

Exploring Peer Support as an Approach to Supporting Self Management

Feasibility Study Report
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mental
health
foundation

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Mental Health Foundation

The Mental Health Foundation (MHF) is the leading UK research and development charity working in mental health, learning disabilities and dementia. The Foundation is unique in bringing teams that undertake research, develop services, design training, influence policy, and raise public awareness within one organisation.

MHF works across the UK and Europe, with a wide variety of partners including the voluntary sector, businesses, local authorities, health boards, national bodies and networks. This breadth means that we are ideally placed to bring a vision of the 'bigger picture' of wellbeing to inform everything we do.

In February 2011, the Scottish Development Centre merged with the Mental Health Foundation, at that time, this feasibility study became part of the Mental Health Foundation's work programme.

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Introduction

In January 2010 the Scottish Development Centre for Mental Health (SDC) was awarded funding from the Long Term Conditions Alliance Scotland's (LTCAS) Self Management Fund to develop this feasibility study. In February 2011, the Scottish Development Centre merged with the Mental Health Foundation. At that time, this feasibility study became part of the Mental Health Foundation's work programme.

The study aimed to explore peer support as an approach to support self management and to assess the potential for formalised peer support to be developed for people with long term conditions. In February 2011 SDC merged to become the Mental Health Foundation (MHF). Work on the feasibility study continued as a part of the MHF's work programme. The funding was then extended by LTCAS to disseminate the findings of the feasibility study and to work with key stakeholders to put the feasibility study recommendations into action by creating a network of motivated people and involving them in kick-starting the further development of peer support.

Background

In 2006, Delivering for Mental Health¹ set out a commitment to support recovery based mental health services and recognised the contribution of peer support to this:

"Commitment 2: We will have in place a training programme for Peer Support Workers by 2008 with Peer Support Workers being employed in three board areas later that year."
(Delivering for Mental Health, 2006)

Towards a Mentally Flourishing Scotland: Policy and Action Plan 2009-2011² peer support provided further help for the promotion of the principles of recovery and the implementation of peer support championed by the work of the Scottish Recovery Network.

The 'Guan Yersel' The Self Management Strategy for Long Term Conditions (2007)³ defines self management as the process each person develops to

manage their conditions. LTCAS's vision is that people with long term conditions 'enjoy, not endure, full and positive lives - lives free from discrimination and supported by high quality services'. Self management is:

"the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living for the rest of their life with one or more long term conditions."
(Guan Yersel, 2007)

The Scottish Government's definition of recovery in mental health echoes LTCAS's vision:

"Recovery is being able to live a meaningful and satisfying life, as defined by each person, in the presence or absence of symptoms. It is about having control over and input into your own life. Each individual's recovery, like his or her experience of the mental health problems or illness, is a unique and deeply personal process."
(Scottish Recovery Network, 2011)

Guan Yersel in turn highlights the concept of recovery, which is well developed in the mental health field as something that needs to be developed amongst professionals and patients in long term conditions. There is also recognition here that recovery and self management are interlinked concepts:

"Recovery needs to be adopted as a concept relating to self respect, spirit, self esteem and sense of self. While people are generally unlikely to recover from the condition itself, effective management of symptoms balanced with increased autonomy and independence can help recover optimum wellbeing."
(Guan Yersel, 2007)

Guan Yersel calls for more attention to mental health and increased access to peer support:

"This strategy aims to work towards a situation in which people living with long term conditions have access to

¹www.scotland.gov.uk/Publications/2006/11/30164829/0

²<http://www.scotland.gov.uk/Publications/2009/05/06154655/5>

³www.scotland.gov.uk/Publications/2008/10/GaunYersel

the support they need to successfully manage their condition. This could include: information leaflets; courses run by others with similar conditions; one to one support; structured education; and self management courses. All of these will empower people to learn about their condition, acknowledge the impact on their life, make changes and identify areas where they need support.”

The NICE Guideline (2009) Treating depression in adults with a long-term physical health problem⁴ indicates that treatment for mild to moderate depression should include peer support. The peer support referred to is group meetings with people with the same physical health problem to share their experience.

The Long Term Conditions Collaborative’s report High Impact Changes⁵ (2009) calls for the commissioning of peer support groups for people with long term conditions and their carers and provide relevant, accessible information:

“Community and voluntary groups play an important role in boosting people’s confidence and getting them involved in their community. Many are formed to support people living with specific conditions; provide disease-specific education and training; allow peer support with people in similar circumstances; provide advocacy support; and lobby for service change and improvements. In order to better self manage their health, patients need to be able to find out about national and local support groups and organisations.”
(High Impact Changes,2009)

The recent LTCAS report Seen and not heard? Exploring issues facing children and young people living with long term conditions⁶(2010) highlights that living with a long term condition often has a significant impact on a child or young person’s mental health and wellbeing and makes a number of recommendations for better addressing this need. It recommends that there is improved access to a range of types of peer support for this group.

The need for this feasibility study was identified as a result of SDC’s work with people with enduring mental health problems and with long term physical conditions. Over the last seven years

SDC has been involved in bringing formalised peer support for people with mental health problems to Scotland, working in partnership with the Scottish Government and the Scottish Recovery Network⁷. Currently, in some areas of Scotland, there are trained and paid peer support workers employed in mental health acute and community based services. The Scottish Recovery Network is also developing an SVQ level training course for mental health peer workers.

In addition, SDC jointly led Living Better⁸, which aimed to improve the mental health and wellbeing of people with diabetes, chronic obstructive pulmonary disease (COPD) and coronary heart disease (CHD). In 2010 early Living Better patient and carer focus groups on the experience of living with a long term condition (attended by over 200 people with long term conditions and their carers) indicated that people with these long term conditions wanted more attention paid to their mental health and wellbeing. A consistent finding to emerge across all five Living Better sites was that living with one or more long term condition can be both an acute and chronic stress to individuals and their families. People with COPD, diabetes or CHD talked about how living with a long term condition can result in experiencing a range of emotions including ‘frustration’, ‘anger’, ‘feeling down’, ‘isolated’, ‘financial worries’, ‘loss of confidence’, ‘lack of energy’, ‘frightened’, ‘having to make major lifestyle changes’. The stigma of mental illness made it difficult for many with long term conditions to reveal the true extent of their emotional distress and have the confidence to seek appropriate help.

Patient survey findings from Living Better, based on the experiences of 500 people living with COPD, diabetes or CHD, found that:

- Over 50% lived with more than one long term condition;
- More than one third scored mild/moderate/severe for depression and anxiety based on the Hospital Anxiety Depression Scale;
- More than one third reported that their social and leisure activities were significantly impaired due to their condition;
- When asked whether they felt

⁴ www.nice.org.uk/nicemedia/pdf/CG91PublicInfoWord.doc • DOC file

⁵ www.scotland.gov.uk/Publications/2009/03/06084301/0

⁶ www.ltcas.org.uk/policy_reports.html

⁷ www.scottishrecovery.net

⁸ www.livingbetter-scotland.org.uk

optimistic about the future, over a quarter of respondents replied 'none of the time or rarely'.

These patient groups expressed the need for more mental health support than was currently on offer which was not meeting their needs. They wanted more formalised social support and someone to talk to, especially someone who has been through a similar experience to themselves.

Recent literature reviews⁹ on peer support in mental health and a number of evaluations of peer support pilots in prison, community and mental health care settings, including the Scottish Government's Delivering for Mental Health peer support worker pilots in 2009¹⁰ demonstrate the significant positive impacts on peer workers and those receiving peer support in terms of their ability to self manage their mental wellbeing and live fulfilled lives.

This project draws on knowledge about the need to better address the mental health needs of people with long term conditions and learning from the formalisation of peer support in mental health. Formalised peer support in mental health is where people with a lived experience of recovering from a mental health problem are trained and paid to be peer support workers who work as a fully integrated member of the multidisciplinary care team; not an add on to the team. In Scotland, this model has been shown to have considerable benefits for patients and multi-disciplinary teams in community and inpatient mental health care settings (see above). The formalised peer support model is currently not available in multidisciplinary care teams supporting those with long term physical conditions in primary or acute care in Scotland. Despite the perceived need to better address the mental health and wellbeing needs of those living with long term conditions and the growing evidence base about the potential role of peer support in meeting this need, currently there is no national lead or direction on how to take this forward.

Aims of this study

This project aimed to build on existing examples of informal peer-based support for people with long term conditions by working with individuals and agencies which had experienced management services. The project

aimed to promote holistic care and increase the attention on mental health and wellbeing for people with physical conditions. In the long term, by elucidating the advantages of peer support, its relationship to self management and how it might be implemented by agencies working with people with long term conditions, it is anticipated that this work will benefit many people with all types of conditions.

