Acceptability and feasibility of groups for specific versus mixed-diagnosis patients with long-term conditions

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Abstract

Background:

Many people live with long-term conditions and subsequent difficulties with their mental health. Demand on psychological services is high, and initiatives need to address barriers to accessing these services. Group programmes use resources efficiently, but the relative effectiveness of different types of groups is unknown. This research adapted an evidenced-based acceptance and commitment therapy group intervention. It aimed to compare the feasibility, acceptability and preliminary effectiveness of this intervention, among specific-diagnosis and mixed-diagnosis groups.

Methods

A mixed methods pilot and feasibility study. Participants attended a specific-diagnosis or mixed-diagnosis group. The intervention comprised of 7, two-hour weekly sessions with an 8-week follow-up session. Outcomes included health-related quality of life, illness perceptions, depression, and anxiety, measured at baseline, post-intervention, and 8-week follow-up. Subsequently participants and health professionals (facilitators and referrers) attended qualitative interviews which explored their views on acceptability, informed by the Theoretical Framework of Acceptability.

Results

Both group conditions had similar improvements in psychological distress, illness perceptions and health-related quality of life, with significant improvements across time for anxiety, depression, energy, emotions, and general health. There was no overall differential effect of group, or a group by time interaction on any of the outcomes. Feasibility measures including retention (attended at least 3 sessions), true completion (attended all 8 sessions) and mean adherence rates were high and comparable across both group conditions. Acceptability was high across patient and health professional perspectives, with no marked difference between group conditions.

Conclusions

Pilot and feasibility testing revealed the intervention was feasible and acceptable in both group conditions. This preliminary data indicated a similar degree of improvement across group conditions. A randomised controlled trial and further comparative research is necessary to confirm tentative findings. This research indicates that services could flexibly plan their resources, based on patient need and capacity demands.

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Chapter 1 Introduction

1.1 Long-term conditions

Long-term conditions (LTCs) are defined as conditions that affect both mind and body and last for 12 months or more (NHS Digital, 2019). The Health Survey for England, 2018, reported that the prevalence of at least one LTC is 43% among adults aged 16 or over (NHS digital, 2019). LTCs place a huge demand on health services with 70% of the total health budget in England spent on supporting the management of LTCs (Department of Health, 2012). Furthermore, survey data revealed that owing to our ageing population, the presence of multiple LTCs is increasing (NHS digital, 2019) and these are commonly associated with mental health problems such as depression and anxiety (Naylor et al., 2012). For example, research has shown that people with an LTC can experience “significant functional impairment, economic disenfranchisement and social isolation” (Naylor et al., 2016, p.9), and over the last few decades this has been acknowledged to impact their psychological wellbeing and quality of life (Taylor & Aspinwall, 1996; Turner & Kelly, 2000; De Ridder et al., 2008). Thus, addressing patients’ psychological and emotional needs has been established as necessary to improve health outcomes, reduce distress and reduce demand on health care resources (Mental Health Taskforce, 2016).

1.2 Clinical health psychology

Within the NHS, there are specialist physical health services that are funded to support the physical and psychological needs of patients with LTCs. Clinical health psychology services have been commissioned in health care organisations across NHS England, often as part of a stepped care system. ‘Stepped care’ is a model recommended by the National Institute for Health and Clinical Excellence (NICE), particularly for people with common mental health disorders (NICE, 2011). This model (figure 1) typically describes the provision of mental health services, by offering the least intensive intervention appropriate for a person first, who can be stepped up or down the pathway. This model was adopted by the Improving Access to Psychological Therapies (IAPT) programme which began in England in 2008, and has helped increase the provision of evidence-based treatments to people with common mental health disorders using evidence-based treatment (NHS England, n.d.). Recently the need to increase access and expand services to focus on people with LTCs has been recognised (NHS England, 2019). Clinical health psychology services (that often pre-date the development of IAPT) have become part of this stepped care model, usually providing a specialist ‘step 4’ service, working in conjunction with primary care and IAPT services. This is representative of the Clinical Health Psychology service where this study took place (further detail on the setting is provided in section 1.3). Overall, the role of clinical health psychology services is to help improve health outcomes for service users with LTCs by assessment and psychological intervention (individually and in groups), working in multidisciplinary teams, providing consultation, teaching, training and conducting research (British Psychological Society, BPS, 2008).

Figure 1: Stepped Care Model (adapted from Wellbeing info, n.d.)

Responsibility of care	**Focus**	**Intervention**
Step 5: Inpatient care, crisis teams	Risk to life, severe self-neglect	Medication, combined treatments
Step 4: Mental health specialists, including crisis teams	Those at significant risk with treatment-resistant, recurrent, atypical, and psychotic depression	Medication, complex psychological interventions, combined treatments
Step 3: Primary care team, primary care mental health worker	Moderate or severe depression	Medication, psychological interventions, social support
Step 2: Primary care team, primary care mental health worker	Mild depression	Watchful waiting, guided self-help, computerised therapy, exercise, brief psychological interventions
Step 1: GP, practice nurse	Recognition	Assessment

1.3 The Clinical Health Psychology service, Northwest England[1]

The Clinical Health Psychology service in which this study took place provides in-patient and out-patient support to individuals with LTCs and employs Clinical Psychologists, Counselling Psychologists, Health Psychologists, Cognitive Behavioural Therapists and Assistant Psychologists.

