ADAPTING GUIDED SELF-HELP FOR PEOPLE WITH LONG-TERM CONDITIONS

Assignment/Assessment: Conduct of Major Research

Title: Adapting Cognitive Behavioural Therapy Interventions for Anxiety or Depression to Meet the Needs of People with Long-term Physical Health Conditions: A Mixed-Methods Study.

Keywords: Anxiety, depression, guided self-help, long-term conditions

Author name and affiliation: Aimée Hadert
College of Life and Environmental Sciences, Washington Singer Laboratories, Perry Road, Exeter, EX4 4QG

Supervisors: Dr Paul Farrand (Mood Disorders Centre, University of Exeter)

Target Journal: Journal of Clinical Psychology

Corresponding Author: Dr Paul Farrand, phone 01392 725121, Fax 01392 724623, email P.A. Farrand@exeter.ac.uk

Word Count: 7996 (Appendices 6443)

Submission Date: 3 June 2013

Statement of academic probity and professional practice:
“I certify that all material in this assignment which is not my own work has been identified and properly attributed. I have conducted the work in line with the BPS DCP Professional Practice Guidelines.”

Submitted in partial fulfilment of requirements for the Doctorate Degree in Clinical Psychology, University of Exeter
Copy of Instructions for Authors

Journal of Clinical Psychology

Manuscript Preparation.

Format. Number all pages of the manuscript sequentially. Manuscripts should contain each of the following elements in sequence: 1) Title page 2) Abstract 3) Text 4) Acknowledgments 5) References 6) Tables 7) Figures 8) Figure Legends 9) Permissions. Start each element on a new page. Because the Journal of Clinical Psychology utilizes an anonymous peer-review process, authors' names and affiliations should appear ONLY on the title page of the manuscript. Please submit the title page as a separate document within the attachment to facilitate the anonymous peer review process.


Reference Style and EndNote. EndNote is a software product that we recommend to our journal authors to help simplify and streamline the research process. Using EndNote's bibliographic management tools, you can search bibliographic databases, build and organize your reference collection, and then instantly output your bibliography in any Wiley journal style. Download Reference Style for this Journal: If you already use EndNote, you can download the reference style for this journal. How to Order: To learn more about EndNote, or to purchase your own copy, click here. Technical Support: If you need assistance using EndNote, contact endnote@isiresearchsoft.com, or visit www.endnote.com/support.

Title Page. The title page should contain the complete title of the manuscript, names and affiliations of all authors, institution(s) at which the work was performed, and name, address (including e-mail address), telephone and telefax numbers of the author responsible for correspondence. Authors should also provide a short title of not more than 45 characters (including spaces), and five to ten key words, that will highlight the subject matter of the article. Please submit the title page as a separate document within the attachment to facilitate the anonymous peer review process.

Abstract. Abstracts are required for research articles, review articles, commentaries, and notes from the field. A structured abstract is required and should be 150 words or less. The

1 For the purposes of readability, Figure legends are included on the Figures within the report.
headings that are required are:

**Objective(s):** Succinctly state the reason, aims or hypotheses of the study.

**Method (or Design):** Describe the sample (including size, gender and average age), setting, and research design of the study.

**Results:** Succinctly report the results that pertain to the expressed objective(s).

**Conclusions:** State the important conclusions and implications of the findings.

In addition, for systematic reviews and meta-analyses the following headings can be used, Context; Objective; Methods (data sources, data extraction); Results; Conclusion. For Clinical reviews: Context; Methods (evidence acquisition); Results (evidence synthesis); Conclusion.

**Permissions.** Reproduction of an unaltered figure, table, or block of text from any non-federal government publication requires permission from the copyright holder. All direct quotations should have a source and page citation. Acknowledgment of source material cannot substitute for written permission. It is the author's responsibility to obtain such written permission from the owner of the rights to this material.

**Final Revised Manuscript.** A final version of your accepted manuscript should be submitted electronically, using the instructions for electronic submission detailed above.

**Artwork Files.** Figures should be provided in separate high-resolution EPS or TIFF files and should not be embedded in a Word document for best quality reproduction in the printed publication. Journal quality reproduction will require gray scale and color files at resolutions yielding approximately 300 ppi. Bitmapped line art should be submitted at resolutions yielding 600-1200 ppi. These resolutions refer to the output size of the file; if you anticipate that your images will be enlarged or reduced, resolutions should be adjusted accordingly. All print reproduction requires files for full-color images to be in a CMYK color space. If possible, ICC or ColorSync profiles of your output device should accompany all digital image submissions. All illustration files should be in TIFF or EPS (with preview) formats. Do not submit native application formats.

**Software and Format.** Microsoft Word is preferred, although manuscripts prepared with any other microcomputer word processor are acceptable. Refrain from complex formatting; the Publisher will style your manuscript according to the journal design specifications. Do not use desktop publishing software such as PageMaker or Quark XPress. If you prepared your manuscript with one of these programs, export the text to a word processing format. Please make sure your word processing program’s "fast save" feature is turned off. Please do not deliver files that contain hidden text: for example, do not use your word processor’s automated features to create footnotes or reference lists.
Article Types.

- **Research Articles**. Research articles may include quantitative or qualitative investigations, or single-case research. They should contain Introduction, Methods, Results, Discussion, and Conclusion sections conforming to standard scientific reporting style (where appropriate, Results and Discussion may be combined).

- **Review Articles**. Review articles should focus on the clinical implications of theoretical perspectives, diagnostic approaches, or innovative strategies for assessment or treatment. Articles should provide a critical review and interpretation of the literature. Although subdivisions (e.g., introduction, methods, results) are not required, the text should flow smoothly, and be divided logically by topical headings.

- **Commentaries**. Occasionally, the editor will invite one or more individuals to write a commentary on a research report.

- **Editorials**. Unsolicited editorials are also considered for publication.

- **Notes From the Field**. Notes From the Field offers a forum for brief descriptions of advances in clinical training; innovative treatment methods or community based initiatives; developments in service delivery; or the presentation of data from research projects which have progressed to a point where preliminary observations should be disseminated (e.g., pilot studies, significant findings in need of replication). Articles submitted for this section should be limited to a maximum of 10 manuscript pages, and contain logical topical subheadings.

- **News and Notes**. This section offers a vehicle for readers to stay abreast of major awards, grants, training initiatives; research projects; and conferences in clinical psychology. Items for this section should be summarized in 200 words or less. The Editors reserve the right to determine which News and Notes submissions are appropriate for inclusion in the journal.

Editorial Policy.

Manuscripts for consideration by the *Journal of Clinical Psychology* must be submitted solely to this journal, and may not have been published in another publication of any type, professional or lay. This policy covers both duplicate and fragmented (piecemeal) publication. Although, on occasion it may be appropriate to publish several reports referring to the same data base, authors should inform the editors at the time of submission about all previously published or submitted reports stemming from the data set, so that the editors can judge if the article represents a new contribution. If the article is accepted for publication in the journal, the article must include a citation to all reports using the same data and methods or the same sample. Upon acceptance of a manuscript for publication, the corresponding author will be required to sign an agreement transferring copyright to the Publisher; copies of the Copyright Transfer form are available from the editorial office. All accepted manuscripts become the property of the Publisher. No material published in the journal may be
reproduced or published elsewhere without written permission from the Publisher, who reserves copyright.

Any possible conflict of interest, financial or otherwise, related to the submitted work must be clearly indicated in the manuscript and in a cover letter accompanying the submission. Research performed on human participants must be accompanied by a statement of compliance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and the standards established by the author's Institutional Review Board and granting agency. Informed consent statements, if applicable, should be included with the manuscript stating that informed consent was obtained from the research participants after the nature of the experimental procedures was explained.

The Journal of Clinical Psychology requires that all identifying details regarding the client(s)/patient(s), including, but not limited to name, age, race, occupation, and place of residence be altered to prevent recognition. By signing the Copyright Transfer Agreement, you acknowledge that you have altered all identifying details or obtained all necessary written releases.

All statements in, or omissions from, published manuscripts are the responsibility of authors, who will be asked to review proofs prior to publication. No page charges will be levied against authors or their institutions for publication in the journal. Authors should retain copies of their manuscripts; the journal will not be responsible for loss of manuscripts at any time.
Abstract

Objective(s). An increasing demand exists for psychological interventions to increase recovery from depression and anxiety in people with long-term physical health conditions (LTCs). Guided self-help (GSH) may meet this need, however, there is limited evidence of GSH’s appropriateness for people with LTCs.

Design. A mixed-methods study using qualitative interviews with people with stroke and Chronic Obstructive Pulmonary Disease (COPD), and a quantitative survey of professionals who support guided self-help, explored opinions about whether self-help is appropriate, and whether suggested adaptations varied across LTCs.

Results. Opinions varied about the appropriateness of standard self-help and adaptations required. Illness beliefs may help explain differences between the two LTCs and individual interviewees. The majority of professionals surveyed felt competent supporting people with LTCs, and reported having access to appropriate self-help material.

Conclusions. Recommendations for improving the appropriateness of contents of guided self-help for people with LTCs are provided. Supporting professionals need relevant knowledge and skills to integrate information about the LTC into the intervention, and offer flexible, personalised delivery to support participation.

---

To provide sufficient information, the abstract section exceeds the 150 word limit for the intended journal.
Adapting Guided Self-Help (GSH) for Anxiety and or Depression to Meet the Needs of Individuals with Co-morbid Long-Term Physical Health Conditions (LTCs).

Around 15 million people have one or more LTC in England (Department of Health; DH, 2012a). There is a higher prevalence of common mental health problems (e.g. anxiety or depression) in people with LTCs compared to the general population (Egede, 2007; White, 2000), for example cancer (Breitbart, 1995), chronic obstructive pulmonary disease (COPD; Yohannes, Baldwin & Connolly, 2006), diabetes (Anderson, Freedland, Clouse, & Lustman, 2001), multiple sclerosis (Siegert & Abernethy, 2007) and stroke (Gordon & Hibbard, 1997).

Evidence-Based Psychological Interventions

Treating co-morbid mental health difficulties can have a substantial positive impact on health-related quality of life (NICE, 2009a) and improve the course and outcome of the LTC (DH, 2008; Haddad, 2010). Effective treatment will also save costs for the healthcare system (DH, 2008). Due to the benefits outlined it is important that people with LTCs have access to evidence-based psychological interventions. However, they are often not referred for psychological interventions (DH, 2011a).

NICE (2009a) recommends people with co-morbid LTCs receive low and high intensity cognitive behavioural therapy (CBT) for anxiety and depression. Under the stepped care approach to mental health (Figure 1) people first receive a low-intensity intervention such as GSH (NICE, 2009b, 2011a). GSH refers to the use of self-help materials, either through written bibliography or in computer technology formats, which are supported through minimal professional contact (Gellatly et al., 2007). The effectiveness of self-help is increased by basing the material on standardised cognitive-behavioural techniques, and the provision of support (Gellatly et al., 2007): Although, providing support is only beneficial if
the materials used are appropriate for the user (Improving Access to Psychological Therapies [IAPT], 2010).

**Improving Access to Psychological Interventions for People with LTCs**

The implementation of evidence-based practice requires integration of research evidence with clinical expertise and judgment, and considerations of acceptability for service users (Aarons, Wells, Zagursky, Fettes, & Palinkas, 2009). As detailed below, the needs of people with LTCs may differ to that of the general population (Gulliford et al., 2001). Therefore standard interventions may require adapting to make them appropriate. Gulliford and colleagues (2001, 2002) outline four considerations that determine whether people receive appropriate health care resources: availability, utilisation, relevance and effectiveness, and equity.

- **Availability.** GSH may be one solution for meeting the increased demand for psychological interventions (Khan, Bower & Rogers, 2007; Mead et al., 2005). However availability does not reflect whether people will take up the intervention.