The specific aims of the feasibility study were to:

1. Promote holistic health care for people with long term conditions with particular emphasis on support for mental wellbeing.
2. Transfer learning from the introduction of formalised peer support worker roles within mental health services to long term condition services and raise awareness of existing (informal) peer services within long term conditions care.
3. Scope the potential for formalised peer support roles for individuals with long term conditions, with an initial focus on coronary heart disease.
4. Support improved health outcomes for people with long term conditions.
5. Include more people with long term conditions in service design and delivery.

Report Structure

This report provides a detailed findings section of the feasibility study covering: how a peer and peer support are currently defined in long term conditions; the kinds of peer support currently available for people with long term conditions; who does and would benefit most from peer support and how well their needs are currently met; gaps and challenges to current delivery and finally the potential for further developing peer support for long term conditions.

This is followed by conclusions and recommendations for the future, taking into account the seminars conducted with the top-up funding received from LTCAS. A separate full report of the seminar proceedings and their evaluation is available. The short paper and article have also been produced as separate documents.

⁹ <http://www.scottishrecovery.net/Peer-Support/supporting-resources.html>
¹⁰ <http://www.scotland.gov.uk/Publications/2009/11/13112054/4>

Methodology

Because of the complex nature of this subject, a variety of participative and qualitative methods were used to understand the potential for introducing formalised peer support for people with long term conditions. This included working with people from diverse backgrounds, both those experiencing long term conditions and those responsible for providing support for them, to maximise the number of perspectives considered in the study. The project team worked with a wide range of individuals and agencies which have experience of providing peer support and self management services.

Desk based research

The first part of the desk research entailed a review of Scottish literature, including any unpublished materials available from service providers. These reports were used to obtain a picture of existing models of peer support within the long term condition sector in Scotland and of the current Scottish policy positions of key institutions such as the Scottish Government and LTCAS on peer support in long term conditions. This was then compared with the formalised peer support worker role as it has developed within mental health services in Scotland.

The next stage of the desk based research was an internet search for national organisations which support people with long term conditions to gain information on what peer support already existed.

Survey

To build on the information gleaned from the internet search, a short internet survey was designed on Survey Monkey. The survey was disseminated electronically to the 81 projects funded by the LTCAS Self Management Fund by sourcing contact details from their websites, as well as to the 15 designated long term conditions health board leads and additional organisations identified in the internet search.

The email invitation to participate in the survey sent out to contacts included an information sheet about the project, an outline of the purpose of the research and a link to the survey. The email and information sheet can be found in Appendices 1 and 2. The survey asked respondents to input brief details of any projects with a peer support element that they were aware of (see Appendix 3). In addition, LTCAS posted the survey link on their website and sent it out via their e-bulletin. A total of 46 responses to the survey were received, 38 of which were complete.

In-depth discussion with professionals and peers

All those who had responded to our survey and/or whom we had identified through the internet search, were invited to participate in in-depth discussion groups (see Appendix 4.)

Sixteen in-depth discussions were held with health (including local Collaborative Managers), social care and voluntary agencies that had responded to the survey and /or who had been identified in the internet search or through existing working partnerships that the study team were involved in through other projects.

The discussion groups ranged in size from 1 – 6 people and in total 38 people participated in the discussions. Of these, 13 people identified themselves as having a long term condition; these people were either professionals or voluntary workers who described themselves as peers. The remaining 25 participants were professionals working with those who have long term conditions but did not disclose that they had long term conditions themselves.

The groups explored the availability of, and started to think about, the supportive and progressive working environment necessary for formalised peer support workers. The full interview schedule can be found in Appendix 5.

Findings

The findings below are based primarily on the in-depth discussions and, to a limited extent, on the survey responses. There were no significant differences between the data provided by peers and non-peers/professionals therefore participant's views are reported as one group. However where a specific point was made only by either a professional or a peer or a particular organisation, reference is made to this.

What is a peer in long term conditions?

Participants offered a range of definitions of peer support, some examples are:

"Having a similar condition and experience of mental health problems/distress." (Interviewee CHSS)

"If you have a long term condition you have so much in common with another person with a long term condition in terms of the emotional impact and challenges involved that you can identify as peers on that level." (Interviewee GC)

"Someone with a similar condition, who has lived with their condition for some time and is making a go of it." (Interviewee WC)

"Someone who has been through similar situations and problems as another person." (Interviewee PL)

The discussions in this study suggest that there are two key elements within the definition of a peer in long term conditions. The first element is the peer connections between those in the relationship and the second is the quality of the peer relationship.

Peer connections

Between any two individuals or a group, there is the potential for peer connections. Peer connections can be found on a number of levels; for example it might be a similar health condition, similar leisure interests, professional backgrounds, religious beliefs, social values, or age. One

important area of peer connection is the capacity of peers to understand what it is like to live on benefits or to lose your job or have to give up working because of the limitations that a long term condition has imposed.

A few participants felt that age differences can be a barrier to people feeling that they are in a peer situation, perhaps more so in a group setting. In Chest Heart and Stroke Scotland (CHSS), some peer groups that are led by people who began them in their 60's are becoming an 'older' group. This can put off some younger people. There is work going on in both NHS Dumfries & Galloway and CHSS to consider what younger patients need from continued rehabilitation and self management support.

Discussions with participants revealed that peer connections can be measured quantitatively and qualitatively but that judgement is always subjective. For example two people may be connected solely because they have the same long term condition, another two may be connected because they are from the same part of town, same sex, have the same professional background but have different long term conditions. It is difficult to judge on this information which two have a stronger peer connection. To understand the value of a peer, the quality of the peer relationship needs to be taken into account.

The peer relationship

Peer support cannot exist without the peer relationship. What is deemed to constitute a peer and a peer based relationship will vary by the individual requiring support and the care providers delivering a peer service. In that relationship there are always at least two people. Between people a number of different elements may be more or less important in terms of establishing a good peer relationship.

When asked to really look at what it is that makes peer support successful, participants stated empathy and trust. Identifying peer connections can increase the chances of facilitating a good relationship with empathy and trust as central components.

It is possible to find valuable levels of connection other than the person's condition. What a peer may need is to be adapted on an individual basis, otherwise, generalisations in terms of condition could mean that other more important peer elements are missed and the peer relationship is weaker. What people want from a peer relationship is very personal and a coordinator or peer facilitator can only go so far in setting the foundations for a good relationship. Some organisations provide flexibility for individuals by giving them the options of sticking to one peer, changing their peer if they want or choosing not to have one specific peer they work with.

Peer matching

Peer facilitators from two organisations participating in this study have developed systems to match individuals with a peer volunteer. These facilitators try to identify the peer elements that are most important for an individual's support needs on a case by case basis in an attempt to build the foundations for a good peer relationship. This is the challenge of matching.

CHSS do not require their volunteers to have had similar health experiences as those they may be supporting. However, they have a rigorous matching process for each client and volunteer. Within this, they do not include any consideration of gender, having found that it is difficult to know when and how it is appropriate to bring this into play. Another difficult area is cultural background, one participant recalled both a volunteer and individual being highly offended when matched primarily for this reason. Ideally, matching will be based on a number of peer connections.

Participants have found that matching is not something that can be done on paper. The coordinator/professional needs to get to know the client a little as well as knowing the volunteer/peer before matching them. In Waverley Care (WC) the coordinator has initial meetings with individuals and matches them based on their knowledge of the individual and the peer volunteers. They also take into account what stages of the illness both peer volunteer and the individual are at.

In reality, matching peers depending on their long term condition is problematic, as many people have multiple long term conditions. Furthermore, some long

term conditions (e.g. heart failure) have such a physical impact on people that they simply are not able to work as peers. Therefore, participants felt that the one thing that people with long term conditions do have in common is their mental wellbeing and they can nearly all connect on that level.

Generic or condition specific

Based primarily on their belief that peer support is focused mainly on the emotional/mental wellbeing aspects of self management, most participants felt that the idea of a generic peer worker could work. However many participants also made the case for condition specific peer workers. The key arguments put forward are summarised in Table 1 on the next page.