The whole department is split into the following specialities:

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[1] The exact location of the Clinical Health Psychology service, where this study took place has been anonymised.

- Gastro-Intestinal/Intestinal Failure
- Chronic Fatigue Syndrome
- Renal
- Bariatric & Weight Management
- **General Medicine** (including cardiology, dermatology, diabetes, endocrinology, ear nose & throat, gynaecology, immunology, neurology, oncology, orthopaedics, respiratory medicine, rheumatology, speech and language, surgery/anaesthesia, and urology)

This research was conducted within the General Medicine (GM) team of the Clinical Health Psychology service. The GM team accepts referrals from the 15 specialities listed and receives on average 359 referrals per year with upward of 100 patients on the waiting list at any one time. The GM team is made up of 4.6 whole time equivalent posts, of which I am in a 1.0 whole time equivalent post. For each clinician across the Clinical Health Psychology team, a job plan is made up of clinical work, administrative tasks (note writing, letter writing, updating databases) and continuing professional development (which includes a range of activities, from formal training courses, to attending a conference and conducting research). The Health Care and Professions Council (HCPC) requires that 'Practitioner Psychologists' (of which I am registered), meet certain standards including the ability 'to draw on appropriate knowledge and skills to inform practice' which includes many sub-category standards related to conducting research (HCPC, 2018).

1.4 Clinical research

Clinical research is considered important, to aid the development of improved evidence-based treatment for patients (Royal College of Physicians, 2018), and studies have shown that hospitals where research participation is higher, have reported better patient outcomes (e.g., Downing et al., 2017). For example, one retrospective cross-sectional study found a significant correlation between increased research and reduced deaths from data collated across 129 NHS English hospital trusts (Jonker & Fisher, 2018).

In the context of a clinical health psychology service, given the aforementioned link between living with an LTC and psychological wellbeing, it is unsurprising that research is often focused on developing innovative approaches to patient care and evaluating the effectiveness of interventions, for example on quality of life (Anderson & Ozakinci, 2018). This has been further evidenced by several systematic reviews. For example, online cognitive behavioural therapy (CBT) for gastrointestinal disorders (Hanlon et al., 2018); digital health behaviour change interventions for people with cancer (Roberts et al., 2017); psychological interventions for psoriasis (Qureshi et al., 2019) and mindfulness-based interventions for rheumatoid arthritis (DiRenzo et al., 2018). However, one of the most consistently reported barriers to patients being able to access psychological support is that NHS services are under-resourced, under-funded and over-stretched (Royal College of Physicians, 2016) resulting in long waiting times (Thorlby, Gardner & Turton, 2019). For example, data has revealed 86% of patients wait more than 18 weeks for treatment in mental health services (NHS England, 2021). In the Clinical Health Psychology service (where this study took place), the average waiting time for psychological therapy, between 2018-2019, was 24 weeks. Thus, services must strive to develop efficient initiatives that address waiting lists to meet the needs of service users.

1.5 Waiting list initiatives

Managing waiting lists is important considering the potential detrimental impact ‘waiting’ has been found to have on patient outcomes (Reichart & Jacobs, 2018), and patient engagement in therapy (Mental Health Foundation, 2017). Ní Shiothcháin and Byrne (2011) outlined several waiting list initiatives often implemented in services. One such initiative is to use prioritisation systems. This involves prioritising patients dependent on factors such as clinical need or the potential costs of treatment being delayed (Mullen, 2003). However, criteria for prioritisation has been known to be inconsistent and unstandardised (Hughes, Carrick & Byrne, 2013). Another initiative is to use opt-in schemes, whereby patients are required to confirm, either by post or telephone, whether they want to be placed on a waiting list or seen for therapy. Opt-in schemes have been acknowledged as ‘active waiting-list management’ initiatives as they allow services to identify and direct treatment to those who want it (Jenkins, Turner & Morton, 2014).

Telephone triaging has also been implemented in many services as a way of administering a brief assessment to determine severity and clinical needs, with positive impacts found on reducing waiting times (Sowter, King & Eccles, 2019). Furthermore, assessment sessions can provide an opportunity to include brief therapeutic elements. For example, a recent study found a single-session assessment with a psychoeducational intervention reduced the number of patients on a waiting-list from 72 to 34 patients over a 12-month period, by identifying those who were not suitable for further treatment and providing brief information that meant patients required no further treatment (Fursland et al., 2018). A more recent initiative evaluated the sub-contracting of voluntary (third sector) counsellors to join a community mental health service to deliver therapy, which reduced waiting times from 2 years to around 18 weeks (Cartmell, 2019).