- **Service utilisation.** The extent to which a population ‘gains access’ to health care also depends on financial, organisational and social or cultural barriers that limit utilisation. Thus utilisation is dependent on the affordability, physical accessibility and acceptability of services and not merely the adequacy of supply (Gulliford et al., 2001, p3).

LTC’s may create additional barriers to participating in psychological interventions (Andrykowski & Manne, 2006; Coventry & Gellatly, 2008). For example, fluctuations in symptoms may interrupt engagement during therapy intervention (White, 2000). GSH’s flexibility may increase accessibility for people with limited mobility by delivering services in their homes via telephone or Internet (NICE, 2009a).
To increase utilisation, the supporting professional should adapt duration, frequency and length, and liaise with the physical health care team to integrate the depression care with rehabilitation care (NICE, 2009a). However, implementation of these recommendations could be affected by the professional’s knowledge and motivations (Benzer et al., 2012; Koh, Manias, Hutchinson, Donath, & Johnston, 2008) to work with people with LTCs, as well as the separation of physical and mental health services, which create organisational barriers to collaborative care (Benzer et al., 2012; Naylor et al., 2012). “Many good initiatives flounder because insufficient attention is paid to the staff themselves and the actions needed to create the climate in which the desired attributes can ensure success” (DH, 2009, p26).

**Relevant and effective services.** The evidence-base for effective psychological interventions in people with LTCs is limited because physical co-morbidity is often an exclusion criteria in research (Creed, 1997). NICE identified three studies of GSH in people with co-morbid LTCs; their results showed a moderate but non-significant effect. This finding was replicated in a meta-analysis examining the effectiveness of GSH in individuals with LTCs (Farrand & Woodford, submitted): The authors recommend further investigation to identify under which conditions self-help may be effective for individuals with co-morbidity.

NICE (2009a) recommended standard low-intensity interventions (NICE, 2009b, 2011b) for people with LTCs based on the assumption that depression was the same for people with and without co-morbid LTCs. However, research indicates that standard self-help may not address the needs of people with LTCs (Hind et al., 2010; Moss-Morris et al., 2012; van Bastelaar, Cuijpers, Pouwer, Riper & Snoek, 2010). Acceptability is important to reduce attrition rates from treatment (Fitzpatrick, Simpson & Smith, 2010). Improving the acceptability of the material may be a first step in improving access.
How self-help is supported also determines efficacy (Gellatly et al., 2007; IAPT 2010). It is important that interventions are delivered by competent practitioners (NICE, 2009a) who will need the right knowledge, skills, training, and behaviours to appropriately adapt interventions (DH, 2012b). However, as current training for supporting self-help does not include teaching on working with long-term conditions (DH, 2011a), the supporting professionals may not have the right skills.

**Equity of services.** Services must meet the additional requirements of people with LTCs (DH, 2011b). As outlined above, whilst the flexibility of GSH may increase availability and reduce physical barriers to accessing services, standard interventions may not be acceptable or evidence-based for people with LTCs. Therefore people with LTCs may not be receiving equal access to appropriate care (Gulliford et al., 2002).

**Improving Access to Appropriate Interventions**

There is a need for research that explores both the recipients’ and deliverers’ perspectives on acceptability of GSH (Lewis, Pearce, & Bisson, 2012). This can inform whether there is a need to adapt standard GSH for people with LTCs, and how they should be adapted to improve acceptability. Qualitative research is particularly important in the initial stages of considering whether interventions meet the needs of specific groups (Campbell et al., 2007). People with LTCs can provide an expert resource to identify how to adapt interventions to best meet their needs (Andrykowski & Manne, 2006; DH, 2001, 2010; Gagnon et al., 2011; Morton & Morgan, 2009).

If adaptations are required, there is a need to determine whether these can be applied across LTCs. By identifying commonalities in the relationship between LTCs and co-morbid anxiety or depression, interventions could be developed that are applicable across multiple
disorders (Piette, Richardson, & Valenstein, 2004). A literature review to determine how CBT interventions for anxiety and depression have been adapted for people with LTCs highlighted that studies generally focused on adapting the intervention for specific LTCs rather than investigating whether interventions can be generalised across conditions. Where generalizability was considered this occurred within disease categories, for example cancers (e.g. Cluver, Schulyer, Frueh, Brescia & Arana, 2005), or between two conditions as in diabetes and COPD (e.g. Cully et al., 2010). Furthermore interventions were delivered within specific physical health care services, with no studies focusing on how to adapt practice in mental health services.

To date there have not been any studies investigating either acceptability or how to adapt low-intensity GSH for people with LTCs, as supported within the mental health services. As such, there is also a need to identify mental health professionals’ attitudes and competencies around supporting people with LTCs to use GSH. This research aims to explore whether standard GSH is acceptable or needs adapting for people with LTCs.

Research Questions

1. To what extent do people with LTCs of stroke and COPD, and the supporting professionals perceive standard GSH to be appropriate for people with LTCs?

2. In what ways could the content and delivery of GSH be adapted in order to improve its appropriateness for people with LTCs?

3. To what extent is there a consensus about acceptability and adaptations between participants with two different LTCs (stroke and COPD) and the professionals who support GSH?

Methods
Design

A mixed-methods approach can provide a better understanding of research issues than either quantitative or qualitative data alone (Robins et al. 2008). The mixed-methods design consisted of two studies. Qualitative interviews with people with LTCs guided areas of relevant discussion about GSH: interviews were chosen because the participants had limited knowledge about the approach. A quantitative survey of professionals supporting people with LTCs enabled data to be collected from a larger sample with a wider range of experience, than would be possible with interviews. A survey method is an appropriate method for gathering perceptions of self-help by UK CBT practitioners (Keeley, Williams, & Shapiro, 2002). Within this study qualitative inquiry was the main method with simultaneous quantitative inquiry (Morse, 1991). The data of the two methods will be triangulated throughout to compare opinions on the issues discussed.

Study 1. Semi Structured Qualitative Interviews: The Service Users’ Perspectives

Participants. It is important to consider whether adaptations generalise, therefore semi-structured interviews were carried out with participants with two different LTCs. Stroke and COPD were selected because they comprise two of the four largest categories of non-communicable diseases, which accounted for 88% of all UK deaths in 2010 (World Health Organisation, 2011). These conditions vary in terms of degenerative versus stable presentation, and primarily cognitive versus physical impact.

Participants were aged over 18 years. Participants were not required to have experience of anxiety or depression and, due to the increased rate of co-morbidity, were not excluded if they did. Participants with experience of GSH were not sought because their opinions may reflect experience of the particular service or professional who delivered the
interventions, rather than attitudes towards the material discussed or perceptions about how their LTC would impact on how they were supported. Additionally it may not have been feasible within the project timescale to recruit enough participants with the relevant LTC and experience of GSH.

An opportunistic sample was used. Participants were recruited from community stroke and COPD support groups which the researcher visited, and research invitation posts on condition specific Internet forums (further recruitment information is provided in Appendix B1). Due to geographical accessibility, participants recruited online were interviewed by telephone, whereas those recruited from support groups were interviewed face-to-face in their home: Eleven participants were recruited to the study, five stroke (4 face-to-face, 1 telephone), six COPD (2 face-to-face, 4 telephone). No-one was excluded. Table 1 summarises participant characteristics, method of recruitment and interview format. All participants were White British with mean age of 65.63 years (SD=11.48). Only two participants did not self-report suspected or diagnosed anxiety or depression.

**Procedure.** Participants were provided with the participant information sheet, demographics questions and consent form (Appendix A1), and were required to return completed forms to participate. Demographic information was collected to help contextualise differences and similarity in the themes that emerge, for example history of mental health difficulties.

Participants were sent information to read prior to interview. This included a copy of “A Recovery Programme for Recovery” (Lovell & Richards, 2012), a standard self-help book for depression which was freely available online, and information explaining the nature of GSH and CBT: Three individuals with stroke were consulted at this stage to improve the readability of the information.
A semi-structured interview schedule (Appendix B2) was developed based on themes that emerged from a literature review on adaptations to CBT for LTCs. Consent was gained to digitally record interviews. Interviews lasted between 60-90 minutes with a short break where required. To facilitate responses about acceptability of material, participants were asked their opinions on the “A Recovery Programme for Recovery” book and the need for adaptations. Open questions were also asked about “guided” support. The amount of time participants spent reviewing the self-help book varied, therefore some interviews focused more on the GSH approach rather than the material.

In addition, in the last ten minutes of the interviews, four of the six face-to-face participants were shown a range of self-help books and asked to comment on factors such as layout and readability.

**Interview data analysis.** Interviews were conducted by the principal investigator (PI) between February-April 2013. Verbatim transcription of interviews was carried out continuously to allow an iterative process, in which emerging themes could be explored in subsequent interviews.

Framework analysis (FA), a form of qualitative thematic analysis (Ward, Furbe, Tierney & Swallow, 2013), was used. The five stages of FA (Table 2) were followed (Ritchie & Spencer, 1994). NVivo was used to increase transparency of data analysis and interpretation. The thematic framework was created based on results of the adaptations identified in a literature review. This was modified throughout the process by themes emerging from interviews as they were completed and transcribed. (A rationale for using FA is provided in Appendix B2).
Study 2. Quantitative Survey: Professional’s Perspectives

Participants. Professionals with experience of supporting GSH were recruited to an online survey (Appendix B2) exploring their knowledge and attitudes towards working with people with LTCs.

Procedure. A purposive strategy was used to recruit respondents via an email link to the Self-help and LTCs special interests groups of the British Association for Behavioural & Cognitive Psychotherapies. An opportunistic strategy was then used to increase response rate. A post was also created on two online forums relevant for professionals who use CBT. Finally an email request to forward the survey link to previous cohorts was sent to 17 universities that delivered post-graduate training in low-intensity interventions. Participants who followed the link were provided with further study information, informed about confidentiality and required to confirm their consent to participate.

A survey was developed for the study. The questions were informed by a previous survey of staff attitudes towards self-help material (Keeley et al., 2002) and by a systematic review of the literature relating to adaptations to CBT for people with LTCs. The survey consisted of a series of 5-point Likert-type scales, yes/no response options, and one qualitative question about which self-help resources they use with people with LTCs. Open questions were avoided to reduce participation burden. Time restrictions meant a pilot of the survey and measure of test-retest reliability were not undertaken.

Respondents were asked to provide initial information on their CBT experience, and training and experience supporting people with LTCs: those who had worked with LTCs were directed to questions about whether and how they adapted practice, and their perception of acceptability of the approach. Respondents were asked questions related to their knowledge, attitudes and intentions about using GSH to support people with LTCs.
Sample Characteristics. A total of 124 people took part in the survey, including 20 who did not complete all questions. Seventy-nine per cent of respondents had experience supporting one or more people with a variety of LTCs. Respondent characteristics are summarised in Table 3.

Survey data analysis. Explorative statistics will be reported based on the total number completing that question. Due to the small sample size in each of the different job professions statistical comparison was not possible.

Ethics

Ethical approval was received from the University of Exeter, School of Psychology Ethics Committee (Appendix A2).

Results

The interviews were coded into eight themes, three of which were unrelated to the research questions and therefore not considered further (Appendix C1). Separate charts were created for each theme and responses compared between the LTCs. The concepts within each theme, supported by interviewee quotes, are provided in (Appendix C2). To facilitate comparison between conditions participants are coded according to whether their main condition was stroke (S) or COPD (C).

Although telephone interviewees tended to spend more time talking about their journey to diagnosis and specific experiences during the interviews, data analysis of telephone and face-to-face interviews found similar themes related to the research questions. There were also no notable differences between participants with or without experience of mental health conditions on themes related to the research questions.
At the mapping and interpretation stage of analysis the PI identified two major themes related to the research questions. The results are organised according to these major themes: the interview data is first reported followed by interpretation of the related survey data.

**Major Theme 1. The Self-Help Intervention**

**The impact of the LTC.**

*Cognitive impact.* Participants across both LTCs described difficulties with understanding information, concentration and memory which could affect engagement. This was particularly emphasised in participants with stroke.