Table 1: Arguments for generic or condition specific peer workers

Arguments for generic	Arguments for condition specific
<p>Empathy is not condition specific: Empathy is central to building a trusting relationship with someone who is seeking support. Someone who has experienced a similar illness or condition to you may be better placed to offer empathy than someone who has not. However feeling and acting on empathy is a quality that many people possess, and does not have to be condition specific.</p>	<p>There is an organic supply of peers: Participating organisations reported that people who have had the same condition as those they work with often feel compassion and want to support other people with the same condition as them. This offers a continuous source of elective volunteers.</p>
<p>People often have multiple conditions: People may have more than one long term condition but only want to access one source of peer support.</p>	<p>Benefits in sharing symptoms: Some peer support services/groups find that there is a need for the peer support to be condition specific as they want to discuss shared symptoms.</p>
<p>Capacity: Not all long term conditions are conducive to face-to-face peer work because of their physical limitations. The coverage of peer support for specific conditions is very patchy. For some conditions people may never be well enough to become a peer or a volunteer. Furthermore some people have such rare conditions that mean that they cannot, or it is very unlikely, that they will receive support from a condition specific peer. This might be a situation where a non-peer facilitator or a generic peer worker could provide input.</p>	<p>Degenerative and non-degenerative illness can have significantly different impacts on people's lives, mental wellbeing and ability to self manage: Participants identified that there may be a difference in terms of degenerative (e.g. Parkinson's, Multiple Sclerosis) and non-degenerative long term conditions. For these conditions, condition specific peer support may have a special value.</p>
<p>Some symptoms are universal: The Pain Association provides support for chronic pain, whatever the cause. Should mental health support be the same, whatever the cause?</p>	
<p>Impact on mental wellbeing is universal: For support regarding emotional wellbeing participants were able to envisage a generic peer support worker.</p>	
<p>Each person's needs are different: Providing peer support for self management of long term conditions based primarily on same conditions could limit or reduce attention to the important fact that each person has personal needs that are different.</p>	
<p>There are current generic models operating: A few organisations that participated in this study do not ask delegates to their courses about their conditions. One participating group described their peer service as a generic, solution focused recovery model, not focused on the specific condition but on positive lifestyle choices.</p>	

The findings in Table 1 suggest that there is good potential for generic peer support to be developed for people with long term conditions. The majority of participants felt that peer support for people with long term conditions did not have to be condition specific. However it is clear from current peer support provision that those who end up providing peer support naturally do so through an organisation that supports people with a condition they are living with.

Also, having given full consideration to the views of participants in this study, peer support may need to be condition specific for the following conditions:

- Mental illness
- Degenerative illnesses
- Gender specific illnesses that have gender specific impacts such as prostate cancer

What kinds of peer support are currently available?

Delivery models

A range of peer support services for people with long term conditions were described by participants in this study (see Appendix 6 for some examples of the range of services available). Many of the peer support services that are currently in operation for people with long term conditions focus on both physical and mental wellbeing. Peer support was usually conducted in a group setting facilitated by professionals or peers. In groups peer support could be didactic (e.g. imparting information through training), interactive training or discussion based groups.

One-to-one peer support, whether face-to-face or by telephone was a less common situation amongst research participants. Some of the participating organisations provided online peer support and/or telephone peer support. Some services provide less formal one to one peer support in social settings such as cafes or on walks.

One-to-one peer support was offered by some peer support service providers as a way to help people move towards attending an actual support group. This might involve the individual meeting one or two peers in a social setting a few times if they did not feel ready to attend a group. One model has a

'welcomer' role, where a peer took on the role of making a new group member feel welcome by making sure they spent some one to one time with them at the group.

Peer support was also offered through on-line forums and peer generated newsletters.

Although there are a range of peer support services available to people with long term conditions, those delivering and using the service may not be clear or explicit about exactly what they mean by peer support. In long term conditions there is no current all-encompassing model of peer support within which these variations can be identified, clarified and developed. However, the types of peer support described by participants in this study, although they have different names, seem to fall into four main categories of peer support delivery models, these are:

- Befriending/buddying

The individual spends time with the befriender who helps the individual to feel valued, listened to, and perhaps gives them something to look forward to. The idea is that by first creating this feeling of wellbeing the individual may be more likely to go on and do things on their own, that is, self manage. They do this by using the information and confidence they have gained from the befriending relationship. Befrienders will not have a huge impact on the individual's social network. They will rarely try to impart skills. There may be a peer element in befriending but this is not necessary and if it does exist it does not need to be based on the health condition.

- Peer mentoring

The individual spends time with the mentor who actively focuses on developing the individual's skills, often through modelling based on the mentor's own experiences. The mentor proactively provides the individual with information that can help them to take some control of their situation and move on in their self management. A peer element in mentoring is necessary as modelling is not possible without it. The peer element does not need to be condition specific but it may increase the ability of the mentor to engender trust, and provide hope and inspiration. Having a condition specific peer relationship may also increase the number of self management strategies/solutions the mentor has to share.

- Facilitated peer support

A non-peer professional (sometimes with self management expertise) facilitates peer support in a group setting by encouraging group members to reflect on and respond to other group member's contributions. The facilitator can encourage and manage the safe sharing of group members' self management stories to support their peers. An extension of this is where peer volunteers or sessional workers are asked in to provide specific input to a course or group run by a non-peer facilitator. In some organisations (e.g. Waverley Care, Pink Ladies) the long term aim with this model is to develop towards completely peer led peer support groups/courses.

- Peer led support groups

Self help groups have been developing for people with long term conditions over many years; it is more recently that they are being referred to as peer support groups. These groups will be facilitated by a peer volunteer and may be fully independent. Some whilst maintaining their independence are affiliated to large voluntary sector organisations. In such cases coordinators usually support peers to set up/lead/get involved in self help/self management initiatives.

A list of some specific examples of peer support services are provided in Appendix 1.

Co-ordination

For many of the peer services we came across in this study, there are paid, non-peer coordinators or facilitators. The coordinators can be directly involved with the peer group (e.g. facilitating the group) or have a more peripheral role (e.g. meeting the group very occasionally but providing materials and telephone support). These coordinators provide support to the groups in the following ways:

- Facilitating group discussions
- Providing support to peer volunteers by telephone/email
- Training peer support volunteers
- Making sure safeguards are in place to ensure that peer workers and individuals using the service are safe- Attending and supporting peer group events
- Producing and updating materials to support the structure and running of the peer group/service
- Management issues/resolving problems between peers within groups
- Co-ordination of services
- Paperwork

Peer worker roles

Peers are involved in a range of roles including:

- Feeding in to the development of self management courses
- Facilitating/delivering self management courses
- Providing one to one peer mentoring support
- Facilitating self-help groups
- Training professionals about self management
- Befriending
- Leading self help groups
- Acting as self management champions
- Signposting to services and resources that can assist self management and encouraging their use.

“A peer support worker helps coach people to cope better and move on to something more sustainable. Peer support workers do not tell people what to do but empower them to do it for themselves.”

(Interviewee SG)

The skills long term conditions peers need

Participants were asked to describe the key skills that a peer working with people with long term conditions would require to do their job well. The skills described below do not necessarily represent the skills that all peers currently have, rather they are the skills that participants think peers should have.

- Needs assessment and goal setting skills

Peers should be able to assess the needs and readiness of the individual to engage in self management. They also need to be able to identify when it is not appropriate or worthwhile to start the process. To assess the support, training and information needs of individuals, peers should have the ability to identify individuals' strengths and weaknesses regarding self management. Peers need to help people identify their self management outcomes and how to achieve them.

- Communication skills

Talking about mental wellbeing issues is difficult for most people. Peers need to have the ability to relate to people and tease their issues out. It is important that a peer can make sure the person is equipped with the support and reassurance they need to share their experiences.

- Motivational skills

Peers need to be able to impart motivational support. This might include having knowledge of the link between activation levels and self management success. They need to be able to engage with people and encourage them to get involved and to learn more about their condition(s).

- Role modelling

One participant suggested that peers share their own light bulb moments as a motivational tool. The role modelling that peers can offer was identified by some participants as the key to the help they provide.

- Knowledge of the care system

Knowledge of the care system and the ability to guide people through the steps following diagnosis was thought to be an important capability for peer workers.

- Ability to empathise and show understanding

Peer support should be empathetic and help people transition from diagnosis to self management. This means they need awareness of the impact of a long term condition on individuals' personal, social and working lives. Peers also need to be aware of health inequality issues and the challenges that an individual's situation in society may impose on their ability to self manage (e.g. poverty, ethnicity).

*"Not everyone can do it... they need the ability to empathise about where the individual they support is coming from and to realise that they are different from them."
(Interviewee WC)*

- Ability to self manage their own condition

In order to support others, the peer needs to be in a good place with their own recovery, mentally and physically, that is, successfully self managing. For participants, knowledge and skills about self management are central to the peer worker role.

- Relationship management skills

Peers need to have the skills to establish boundaries with the individual and know when the individual's support needs are beyond the peer. They need the ability not to be drawn in to a victim/survivor relationship, as the aim of peer support is for the individual to stand on their own two feet.

To what extent are peer support services currently formalised?

Training

Most peers working in long term conditions have some form of training, at least volunteering training, but rarely peer support specific training and rarely mental wellbeing specific training. Some examples are:

- Waverley Care has developed training for their peer support volunteers. It involves generic volunteering training and a separate training on peer support.

