interpersonal relationships, and in turn reducing the emphasis or reliance on counselling services (Dennis, 2003).
There are three forms of peer support groups that have been suggested in the literature; naturally occurring mutual support groups, consumer-run groups, and the employment of consumers in clinical and rehabilitation settings. (L. Davidson et al., 1999; L. Davidson, Chinman, Sells, & Rowe, 2006; Oades et al., 2012). L. Davidson et al. (1999) defines mutual support groups as people who voluntarily meet to solve or manage similar problems or concerns, through sharing life experiences, providing feedback, and gaining new knowledge, coping strategies and perspectives. Through this process individuals are offered acceptance, understanding, and assistance which helps develop a sense of community and self-efficacy.

Both consumer-run groups and consumers in clinical and rehabilitation settings have similar processes whereby individuals meet to address shared problems, and the facilitators of these groups are employees of an organisation. Therefore, the relationship between group members and the facilitator may be dictated to some degree by organisational boundaries (L. Davidson et al., 1999; L. Davidson et al., 2006). Consumer-run groups can also offer additional benefits of advocacy, public awareness, education, and knowledge building through the use of established social and organisational networks (Brown, Tang, & Hollman, 2014). Within the clinical and rehabilitation setting, peers can provide a more remedial role in helping recovery from health problems through developing treatment plans and encouraging specific tasks and goal setting as part of the group process (M. B. Cohen & Mullender, 2006).

Other key features of peer support groups include the non-professional peer must be based in a professional program, rehabilitation service, community organisation, or volunteer agency that has access to resources and organisations that can help recovery. An individual who offers support due to convenience such as a neighbour or co-worker does not constitute as peer support (Dennis, 2003). The peer may be paid or self-selected. In addition, there can be a number of providers of peer support groups, from community-based services, hospitals, and volunteer organisations (Dennis, 2003). More generally peer support groups may be found in schools, clinics, prisons, hospitals, community settings, home-based settings, and indirectly via online or telephone means (Dennis, 2003). Peers can adopt a number of roles, from educator and leader, to counsellor, mediator and advocator. Whilst peers are required to undergo some training to familiarise them to the process of support groups, and the skills required to effectively engage in these groups, training is ideally kept to a minimum as to not compromise the ‘peer’ relationship (Dennis, 2003). As Pfeiffer et al. (2011) explain, the peers may be experienced or novice in providing support services, and often provide voluntary assistance, hence making support groups more accessible through reduced costs.

**Self-help groups**

Self-help groups are commonly formed by individuals who get together to address a specific need or issue, to manage a particular problem, or to bring about change, through discussing
different coping strategies. This is distinct from self-help resources such as books and videos, and like peer support groups, directly excludes support groups run by health professionals (Gray et al., 1998). The term ‘self-help’ signifies that a person has identified that they need assistance, and take action to solve their problem (Pretto & Pavesi, 2012). The self-help principle distinguishes between mutual help and mutual self-help, in that self-help groups are not simply one group member helping another, but every group member should gain some insight and awareness into their issue through the support of others (Vanderavort & Vanharberden, 1985).

Self-help groups do not need professional involvement or a trained peer, unlike professionally-led groups and peer support groups. Self-help groups are run by a volunteer community member with a particular problem or concern, who wants to help others who have the same or a similar issue. According to Humphreys and Ribisl (1999) self-help groups are “self-governing groups whose members share a common health concern and give each other emotional support and material aid, charge either no fee or a small fee, and place a high value on experiential knowledge in the belief that it provides special understanding of a situation”. It is assumed that all members of a self-help group have experiential knowledge of the issue, and those who have already solved the problem or have made breakthroughs can use this knowledge to help others (Pretto & Pavesi, 2012). Self-help groups are applicable to a variety of health areas including chronic illness, mental health, disabilities, addictions and caregiving (Seebohm et al., 2013).