I bet when I come across one I won't remember it (laughs). (S4)

Cognitive deficits, such as word-finding difficulties, may affect the format of delivery needed. For example, the telephone may not be suitable due to lost visual cues that aid conversation, whereas written emails may help.

*Physical impact.* Although tiredness was emphasised as an impact of LTCs, the relevance of this for engagement was not stated. Stroke participants spoke about mobility problems that would impact on ability to attend appointments and complete activities, and for one participant to physically manage reading a self-help book. Participants with COPD thought symptom fluctuations would affect ability to attend regular appointments. Delivering interventions in the participants’ homes may overcome LTC related barriers.

…behaviour necessitates er in many instances movement and mobility of some kind, getting out of the shop, or getting out to visit one someone. (S5)
Interaction between physical and emotional health. Maintenance cycles of anxiety and depression, which were related to the impact of the LTC, were apparent within participant’s narratives. This highlighted the appropriateness of a CBT approach.

Now if you get up and you think “phew no I feel alright today, I feel alright I I haven’t got a chest infection, fabulous” then your mood is lifted, but if you get up and you think “oh I feel a bit tight chest- yeah, or I got pains in my back” straight away mood is changed, and you’re down. (C6)

Participants across the conditions held mixed beliefs about causes of depression. For some, depression was caused by real losses and hopelessness about the future, due to the LTC. Others thought depression was caused by negative thinking or loss of motivation to engage in activities and being on a downward spiral.

…it’s changed, changes their live lives completely as mine has has changed, changed me a lot as well, um, some people do well from that, some people don’t. (S1)

Stigma around mental health was a barrier to accessing services. Some participants felt it was important to distinguish between depression as a natural reaction to the condition, and mental illness.

…it's depression that attached to the physical problem, it doesn't mean you you you’re mentally unstable, it's a natural reaction to feel down if you've got severe pain. (C3)

The self-help material.
Focus of self-help. Opinions about the appropriateness of standard self-help material varied across participants. Only two COPD participants thought the example book would be appropriate, providing there was appropriate support from a professional to modify approach to tasks. Five participants with COPD thought the self-help book needed to integrate information about how the LTC would impact on abilities: One of these however felt this had been achieved through the vignette of a person with a LTC.

The examples of intervention techniques did not always reflect the experience and perceived abilities of people with LTCs. There was an identified need for the material to explain how physical and emotional health connect together.

But that is another area where, I found it er a clash because they was, they were putting over that, and trying to make it look as if you were depressed and that's why you weren't doing things (C3)

It may be important to consider how the topics of cognitive restructuring and unrealistic beliefs are addressed within self-help books for people with LTCs. Two participants (C5 and S3) questioned the value of the approach for people with LTCs where there could not be physical improvements. For people with LTCs there may be a reality to their thoughts, which leads to hopelessness. Despite reading about the technique of cognitive restructuring to challenge inaccurate beliefs, no participant offered reflection that the statements they made about the reality of their condition might not be completely true. Participants repeatedly communicated about the things they could not do, with “recovery” viewed as how they were before their LTC.

Um, well, perhaps it's not a very good thought, I don't know but um, again it's a question of what you know because you know that your disease, mine will never get
better it will only get worse um so there are bound to be occasions when you will not be able to do what you used to do, which I feel very strongly now... (C2)

Participants acknowledged that people with LTCs reduce activities and therefore behavioural activation was valuable. Avoidance or withdrawal from valued activities was recognised to link to emotional difficulties.

…some people er er, just don’t do very much, now I think they prop, they could possibly that could help them if if they did…(S1)

The examples within the book were perceived as what “able bodied” people could do (S5) and did not acknowledge that reduced activities may be due to physical symptoms, either permanently or on a day-to-day basis, rather than due to depression.

…the examples within the book were perceived as what “able bodied” people could do and did not acknowledge that reduced activities may be due to physical symptoms, either permanently or on a day-to-day basis, rather than due to depression. (S5)

Due to the physical impact of LTCs, information about sleep, relaxation and breathing techniques, and physical activity were also regarded as having particular merits.

**Difficulties generalising.** Participants frequently stated they would be unable to do the self-help examples due to their LTC. For people with cognitive difficulties this may pose a greater problem due to the cognitive flexibility required to generalise from the point.

That's definitely not me ‘cause I have it and it’s almost white my coffee is, there’s about that much, quarter of a teaspoon of coffee and the rest is water and milk…(S4)
Participants dismissed examples of participant’s thoughts or goals because they were perceived to be real impacts of the LTC (C2, C4). Indeed it was suggested that unachievable examples could worsen the depression by increasing hopelessness

… I can read that and relate to it, “well yeah I can't do this that and the other” but I get the general principle of what's being said here. And, other people perhaps wouldn't be able to, like I say it could add to their depression. (C4)

**Recovery stories.** Participants favoured the inclusion of a recovery story about a person with a LTC, as this offered hope for recovery, and decreased their sense of isolation. The inclusion of a mixture of people with and without a LTC was seen as an appropriate way to do this, so that people could relate to the relevant trigger of their mood difficulties. There was a desire for stories to be real examples, and to clearly outline the stages and struggles of using self-help.

But I think that would be the main thing to realise that other people are in the same position (S4)

I've always had a little bit of er, I've always had a little bit of a problems with with stories that are all put together in er you know knowing that er in end, who has rewritten them are are they factually accurate erm, how have they been edited. (C5)

**Overall format of book.** A common view was that the length of self-help books could overwhelm people and put them off starting. However, this related more to beliefs about motivation when depressed rather than impact of the LTC.
Yeah, this is probably better for, you know the counsellors than it is for the people. So you just, for the people in depression you just want it short and sweet.... (S2)

The active approach towards completing tasks and the structured format was valued for helping to overcome memory difficulties. The use of formatting to include bullet points, bold catchy statements that summarised key messages, concise sections and shorter book length were valued, particularly for people with cognitive deficits.

*Modifying expectations.* The interviews highlighted the need to support people to modify their expectations and set smaller realistic and achievable goals. However, the self-help material did not appear to convey this message for people with LTCs. Modifying expectations also included the need to allow flexibility around good and bad days..

**Survey data: professionals’ views on the self-help approach.**

Eighty one respondents had supported people with LTCs using self-help (65%). Of these, 56% of respondents either “Agreed” or “Strongly Agreed” that the self-help materials they used were relevant, 15% “Disagreed” whilst 29% “Neither Agreed or Disagreed”. Similar figures were reported regarding beliefs about effectiveness. Sixty eight of the respondents who had worked with people with LTCs provided a list of example resources they used. Eighteen of these reported that they used information booklets specifically related to the LTC, for example chronic pain. Ten respondents, four of whom also used condition specific books, reported adapting standard self-help books or worksheets to the individual’s presenting problems. The high reports of satisfaction with materials may therefore relate to the use of a diverse range of material. This is reflected in the survey responses that when
choosing self-help material to use, professionals would be likely to consider issues such as how the LTC affected them, relevance and potential effectiveness (Figure 2).

Sixty five per cent of responders, “Agreed” or “Strongly Agreed” it was important to use relevant case examples in the material, 17% “Neither Agreed or Disagreed” whilst 6% “Disagreed” and 10% “Strongly Disagreed”.

Major Theme 2. The “Guided” Support

Service setting. Communication between services was seen as important to improve understanding of how different conditions will interact and to increase detection of mood problems. Participants wanted health professionals to raise awareness of, and normalise the potential for anxiety and depression due to the LTC in the early stages of physical rehabilitation.

I think a mental health pro-professional um should should almost be involved in a in a at some point, erm almost in a triage capacity if you like… (S5)

COPD participants favoured the delivery of support within physical health services, particularly because they perceived the nature of depression to be different when related to the LTC. One participant maintained this view even if depression was related to a life event.

Yeah I still think ph-physical rehab setting. Um. But for the reason that it could then be related back to the physical condition rather than er not being able to cope with life changes. (C5)
Perceived benefits of mental health services included staff qualification, more time to spend with patients and competing demands of staff in physical settings to focus on the management of the LTC.

**The supporting professional.** The supporting professional was regarded as important for motivating and keeping the person on track, particularly for people with memory and concentration problems. They could also help people generalise from the examples

… I think the the crux of this like so many i-in-interventions is in the competence and and and desire of the person who is supplying the intervention. (S5)

There was an expectation that the supporting professional would ask about their LTC; four participants reported negative personal experiences of conditions being treated separately. Participants wanted the supporting person to understand about the condition so that they can help to modify the approach and take into consideration the impact of the condition and the person’s abilities

…you know the potential um um the potential problems that I would face so they’d they’d have a sort of basic understanding of what they were perhaps going to encounter when they met me…(C4)

Other benefits of support were not unique to people with LTCs, for example talking to someone outside of the family.

**Inclusion of a significant other.** The inclusion of a significant other in the care was valued by all participants; however it was highlighted that some people may not be able to identify a relevant person who they could trust.
Well…….. you got to get somebody who really cares. Haven’t you? If they want to support you…(S3)

Participants recognised the impact of the person’s depression and LTC on the relationships and wellbeing of significant others. One COPD participant felt that the self-help material focused solely on the person with depression and needed to acknowledge the relational context in which depression may affect others.

Er but the one thing I did think about the booklet was it’s all “me, me, me”. (C5)

A significant other may be particularly beneficial for people with memory problems to help them remember what was talked about within sessions. Indeed one participant felt that it would be beneficial for the significant others to take a more active role than the supporting professional.

I could envisage a mental health service professional almost coaching a very good friend to be the person who is actually doing the motivation and prompting on a weekly basis, with a healthcare professional being one step away. (S5)

**Format of delivery.** Overall there was a preference for face-to-face support. Participant’s valued the opportunity for home visits, or for services to be delivered in the home through telephone, email or televideoing to overcoming LTC associated burden. If the person was to travel for face-to-face sessions there was a need to consider venue accessibility. COPD participants highlighted the importance of session length due to the burden of travelling and the need to recover from breathlessness on arrival.
It was highlighted that people with LTCs may be older and not have access to computers, or may value social company from face-to-face contacts. Preference was also determined by cognitive deficits, for example speech and writing difficulties.

**Frequency of delivery.** The frequency of contact and session length may need to be determined by severity of both the depression and LTC. People with cognitive difficulties may benefit from shorter and more regular contacts to prompt task engagement. The supporting person would need to be flexible to accommodate missed sessions due to fluctuating symptoms. A theme emerged relating to desire for contact between sessions either through telephone or email prompts from the supporting professional, or access to a telephone line, email service or online forum which could meet information or support needs.

**Survey data: professionals’ views on the support.** Only ten (9%) of the 111 respondents thought that psychological interventions should only be offered within specialist services for people with LTCs. The majority 75 (72%) “Disagreed” or “Strongly Disagreed” with this statement. Professionals generally “Agreed” or “Strongly Agreed” (n=82, 76%) that it was important to consider communicating with other health care professionals involved, with only two people disagreeing (Figure 3). Eighty seven (78%) professionals reported that it was important to consider signposting to relevant community organisations for support related to their LTC.

Respondents generally reported they felt confident starting a conversation about the person’s LTC (Figure 4) and able to include this in a formulation (Figure 3). Furthermore, 100 (90%) professionals agreed that it is important to include the LTC in the statement. Respondents “Agreed” or “Strongly Agreed” (n=108, 97%) that adapting the intervention to
accommodate the LTC was important. There was mixed concern about whether adapting an intervention would affect it being evidence-based.

There was a mixed response to whether professionals would consider including a significant other (Figure 3). The majority of people “Neither Agreed or Disagreed” (n=59, 53%).

Professionals would consider a variety of support methods (Figure 5). All respondents were “Likely” or “Very Likely” to delivery interventions face-to-face. Opinions about whether they would offer email or telephone support were divided. Due to the question wording it could not be determined whether differences in intentions towards offer groups reflected service opportunities or attitudes about appropriateness.