The peer support training covers issues such as confidentiality, relationship boundaries, one to one support and group support, supervision and support. They also have a quarterly refresh and update meeting.

- CHSS train their volunteers, some of whom are peers in a range of ways. They provide training on the matching process which has peer elements to it.
- Lothian Centre for Inclusive Living (LCIL) have counsellors who are professionally qualified and peers.
- That no-one understands how the long term condition has impacted on their mental health and relationships (particularly with carers)
- Unable to cope
- Unable to accept their condition
- Challenged by their condition

Contracts and pay

In this study we came across only one situation where peer workers were paid. This was the case in Waverley Care, where peers are paid on a sessional basis to deliver self management courses. Most peers had some kind of volunteering agreement.

Integration with statutory services

All of the peer services that participated in this study were operating in the voluntary sector. Joint working with statutory services varied greatly but was generally not well developed. The most integrated peer services were those who received referrals from clinical staff and those who were involved in working with health boards to identify service development priorities for people with long term conditions.

Who would/does benefit most from peer support?

Peer support should be targeted at those with mental health needs

Participants described that in their experience, people with long-term conditions who need peer support are feeling:

- Isolated and lonely
- Frightened
- Stressed
- Anxious
- Upset
- Afraid to go out
- Stigmatised
- That they are losing control/ independence
- That no-one cares how they feel
- That they are expected to be coping better

These feelings are not condition specific. People with long term conditions are exposed to multiple mental ill-health risk factors and will often be experiencing at least mild depression and/or anxiety. Peers can share this. For those with existing mental health problems, a diagnosis of a long term condition can make them particularly vulnerable.

*“People need support as a whole person.”
(Interviewee X)*

The overarching need amongst those with long term conditions was identified by participants as that of overcoming isolation and loneliness. Research (Holt-Lunstad et al, 2010) has shown that social isolation itself is a mortality risk factor comparable to smoking. In fact social isolation is a compounding factor for those with established morbidity. Participants felt that some people just need social contact. Some peer groups are purely social and educational.

*“Peer support should be for mental health... emotional, because that’s what is missing.”
(Interviewee PL)*

One group of participants reported that the individuals with long term conditions that they work with are usually appalled at the lack of mental health support for newly diagnosed long term conditions patients. Many participating service providers and peers in this study identified a lack of the acknowledgement by medical services of the psychological impact of living with a long term condition. There was a sense amongst participants that mental health needs are assessed in the NHS as a token gesture only. One participant said that this issue comes up through the peer groups she is involved with without fail.

Participants from one large organisation reported feedback from those with long term conditions that peer support is the most valuable form of support for mental health and wellbeing. According to these participants, for many, the peer support that they have is their only source of mental health support. However talking about mental wellbeing can be difficult and in some participants' experience, a certain level of trust needs to have been built up in the peer relationship before this happens. Some male participants felt that for men in particular admitting that they are struggling to cope and feel down can be extremely difficult.

"You need an empathetic ear to tease it out."
(Interviewee GS)

This same participant described supporting people to be mentally well as one of their key challenges and they indicated that they struggle to support people with long term conditions who then develop or already have depression. These clients are particularly difficult to support with volunteers, as they require more in-depth support which is often beyond the experience, knowledge or skills of volunteer peer supporters. These clients often end up therefore being seen by the paid coordinator instead of the volunteers. In such instances peer support offered from a peer worker who had experience, awareness of and training on the issues around mental ill-health was considered to be a potential solution.

People who are socially excluded

People with long term conditions may experience a number of mental health inequalities, such as discrimination, stigma, benefits, unemployment and access to mental health support. A number of participants felt that peer support should be targeted at those who are most disadvantaged in society. Many people with long term conditions find themselves dealing with stigma and discrimination, and also self stigma, both of which hold them back in their recovery and ability to self manage.

"There is something within each long term condition that will impact on an individual's mental wellbeing and merits support for self management and peer support."
(Interviewee GS)

Diagnosis is a crucial point for peer support

Early intervention with peer support at the point of and/or soon after diagnosis was considered essential. Many participants felt that for many conditions at first diagnosis and in the following months is the time where individuals have the most need for peer support. One participant described this as a crucial point when there is a need to get across to an individual that their diagnosis of a long term condition can be a life changing event that may impact on their social relationships, work and mental wellbeing but that self management is a way of coping with this. Peer support could play a role here.

Individuals with low motivation to self manage

One participant suggested that self management in progressive illnesses such as COPD was more challenging because the motivation levels of people with progressive illnesses may be lower. With progressive illnesses diagnosis is not always an immediately life changing event to the same extent as other illnesses such as a heart attack. Participants suggested that the extra support focused on motivation that these people need could be delivered by peer supporters.

"Some people need to be made aware about the potential for self management and that they have a responsibility to put as much as they can into managing their own condition".
(Interviewee X)

People who want to start rebuilding their lives

Participants identified that those who are ready to self manage following a diagnosis and who want to start engaging with support services and others who have similar problems are ideal for peer support. They need to be guided by someone who is already actively self managing, who does not advocate for them but supports them to find their own way through the maze of options. Participants felt that this was a valuable part of the peer support role, and a way for people with long term conditions to give something back.

People who want to continue their rehab

CHSS have found that many people want to continue their rehabilitation after the formal NHS rehab programme activities. Walking groups are run

by Waverley care, to provide space and relaxation for the women who participate and the activity has also been found to be conducive to building social relationships and providing peer support.

People who need one-to-one support from someone who understands

Some participants said that their clients wanted support from someone who “understands”. They thought that their non-peer volunteers did not quite understand in the same way as someone who has a similar condition.

“Many people feel life has changed irrevocably, that they are on a slippery slope and things can’t get worse, and they will never be able to do things again.”
(Interviewee GS)

One group of peers described how the physical limitations that a long term condition imposes can multiply with time and become more severe. This can cause complex feelings of frustration and anxiety which can manifest in many ways. Participants felt that people experiencing this level of complexity of feelings definitely would not want to talk to a peer group and would need peer support on a one-to-one basis.

How well are these needs met?

“Some social workers haven’t had life experience and don’t know what it’s like.”
(Interviewee PL)

None of the peer support services involved in the feasibility study were independently evaluated for their impact on the individuals that used them. This is an area that would benefit from more research. However participants were able to give informed opinions on how well the peer support that is currently available is meeting the needs of individuals. This was based on their own observations as peers and/or feedback from peer workers and individuals who had used the services.

The needs that participants reported that peer support is currently meeting are described below:

Preventing mental ill-health

In terms of prevention, peer support is a unique source from which to learn about self management strategies for physical and mental wellbeing and

to become more involved with other services and supports that people know have helped others. This can prevent people developing depression and anxiety that requires specialist treatment.

The Pain Association self management course outcomes are usually about wellbeing and positive lifestyle issues rather than reducing symptoms. The focus is more on reducing stress. For them the lines between addressing pain and mental health are blurring.

Providing an outlet for individuals to safely share their thoughts and feelings

“Having spoken to many people over the years, if you can’t speak to family or friends, a peer is someone you can relax with.”
(Interviewee GS)

“When people are away from their home environment, in hill walking groups, they would discuss their most intimate worries. There is safety in just walking, a kind of confidentiality.”
(Interviewee WC)

Most participants agreed that discussions about mental wellbeing evolve as peer relationships evolve. Peer support provides a safe place for people who often have to cope with stigma and discrimination, a place where they can talk honestly, for some, the first opportunity to verbalise their thoughts and feelings about living with their condition.

Helping individuals overcome their loneliness

Peer support groups, even those that are purely focused on exercise are, for some, the key to overcoming isolation and maintaining their mental wellbeing. One participant (PA) described that their service taught people self management skills but for some, the service was just something to look forward to which helped, especially for those who were depressed.

Motivating and supporting people with their own self management aims

Participants felt that peer support groups go some way towards meeting the self management aim. Longer term groups and one-to-one services keep people motivated to maintain their physical and mental wellbeing and be their partner in care. It was the opinion of many that it is the voluntary sector that can support people best living with

their condition.

The Pain Association have experienced problems with people coming to their service who were not ready for self management, and it is useful to recognise therefore that some people are at the stage where they can be helped through self management and some are not. They have also found however, that some people who may not feel at first that they are ready for self management, buy into the idea as a result of the peer support on their group helping them to put aside their cynicism. Other ways in which peer support was thought to motivate people included:

- Giving individuals something to look forward to
- One peer service prepared people with a foundation for going back to work following a diagnosis, whether on a paid or, more often, voluntary basis
- Helping individuals make proactive approaches to professionals/ clinicians about their care

Providing a type of support that professionals cannot

*“There’s something about working with someone who understands the impact of physical impairments (e.g. tiredness, difficulty going to the loo, living on benefits) on an individual’s lifestyle and mental wellbeing.”
(Interviewee CIL)*

For some individuals, entering a peer support service can be the first time they have support that is not medical, and this can bring a unique and personal dimension to the support they receive.