As self-help groups are a volunteer and autonomous service, group members willingly commit to social and personal change through engaging in group processes, such as sharing knowledge, experiences and offering assistance (Borkman & Munn-Giddings, 2008; Brown et al., 2014; Gartner & Riessman, 1982). Group members are reliant on their own skills, efforts, experiences and knowledge to help each other and bring about change (Levy, 1976). Unlike peer support groups they do not require involvement in any organisation or agency and hence remain independent self-governing programs. As Munn-Giddings and McVicar (2007) state, self-help groups are founded on sharing experiences, peer education, practical information and coping skills, all of which is directed by the group members themselves, enabling the individuals to have ownership over the way their group operates.

Humphreys and Ribisl (1999) contend that self-help groups offer accessible and effective interventions for specific problems, such as alcohol abuse, bereavement and adjustment difficulties, as well as augment professionally run programs and organisations. In addition self-help groups can take a significant burden off the healthcare system and provide greater access to health care services (Humphreys & Ribisl, 1999). Seebohm et al. (2013) reports that
the available evidence on self-help groups indicates the benefits of such groups can be personal, interpersonal and shared, including improving confidence and self-esteem, support, coping skills, and widening perspectives. Gartner and Riessman (1976) explain that self-help groups are not only applicable for people with acute and chronic illnesses, but also for those who have adjustment difficulties, behavioural problems and maladaptive coping skills, for example over-eating and over-drinking behaviours.

Summary
This section has discussed the origins and role of support groups, with an emphasis on health care settings. Whilst the literature is often unclear as to the distinctions between support groups, it is important to make this clarification in order to appreciate the role of the different types of support groups and the benefit each can offer. The primary difference between support groups lies with the knowledge and level of training held by the group facilitator, and the setting in which the groups are based. Professionally-led support groups are distinct from volunteer groups as they involve a qualified facilitator who is an expert in their field, and who generally does not have personal experience with the problem or concern being addressed in the group (Stevinson et al., 2010). A requirement of volunteer groups is the experiential knowledge of the issue, in which group members have a unique understanding of the problem and hence can offer empathy, advice and support which cannot be provided from other sources (Dennis, 2003; Oades et al., 2012; Pretto & Pavesi, 2012). Peer support groups however involve a novice facilitator who has received some training, and is involved in an organisation or agency that gives them the skills and resources to educate, counsel and advocate for their peer group (Dennis, 2003; Pfeiffer et al., 2011). This differs from self-help groups as these latter groups are run by untrained community members but commonly by those with lived experience, and are independent, self-governing programs, reliant on group members existing skills, knowledge, experience to operate (Levy, 1976; Munn-Giddings & McVicar, 2007). Overall, these groups are all based upon common principles of change, empowerment, and improved self-esteem; however each can offer different benefits to consumers (Pistrang et al., 2008).
Literature review

THE EFFICACY OF PEER SUPPORT AND SELF-HELP GROUPS TO IMPROVE THE MENTAL HEALTH OF PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE AND CARDIOVASCULAR DISEASE

Introduction

Chronic obstructive pulmonary disease (COPD) and cardiovascular disease (CVD) are two of the leading burdens of disease worldwide (World Health Organization, 2008). COPD is an irreversible lung disease characterised by airflow obstruction, and results in breathlessness, a chronic cough, and sputum production (Salvi & Barnes, 2009). In 2011 COPD was responsible for 102 per 100,000 deaths of people over the age of 55 in Australia, and is estimated to become the third leading cause of death worldwide by 2030 (Australian Institute of Health and Welfare, 2014; World Health Organization, 2008). CVD is a broad term that incorporates a number of heart diseases, including but not limited to coronary heart disease, peripheral arterial disease, rheumatic heart disease, congenital heart disease and cerebrovascular disease (World Health Organization, 2013). CVD is the most common group of diseases causing death in Australia, accounting for 14% of the total burden of disease (Australian Institute of Health and Welfare, 2014). Internationally, CVD is the single leading cause of death, and 23 million people are estimated to die annually from CVD by 2030 (Mathers & Loncar, 2006).