Responses to how to adapt frequency of delivery were spread across the response options (Figure 6). Across all profession groups, professionals tended to be “Likely” or “Very likely” to offer shorter sessions. There was a mixed response as to whether professionals would offer longer sessions and whether they would offer follow up sessions. The majority of professionals “Agreed” or “Strongly Agreed” that it was important to be flexible when supporting a person with a LTC to ensure that they can access support (n=108, 97%), and to reduce dropout rates (n=100, 89%), with only one professional reporting they did not agree with the statements.

**Discussion**

This mixed-methods research aimed to explore whether the standard GSH approach is acceptable or needs adapting when used with people with LTCs. These are explored below in relation to the wider literature. In summary, the interviews revealed a need to integrate
information about the co-morbid LTC within the intervention for anxiety and depression either through the self-help material, or via the professional individualising the approach. There is also a need to improve the person’s ability to relate to the material’s content and examples provided, for example by helping the person set achievable goals which take into consideration the impact of the LTC. Triangulation with the survey data highlighted that professionals reported relevant knowledge and skills to adapt interventions for people with LTCs and felt they had access to relevant material.

**Self-help Content**

There were mixed views, both within and between people with LTCs and the supporting professionals about the need for specific self-help books for LTCs. Whilst staff attitudes can create a barrier to the implementation of interventions (Pratt, Halliday & Maxwell, 2009), the survey results indicated professionals held positive attitudes towards using GSH with people with LTCs. The survey showed professionals also accessed a range of self-help resources specifically developed for working with LTCs alongside the standard material therefore the responses may not have solely reflected attitudes towards standard self-help.

Engagement may be affected where the material does not acknowledge the interaction between the conditions (Hind et al., 2010). For example, throughout the interviews participants normalised avoidance of activities and safety behaviours due to their LTC. This contrasts with self-help material’s focus on exposure and behavioural activation, and could cause barriers to engagement because it does not fit with the user’s understanding of their conditions (Khan et al., 2007)

The common sense model of illness representations predicts that the person’s illness beliefs are related to emotional distress and adjustment to the LTC, and that this relationship
is mediated by coping strategies they use (Hagger & Orbell, 2003). Illness beliefs refer to the cognitive representations the person has formed about their LTC either from direct experience or various sources of information; these beliefs may not be medically accurate (Kaptein et al., 2008). Research suggests that even when severity of the condition is controlled for, illness beliefs can determine the extent of psychological distress (e.g. Kaptein et al., 2008; Scharloo et al., 1998).

Illness beliefs may account for the differences between participants with COPD and stroke because research has demonstrated that beliefs vary across LTCs (Heijmans, & de Ridder, 1998; Scharloo et al., 1998). Differences in illness beliefs were identified in the interviews relating to whether the LTC had a cognitive or physical impact, and whether it was stable or progressive condition.

A CBT approach can be useful for identifying and addressing important misconceptions about the LTC (Kaptein et al., 2008). The interviews captured how illness beliefs may create barriers to motivation and engagement with self-help. Exploration of illness beliefs may help the supporting professional tailor the approach as appropriate.

Behavioural activation aims to increase engagement in behaviours that promote contact with environmental reinforcers (Hopko, Lejeuz, Ruggiero, & Eiffert, 2003). However, participants thought that examples provided in the self-help book reflected activities they could no longer do. Examples may need to direct people with LTCs to focus their efforts into areas of life that can be controlled or changed (Schwartz & Rogers, 1994). Incorporating the ideas of acceptance versus change may be beneficial when working with people with LTCs (Beatty & Koczwara, 2010; Hopko et al., 2008; Vriezekolk et al., 2012). People who continue to try to achieve unattainable goals that they have limited personal control over may experience higher emotional distress than those who abandon these and
redirect efforts to alternative valued goals (Brandstädtter & Renner, 1990). Adapting the self-help material to include an acceptance based philosophy (Hayes, Strosahl & Wilson, 1999), and supporting the person to develop skills around whether to use a problem-solving or acceptance approach (Vriezekolk et al., 2012) may improve outcomes.

Social support is recognised as an important coping strategy (Schaefer, Coyne, & Lazarus, 1981). Where support is delivered one-to-one there is a need to consider how the benefits of social support can be achieved. Inclusion of relevant examples, for example, through recovery stories which promote shared experiences, hope, and struggles would increase relevance of self-help and are desired by users (IAPT, 2010; Lovell et al., 2008; Hind et al., 2010; Moss-Morris et al., 2012; van Bastelaar et al., 2010; MacDonald et al., 2007). Relevant examples help people feel less isolated in their experience (Garvin, Striegel-Moore, & Wells, 1998). Interviewees in this study thought it important to include examples relevant to people with LTCs in self-help material, the examples did not need to be condition specific, but should reflect the additional difficulties that a person with a LTC may encounter using the approach.

Mansell (2007) recognised the difficulty in self-help material of balancing the need to present generalised CBT principles whilst maintaining a personalised approach. The interview data indicates that this needs to be considered when supporting people with LTCs because of difficulties generalising from examples, and the need to integrate additional information about the LTC. The supporting professional needs the knowledge and skills to make the CBT self-help information relevant for the individual, as well as to adapt the approach for example by considering appropriate goal setting and pacing of activities (Hind et al., 2010). People with LTCs may be more reliant on the supporting professional to adapt the self-help intervention. This could shift the balance of power and undermine the
importance of the individual as the agent of change (Khan et al., 2007). An adapted self-help book that reflects the needs of people with LTCs may overcome this potential problem.

Participants favoured less formal, less text heavy self-help books, and emphasised the need for realistic examples and exercises; which is similar to populations without LTCs (Mansell, 2007). Additionally the reading level should be considered because LTCs may cause additional concentration problems above that associated with depression (Richardson, Richards, & Barkham, 2008).

Supporting the Intervention

The presentation of mental health conditions may be influenced by co-morbid LTCs (Piette et al., 2004; White, 2000). To overcome barriers to engagement, professionals are encouraged to know about the LTC they are supporting, integrate the co-morbid conditions, and provide clear rationales for the CBT techniques. Based on the interview responses, professionals could promote engagement despite the person’s LTC, for example, by pacing activities (e.g. complete more activities on good days, small achievable goals) to avoid fatigue, or strategies to overcome concentration and memory difficulties (e.g. less text-heavy material, using email or telephone to remind people of homeworks).

Implementation of evidence-based interventions can be affected by staff knowledge, motivation and resources (Benzer et al., 2012). The survey found professionals were confident in their ability to integrate the co-morbid LTC and adapt practice as required. Individuals who have received training feel more confident about the use of self-help materials (Keeley et al., 2002) which may explain the favourable results of the survey. However, training quality and content was not captured. Relevant training topics could include the following: how to find out about the LTC and its treatment; recognising the role
of significant others; identifying illness perceptions; and addressing realistic negative thoughts and hopelessness (Moss-Morris et al., 2012)

Current policies encourage collaborative care between services. Indeed participants felt there was a need to address emotional problems early on as part of the physical care to help normalise the occurrence of anxiety and depression as a response to the impact of the LTC. The survey suggests that supporting professionals within mental health settings have appropriate knowledge and skills to enable them to meet the needs of people with LTCs. However, participants highlighted the stigma around accessing support for anxiety and depression; which reflects the opinions of people without LTCs (Kadam, Croft, McLeod, & Hutchinson, 2001). To increase acceptability it may be desirable to embed psychological support within physical rather than mental health services.

The fluctuating nature of symptoms may require more flexibility around contact. The results support the benefit of alternative formats of delivery, for example telephone (Bee et al., 2008), to overcome barriers to attendance (NICE, 2009a): Although these tended to be viewed as an additional support component to face-to-face encounters.

Professionals reported that they were likely to make a number of adaptations to accommodate the LTC. A limitation of the survey was that it could not be determined whether responses indicating that professionals would not adapt their practice, reflected attitudes about intention or constraints on practice. However, the majority of professionals reported they did not feel constrained by their service.

One hypothesis for the weak effect size of GSH with people with LTCs (Farrand & Woodcock, submitted; NICE, 2009a) may be due to the additional demands on time caused by integrating the two conditions and responding to symptom fluctuations. The evidence base for GSH requires the intervention’s focus to be on CBT techniques as the effective
mechanisms of change (Mead et al., 2005). The professional may need to consider issues around frequency of contacts and length of intervention to ensure sufficient focus on techniques during the support sessions (Mead et al., 2005).

**Strengths and Limitations**

Research into the effectiveness of self-help has ignored the importance of acceptability (Lewis et al., 2012). The mixed-methods approach enabled exploration of both the deliverers’ and recipients’ perceptions about acceptability of GSH for people with LTCs. The results highlight practical suggestions for how to support people with LTCs to improve acceptability when standard self-help is used. This study did not seek to recruit participants who had used GSH, responses were therefore based on perceived barriers and attitudes to the information presented. However this may limit result’s the ecological validity.

Due to stroke-related cognitive difficulties of some of the participants, and the abstract nature of the task for people who had limited familiarity with GSH, the PI needed to be more concrete in interview question wording which may have resulted in leading questions. When carrying out qualitative research it is important to acknowledge how the researcher influences interpretations (Flick, 1998), for example how prior knowledge influences indexing (Taylor & Ussher, 2001). Using FA helped to overcome hidden bias because the process of analysing and interpreting data is designed to be accessible to others (Ritchie & Spencer, 1994); an extract of an indexed transcript and example of the summarised framework matrices are therefore included in the appendices (Appendix C3, C4).

A weakness of the qualitative study is the small sample size which may not adequately capture diverse opinions within the two LTCs. Furthermore, participants were recruited through self-selection, and their opinions may not be representative of the wider population.
Survey responses may have been biased because professionals recruited from the special interest groups might have greater knowledge and experience of working with people with LTCs. It was not possible to separate the source of recruitment, therefore analysis could not support whether responses of those recruited from special interest groups differed to those recruited from other sources.

The survey method relied on professionals’ honest self-reporting. Despite assuring respondents of data confidentiality, desirability in responding may still have occurred (Constantine & Ladany, 2000). Due to lack of experience of the intervention to base opinions on, interview responses may also have been influenced by desirability.

**Clinical Implications**

The Government’s “No Health Without Mental Health” paper (DH, 2011b) placed responsibility within IAPT services to offer people with LTCs equal access to evidence-based psychological interventions. The Government intends to introduce a training module on supporting low-intensity interventions in people with co-morbid LTCs (DH, 2011a). However, the survey indicated that the majority of professionals felt they have relevant knowledge, skills and resources to adapt their practice. Therefore staff competency does not appear to be a barrier to access.

This study contributes to improving access to GSH for people with LTCs by identifying factors that may affect acceptability, and suggesting ways to adjust the content of materials, nature of support and delivery format. If emotional difficulties are caused by the burden of the LTC then it may be important to focus on the changes caused, however where depression and anxiety are causally unrelated to the condition (van Bastelaar, 2010) it may be more useful to consider adaptations to delivery rather than content.
If anxiety or depression directly relates to the LTC, NICE (2011a) recommends commissioners consider whether the psychological needs of people with LTCs would be best met within the physical care pathway rather than mental health pathway. The interviews support that this would provide a patient-centred approach to meeting the needs of people with LTCs.

**Recommendations for Future Research**

Competency to support interventions was based on self-report, which does not always correlate with other methods of assessing skills, for example, direct observations (Chevron & Rounsaville, 1983). An area for further investigation relates to how recipients perceive the appropriateness and acceptability of GSh when supported by self-reported competent professionals within mental health services.