Helping people to accept their condition

Acceptance can be very difficult for some individuals with long term conditions. Interacting positively with

other people with a similar condition can help to normalise the experience of a long term condition which can be the first step to gaining control over their life again.

Inspiring people

Those who graduate from the Thistle Foundation’s Lifestyle Programme often find inspiration to become peer workers themselves, to help others achieve what they have in terms of their self management.

Key gaps in peer support for people with long term conditions

Participants identified a number of gaps in current peer support provision for people with long term conditions:

Access

Participants felt that current peer support provision was patchy and not well integrated with or supported by the statutory sector. Low levels of awareness, support and/or trust amongst statutory services about peer support services available acted as a barrier to participation and often there were few clear referral routes in place from the NHS to peer support services.

Lack of support for people with multiple conditions

Much of the peer support currently provided is condition specific and participants highlighted a gap in provision for people who have multiple long term conditions.

Low awareness of and confidence to deal with mental wellbeing issues

Participants identified a lack of peers trained to be aware of and able to identify individual’s mental wellbeing needs and to provide appropriate peer mentoring and model self management strategies specific to mental well being. There are examples of organisations who provide additional training and support for peers to help them deal with the emotional and mental health issues, but there is a need to extend this much further.

Little focus on work life

The peer services discussed in this research did not seem to focus to any great extent on supporting people with long term conditions to stay in or get back to work.

“Users of our service find that the peers ‘get it’, this is a huge advantage over non-peer professionals in providing emotional support.”

(Interviewee CIL)

Lack of training opportunities

Peers in general did not have opportunities to participate in either specific peer support or mental wellbeing training. This could cause credibility issues with referrers and potential users of peer services as well.

Participants also identified complimentary peer support training for peer coordinators and other professionals working with or referring to the peer as a key gap.

Sparse monitoring, research or evaluation evidence

Participants highlighted a lack of evaluation of the impact of peer support activities, which prevents the building up of an evidence base, required to push peer support up the policy agenda.

Some peer services provide individuals with the opportunity to establish their needs and where they are with the self management of their conditions at the outset of their interaction with a peer service. This can be revisited to help individuals see how far they have travelled since starting to receive peer support. Other organisations collect various forms of information about their peer activity for funders. This is a potential source of evidence that could be gathered to promote the idea of peer support and to share good practice.

Lack of peer support for younger people

Unsurprisingly, much of the current peer support provision in long term conditions is for older people. Participants identified peer support for younger people as a gap.

Shared peer role structures

In long term conditions, at practice and policy levels, the role of peer supporter is vaguely defined and varies greatly. Participants felt that a key gap was a lack of a shared definition of the peer role and a lack of shared information about different structures for the peer support role.

For example, the levels of peer responsibility can vary considerably from service to service. From informal peer support as a group member and volunteering to provide input to self

management courses to providing one-to-one peer support, leading and facilitating peer group discussions and running a peer led service.

The study revealed very little was in place regarding specialised supervision and support for peers who can themselves be vulnerable.

National lead/network on peer support

Peer support in long term conditions has developed organically to meet needs identified by service users and key interest groups. It is very much led from within the voluntary sector, but lacks “joined-upness”.

There is no clear national lead or agenda for peer support for people with long term conditions. Peer support is mentioned a little in self management literature and policy documents which as an issue is more explored than peer support is.

There is no strategic overview locally or nationally of how peer support resources are allocated, e.g. equity of access, which conditions, availability in areas of high deprivation/need etc.

Current delivery challenges

Participants were asked to consider the challenges they and others face in delivering peer support to people with long term conditions. Interestingly many of these challenges are exactly the same as those encountered in the development of peer support in the mental health field.

Sustaining peer services

Participants described the difficulties of sustaining local peer groups due to burn-out of volunteers coordinating them, difficulties in recruiting new volunteers with the right skills and a lack of adequate supervision support for peer supporters. Another problem was that groups could become ‘stale’ and resistant to change limiting their attractiveness to new members. Participants suggested that a more formalised approach with some central direction and linked to other similar groups may help to overcome this.

Confidentiality

A number of participants felt that an individual’s ability to ‘open up’ depends on whether only their peer worker will

know about their problem. This raises issues of the peer respecting individuals' confidentiality as well as how to protect that confidentiality if peer services are to become more fully integrated, for example within primary care.

In some communities, people may come across the person they receive peer support from in a social setting; it is crucial that this is recognised and both peer and individual feel safe. Some services continually remind their peer volunteers about the risks of talking aloud in public places about their work.

Some services take GP details from people but only share information where they feel there may be a risk of self harm or suicide.

Stigma

Some participants felt there was evidence to suggest that there can be a stigma attached to attending peer support or self help groups.

Lack of training

Few peers have access to specific training on the principles and practice of peer support or mental health and wellbeing.

Dependency

One pitfall of non-trained peer support identified by participants was the danger of a dependency relationship developing. This can occur where the peer adopts a "saviour" role or where individuals want their peer to do things for them and to continue with them indefinitely.

Managing the potential for dependency, either from the individual or the peer is a key challenge for organisations offering peer support. To mitigate this, some peer services offer individuals the option to meet with a variety of peers.

A balance needs to be struck between providing long term peer support that helps individuals to maintain their self management and providing people with the confidence to move on from and not become dependent on the peer support.

Arguments against peers working as professionals

The uncertain quality of peer support was quoted by many as a problem. One organisation that participated in the research had developed a non-peer

based self management model of care because the clinicians they worked with would not send their patients to receive peer support or to anything run by patients/peers.

The Pain Association (PA) programme has been developed by professionals but draws heavily on input and learning from peers over a number of years. For them peer support is part of their model for self management support but doesn't define it.

*"No-one can know what someone else is feeling as they are not them, they can only empathise."
(Interviewee PA)*

*"Everyone has a different set of circumstances with which people exist and no -one will have exactly the same pain or distress."
(Interviewee PA)*

The Pain Association states that whilst peer support is part of what they do, they have tried to position it to get maximum benefit and maximum safety for all those involved. The Pain Association, having provided peer support for a number of years, began to introduce paid non-peer workers to provide some professional input to the groups with the aim of raising standards. Although they indicated that the peers did a good job, the groups they were supporting were challenging to work with, with factors arising (e.g. aggression) that were beyond the comfort zone of the peers to manage themselves. Often, as is common in the voluntary sector, people can come directly to the service with little known about their background and therefore there is a risk that some individuals will be holding in distressing issues that come out in groups. It was felt that in such circumstances professional facilitators can provide the right amount of empathy and professionalism to provide a safe and effective service.

The professional self management staff at Pain Association gain a certain credibility that neither patients nor clinicians have. Furthermore, in this set up, people are still able to benefit from peer support via their fellows in the group.

Supporting peers' wellbeing

Some organisations offer support to their peers to help them deal with mental health and emotional issues

that come up during their support sessions and also the effects of offering peer support on their own mental health and wellbeing. For peers hearing things that trigger memories of their own difficult times can be very challenging. It can also be challenging for peers to use their own stories and to be asked to share these with professional staff.

Integration with statutory services

Generally peer services for people with long term conditions are not well integrated with the NHS. Some participants identified joint working between statutory and voluntary sector based peer/self management support services as being very under-developed. Some services have close integration with one or more health boards but find a closed door with others. Some have no links at all with statutory services, whilst others enjoyed good links with statutory services as referrers. No participants described a model where statutory services were partners; this may be due to commonly mentioned barriers such as confidentiality.

This general lack of integration could equate to a huge missed opportunity in access to services that could help individuals on their self management journey and improve their mental wellbeing. Low levels of integration can also mean that peer services do not give feedback to referrers reducing the potential for the improvement and growth of the service.

A key challenge is improving access to peer support through primary care, where the majority of contact is made with people with longterm conditions. Participants who had tried to work more closely with GPs described this as challenging as GPs either lacked interest, were too busy, or had other priorities. One organisation had never met any GPs; although they felt that GPs could refer to them, they had never got past the practice manager.

*“We suffer from people’s misconception of what might happen in a group, there is a reluctance to refer out with a clinical service.”
(Feasibility study interviewee)*

There are a few examples of peer support services which have good links with and receive referrals from GPs. The factors that facilitate these system links need to be explored further.

One peer supporter described a situation where he became involved in an informal peer support service which grew organically from a need he identified himself. He was linked in to a ward sister who would call him to reassure people who were anxious about their upcoming operations. One day he was asked to leave and not come back by a consultant. The service he was offering was deemed to be too informal and although he may have had a positive impact on some individuals, there were no formalities and built in safeguards. Many participants described problems they have in gaining referrals from clinicians to voluntary based physical activity classes due to clinicians’ fears that they will place their vulnerable patient in a situation that may harm them.