According to the latest publication from the Australian Institute of Health and Welfare (Australian Institute of Health and Welfare, 2014), the four major chronic disease groups of CVD, COPD, cancers and diabetes account for three-quarters of all chronic disease deaths. COPD and coronary heart disease in particular are greatly influenced by modifiable risk factors such as tobacco smoking, poor diet, and physical inactivity (Australian Institute of Health and Welfare, 2006). COPD and CVD are associated with long term health problems and declining functioning which not only is difficult for the individual but also places significant cost on the health care system (Calverley, 2008; Endo, Utz, & Johnston, 2012; Parry et al., 2009; Wiliamson, 1997). Indeed, both COPD and CVD patients suffer from increased mental ill-health particularly anxiety and depression, than the general population (Kessler et al., 2003; Polsky et al., 2005; Yohannes, Baldwin, & Connolly, 2000; Yohannes, Willgoss, Baldwin, & Connolly, 2010). Patients who suffer from poor mental health are more likely to have reduced quality of life, die younger, and have poor adherence to medication (Coleman, Katon, Lin, & Von Korff, 2013; Moussavi et al., 2007; Turner & Kelly, 2000).
Support groups attempt to overcome these problems by establishing social networks, increasing self-efficacy and enhancing coping skills (Pistrang et al., 2008). As Moullec et al. (2008) state, patient-run support groups encourage interaction between patients which expand their social support networks and promote autonomy over their own health care. This not only reduces demands on the healthcare system but also has substantial benefits for patient’s mental health. As Jackson et al. (2009) state, there is research to indicate that support is valuable in improving psychological and emotional wellbeing, in addition to fostering lifestyle changes that are crucial to disease management and recovery.

Volunteer run groups, self-help and peer support groups, are two distinct types of support groups. Self-help groups are run by untrained individuals and aim to provide mutual support, and are hence reliant on group members own skills, efforts, experiences and knowledge to help each other and bring about change (Levy, 1976). Peer support groups however are run by community members who have received some training in how to operate a support group, and are based in an organisation or agency that has access to resources which can help recovery (Dennis, 2003; Pfeiffer et al., 2011). As such peer support leaders can offer education, counselling, mediation and advocacy in addition to the fundamental mutual support provided in self-help groups (Dennis, 2003).

A review of the research on volunteer support groups by Kyrouz, Humphreys, and Loomis (2002) indicates that bereavement, weight loss, mental health, cancer and diabetes groups can improve psychological adjustment, increase self-esteem, reduce psychological distress, enhance coping skills, and build social networks. Therefore this paper aims to investigate the efficacy of volunteer support groups, self-help and peer support, in improving the mental health of people with COPD and CVD.

Method
A comprehensive search of the Medline database, PubMed, was undertaken in August 2014. Based upon previous systematic reviews on COPD and CVD, search terms were developed for disease specific terms, and self-help and peer support groups. All search terms were agreed upon by ConnectGroups and the research team (Table 1).
Table 1. Systematic search terms

<table>
<thead>
<tr>
<th>Constant keywords</th>
<th>Combined with</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Chronic obstructive pulmonary disease</em></td>
<td>Support groups</td>
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<tr>
<td>COPD</td>
<td>Consumer run organisations</td>
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<tr>
<td>Asthma</td>
<td>Peer support groups</td>
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<tr>
<td>Pulmonary disease</td>
<td>Peer interventions</td>
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<tr>
<td>Lung disease</td>
<td>Mutual help groups</td>
</tr>
<tr>
<td>Emphysema</td>
<td>Mutual support groups</td>
</tr>
<tr>
<td>Chronic bronchitis</td>
<td>Mutual aid groups</td>
</tr>
<tr>
<td><em>Cardiovascular disease</em></td>
<td>Self-help groups</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>Self-help programs</td>
</tr>
<tr>
<td>Coronary heart disease</td>
<td>Self-help interventions</td>
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<tr>
<td>Coronary artery disease</td>
<td>Community support services</td>
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<tr>
<td>CHD</td>
<td></td>
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<tr>
<td>CAD</td>
<td></td>
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<tr>
<td>Myocardial infarct*</td>
<td></td>
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<tr>
<td>Myocardial ischemia</td>
<td></td>
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<tr>
<td>Peripheral arterial disease</td>
<td></td>
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<tr>
<td>Peripheral vascular disease</td>
<td></td>
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<tr>
<td>Heart disease</td>
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</tbody>
</table>