The small sample and qualitative approach introduces difficulties with generalisability. Due to participants’ unfamiliarity with GSH, interviews were chosen because they allowed the PI to clarify information. To gather data from a larger sample, a Delphi method could be used to further explore and refine consensus on issues of acceptability and adaptations of people with LTCs who have used GSH within the stepped care approach (Vernon, 2009; Witt & de Almeida, 2008). However, the burden of participating in Delphi research may be a barrier for people with cognitive deficits.

Barriers to acceptability were identified. To enhance effectiveness there may be benefit in developing or evaluating self-help material specifically for LTCs. The development of a new text should follow the guidelines for developing and evaluating complex interventions (Campbell et al., 2007; Craig et al., 2008). People with LTCs and the supporting professionals should be consulted at each stage.
Conclusions

Qualitative interviews with people with LTCs and a survey of professionals indicated mixed views about the perceived acceptability of the standard GSH approach. Acceptability of the material can be enhanced by providing examples of people with LTCs, and emphasising the importance of adapting activities around the LTC to improve how the reader relates to the material. The supporting professionals are encouraged to have relevant knowledge to enable them to integrate how the LTC will interact with the person’s presenting anxiety or depression, and to support people to set achievable, valued goals. The survey responses indicate that professionals are confident in their abilities to support GSH in people with LTCs and report having access to a relevant range of self-help resources.
Acknowledgements

Firstly, thank you to Dr Paul Farrand for his guidance and advice during the project phase and Dr Phil Yates for his support and advice in completing the final report.

I would like to thank the participants who gave their time to take part in this study, including the people who advised on the readability of the written contents in the development stage.

Finally, I would like to thank my partner Kev for his feedback on the report and help with proof-reading, without which achieving a project within the word limit seemed impossible.
References


Gulliford, M., Morgan, M., Hughes, D., Beech, R., Figueroa-Munoz, J., Gibson, B.,…


ADAPTING GUIDED SELF-HELP FOR PEOPLE WITH LONG-TERM CONDITIONS


Table 1

Participant Characteristics

<table>
<thead>
<tr>
<th>Participants</th>
<th>Gender</th>
<th>Main LTC</th>
<th>Years diagnosed</th>
<th>Other comorbid LTCs</th>
<th>History of depression and anxiety</th>
<th>Method of recruitment</th>
<th>Interview format</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S1</td>
<td>Male</td>
<td>Stroke-aphasia</td>
<td>9.5</td>
<td>Q</td>
<td>Y</td>
<td>Talking therapies,</td>
<td>Face-to-face</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>supported self-help</td>
<td></td>
</tr>
<tr>
<td>S2</td>
<td>Male</td>
<td>Stroke</td>
<td>2.5</td>
<td>N</td>
<td>Y</td>
<td>Counsellor and</td>
<td>Face-to-face</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Support group</td>
<td></td>
</tr>
<tr>
<td>S3</td>
<td>Male</td>
<td>Stroke</td>
<td>5</td>
<td>N</td>
<td>N</td>
<td>NA</td>
<td>Face-to-face</td>
</tr>
<tr>
<td>S4</td>
<td>Female</td>
<td>Stroke</td>
<td>1</td>
<td>Heart attacks</td>
<td>Y</td>
<td>N</td>
<td>Face-to-face</td>
</tr>
<tr>
<td>S5</td>
<td>Male</td>
<td>Stroke</td>
<td>4</td>
<td>Ischaemic Heart Disease and Angina</td>
<td>N</td>
<td>Y</td>
<td>Medication</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants</th>
<th>Gender</th>
<th>Main LTC</th>
<th>Years diagnosed</th>
<th>Other comorbid LTCs</th>
<th>History of depression and anxiety</th>
<th>Method of recruitment</th>
<th>Interview format</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1</td>
<td>Male</td>
<td>Emphysema</td>
<td>5 years +</td>
<td>Q</td>
<td>Y</td>
<td>Support group</td>
<td>Face-to-face</td>
</tr>
<tr>
<td>C2</td>
<td>Male</td>
<td>Asthma</td>
<td>25 years</td>
<td>N</td>
<td>N</td>
<td>NA</td>
<td>Support group</td>
</tr>
<tr>
<td>C3</td>
<td>Female</td>
<td>Emphysema</td>
<td>1</td>
<td>Osteoporosis</td>
<td>N</td>
<td>Y</td>
<td>Medication</td>
</tr>
<tr>
<td>C4</td>
<td>Male</td>
<td>Asthma</td>
<td>3</td>
<td>Bronchiectasis, Polycythemia, Chronic cluster headaches</td>
<td>Q</td>
<td>N</td>
<td>Online forum</td>
</tr>
<tr>
<td>C5</td>
<td>Female</td>
<td>Emphysema</td>
<td>15</td>
<td>Y</td>
<td>Y</td>
<td>Medication</td>
<td>Online forum</td>
</tr>
<tr>
<td>C6</td>
<td>Female</td>
<td>Asthma</td>
<td>4</td>
<td>Osteoarthritis, Hypertension</td>
<td>N</td>
<td>Y</td>
<td>Bibliotherapy</td>
</tr>
</tbody>
</table>

*Responses coded as follows: Y=Yes, N=No, Q= Participants questioned whether they have current difficulties*
### Table 2

*Stages of Data Analysis (Ritchie & Spencer, 2004)*

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Familiarisation</strong></td>
<td>Familiarise self with diversity of the data through immersion. For example, by listening to and reading material. List key concepts and themes that begin to emerge. Begin to conceptualise the framework.</td>
</tr>
<tr>
<td><strong>Identifying a thematic framework</strong></td>
<td>Develop the thematic framework. This is initially based on the a-priori issues related to the research aims (that guided the interview questions) and developed by integrating the key, concepts and themes identified during familiarisation. The framework provides a template for sorting the data. The researcher influences the process by making judgements based on knowledge and intuition about the relevance and significance of the emerging concepts to the research questions. The framework is sorted into categories by making connections between the emerging themes. These are grouped under major subject headings.</td>
</tr>
<tr>
<td><strong>Indexing</strong></td>
<td>Systematically apply the thematic framework the transcribed verbatim data. Coding the data involves the researcher making judgements about the meaning and relevance of the text.</td>
</tr>
<tr>
<td><strong>Charting</strong></td>
<td>Rearranged data according to the thematic framework. Considers the range of attitudes and experiences for each</td>
</tr>
</tbody>
</table>
theme or issue. Develop charts according to the framework, a priori research questions or according to how results are presented. Charts may represent a theme or a case. At this stage the chunks of text indexed are summarised.

**Mapping and Interpretation** Pull out key characteristics and compare and contrast the analysed data to search for patterns and connections that respond to the original research questions.
Table 3

Survey Sample Characteristics

<table>
<thead>
<tr>
<th>Demographics (n=124)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years of Experience</td>
<td>Range= &lt;1 - &gt;11</td>
</tr>
<tr>
<td></td>
<td>Mode= 3-4</td>
</tr>
<tr>
<td>Count (percentage)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Job title</th>
<th>Count (percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accredited CBT practitioner</td>
<td>13 (10.48)</td>
</tr>
<tr>
<td>High Intensity Therapist- Qualified</td>
<td>8(6.45)</td>
</tr>
<tr>
<td>High Intensity Therapist- Trainee</td>
<td>4(3.23)</td>
</tr>
<tr>
<td>Psychological Wellbeing Practitioner- Qualified</td>
<td>52(41.94)</td>
</tr>
<tr>
<td>Psychological Wellbeing Practitioner- Trainee</td>
<td>12(9.68)</td>
</tr>
<tr>
<td>Psychologist- Qualified</td>
<td>3(2.42)</td>
</tr>
<tr>
<td>Psychologist- Trainee</td>
<td>22(17.74)</td>
</tr>
<tr>
<td>Non-accredited CBT practitioner</td>
<td>3(2.42)</td>
</tr>
<tr>
<td>Other</td>
<td>7(5.65)</td>
</tr>
</tbody>
</table>

Completed training in supporting CBT self-help

| Yes                                           | 92 (74.19) |
| No                                            | 30 (25.81) |

Received specific training on working with individuals with LTC

| Yes                                           | 76 (61.29) |
| No                                            | 47(37.90)  |
| No answer                                     | 1 (0.81)   |
Supported a client with LTC  
Yes  
No  
No answer

Long-term conditions worked with*

*Coronary Heart Disease*

*Diabetes*  20  
*Cancer*  38  
*Stroke*  19

*Rheumatology conditions (e.g. osteoarthritis)*  23

*Respiratory conditions (e.g. asthma, COPD)*  23

*Neurological diseases (e.g. multiple sclerosis)*  39

*Neuro muscular Diseases (e.g. Spina Bifida, Muscular Dystrophy)*  22

*Sensory Impairment*  8

*Cognitive difficulties*  16

*Mobility difficulties*  20

*Pain conditions*  34

*Conditions associated with what are termed medically unexplained symptoms (e.g. fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, atypical pain)*  63

*Other*  15

Table 4

Interview Themes
Themes

Theme 1. Impact of the condition on participation
Theme 2. Attitudes to Standard Guided Self-help Approach
Theme 3. How to support interventions
Theme 4. Guidance for adapting guided self-help
Theme 5. The intervention
Theme 6. Barriers to Mental Health Support*
Theme 7. Reasons for Mental Health Problems*
Theme 8. Social Support*

* Themes 6-8 were not further considered within the report.
<table>
<thead>
<tr>
<th>Focus of Intervention</th>
<th>Nature of Intervention</th>
</tr>
</thead>
</table>

*Figure 1. The Stepped-Care Model of Depression and Generalised Anxiety Disorder (adapted from Clark, 2011, p319; NICE, 2011a, p9). (Removed to ensure Copyright is protected.*)*
Figure 2. Selecting self-help material. Responses to the questions “When choosing self-help material for a person with a comorbid long-term health condition, to what extent would you be likely to consider the following?” (n=111).
Figure 3. Delivery of self-help interventions. Responses to the question “Please rate the extent to which you believe the following are important considerations when working with a client who has a long-term condition?” (n=111)
Figure 4. Delivery of self-help interventions continued. Responses to the question “The following questions examine your attitude towards adapting your practice in order to support CBT self-help for anxiety or depression in people with long-term condition. To what extent do you agree with the following statements?” (n=111)
Figure 5. Format of support. Responses to the question “To what extent would you be likely to consider the following options when working with people with a long-term health condition?” (n=111)
Figure 6. Scheduling contacts. Further responses to the question “To what extent would you be likely to consider the following options when working with people with a long-term health condition?” n=111
Figure 7. Flexibility of practitioners. Further responses to the question “The following questions examine your attitude towards adapting your practice in order to support CBT self-help for anxiety or depression in people with long-term condition. To what extent do you agree with the following statements?” (n=111)
Appendix A: Ethics Documentations
Appendix A1. Participant Information Sheet and Consent form

Participant Information Sheet

Adapting self-help to meet the needs of people who also have physical health problems

**Invitation.** You are being invited to take part in an interview as part of a research project. Before you decide whether you would like to take part, it is important that you understand why this study is being carried out and what it involves. Part 1 tells you about the purpose of the study and what will happen to you if you decide to take part. Part 2 provides more detailed information about the study process. Please take time to read the following information carefully and discuss it with others (family, friends) if you wish before making a decision.

**Part 1.**

**Background of this study.** Twenty per cent of people with a long-term physical health condition also experience depression or anxiety. However, many of these people do not receive specific psychological support for their emotional problem. Research has shown that psychological self-help techniques are effective at treating mild to moderate depression or anxiety. Self-help interventions support individuals to develop their understanding about, and skills in overcoming their anxiety or depression. However, the majority of research on self-help has not included individuals who also have a long-term physical health condition. This may limit the usefulness of the research.

**What is the purpose of the study?** I am interested in the ways that self-help could be adapted to meet the needs of individuals who also experience a physical health condition. I hope to find out whether self-help interventions for anxiety or depression take into consideration the additional needs the person has as a result of their physical health condition, and identify what could be improved to make it more suitable for someone with your medical condition. The findings from this study can be used to improve the care of patients in the future.