Generally the concept that peers are given a job primarily because they are qualified by their illness is not viewed sympathetically by clinicians. One organisation had been told by clinicians that they would not engage with their service if it was run by patients.

The credibility issue is symptomatic of a wider problem of a lack of trust and confidence on the part of some clinicians about the voluntary sector and the failure of the voluntary sector to promote evidence of the positive impact of their work and to build in safeguards.

It takes time to gradually build up an appreciation of the value and safety of peer support amongst clinicians and other professionals. Peer support can feel threatening to them and their clients. However it is the case that many individuals are more likely to use a service if they have been referred to it by a professional working in statutory services or even if the professional appears to support the organisation.

Often the good links have been forged over an extended period of time between a voluntary sector organisation and an individual clinician. However, these groups that have managed to break down the barriers with some clinicians who refer to their service, do not have confidence that this support would continue were a new clinician to take over. Some groups find that one clinician being against referring to a group can have a huge impact on the group’s success. This can be a common feature for voluntary sector services in

general and is not a feature unique to peer support. Therefore the problem needs a systemic solution.

A benefit of integration with statutory services cited by one group of participants was that through formal referrals they could increase the proportion of people who were appropriate for their service and ready for self management. Clinicians' understanding of peer support is however, essential. Often, given the current state of peer support in long term conditions, clinical professionals tend to feel that peers simply are not qualified to work with individuals.

Low health literacy

Health literacy is essential to successful self management. However, low health literacy is particularly prevalent amongst lower socioeconomic groups, ethnic minorities, the elderly, and those with chronic conditions or disabilities. People with low health literacy have poorer health status, greater risk of hospitalisation, less knowledge of disease management and health promoting behaviours, and less ability to self manage and to share decision making with healthcare professionals. This is a potential area where peer supporters with good communication skills could perhaps overcome barriers to self management for people with poor health literacy.

Contractual issues

Some participants felt that volunteers are more difficult to dismiss, and so they are not measured on the same parameters as employees. Some participants felt that the more formalised the system the more difficult it would be to stop working with volunteers or paid peers who may not be doing a good job.

Peers' own self management and illness

For peers who have physical long term conditions, managing their illness in a way that enables them to commit to regular work can be challenging. The physical impairments of long term conditions often result in low energy levels, for example.

Viability of entirely peer led and delivered services

A number of participants questioned whether peers, especially volunteer peers, would have the ability, training and/or experience to deal with the most

difficult times in group sessions. They felt that there is usually a need for the expertise of a professional facilitator in such situations.

Potential for developing peer support in long term conditions

Taking into account the need for peer support, current provision and challenges, participants considered the opportunities for developing peer support in long term conditions:

Potential for formalising

There was awareness amongst participants that more and more peer support is becoming available, often coming about organically, and there was a sense that there was a need to begin to formalise peer support more now. Many people who need peer support and those who want to work as peers are vulnerable and need safeguards and structures in place to protect them as well as making a good quality service accessible by many.

Because they are beginning to realise the value of peer support, some participants found it frustrating that peer support has not previously been highly valued and rewarded. Participants identified a clear need to define clearly how peers would fit into any current care system and what the added value outcomes would be of the service.

Participants identified physical impairments and physical illness as the main barriers to formalising peer support work as far as paid employment. As good as peers can be, they can become physically ill and need to be off work and not available to do their work. There was a concern amongst those who facilitate peer support about how well an entirely peer led service could function without the support of paid coordinators.

Participants felt that they also needed to know more about the impact of peer support on individuals, whether peer support for people can be generic and when it has to be condition specific.

Could and/or should peer workers in long term conditions be paid?

The idea of formalising peer support to the extent of paying peer support workers, as has happened in the mental health field, was put forward to

participants. The idea of employing and paying peers was new to all but one of the discussion groups where there was an organisation that pays peer workers on a sessional basis to input to self management courses. Participants tended to err on the side of volunteering given their experience. Participants felt that volunteering with some aspects of formalisation would be a better model.

However, all felt that paying peer workers was an idea that should be explored further given the credibility issue. If the complications of being flexible around working patterns and additional support to fit with a peer's needs could be addressed, then participants felt there may be some mileage in looking into paying individual peers for their role. Needless to say, the flexibility and additional support needs of volunteers were viewed to being equally as important and clearly also need to be addressed within services. Table 2 summarises the arguments that participants made for and against paying peer workers.

If peer support is to be more formalised, where should peers be based?

All participants felt that any formalised peer service should be linked in to primary care, through direct referrals, working either directly within a GP practice or employed by the CHP and working across a number of practices. There was a suggestion that peers could be linked in with condition specific long term condition specialist nurses who work between primary and secondary care.

Participants felt that primary care would be a good setting in which to explore the possibility of paid peer support workers. However, GPs would need certainty that the services they were referring to were worthwhile and would benefit their patients.

Good practice that can be rolled out

All of the organisations that participated in this study have developed to different extents a range of resources for and approaches to peer support working. These resources and approaches are often examples of good practice that could be developed, shared and in many cases adapted to suit different settings and target groups, for example:

- A course to help volunteers see the long term condition from the client's

view in terms of the impact on their mental health

- Peer matching procedures and tools
- Tools for needs assessment and follow-up to measure progress with self management
- Training for peers on mental wellbeing and emotional issues, how to support others and protect themselves
- Structures and materials to support peer led groups
- Support to join / 'welcomer' roles could be developed (e.g. training in stages of acceptance) and rolled out
- Mental health peer support guidelines
- Mental health peer support training
- Mental health self management tools such as WRAP

“Self management is something that a person has to do for themselves but they need support from others to do so, peers with self management experience are the ideal support.”

(Interviewee NC)

Pros

Peers feel more valued:

When a peer is asked to facilitate a group they are doing a job and bringing their skills and experience and they have to be there, so it is right that they should be paid. For some peers, being paid could be the most important way in which they feel their work is valued.

Capacity:

Barriers to entering into contractual responsibility for paid work would apply differently depending on the individual concerned, their financial status and their patterns of illness.

Positive impact on individuals:

In mental health the paying of peers in itself gave service users hope, and broke down self and professional stigma barriers. Paying peers could enhance their status amongst individuals with long term conditions.

Positive impact on professional staff:

Paying peers could improve the status of peers amongst other professionals.

Cons

Capacity:

With pay comes more contractual responsibility. Participants felt that long term conditions peers may have inconsistency in their good and bad days, and may need a lot of down time when they are ill with common illnesses such as colds and flu; they felt that this could result in many absences and essentially a more expensive service than employing non-peer support workers.

Passion and commitment:

It is difficult to find non-peer workers who have the same passion and commitment as peers. Volunteers may demonstrate more commitment than paid peers, for whom peer support becomes 'just a job'.

Negative impact on peer relationship:

The trust and confidentiality central to the peer relationship could be compromised.

Negative impact on professionals:

Professionals may feel threatened by paid peers, increasing the barriers to joint working.

Does not necessarily improve quality:

Paid or not, the peer intervention can be the same, if the peer is valued and respected by the professionals around them and the individuals they are working with. Also, as long as they are trained and working with a good organisation with the right supports and safeguards.

Volunteer guilt:

One participant raised the possibility that volunteers will be less likely to come forward to offer peer support if the position can be paid for fear of taking work away from other people.

Protection through formalisation:

Formalising voluntary peer support in other ways than remuneration can protect the peer relationship and improve the respect and value of peers as viewed by professionals.

Peers can be valued in other ways:

There are a range of ways in which the peer supporter role can be valued by organisations. This could include covering expenses, meeting other volunteers, feeling part of a team, receiving training, the personal value gained from giving through volunteering, having their contribution thoughtfully and repeatedly acknowledged by the organisation they volunteer for.

Predicted lack of uptake of paid positions:

Some services have offered to pay their peer support workers but this had not been taken up. For one service, they feel that the peer support their volunteers provide is something that happens naturally, and therefore the time commitment should be up to the peer. Many peers just want to give something back but only for a short time; few want to make a career out of it.

Benefits trap:

Balancing the benefits system and work can be too difficult to tackle.

Cost:

Participants voiced concern over how formalising peer support to the extent of paying peers could be funded, especially if a national service was to be provided.

Conclusions and Recommendations

The findings from this study support the development of peer support as a way of supporting self management for people with long term conditions. Although a number of key documents refer to the need to develop peer support for people with long term conditions and LTCAS champion this, there is currently no clear leadership or focused networking to take this agenda forward. This project has gone some way to advancing that focus and has developed the beginnings of a network of motivated organisations and individuals who want to work together to share and develop best practice.