Overall 1567 references, which included duplicates, were identified. Abstracts were read, and full texts were obtained if they fulfilled all of the following criteria:

- group members have either COPD or CVD
- an intervention of a self-help or peer support group as defined by:
  - self-help group: a self-governing support group run by an untrained facilitator who has experiential knowledge of the problem, and can provide mutual support, empathy, understanding and acceptance
  - peer support group: a support group run by a trained novice facilitator who has experiential knowledge of the problem and is involved in an organisation or agency, providing education, counselling, advocacy, mediation and mutual support
- primary outcomes included measures of mental health specifically screening for anxiety and depression
- secondary outcomes included quality of life, and social support
- group members meet face-to-face
- published in English
Overall 85 potential studies (27 on COPD and 58 on CVD) were identified. Two of these papers were systematic reviews on cardiac support groups, and reference list searches of these reviews were completed (Jackson et al., 2009; Song, Lindquist, Windenburg, Cairns, & Thakur, 2011). From these searches only 3 studies met the inclusion criteria for review. Eighty-two studies were excluded due to not having an intervention (n=33), support groups were included only as part of a chronic disease management plan (n=9), did not fit the criteria for support groups (n=10), did not have group session (n=8), online support groups (n=7), professionally-run groups (n=6), were not exclusively COPD or CVD patients (n=6), or recruitment was via support groups (n=3).

Results
For CVD, only one group of researchers were found to have conducted studies on the efficacy of volunteer peer support groups. Hildingh, Fridlund and colleagues from 1994 to 2004 conducted a longitudinal research trial examining the mental health and quality of life outcomes for the Heart-ten peer support group programs, which were peer support groups for people with cardiac problems arranged by the Swedish National Association for Heart and Lung Problems. In total five papers were published on the physical and psychosocial outcomes of peer support groups, however only three met our inclusion criteria (Table 2) (Hildingh & Fridlund, 2001a; Hildingh & Fridlund, 2003, 2004; Hildingh, Fridlund, & Segesten, 1995; Hildingh, Segesten, Bengtsson, & Fridlund, 1994). These three papers report the results of a longitudinal study which examined the physical, psychological and social well-being of cardiac patients who participated in a peer support group program compared to those who did not attend support groups over a 3 month, 1 year and 3 year follow-up (Hildingh & Fridlund, 2001b; Hildingh & Fridlund, 2003, 2004). Initially there were 197 patients who took part in the study, 73% were male and 27% female, with a mean age of 63.5 years. Of these, 133 patients attended the peer support groups; the remaining 64 participants were a convenience sample that formed a control group for standard treatment. All patients had been diagnosed with myocardial infarction, treated with percutaneous transluminal coronary angioplasty, or had recently undergone bypass surgery for a CVD. Varying outcomes were identified over the three years including CVD patients who attended the peer support group experienced no greater quality of life or psychological health outcomes than those who did not attend a support group. Social benefits were found in expanding social networks, developing close relationships and increasing engagement at different time points.

No evidence for self-help groups for CVD and COPD patients or peer support groups for COPD patients met our inclusion criteria.
Table 2. Volunteer Group Interventions for CVD patients