**Why have I been chosen?** We are asking people with long-term physical health conditions to take part because they have expert knowledge about the things that might affect their opportunity to benefit from psychological treatment.

**Do I have to take part?** It is up to you to decide whether or not to take part. People often find participating in interviews enjoyable and fun and report sharing their experiences to be worthwhile. If you do decide to take part you will be asked to sign a consent form. You are free to withdraw from the study at any time without giving a reason. Withdrawal will not affect any care you are receiving outside of this research in any way.
ADAPTING GUIDED SELF-HELP FOR PEOPLE WITH LONG-TERM CONDITIONS

Who am I?
My name is Aimée Hadert, I am a Trainee Clinical Psychologist at University of Exeter. I am supervised by Dr Paul Farrand (research supervisor) from the Mood Disorders Centre at the School of Psychology, University of Exeter. This study has been approved by the School Research Ethics Committee and is funded by Taunton and Somerset NHS Foundation trust.

Part 2.

What will happen to me if I decide to take part? If, after you have read the Patient Information Sheet, you would like to take part in the study, please inform the researcher; if you would like more time to think about whether to take part, you can contact the researchers to ask questions over the next fortnight on the details below. We will then need to check that you are suitable for taking part in an interview by asking you some questions about yourself and your emotional health. These questionnaires are about you and therefore some of the questions are personal. You will be asked to return these questionnaires in the stamped addressed envelope provided.

Your health and wellbeing are the first priority of the research team. Please inform the researcher if you require any additional support due to your health condition which will enable you to take part in this study, for example, help with completing questionnaires, support from a carer: Where possible we will try to meet your needs.

Please be aware not everyone will be able to take part in the study, this will depend on the number of people who wish to take part and the information provided on the initial questions: If you are not selected to take part you will be sent a letter informing you of this, and offered the option of receiving a copy of the study findings.

If you are selected to take part, the researcher will contact you to arrange a suitable time for the interview. You will then be sent some information on self-help, and asked to read through this before the interview. The interview will be based on the information that you were sent, and you will be asked to share your opinion on how self-help is suitable or not suitable for someone with your condition. It will last 60-90 minutes and will be audiotaped so that I have a record of what was said. The interview may take place by telephone, in your home or in a community location which is convenient for you.

If at any time you feel you want to end the interview this is entirely up to you. Depending on the stage of research, it may not be possible to remove your contributions to the study if you decide to withdraw at a later stage.

Will my taking part be kept confidential? We may use the words you say in the report of the results but these will be anonymised and you will not be identifiable. All information that is collected about you during the course of research will be kept strictly confidential. The only exception would be if we identified a significant risk of harm to yourself or others, in which case the information may be fed back to your doctor. The recorded interview will be stored on a password protected disk. All recordings will be stored separately from your personal information and will be kept in a secure, locked cupboard in the office of Paul Farrand. Data will be archived and
stored securely for five years at University of Exeter and tapes will be destroyed after use.

**What will happen to the results of the study?** The results of the study will be written up and used as part of the portfolio for a postdoctorate qualification in clinical psychology. We intend to present the results of the study as a scientific paper and also at research conferences. We estimate that the full results will be available in June 2013. If you would like a copy of these results please contact Paul Farrand.

- **What if I have a complaint arising from my taking part in the study?** If you feel you have been treated unfairly or have a complaint about taking part in the study you are encouraged to contact Paul Farrand in the first instance. You may also contact Cris Burgess, Psychology Research Ethics Committee Chair (01392 724627, c.n.w.burgess@exeter.ac.uk).

**Important information.** If you have any questions concerning the research, or would like more information feel free to contact me at email alh213@exeter.ac.uk or Dr Paul Farrand (research supervisor) phone 01392 725121 email P.A. Farrand@exeter.ac.uk

Thank you for taking time to read this information
About you
Please complete the questions below and return this form with the consent form via email. To ensure confidentiality, this information will be stored separately from the recording of the interview.

Name Click here to enter text.  Age  Click here to enter text.

Address  Click here to enter text.

Phone number  Click here to enter text.

Can a message be left?  Choose an item.

Ethnicity

White
☐ British
☐ Irish
☐ Any other white background

Black or Black British
☐ Caribbean
☐ African
☐ Any other Black background

Mixed
☐ White and Black Caribbean
☐ White and Black African F
☐ White and Asian
☐ Any other mixed background

Other Ethnic Groups
☐ Chinese
☐ Any other ethnic group
☐ Not stated

Asian or Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Any other Asian background

1a) Main Physical Health condition(s)  Click here to enter text.

1ai) Length of time diagnosed  Click here to enter text.

1b) Do you have any other medical conditions?  Click here to enter text.

1c) Do you require any specific support to be able to take part in the interview? E.g. regular breaks?  Click here to enter text.
2a) Do you have a current diagnosis of anxiety or depression?

2b) If yes, are you receiving any treatment for this? Please tick all that apply

☐ None
☐ Medication
☐ Talking therapies (e.g. psychologist, counsellor)
☐ Supported self-help
☐ Bibliotherapy (e.g. unsupported use of therapeutic books)
☐ Computerised cognitive behavioural therapy
☐ Waiting for talking therapies
☐ Waiting for supported self help

3a) Have you had a diagnosis of anxiety or depression in the past?

3b) If yes, did you receive any treatment for this? Please indicate

☐ None
☐ Medication
☐ Talking therapies (e.g. psychologist, counsellor)
☐ Supported self-help
☐ Bibliotherapy (e.g. unsupported use of therapeutic books)
☐ Computerised cognitive behavioural therapy

3c) Do you experience recurrent episodes of anxiety or depression?

3d) When was the last time you had these emotional difficulties?

Click here to enter text.

4a) Do you think that you may have current difficulties with anxiety or depression?

4b) If yes, have you spoken to your GP, or health care provider about this?

5) Please indicate your availability to take part in an interview (type Y for “yes”, N for “No”):

<table>
<thead>
<tr>
<th></th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning (9am-12pm)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afternoon (1-4pm)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening (5-8pm)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Consent Form

Adapting self-help to meet the needs of individuals who also have physical health problems

Name of Researcher: Aimée Hadert

Please initial in the box

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I understand that my personal details will be kept secure and no identifiable details will be used as part of the research results.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I understand that I may not be asked to participate in the study</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I agree to be audiotaped during the interview</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I agree to take part in the study.</td>
<td></td>
</tr>
</tbody>
</table>

Signed (please state name) __________________________ Date ___________

Name of person taking consent __________________________ Date ___________ Signature __________________________
Appendix A2: Ethics Application Approval Letter

To: Aimee Hadert
From: Cris Burgess
CC: Paul Farrand
Re: Application 2012/258 Ethics Committee
Date: January 23, 2013

The School of Psychology Ethics Committee has now discussed your application, 2012/258 – Attitude to using self-help material for anxiety and or depression with individuals who have co-morbid long term physical health conditions. The project has been approved in principle for the duration of your study.

The agreement of the Committee is subject to your compliance with the British Psychological Society Code of Conduct and the University of Exeter procedures for data protection (http://www.ex.ac.uk/admin/academic/datapro/). In any correspondence with the Ethics Committee about this application, please quote the reference number above.

I wish you every success with your research.

Cris Burgess
Chair of Psychology Research Ethics Committee
Appendix B: Methodology
Recruitment from Support Groups.

**COPD participants.** An email containing information about the study was distributed to 13 COPD groups within the South West Region. Two groups invited the researcher to talk at the support group. Two participants from one of the support groups returned their consent form and participated in face to face interviews in their own homes.

**Stroke participants.** The researcher telephoned 11 support groups across the counties of Somerset, Devon and Dorset. Nine agreed for the researcher to attend the group to explain the nature of the research and what participation would involve. Four stroke participants were recruited from two out of the support groups visited and interviewed face-to-face in their own homes.

**Recruitment from Online forums.** To increase participation research invitations were posted on two stroke support forums and two COPD support forums. These generated 11 response (3 stroke, 8 COPD), of which one person with stroke and 4 with COPD consented and participated in telephone interviews.
Appendix B2. Question prompts

1) What are your thoughts about the information that I sent?

2) Based on your experience of living with a physical health condition, would guided self-help be suitable?
   a. What would be the pros and cons of guided self-help?

3) Are there any reasons why it would be particularly important to support someone who has had a stroke to use the self-help?

4) Can you think of anything that might need to be changed in order to better support someone with stroke?

5) What do you think is the best way to support someone (face to face, telephone, email?)

6) Who should support you?
   a. Which service
   b. What type of professional background
   c. What should they know about
   d. Do you think support should focus on mental and physical health separately or consider them together?

7) What are your thoughts about involving other people?

8) What are your thoughts about receiving support in a group?

9) What did you like or not like about the self-help book?
   a. Techniques
   b. Exercises
   c. Stories

10) Was there anything missing?
Appendix B3: Rationale for Framework Analysis

FA is a data analysis method not a research paradigm (Ward et al., 2013). It is suited to research where there is an attempt to answer specific research questions (Ritchie & Spencer, 1994; Srivastava, & Thomson, 2009), rather than attempts to produce a new theory (Ward et al., 2013). FA was appropriate because it allows both between- and within-case analysis (Ritchie & Spencer, 1994). FA involves the a-priori construction of thematic categories designed to answer specific research questions, which then forms the basis of data coding (Dixon-Woods, 2011).
Attitude to using self-help material for anxiety and depression with people with long-term health conditions.

Participation in this study involves completing an online questionnaire which will take approximately 10 minutes. You will be asked questions about your experience, practice and beliefs towards working with long-term conditions. Please complete all relevant questions. Your participation in this study is completely voluntary, and you are free to withdraw at any time.

Confidentiality. Responses to the survey will be downloaded to a password protected database. Your responses will be anonymous, and individualised data will not be included in any publications. You will therefore not be identifiable.

What will happen to the results of the study? This study is being completed by Aimée Hadert, under the research supervision of Dr Paul Farrand, University of Exeter. The results of the study will be written up and used as part of the portfolio for a post doctorate qualification in clinical psychology. We intend to present the results of the study as a scientific paper and also at research conferences. We estimate that the full results will be available in June 2013. If you would like a copy of these results please contact the researchers.

What if I have a complaint arising from my taking part in the study? If you feel you have been treated unfairly or have a complaint about taking part in the study you are encouraged to contact Paul Farrand in the first instance. You may also contact Cris Burgess, Psychology Research Ethics Committee Chair (01392 724627, c.n.w.burgess@exeter.ac.uk).

Important information. If you have any questions concerning the research, or would like more information feel free to contact me at email alh213@exeter.ac.uk or Dr Paul Farrand (research supervisor) phone 01392 725121 email P.A.Farrand@exeter.ac.uk

Thank you for taking time to read this information. If you are interested in participating in this study, please click on the button below.
By beginning the survey, you acknowledge that you have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time.

Participation in this study involves completing an online questionnaire which will take approximately 10 minutes. You will be asked questions about your experience, practice and beliefs towards working with long-term conditions. Please complete all relevant questions. Your participation in this study is completely voluntary, and you are free to withdraw at any time.

Confidentiality.

Responses to the survey will be downloaded to a password protected database. Your responses will be anonymous, and individualised data will not be included in any publications. You will therefore not be identifiable.

What will happen to the results of the study?

This study is being completed by Aimée Hadert, under the research supervision of Dr Paul Farrand, University of Exeter. The results of the study will be written up and used as part of the portfolio for a post doctorate qualification in clinical psychology. We intend to present the results of the study as a scientific paper and also at research conferences. We estimate that the full results will be available in June 2013. If you would like a copy of these results please contact the researchers.

What if I have a complaint arising from my taking part in the study? If you feel you have been treated unfairly or have a complaint about taking part in the study you are encouraged to contact Paul Farrand in the first instance. You may also contact Cris Burgess, Psychology Research Ethics Committee Chair (01392 724627, c.n.w.burgess@exeter.ac.uk).