Those who participated in the feasibility study have demonstrated passionate support for the unique added benefits that peer support can bring to those living with long term conditions and the professionals who support them. The people in this network share the common aim of improving access to high quality peer support for people with long term conditions and are keen to work together to progress the good work that already exists.

There are some excellent examples of peer support initiatives in Scotland for people with long term conditions. Currently peer support exists in a range of organisations mainly based in the voluntary sector. The study has shown that there are a range of ways to deliver peer support to people with long term conditions, from peer mentoring to professionally facilitated peer support. However access to peer support is still limited and patchy, usually confined to the voluntary sector and can depend on the Health Board you live in as well as the condition you have. Links in to statutory teams are often weak, although there are some pockets of excellent collaboration that are important to recognise and build on.

Peer support is often provided by people who have a similar condition to those they are supporting. However there is support for the idea of a 'generic' peer worker who embodies many of the wide range of other key factors that contribute to being a successful peer (e.g. ability to empathise and listen, ability to

develop a quality but professional relationship, age and gender, experience of multiple physical and mental health conditions).

The type of individuals with long term conditions who were identified as needing peer support were basically those who are at risk of developing mental health problems. There is an acute need amongst those with long term conditions for early intervention and preventative support for their mental wellbeing and the peer support that is given, regardless of the condition, is usually centred on the mental wellbeing aspects of self management. This study has identified that good mental wellbeing is essential for successful self management and peer support is ideally suited to contribute to meeting the emotional and mental health needs of people with long term conditions. This is something that other professionals do not always have the time or unique insights (that peers can offer) to do well. The contribution that peer workers can make to the self management agenda is potentially immense, as central to good quality peer support is empathy and the ability to role model self management.

There is a need to pursue the aim of increasing access to this valuable and unique form of support and to enhance the quality and impact of peer support. This will involve tackling the following key challenges:

- Raising awareness about the benefits of peer support and the possibilities for accessing and developing new opportunities for delivering access to peer support;
- Developing better levels of meaningful integration between the statutory and voluntary sector on the issue of providing access to high quality peer support;
- Developing some standards that provide guidance and support to those employing volunteer or paid peer support workers to help them better support peer workers;

- Developing a standard training for peer support workers, utilising current knowledge and good practice (gathered in our feasibility study) within long term conditions and from the mental health field.

- Be flexible in the types of peer support that are offered (e.g. facilitated, one-to-one peer led), drawing on the models currently in place.
- Issues such as dealing positively with absence and helping peers negotiate the benefits system need to be looked at in the planning stage.

Recommendations

A number of the participating organisations were interested in furthering this agenda and being involved in the development of peer support for people with long term conditions as a way of supporting self management. To address the need, gaps and challenges for the development of peer support as an approach to supporting self management in long term conditions the key steps forward will be:

To enhance credibility and effectiveness

- Drawing and building on existing models, develop generic peer support and mental wellbeing training for long term conditions peers that are adaptable to specific conditions.
- Developing complimentary training for peer facilitators and other professionals.
- Guidance giving advice and information about good practice in developing and delivering peer support for people with long term conditions should be produced.
- This study has focused on the need for and the potential for developing peer support for people with long term conditions. It does not examine the impact of peer support services. If we are to go ahead and develop peer support services, it is crucial that their impact is measured, preferably with full involvement of people with long term conditions. Individual peer support services may require support to enable them to effectively evaluate their work.

To better meet need:

- Make mental wellbeing central to peer support and promote this as a key aspect of self management to referrers.
- Target peer support at those most excluded and disadvantaged in society who encounter most barriers to self management (in terms of poverty, literacy, culture and language for example).

To gain resources and support to develop peer support

- Voluntary sector organisations supporting people with long term conditions need to be more focused, aware and proactive about mental wellbeing as an issue.
- To go forward, much more work in health and social care settings is required to highlight the value of peer support.
- More joint working between long term conditions and mental health organisations is needed, to share and develop ideas and resources (e.g. training, employer guidance, peer roles). This could take the form of a national network, in addition to local partnerships.
- Peer support is a deep value concept, and should be considered at policy level. Peer support needs to be promoted amongst policy makers and local planning partnerships. This study and other evidence of the need for and benefits of peer support as an approach to supporting self management in long term conditions provide evidence and resources to support this work.
- Develop voluntary and statutory sector partnership bids for funding to take forward pilot peer support projects.

When thinking about going forward with this agenda, there are also some fundamental questions that need to be considered:

- Can generic peer support work in long term conditions?
- How can the credibility of peer workers be enhanced amongst NHS and other professional staff (e.g. training, contracts, more integration with statutory sector)?
- Does pursuing the payment peer workers improve or worsen the chances of improving the quality of and access to peer support?

References

Co-ordinated, integrated and fit for purpose: A Delivery Framework for Adult Rehabilitation in Scotland

Long Term Conditions Alliance Scotland (LTCAS) (2009) Do you live with a long term condition?

Long Term Conditions Alliance Scotland (LTCAS) (2010) Seen and not heard? Exploring issues facing children and young people living with long term conditions

Long-Term Conditions and Depression: Considerations for Best Practice in Practice Based Commissioning. Department of Health

Long Term Conditions Collaborative (LTCC) (2009) High impact changes. The Scottish Government

Long Term Conditions Collaborative (LTCC) (2009) Improving Self Management Support. The Scottish Government

NICE (2009) Treating depression in adults with a long-term physical health problem. Understanding NICE guidelines: Information for people who use NHS Services. Information about NICE clinical guideline 91

The Scottish Government (2009) Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan

The Scottish Government (2007) Living well with long-term conditions. Report of the open space events

The Scottish Government and Long Term Conditions Alliance Scotland (LTCAS) (2008) Guan Yersel, The Self Management Strategy for Long Term Conditions in Scotland

The Scottish Government (2007) Living well with long-term conditions. Report of the open space events

Appendix 1

Mapping Survey

Introductory Email

Can You Help?

The Long Term Conditions Alliance Scotland (LTCAS) has funded the Scottish Development Centre for Mental Health (SDC) to explore the role of peer support for individuals with long term conditions. The Self Management Strategy calls for more attention to be paid to mental health and increased access to peer support.

This project aims to inform and promote the development of peer support services for individuals with long term conditions and, through this, increase the involvement of people with long term conditions in the delivery of holistic care. We have identified the need for this work through working with people with enduring mental health problems, for example in establishing formalised peer support, and with people with heart disease and diabetes, in the Living Better project. Focus group findings from Living Better illustrate that people with long term conditions do want more attention paid to their mental health and wellbeing. People want more formalised social support and someone to talk to, especially someone who has been through a similar experience to themselves.

I have attached an information sheet with further details of the research. The first stage of this research is to map the extent and nature of existing peer support in Scotland for people with long term conditions.

We have identified you as a key organisation working in the field of long term conditions who may be able to provide us with the information we seek. We gained your contact details via your website. To help us, I would be grateful if you could take a few minutes to complete a short survey (<http://www.surveymonkey.com/s/LTCAS>) by the 30th September 2010.

If you require more information or would like to discuss the above, please contact me.

Kind regards

Appendix 2

Project Information Sheet

Exploring Peer Support as an Approach to Supporting Self Management

This project aims to inform and promote the development of peer support services for individuals with long term conditions and, through this, increase the involvement of people with long term conditions in the delivery of holistic care.

The Self Management Strategy calls for more attention to mental health and increased access to peer support. We have identified the need for this work through working with people with enduring mental health problems, for example in establishing formalised peer support, and with people with heart disease and diabetes, in the Living Better project. Focus group findings from Living Better illustrate that people with CHD do want more attention paid to their mental health and wellbeing. People want more formalised social support and someone to talk to, especially someone who has been through a similar experience to themselves.

This project will draw on learning from the recent Delivering for Mental Health pilot of formalised peer support for those with mental health problems. Formalised peer support workers are people with a lived or living experience of recovery from a mental health problem who are trained and paid to support people currently experiencing a mental health problem. Peer Support workers work as a fully integrated member of the multidisciplinary care team; not as an add on to the team. This model has been shown to have considerable benefits for patients, peer support workers and multidisciplinary teams in mental health care community and inpatient settings. The formalised peer support model is currently not available in multidisciplinary care teams supporting those with long term physical conditions in primary or acute care in Scotland.

Aims and Objectives

The main aims of the project are to:

1. Promote holistic health care for people with long term conditions with particular emphasis on support for mental wellbeing;
2. Transfer learning from the introduction of formalised peer support worker roles within mental health services to long term condition services and raise awareness of existing (informal) peer services within long term conditions care;
3. Scope the potential for formalised peer support roles for individuals with long term conditions;
4. Support improved health outcomes for people with long term conditions;
5. Include more people with long term conditions in service design and delivery.