<table>
<thead>
<tr>
<th>Author</th>
<th>Sample/Group</th>
<th>Methodology</th>
<th>Measures</th>
<th>Intervention</th>
<th>Psychosocial Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hildingh et al. (2001)</td>
<td>N = 197</td>
<td>Quantitative</td>
<td>Jenkins Activity Survey</td>
<td>Heart-ten peer support group program</td>
<td>Increase in emotional and informational support. No differences in quality of life; stress, life satisfaction or belief in the future</td>
</tr>
<tr>
<td></td>
<td>Support group attendees (n=64) Controls (n=133)</td>
<td>Longitudinal</td>
<td>Zung self-rating depression scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age: 38 – 85yrs</td>
<td>3 month follow-up</td>
<td>Social Network and Social Support Scale</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Life Satisfaction Questionnaire</td>
<td></td>
<td></td>
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<tr>
<td>Hildingh et al. (2003)</td>
<td>N = 184</td>
<td>Quantitative</td>
<td>Zung self-rating depression scale</td>
<td>Heart-ten peer support group program</td>
<td>Increase in informational support. No further differences between groups</td>
</tr>
<tr>
<td></td>
<td>Support group attendees (n=59) Controls (n=125)</td>
<td>Longitudinal</td>
<td>Social Network and Social Support scale</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Age: 38 – 83yrs</td>
<td>12 month follow-up</td>
<td>Life Satisfaction Questionnaire</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hildingh et al. (2004)</td>
<td>N = 160</td>
<td>Quantitative</td>
<td>Jenkins Activity Survey</td>
<td>Heart-ten peer support group program</td>
<td>Increase in social networks. No further differences between groups.</td>
</tr>
<tr>
<td></td>
<td>Support group attendees (n=35) Controls (n=125)</td>
<td>Longitudinal</td>
<td>Zung self-rating depression scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age: 41 – 83</td>
<td>3 year follow-up</td>
<td>Social Network and Social Support Scale</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Life Satisfaction Questionnaire</td>
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Discussion
This paper has investigated the efficacy of peer support and self-help groups in improving the mental health of people with COPD and CVD. Our comprehensive search of the literature has determined that evidence on the utility of volunteer support groups for improving mental health outcomes among these populations is simply lacking. The three papers were successful in providing longitudinal data on the benefit of support group participation compared to a control group, however as participants were not randomised into groups the results should be interpreted with caution, a limitation acknowledged by the researchers (Hildingh & Fridlund, 2004). This is comparable to studies on support groups for numerous other health conditions such as cancer, epilepsy, scoliosis and diabetes, with the majority of research employing a nonrandomised design (Becu, 1993; Hinrichsen, 1985; Maisiak, 1981; Simmons, 1992).

Indeed, the lack of studies reporting on the efficacy of support groups was recently discussed in a literature review by Cafarella, Effing, Usmani, and Frith (2012). They reviewed the efficacy of interventions for anxiety and depression among COPD patients, and found that whilst group sessions were common in the treatment of COPD, these are often rehabilitation programs or self-management programs. Interventions which were solely self-help groups had not been reported in the literature. It appears that no additional research has been undertaken since 2012 on volunteer support groups for these populations. Of the 27 studies on support groups for COPD patients that were identified in our search, all support groups had some degree of professional involvement, were part of a wider treatment plan, were online support groups, or did not have an intervention.

Due to a lack of evidence on the benefit of volunteer support groups for COPD and CVD patients, we have postulated a number of reasons why this has occurred.

Focus on professionally-led groups
To date the research on support groups appears to focus predominantly on professionally-led groups. Professionally-led support groups are those facilitated by a qualified individual who has extensive training in their field (Stevinson et al., 2010). In a health care context professionally-led groups may be run by nurses, social workers, or mental health specialists (Bright et al., 1999; Stevinson et al., 2010). Evidence suggests professionally-led groups can improve patients health-related quality of life, foster adaptive coping strategies, build stress management skills, increase motivation and engagement, as well as develop social networks which enhances connectedness and reduces isolation (Alberto & Joyner, 2008; Brooks, Krip, Mangovski-Alzamora, & Goldstein, 2002; Jensen, 1983; Mularski et al., 2009; Schulz et al., 2008).
Although not directly searched, we found three studies that reported on psychosocial outcomes from professionally-led groups for COPD and CVD patients (Alberto & Joyner, 2008; Mularski et al., 2009; Schulz et al., 2008). These studies comprised of two randomised control trials and a convenience nonrandomised sample, and suggested that professionally-led support groups are effective in improving quality of life, developing stress management skills, and building hope and optimism (Alberto & Joyner, 2008; Mularski et al., 2009; Schulz et al., 2008). An additional three studies on professionally-led support group were also found, however these papers did not report on psychosocial outcomes (Frey, 2000; Jensen, 1983; Wilson, Fitzsimons, Bradbury, & Elborn, 2008).