Important information.

If you have any questions concerning the research, or would like more information feel free to contact me at email alh213@exeter.ac.uk or Dr Paul Farrand (research supervisor) phone 01392 725121 email P.A.Farrand@exeter.ac.uk

There are 19 questions in this survey

Consent

1 I agree to participate in the study *

Please choose only one of the following:

- ☐ Yes
- ☐ No
Section 1: Experience

2 Job title *
Please choose only one of the following:

- Accredited CBT practitioner
- High Intensity Therapist- Qualified
- High Intensity Therapist- Trainee
- Psychological Wellbeing Practitioner- Qualified
- Psychological Wellbeing Practitioner- Trainee
- Psychologist- Qualified
- Psychologist- Trainee
- Non-accredited CBT practitioner
- Other (please specify in the text box)

Make a comment on your choice here:

3 Approximately how many years of experience do you have supporting clients to use self-help interventions? 
Please choose only one of the following:

- less than a year
- 1-2 years
- 3-4 years
- 5-6 years
- 7-8 years
- 9-10 years
- 11 or more years
4 Have you completed any training in supporting CBT self help? *
Please choose only one of the following:

- ○ Yes
- ○ No

5 Have you received any specific training on working with individuals with long-term physical health conditions? *
Please choose only one of the following:

- ○ Yes
- ○ No

6 Have you ever worked with a client using CBT self help for a long term physical health condition? *
Please choose only one of the following:

- ○ Yes
- ○ No

If “Yes” Please complete Section 1b

If “No” Please go to Section 2
Section 1b: Experience with long-term conditions

7 Please indicate the long-term health conditions that you have used CBT self-help with *
Please choose all that apply:

- □ Coronary Heart Disease
- □ Diabetes
- □ Cancer
- □ Stroke
- □ Rheumatology conditions (e.g. osteoarthritis)
- □ Respiratory conditions (e.g. asthma, COPD)
- □ Neurological diseases (e.g. multiple sclerosis)
- □ Neuro muscular Diseases (e.g. Spina Bifida, Muscular Dystrophy)
- □ Sensory Impairment
- □ Cognitive difficulties
- □ Mobility difficulties
- □ Pain conditions
- □ Conditions associated with what are termed medically unexplained symptoms (e.g. fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, atypical pain)
- □ Other

8 During the assessment, did you discuss with the client how their long-term health condition may contribute to the maintenance of their presenting problem? *
Please choose only one of the following:

- □ Yes
- □ No
9 Did you adapt how you delivered the intervention to account for the following? *
Please choose the appropriate response for each item:
- Yes
- No
- Not relevant

- Any cognitive difficulties the person had
- Any physical difficulties the person had

10 Please rate the extent to which you agree with the following statements about the self-help material you used with people who had a co-morbid long-term health condition. *
Please choose the appropriate response for each item:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The self-help material was relevant</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The self-help material was effective</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

11 Please list the self-help material which you used when working with clients with co-morbid long-term physical health conditions
Please write your answer here:
Section 2: Knowledge

12 To what extent do you agree with the following statements about working with people with long-term health conditions? *

Please choose the appropriate response for each item:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can adapt my practice to accommodate a client’s cognitive difficulties</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I can adapt my practice to accommodate a client’s physical difficulties</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I can competently assess how the long term condition contributes to the present problem</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I can competently include the long-term condition in the problem statement/case formulation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I can work with a range of long-term health conditions</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I developed relevant KNOWLEDGE about how to adapt practice during my professional training</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I developed relevant SKILLS about how to adapt practice during my professional training</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>People should only be seen in specialist services for long-term health conditions</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Section 3: Delivery of self-help interventions

13 The following questions examine your attitude towards adapting your practice in order to support CBT self-help for anxiety or depression in people with long-term condition. To what extent do you agree with the following statements? *

Please choose the appropriate response for each item:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am concerned about adapting practice because this may not be evidence based</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Practitioners should be flexible when supporting someone with long-term conditions to ensure they can access the support</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Practitioners should be flexible when supporting someone with a long-term health condition to reduce dropout rates</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I do not feel confident starting a conversation with the person about their long-term health condition</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am unable to make relevant adaptations due to service constraints, for example, restricted number of sessions</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I do not have the time to make relevant adaptations due to the number of clients on my caseload</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

14 Please rate the extent to which you believe the following are important considerations when working with a client who has a long-term condition. *

Please choose the appropriate response for each item:

<table>
<thead>
<tr>
<th>Consideration</th>
<th>Definitely Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Definitely Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessing how the long-term health condition contributes to the presenting problem</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Including the long-term health condition in the problem statement/ case formulation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Using case examples of people with a long-term condition</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Adapting how the intervention is delivered to accommodate the long-term condition</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Including the person’s significant other during therapy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Communicating with other health care professionals involved in the care of the long-term condition</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Signposting clients to a range of community groups or organisations to support treatment for a long-term condition</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
15 To what extent would you be likely to consider the following options when working with people with a long-term health condition?*

Please choose the appropriate response for each item:

<table>
<thead>
<tr>
<th>Option</th>
<th>Very Unlikely</th>
<th>Unlikely</th>
<th>Not Sure</th>
<th>Likely</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>The option of telephone support</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The option of email support</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The option of face-to-face appointments</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Offering group self-help</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Offering email/telephone support in between face to face/group sessions</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Offering longer sessions</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Offering shorter sessions</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Offering more support sessions per week</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Using a greater number of sessions with the client</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Offering follow up sessions after the intervention has ended</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
**Section 4: Self help material**

**16 The following questions are about your attitude towards using the self-help material for anxiety/ depression that is available when working with clients with long term conditions. * Please choose the appropriate response for each item:**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-help materials can be useful in helping clients with a long-term condition overcome mental health problems</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-help material for anxiety and depression is appropriate for people with long-term conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**17 When choosing self-help material for a person with a co-morbid long-term health condition, to what extent would you be likely to consider the following? * Please choose the appropriate response for each item:**

<table>
<thead>
<tr>
<th>Very Unlikely</th>
<th>Unlikely</th>
<th>Not Sure</th>
<th>Likely</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The nature of how the person’s long-term health condition affected them</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How relevant the material would be for someone with that particular condition (e.g. case examples)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Considering how effective the material would be for someone with that long-term condition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**18 Please rate the extent to which you think self-help for anxiety/ depression material would be effective at promoting change in the following areas when working with clients with long-term conditions * Please choose the appropriate response for each item:**

<table>
<thead>
<tr>
<th>Very Unlikely</th>
<th>Unlikely</th>
<th>Not Sure</th>
<th>Likely</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Raising awareness of problem thoughts/behaviours</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Changing negative thoughts</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Changing unhelpful behaviours</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Increasing motivation for change</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Increasing self-confidence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Improving interpersonal skills</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
19 Self-help programmes specifically developed for people with long-term health conditions have suggested a wide range of relevant interventions. Please indicate whether you feel you have suitable self-help material to support the following interventions in someone with a co-morbid long-term health condition. Please choose all that apply:

- [ ] Cognitive restructuring
- [ ] Behavioural activation
- [ ] Behavioural experiments
- [ ] Activity pacing
- [ ] Setting realistic and achievable goals
- [ ] Sleep hygiene
- [ ] Relaxation skills
- [ ] Stress management
- [ ] Assertiveness training
- [ ] Anger management
- [ ] Enhancing relationship support
- [ ] Coping skills training
- [ ] Relapse prevention

Thank you for your time.

The aim of this study is to explore the type of adaptations which are perceived to be important for supporting effective self-help when working with people with long-term conditions. We are interested in identifying attitudes towards the use of self-help as well as perceived confidence in the ability to support people with long-term conditions to participate in self-help interventions.

If you would like to receive a copy of these results please contact Aimée Hadert (alh213@exeter.ac.uk) or Dr Paul Farrand (P.A. Farrand@exeter.ac.uk)

Thank you for completing this survey.
Appendix C: Expanded Results
## Appendix C1. Research Themes and Concepts

<table>
<thead>
<tr>
<th>Themes</th>
<th>Concepts within theme</th>
<th>Example quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact of the condition on participation</td>
<td>• Recognising links between physical and emotional health</td>
<td>That's right and helping them to live within the confines of the disease and the depression and you know, you know what I mean, I'm sure the depression can be, can be lifted (C5)</td>
</tr>
<tr>
<td></td>
<td>• Physical impact</td>
<td>the very process of erm getting out and getting to that shop m-might, might be more of a hindrance than than the low mood. (S5)</td>
</tr>
<tr>
<td></td>
<td>• Cognitive impact</td>
<td>I bet when I come across one I won't remember it (laughs) (S4)</td>
</tr>
<tr>
<td>Attitudes to Standard Guided Self-help Approach</td>
<td>• Attitudes to standard guided self-help approach</td>
<td>I think everyone should do it, and people with a physical condition, they should just allow that extra, extra support, extra time extra help (C1)</td>
</tr>
<tr>
<td></td>
<td>• Recovery stories</td>
<td>Yes, and you know if possible as near to the truth of the examples, you know, what you've met over over</td>
</tr>
<tr>
<td>Themes</td>
<td>Concepts within theme</td>
<td>Example quote</td>
</tr>
<tr>
<td>--------</td>
<td>-----------------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td>Benefits of being guided</td>
<td>Um you are doing something and um you do need someone there to actually physically help you, to show you the way. Yeah. (S2)</td>
</tr>
<tr>
<td></td>
<td>Difficulties generalising from the point</td>
<td>Yes but the question is, what do you do if you're a patient, you're on your own at home and you see oh, I don't meet that one (C2)</td>
</tr>
<tr>
<td></td>
<td>Self-help book format</td>
<td>Well that, that looks quite alright because that summar-, lots of small little paragraphs and things like that so you, I could probably. (S1)</td>
</tr>
<tr>
<td>How to support interventions</td>
<td>How to support one-to-ones</td>
<td>I mean I don't mind doing face-to-face um, in fact I prefer it that way um, because I feel, I still have that old adage that the telephone is an invasion of your privacy. (C3)</td>
</tr>
<tr>
<td></td>
<td>Scheduling contacts</td>
<td>I think depends again on how how severe your</td>
</tr>
<tr>
<td>Themes</td>
<td>Concepts within theme</td>
<td>Example quote</td>
</tr>
<tr>
<td>--------</td>
<td>-----------------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td>Social support</td>
<td>Well……... you got to get somebody who really cares. Haven’t you? If they want to support you…(S3)</td>
</tr>
<tr>
<td></td>
<td>Who to support</td>
<td>I mean it's good this nurse to actually deal with it but then, it did normalise it but at the end of the day she’s still a respiratory nurse she is not qualified psychiatrist or anything like do you know what I'm saying she's not qualified to tell me what's going on in my head (C6)</td>
</tr>
</tbody>
</table>

**Guidance for adapting guided self-help**

- How to support ability to use approach
  
  “so small bites for anyone with l-like me would would be great for um, and and even doing the same thing you know the the the the repetitive nature actually helps (S5)"