What the project will involve

Scoping: The project will start with synthesising the theory and learning available from mental health peer support and self management. This will be complemented by mapping the extent and nature of existing self management support that is mutually offered or provided by persons with the same health condition in Scotland (and, if appropriate within the UK) and what this support includes.

Professionals' focus groups: To further explore the availability of, and start to create, the supportive and progressive working environment necessary for formalised peer support workers, six focus groups will be held with health (including local Collaborative Managers), social care and voluntary agencies in three geographic areas.

Peers discussion groups: Six discussion groups in two areas will be set up to exchange views and experiences about leading your own care, supporting others, and being involved in formalised peer support. People who have lived experience of mental health problems, some of whom who have been trained or worked as peers in the health system, will be invited to participate in a facilitated discussion. People experiencing a long term condition, and who have had some previous connection to long term condition treatment or support groups, or who have acted as expert patients and their carers, will also be invited to this discussion.

Outcomes

The outputs and outcomes of the project will be:

- A report detailing the links, similarities and differences between recovery and peer support in mental health and self management of long term conditions;
- A series of awareness raising discussions, focus groups and events around the potential role, function and added value of formalised peer support (these will involve health professionals, voluntary organisations, patients and carers);
- The role of formalised peer workers within health services for long term conditions, e.g. managed clinical networks (MCNs) and primary care, including Keep Well, defined;
- Methods for evaluating the development and integration of peer support workers defined.

Research team contact details:

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EH6 5QN

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Email **joanne@sdcmh.org.uk**
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Appendix 3

Mapping Survey

Definition of Peer Support

Peer support (both emotional and practical) is provided by someone who has a living or lived experience of a health condition to those experiencing a similar health condition. Those offering peer support usually impart self management skills. Currently peer support exists in a number of guises such as buddying, peer groups, befriending and support groups. We are interested in exploring the feasibility of paid peer support for long term conditions. In the Mental Health sector in Scotland peer support has already been formalised in this way in a number of places.

1. Your Name:

2. Name of your Organisation:

3. Your contact details:

4. Do you know of any services offering peer support to people experiencing long term conditions in your local area or other areas in Scotland?

- Yes
 No

(if answered 'Yes' to question 4)

Could you please take a couple of minutes to briefly list the name of the service offering peer support, a brief description of the service and the contact details of someone who could tell us more about the service.

Please note, that there is room for up to five services but if you know of more, please list details in the comment box at the bottom of the page.

Service 1

5. Name of organisation and peer support service:

6. Brief description of the service:

7. Contact details of someone who can provide more information on the service:

8. Please list (and give detail where possible) of any additional services you know of that provide peer support to people with long term conditions.

(if answered 'Yes' to question 4)

9. Do you think the current provision of peer support for people with long term conditions meets the current and future needs of service users?

- Yes
 No

Please comment on your answer:

(if answered 'No' to question 4)

10. Do you think there is a need for peer support for people with long term conditions?

- Yes
 No

Please comment on your answer:

Thank you for taking the time to help us with this piece of work.

If you are interested in finding out more about this piece of work please contact Joanne McLean at joanne@sdcmh.org.uk

Appendix 4

Interview Invitation Email

Dear X,

Exploring Peer Support as an Approach to Supporting Self Management

The Scottish Development Centre are currently conducting a research study funded by Long Term Conditions Scotland. This project aims to inform and promote the development of peer support services for individuals with long term conditions and, through this, increase the involvement of people with long term conditions in the delivery of holistic care.

I have attached a copy of the information sheet for the research for you to read. The main aims of the project are to:

- Promote holistic health care for people with long term conditions with particular emphasis on support for mental wellbeing;
- Transfer learning from the introduction of formalised peer support worker roles within mental health services to long term condition services and raise awareness of existing (informal) peer services within long term conditions care;
- Scope the potential for formalised peer support roles for individuals with long term conditions;
- Support improved health outcomes for people with long term conditions;
- Include more people with long term conditions in service design and delivery.

The research activities involve:

- A brief literature review;
- A mapping of the extent and nature of current peer support for those with long term conditions;
- Interviews with key people;
- Local discussion groups with peers and professionals.

As a key professional working in the long term conditions field, I am writing to invite you and/or your colleagues to participate in an interview for this research. This could be either a telephone interview (half an hour) or as a face to face individual or group interview (1 hour) at a venue convenient to you.

It would also be most helpful if we could discuss the possibility of your organisation helping me to identify and/or access participants for the peer and professional discussion groups.

Please let me know whether you (and any other colleagues you think could contribute) will be able to participate and we can organise to meet or talk sometime soon.

Appendix 5

Interview/Discussion Group Schedule

Defining a peer

1. What is a peer in long term conditions?
2. What kind of lived experience do they need to have?
3. Are there / should there be any points of difference? (e.g. degenerative or non degenerative, gender, age?)
4. How might/could/should the above change in the future to improve outcomes for those with long-term conditions?

Defining peer support

5. What is/are peer support / peer support workers currently trying to achieve in long term conditions?
6. Who do they work with?
7. What do they do?
8. What levels of support are offered?
9. In what capacity do they work (i.e. voluntary or paid?)
10. What skills are required?
11. How might/could/should the above change in the future to improve outcomes for those with long-term conditions?

Levels of need and response

12. Who needs peer support? (type of person and scale of need)
13. In what ways do needs differ? (e.g. stage of condition, degenerative or non-degenerative, gender, age?)
14. What are the key gaps in peer support?
15. What opportunities are there for developing peer support?
16. What needs to happen to meet the gaps and opportunities?

Potential for formalising peer support in LTC

17. Should / could peers in LTCs be paid?
18. What would the consequences of formalising peer support be? (for patients, peers, professionals)
19. What steps would be required to make this happen and what resources would be required? (people, political support, financial, structural)

Appendix 6

Examples of peer support projects for people with long term conditions

The projects described briefly below are those that were identified through and then representatives from them participated in this pilot study. The list is therefore not comprehensive. There are other peer support projects currently underway in Scotland, this is an illustrative sub-set.

- Chest Heart and Stroke Scotland (CHSS) have just under 200 affiliated community groups for and by people with chest, heart and stroke conditions, which have established themselves as independent peer support groups. The groups are supported by peer volunteers and CHSS provide comprehensive structure and guidance to these group headed up by paid coordinators. These groups contribute to the Voice of Scotland project which enables people to be involved in NHS service planning. They also provide a steer for CHSS as a charity.
- CHSS provide one-to-one volunteer befriending to people who have experienced heart failure and COPD and who are isolated in Lothian, Lanarkshire and Greater Glasgow and Clyde.
- CHSS provide quarterly Heart Failure and COPD forum meetings providing people with the same conditions with the opportunity to hear talks and have discussion – this is a form of peer support. It is informal, prominent and valuable, provides tips on self management, advice, reassurance and reduces isolation.
- CHSS has a newsletter to which patients and carers contribute
- The Pain Association provides a generic professionally (non-peer) delivered support for the self management of chronic pain, across all conditions in community based settings. Peer support is part of but does not define this service. These services are well integrated with the NHS in a number of areas (Tayside, FV, D&G, Northumberland).
- The Thistle Foundation runs a Lifestyle Programme which is a course delivered by two facilitators who have long term conditions to people with long term conditions who are having difficulty coping. Referral to the course is via GPs.
- Waverley Care provides support nationally for men with HIV, Hepatitis C and a large aspect of what they do is peer support and they have 11 volunteer peer support workers. This service is completely confidential. The service has two delivery modes, in a formal group or in a less formal one-to-one basis in a social setting (e.g. a cafe).
- Waverley Care provides a weekly women's group for those living with Hepatitis C and/or HIV, facilitated by a worker. The sharing of experiences within the group is how the peer support occurs. There is also a walking group which provides healthy activity and fitness as well as space for informal peer support.

- Waverley Care offers peer led self management training initiatives. The programmes are supported by coordinators and partially delivered by peers. The intention is that these programmes become entirely peer supported.
- Waverley Care has a women's network for women with HIV and/or Hep C, which is supported by a coordinator. The service includes an online forum, through which women can provide peer support. The website also provides self management and support information for the women.
- Lothian Centre for Inclusive Living recruit disabled volunteers to offer peer support by telephone. The service is overseen by operations workers. The focus is to support people in their independent living and direct payments. The Independent Living Team is the heart of the organisation. They support people to become personal assistant employers using their direct payments. They help people with financial management and train others to become personal assistant employers.
- Lothian Centre for Inclusive Living have Grapevine, an information service for people with disabilities. Yourcall is a counselling service by telephone on an appointment basis. This was formerly called the Peer Counselling service, which was face to face.

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