Ambiguity of definitions
The different types of support groups are often ill-defined in the literature, with many studies using terms such as mutual aid groups, mutual support groups and self-help groups to describe any type of support group, despite the distinction between self-help groups, peer support groups and professionally-led groups (Jackson et al., 2009; Munn-Giddings & McVicar, 2007; Pistrang et al., 2008). Although we used all of these terms in our searches, upon closer examination of the literature many studies that allege to report on self-help groups are run by trained personnel who do not share the same condition or concerns as group members, or are in essence psychotherapy groups requiring the involvement of healthcare professionals (Kyrouz et al., 2002). This could account for the high number of studies on professionally-led groups obtained in our searches. In addition, as Kyrouz et al. (2002) asserts, in practice volunteer support groups often use professionals as advisors and assistors in establishing and maintaining their support services, and this blurs the boundaries between groups that are member run and classed as peer support and self-help groups, and those that have professional involvement and are categorised as professionally-led groups. In fact, the degree to which professionals can be involved in volunteer support groups, without jeopardising the mutual support upon which these groups are founded, remains undetermined. Some volunteer groups remain autonomous and adopt an anti-professional position, whilst others seek the advice of professionals to help in the operation and management of their program (Hildingh et al., 1994).

There are also a number of support groups that have professionals and peers as co-facilitators. Two studies were identified in our searches that included both professionals and peers in support group facilitation. The first was a hospital-based support group for heart disease patients (Hughes, 1980). In this study health professionals were involved in setting the topic for discussion for the support groups each week, and ensuring the groups proceeded according to the program goals, however the group was led by a volunteer with heart disease who could relate to the emotional and psychological difficulties associated with the condition.
Hughes, 1980). The other more recent study examined the efficacy of a support group for patients with myocardial infarction, in which health professionals offered information about heart disease, possible causes and symptoms, as well as relaxation techniques and dietary information, and a peer co-facilitator provided emotional support, positive feedback, encouragement and hope (M. Stewart, Davidson, Meade, Hirth, & Weld-Viscount, 2001). Although these additional studies blur the boundaries between professionally-led support groups and volunteer support groups, they also provide positive evidence for the efficacy of these types of groups.

Integrated chronic disease management including support groups
A trend among the literature is the inclusion of support groups as part of chronic disease management plans. It is now common for research studies to design a multi-disciplinary rehabilitation program with a view to holistic patient care. Whilst support groups are included in the intervention, often treatment outcomes are reported on the overall efficacy of the treatment plan, and therefore it is difficult to discern the benefit of support groups alone. This was apparent when reviewing our search results. For example, two studies unveiled in our searches evaluated an intervention for COPD patients that incorporated exercise training, health information sessions, and a monthly peer support group for psychosocial support supervised by a psychologist (Moullec & Ninot, 2010; Moullec et al., 2008). Measures of dyspnea, quality of life, healthcare utilisation and lung function were undertaken, and whilst the program was found to be effective overall in reducing hospitalisations and improving quality of life, neither paper undertook analysis on the role of support groups alone (Moullec & Ninot, 2010; Moullec et al., 2008). In both cases conclusions were only made on the supposition that support groups improve well-being, self-esteem, as well as functional and emotional dimensions of quality of life. A number of other studies for both COPD and CVD followed this line of reporting, with the majority of studies devising treatment plans for COPD and CVD patients in which the support groups were professionally-led, both of which limit the quantity of articles from which volunteer support group outcomes could be derived (Brooks et al., 2002; Channer, Barrow, Barrow, Osborne, & Ives, 1996; Christenhusz, Pieterse, Seydel, & van der Palen, 2007; D. M. Davidson & Maloney, 1985; Heisler et al., 2013; Scherer, Janelli, & Schmieder, 1992; Wiliamson, 1997).