- The need to individualise the approach
  
  The thing is to get to know the person and how they
<table>
<thead>
<tr>
<th>Themes</th>
<th>Concepts within theme</th>
<th>Example quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>The need to integrate physical and psychological conditions</td>
<td>• The need to integrate physical and psychological conditions</td>
<td>• What is expected of the supporting professional</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Um, I wouldn’t associate, if they didn't do that I wouldn't associate any sort of depression or anxiety with the condition (C4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Well they’ve really got to, they’ve got to find out what the problem is, but often, sometimes they get people to speech more slower (S1)</td>
</tr>
<tr>
<td>The intervention</td>
<td>• Behavioural activation</td>
<td>• Cognitive restructuring</td>
</tr>
<tr>
<td></td>
<td></td>
<td>When you are hit with a sudden illness and it and it incapacitates ya, er you may recover slightly from the illness with medication, but when you go back to the activities you used to do, you notice you don't enjoy them as much (C1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I know where this disease is going erm and there are times when I feel like you know, so what's the</td>
</tr>
<tr>
<td>Themes</td>
<td>Concepts within theme</td>
<td>Example quote</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-----------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>• Modifying expectations</td>
<td></td>
<td>And it was small little goals trying to aim for the big goal (S2)</td>
</tr>
<tr>
<td>• Relaxation</td>
<td></td>
<td>Absolutely, meditation staying calm you have to be mentally, you have to switch yourself off from the outside world and go within (C1)</td>
</tr>
<tr>
<td>• Sleep</td>
<td></td>
<td>it's very easy to er to completely ruin a your your sleep pattern erm by having a a couple of days of really bad time or a couple of days of pain (S5)</td>
</tr>
<tr>
<td>• Needs of significant others</td>
<td></td>
<td>but I know that, the way I am um does affect him (C5)</td>
</tr>
<tr>
<td>• Physical activity</td>
<td></td>
<td>Definitely both because the physical ex-exercise makes you more, makes you want to deal with the mental health side more. (C6)</td>
</tr>
</tbody>
</table>
Appendix C2: Themes Excluded from Further Interpretation

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Concepts within theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barriers to access</strong></td>
<td>• Not referred</td>
</tr>
<tr>
<td></td>
<td>• Stigma around mental health</td>
</tr>
<tr>
<td></td>
<td>• Individual personalities</td>
</tr>
<tr>
<td></td>
<td>• Availability of services</td>
</tr>
<tr>
<td></td>
<td>• Resistance to accessing medical support</td>
</tr>
<tr>
<td></td>
<td>• Burden of condition</td>
</tr>
<tr>
<td></td>
<td>• Belief in appropriateness</td>
</tr>
<tr>
<td>**Reasons for mental health</td>
<td>• Individual differences</td>
</tr>
<tr>
<td>problems</td>
<td>• Isolation</td>
</tr>
<tr>
<td></td>
<td>• Lack of understanding about the LTC</td>
</tr>
<tr>
<td></td>
<td>• Avoidance of activity</td>
</tr>
<tr>
<td></td>
<td>• Unpredictability of condition</td>
</tr>
<tr>
<td></td>
<td>• Loss (of role and abilities)</td>
</tr>
<tr>
<td></td>
<td>• Own mortality</td>
</tr>
<tr>
<td></td>
<td>• Burden of condition</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td>• Isolation</td>
</tr>
<tr>
<td></td>
<td>• Empathy from shared experiences</td>
</tr>
<tr>
<td></td>
<td>• Online support</td>
</tr>
<tr>
<td></td>
<td>• Access to a supportive other</td>
</tr>
<tr>
<td></td>
<td>• Providing support to others</td>
</tr>
<tr>
<td></td>
<td>• Comparison to others</td>
</tr>
<tr>
<td></td>
<td>• Belonging to a group</td>
</tr>
</tbody>
</table>
Appendix C3: Example of Indexing
### Appendix C4: Example of Framework Matrix

#### How to support self-help

<table>
<thead>
<tr>
<th>Participants</th>
<th>How to support engagement</th>
<th>Need to individualise</th>
<th>Need to integrate conditions</th>
<th>What is expected of supporting professionals</th>
</tr>
</thead>
</table>
| C1           | • Need to check the person’s able to understand the information  
• Person may forget information therefore extra person involved may be beneficial | • Important to find out what the person can and cannot do  
• Focus on the individual’s abilities  
• Individuals will present differently with the same LTC label | • Need to understand what triggers the anxiety or depression.  
• Link physical symptoms of LTC into maintenance cycle. | • People who have not had the LTC will only be able to talk from what they’ve been taught. Without experience wonder whether professional would understand  
• Need to be aware of wide variety of presentations under condition label  
• Should find out about stage of illness and struggles faced  
• Staff should ask about how it affects the individual |
| C2           | • Conditions are all different under the umbrella term of the LTC | | | • Conditions are all different under the umbrella term of the LTC  
• See the actual depression  
• Need to find out whether the person is inward or outward looking.  
• Find out what may create mental difficulties for that particular patient  
• Should know how condition is measured (lung function), basics of treatment and that the condition is palliative because that is one of the things that causes mental health problems  
• Supporting people would need to know what the person’s abilities are  
• Depression not because loss of faculties but absence of physical help which means physical health worsens if do not keep up with rehab. |
<table>
<thead>
<tr>
<th>Participants</th>
<th>How to support engagement</th>
<th>Need to individualise</th>
<th>Need to integrate conditions</th>
<th>What is expected of supporting professionals</th>
</tr>
</thead>
</table>
| C3           | • The supporting person is very important and needs to be aware how to work with the person with the LTC  
• Need to recognise individual differences in the way the condition affects the person  
• Number of treatment contacts and frequency should depend on the extent of the person's problems                                                                 | • Important to ask about physical condition as need to see how this impacts on mental health.  
• Need to have the additional impact of LTC acknowledged so not just treated like someone with normal depression  
• Recognise that a number of symptoms of depression would overlap with the symptoms of long-term conditions  
• Need to focus on both                                                                                                                                                                                                  | • People with anxiety or depression due to LTC want to be treated differently, don't want to be labelled as a mental health problem rather as a understandable reaction  
• Need to how the illness affects the individual as it may impact on people differently                                                                                                                                     |                                                                                                                   |
| C4           | • Important that individual supports someone so that examples in books do not get people down if they cannot do the suggestions.  
• Professional needs to understand condition so they can guide appropriate activities                                                                                                                                   | • If the depression is caused by the LTC it is important that therapist knows something about the condition  
• Even if depression due to another event, need to still understand LTC because that could link to worse depression  
• If did not ask about LTC, the client may not associate the two                                                                                                                                                    | • Need to have some level of understanding of condition  
• If not have some knowledge about condition and effects of it may not feel they will understand  
• need to know about condition even if did not mean nature of depression is different because that would help them understand reasons for depression better  
• Bad experience of people focusing on only one condition and ignoring the others  
• Recommend supporting professional has the condition so that they can normalise having mental health problems. Someone without condition does not understand |                                                                                                                   |
<table>
<thead>
<tr>
<th>Participants</th>
<th>How to support engagement</th>
<th>Need to individualise</th>
<th>Need to integrate conditions</th>
<th>What is expected of supporting professionals</th>
</tr>
</thead>
</table>
| C5           | • Suggest importance of writing things down because have concentration (and memory problems). | • Suggest needs to be aware and take a different approach if positive or negative person | Would be perceived negatively if not ask about conditions because believes it is the condition which causes the problems therefore need to know about implications of condition | • To give hope particularly if severe condition  
• Beneficial if had some knowledge of the condition and its effects before the client saw the professional  
• If don’t ask people may not think professional will be as helpful  
• Helpful if professional finds out about loss of abilities because of the impact this has  
• Feels it is important to find out whether a positive or negative person normally |
| C6           | • Benefit of communicating with someone who knows how both physical and emotional side affects you because they can understand you  
• Helps having it normalised as a reaction to LTC and being able to talk about this  
• Need to know something about condition for example that it is a label for a variety of conditions.  
• Not be able to help somebody if cannot understand the condition. | Need to integrate conditions because mental health side also impacts on physical health | |

<table>
<thead>
<tr>
<th>How to support engagement</th>
<th>Need to individualise</th>
<th>Need to integrate conditions</th>
<th>What is expected of supporting professionals</th>
</tr>
</thead>
</table>
| • Suggest importance of writing things down because have concentration (and memory problems). | • Suggest needs to be aware and take a different approach if positive or negative person | Would be perceived negatively if not ask about conditions because believes it is the condition which causes the problems therefore need to know about implications of condition | • To give hope particularly if severe condition  
• Beneficial if had some knowledge of the condition and its effects before the client saw the professional  
• If don’t ask people may not think professional will be as helpful  
• Helpful if professional finds out about loss of abilities because of the impact this has  
• Feels it is important to find out whether a positive or negative person normally |
| Need to integrate conditions because mental health side also impacts on physical health | | | |

<table>
<thead>
<tr>
<th>What is expected of supporting professionals</th>
</tr>
</thead>
</table>
| • To give hope particularly if severe condition  
• Beneficial if had some knowledge of the condition and its effects before the client saw the professional  
• If don’t ask people may not think professional will be as helpful  
• Helpful if professional finds out about loss of abilities because of the impact this has  
• Feels it is important to find out whether a positive or negative person normally |
<p>| Need to integrate conditions because mental health side also impacts on physical health | | | |</p>
<table>
<thead>
<tr>
<th>Participants</th>
<th>How to support engagement</th>
<th>Need to individualise</th>
<th>Need to integrate conditions</th>
<th>What is expected of supporting professionals</th>
</tr>
</thead>
</table>
| S1          | • Need to consider how to communicate.  
• Slower speech  
• Encourage to write things down  
• Allow more time in conversation  
• Use not word based formats e.g. pictures to help understand  
• Need to understand type of aphasia or communication problems to be able to help and understand | |
| S2          | • Communicate with professionals who have knowledge of how to communicate with people  
• Use of writing things down or communicate differently depending on deficits  
• CDs with positive focus may be useful for some but everyone is individual  
• Option of audio self-help | • Find out whether positive or negative person and what they're goals are  
• One approach won't fit all  
• Everyone as different  
• CDs with positive focus may be useful for some but everyone is individual | • Need to find out about LTC: everything has something to do with it.  
• LTC may be one of main reasons for depression which pulls the person down |
| S3          | • Read aloud if difficulties reading  
• Need to be caring | |
| S4          | • Write things down to aid memory  
• Prompt memory with telephone contacts between sessions  
• Use written prompts during contacts to support spoken information | • Want the professional to understand the difficulties they have |

Need to understand impact of condition as that causes change in person and may lead to mental health problems  
Need to understand type of aphasia or communication problems to be able to help and understand  
Find out whether positive or negative person and what they're goals are  
LTC may be one of main reasons for depression which pulls the person down  
Want the professional to understand the difficulties they have
<table>
<thead>
<tr>
<th>Participants</th>
<th>How to support engagement</th>
<th>Need to individualise</th>
<th>Need to integrate conditions</th>
<th>What is expected of supporting professionals</th>
</tr>
</thead>
</table>
| S5           | • Write things down and display on show to aid memory  
              • Shorter information as difficulty taking information forward across pages.  
              • Small repeated bites of information  
              • Find out best way to communicate. Writing may overcome word finding difficulties. Depends on faculties affected | • Person supporting needs to individualise how they support the person rather than individual information books. | | • Need to understand how fluctuating condition may impact on participation  
• Need to tailor how to best take in information, so supporting professional needs training and skills to help the person  
• Need to have basic level of awareness of how the condition affects the majority of people e.g. may cause memory problems which may affect how the person presents and engages.  
• Ask the person how it is affecting them (but want some basic knowledge as well)  
• Use examples of other people who have gone through it to show that they have knowledge and understanding. |
Appendix C5: Expanded Interpretation of Results

**Social support.** Participants valued opportunities to seek social support either through groups or online forums. They valued the shared experiences to help decrease isolation and comparison against other people with a similar condition. However, there were mixed opinions about the benefit of attending groups for anxiety and depression that were not solely for people with LTCs, and people were concerned about talking about mental health difficulties in front of others.

… you know if you’re all in a group and you’re perhaps talking or whatever they wouldn't necessarily be able to relate to the person who's got the physical condition as well as other people with physical conditions of any sort would. (C4)
Plan for Dissemination

It is intended that the results will be disseminated through publication in a peer reviewed journal and a research presentation and/or academic poster at a national conference, for example, the BABCP Conference. The project supervisor will also disseminate the results to various IAPT national committees.

Feedback of the results will be provided to survey responders and interview participants who requested a copy of the results. Dissemination of the results to mental health professionals who took part will provide guidance on adapting practice.