Online support groups
Face-to-face contact is no longer a requirement of support groups with online social networks becoming increasingly common, providing more accessible forms of health service delivery (Magnezi, Bergman, & Grosberg, 2014; Medina, Loques, & Mesquita, 2013). In turn there is a subsection of the support group literature that focuses on the benefit of online support groups.
Medina et al. (2013) recently investigated the efficacy of online support groups for CVD patients, and found four articles which met their criteria. These papers all identified psychological and emotional benefits from online support group participation, such as reducing isolation, increasing motivation, instilling hope and increased quality of life (Medina et al., 2013). For example, a randomised control trial investigated the benefit of online heart disease support groups in bringing about behavioural change in patients with coronary heart disease (Lindsay, Smith, Bellaby, & Baker, 2009). This study compared moderated online groups, that is, online groups that are facilitated by health professionals, to un-moderated online support groups which are based solely on peer interactions (Lindsay et al., 2009). Lindsay et al. (2009) found that moderated online support groups help to increase social support, build motivation and self-confidence, and in turn reduce risky behaviours such as poor dietary intake, outcomes which were not replicated in the un-moderated support group phase. Overall, the literature suggests there is a growing movement towards online support groups, and there is a potential for research to be focused on this growth area.

**Emphasis on qualitative data and case studies**

Much of the research undertaken on self-help and peer support groups originated in the 1970s, where support groups emerged in the form of community run health clinics, designed to enable autonomy over one’s own healthcare (Borkman & Munn-Giddings, 2008). It was not until the mid-1990s that quantifiable data started to emerge on the efficacy of support groups. As such a substantial proportion of the literature is based upon qualitative data and case studies. Because these studies do not provide outcomes from a measurable intervention they did not meet the criteria for this paper (Francis, Petty, & Winterbauer, 1984; Gilliland, 1979; Hildingh et al., 1994; Imhoff, 1976; Klinger, 1985; Morland, 1992; Stanford, Buttery, & Di Ciacca, 1996). These papers do however indicate that COPD and CVD patients find support groups helpful and reassuring (Morland, 1992), increase emotional support and companionship (Hildingh et al., 1994), build confidence, enhance coping skills, and develop a sense of belonging (Gilliland, 1979), all of which are essential psychosocial needs.

**Conclusion**

It is difficult to make conclusions as to the efficacy of volunteer support groups for COPD and CVD patients, primarily due to the ambiguity in support group processes and definitions, and the focus on healthcare professionals in support group programs (Alberto & Joyner, 2008; Jackson et al., 2009; Mularski et al., 2009; Munn-Giddings & McVicar, 2007; Pistrang et al., 2008; Schulz et al., 2008). Whilst there is some evidence to suggest that self-help and peer support groups may be beneficial in increasing patient’s confidence, self-esteem, coping skills, and overall quality of life, this evidence is tentative, and a greater body of research is required before any substantial conclusions can be made (Hildingh & Fridlund, 2001a; Hildingh &
Studies on volunteer support groups for cancer patients, people with mental illnesses, diabetes patients, people with weight concerns, individuals with alcohol additions, and those who are experiencing bereavement, indicate that support group participation can improve psychological adjustment and reduce distress, increase self-esteem, and promote adaptive coping skills, however the evidence is lacking for COPD and CVD populations (Kyrouz et al., 2002). There is preliminary evidence to suggest volunteer support groups offer social benefits, through reducing isolation, increasing social networks and building close empathetic relationships (Hildingh et al., 1994; Song et al., 2011), however more research is required to determine the efficacy of self-help and peer support groups in improving the mental health of these two populations relative to other treatment options.
Website search

Introduction
The aim of section two was to identify domestic and international organisations which completed similar activities to ConnectGroups. The outcome of this section enables ConnectGroups to have a direct comparison of their organisation to advocate for their organisation and potentially improve their online presence.

Method
To compare and contrast ConnectGroups with similar organisations, a list of activities that are currently being undertaken ConnectGroups were discussed with key personnel. This resulted in the following activities being determined for comparison; the development of support groups; education and training which includes the delivery of workshops; a referral service and/or directory; advocacy; promotion; the participation in research; and support group membership to the organisation.

Search
A comprehensive search of Google was completed. The search string included the following keywords:

- **Constant keywords**: self-help group, support group, peer support group
- **Combined with**: training, service, referral, education, information, mentor, community, advocacy, repository, clearinghouse, peak body, research, promotion

Google yielded 16,400,000 hits; most of which were irrelevant or repeats. All resultant sites were visited until repeated listings suggested no more new sites would be found. All websites identified were checked for directories of other similar websites, which were also searched for comparable websites. Websites were excluded if they were about a specific disease, were based on one area of health (e.g. mental health), were not in English and did not have at least two of the activities performed by ConnectGroups.

Results
Overall there were 12 websites identified that had similar characteristics to ConnectGroups. Of these three were domestic and nine were international websites. Table 4.1 provides a comparison of all websites to ConnectGroups activities.

No other organisation completed all of the activities that ConnectGroups participates in. Three organisations completed six of the activities; Self-Help Queensland Inc (domestic); Collective of Self Help Groups (domestic); and Self Help Connect UK (international). The three most common activities completed by organisations were the aid in the development of support
groups, education and training, and referral to or the provision of an online directory of support groups. In addition, two organisations, Self Help Organisations United Together (SHOUT) and the New Jersey Self-help Clearinghouse, had directories of similar domestic and international organisations. ConnectGroups was incorrectly identified on the SHOUT website and was absent on the New Jersey Self-help Clearinghouse.
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Aid in the development of support groups</th>
<th>Education and training</th>
<th>Referral service and/or directory</th>
<th>Advocacy</th>
<th>Promotion</th>
<th>Complete research</th>
<th>Membership to organisation</th>
<th>Other</th>
<th>Total activities completed (excl. Other)</th>
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<td>x</td>
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<td>✓</td>
<td>x</td>
<td>6</td>
</tr>
<tr>
<td>4. SHOUT (Self Help Organisations United Together)</td>
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<td></td>
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<td>7. Alaska peer support consortium (USA)</td>
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<td>8. PeerNetBC (Canada)</td>
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</tr>
<tr>
<td>9. American self-help Clearinghouse (USA)</td>
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</tr>
</tbody>
</table>
Recommendations

The recommendations from this report are provided below.

Section 1
It would be beneficial for individuals who are working at ConnectGroups to be clear in their definition of support groups, particularly in the role of self-help and peer support groups, and the mutual support and experiential experience of facilitators that is provided. Ultimately, this would help in the promotion of ConnectGroups.

Section 2
1. Given the limited evidence found for CVD and COPD broadening the search to include cancer and stroke may provide additional evidence on the efficacy of volunteer support groups.
2. ConnectGroups is in a unique position to complete research into the efficacy of volunteer support groups, specifically mental health, quality of life, and social support outcomes for participants. Potential projects could include:
   a. Assessing individuals who are referred to a support group using a pre- and post-design whereby the controls are those that don’t take up the support group
   b. Determine whether a specific chronic disease may benefit from a particular support group e.g. Does COPD patients have improved mental health if they attend a self-help versus a peer support group?
   c. A randomised control trial to compare a volunteer support groups and professionally-led group to a control group.

Section 3
1. Contact SHOUT and organise for ConnectGroups to be updated on their web page.
2. Contact the New Jersey Self-help Clearinghouse and organise for ConnectGroups to be added to their Clearinghouse directory.
   (http://www.mededfund.org/NJgroups/CLEARINGHOUSES.htm)
## Appendix 1

<table>
<thead>
<tr>
<th>Organisation</th>
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<th>Country</th>
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</thead>
<tbody>
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<td></td>
</tr>
<tr>
<td><strong>International</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Center for Community Support and Research, Wichita State University</td>
<td><a href="http://www.wichita.edu/thisis/home/?u=ccsr">http://www.wichita.edu/thisis/home/?u=ccsr</a></td>
<td>USA</td>
</tr>
</tbody>
</table>


Endo, T., Utz, M., & Johnston, P. (2012). Hospital utilisation and funding for patients with selected chronic conditions - 1. Asthma/COPD. State of Queensland