One further example of a waiting list initiative is group-based interventions, with the advantage of being able to treat multiple people at the same time. Several studies have reported reductions to waiting lists (Davies et al., 2011; Ruesch, Helmes & Bengel, 2017; Doyle, Hitchcock & Christie, 2019) and other advantages such as an improvement in patient outcomes (Hoddinott et al., 2010).

1.6 Group interventions

Group therapy has become a common method of providing a psychological intervention. Research led by Lorig in the 1990s has been hugely influential in the development of group programmes, with a particular focus on self-management in LTCs. Lorig et al., (1999 & 2001) found that a 7-week self-management programme (based on Self-Efficacy Theory, (Bandura, 1997)), focused on the day-to-day self-management of symptoms, could improve outcomes such as health status and reduce hospitalisations. For example, the 2001 paper that was conducted in a ‘real-world’ setting, found that at 1 year follow-up, participants who had completed the program had statistically significant improvements in health behaviours (such as exercise), and health status (such as fatigue, pain, and breathlessness). Furthermore, they reported a significant reduction in visits to the emergency department (Lorig et al., 2001).

Since then, group therapy using a range of therapeutic approaches has grown a body of evidence for its use with patients with a range of specific LTCs (Booth et al., 2016). One study, exploring a group-based mindfulness therapy in psoriasis patients, found a significant impact on improving psychological wellbeing & reducing psoriasis severity (Maddock et al., 2019). Another systematic review included three studies of a CBT group intervention for people with Chronic Obstructive Pulmonary Disorder and found a positive effect on mental health outcomes (Ma et., 2020). Group metacognitive therapy delivered alongside cardiac rehabilitation was effective in reducing anxiety and depression in patients with cardiovascular disease (Wells et al., 2021). An Acceptance and Commitment Therapy group for patients with inflammatory bowel disease found 39% and 45% reductions in stress from baseline to 8 and 20 weeks respectively, compared with 8% and 11% in the treatment as usual control condition (Wynne et al., 2019). These studies illustrate the wide variety of therapeutic approaches that have been applied to improving patients’ outcomes of people with a LTC, of which the latter, Acceptance and Commitment Therapy, has received increasing attention in the last 20 years (Graham et al., 2016).

1.7 Acceptance and commitment therapy

Acceptance and Commitment Therapy (ACT) is a psychological approach and considered one of the third wave cognitive behavioural therapies (Hayes, 2009). ACT aims to help people accept what is out of their control and commit to behaviours that can improve their lives (Hayes, 2004), by developing a skill called psychological flexibility. Psychological flexibility is described by Bai et al., (2020) as the ability to be in the present moment, noticing experiences mindfully, in a non-judgemental and accepting manner whilst making valued-committed actions, despite any thoughts and feelings that might oppose doing so. There are six core processes of ACT that overlap and interrelate and are described by Grégoire et al., (2017 p.5):

- “Acceptance – the willingness to open fully to unwanted experiences such as difficult thoughts, memories, or emotions
- Contact with the present moment – being mindful and aware of one’s experiences
- Self as context – maintaining the perspective about oneself within one’s experiences
- Cognitive defusion – being able to step back from unwanted experiences without getting stuck in them
- Committed action – engaging in actions that move toward important aspects of life
- Values – staying connected to personal values or areas of life that are important”

ACT has been found to be highly applicable to people with LTCs, as evidenced by a comprehensive systematic review by Graham et al., (2016). People with LTCs cannot change the fact that they have an LTC, or that effectively self-managing can often be relentlessly demanding of time and effort. Thus, focussing on other areas of life with higher perceived value, including caring for family or hobbies, can help people to live a meaningful life even with an LTC. ACT is also suitable as a transdiagnostic approach (Barnes-Holmes & Roche, 2001), which means ACT has broad applicability, goes beyond any single mental or physical health condition, and offers a unified model of behavioural change with multiple favourable outcomes (Dindo, Van Liew & Arch, 2017).

1.8 Specific-versus mixed-diagnosis in group composition

Over the last 10 years, evidence has grown demonstrating the applicability of ACT to people with LTCs, as summarised by Graham et al., (2016). Despite ACT being recognised as a transdiagnostic approach, of the 18 studies included in this systematic review, only 1 was applied transdiagnostically. The remaining 17 applied to a specific-disease group, which included brain injury, cancer, cardiac disease, type 2 diabetes, epilepsy, and multiple sclerosis (Graham et al., 2016). Targeting a specific-disease group is typical of health research, particularly since health services are organised into medical specialities. Furthermore, tailored health interventions have been heralded by both patients and health professionals (Beck et al., 2010), since they can be designed to address salient characteristics such as patient symptoms of a specific diagnosis (Carlbring et al., 2011). However, given that services are under significant pressure to manage waiting lists, whilst also striving to meet the needs of patients, transdiagnostic approaches have been considered advantageous with pragmatic implications regarding resources and costs (Dear et al., 2015). Furthermore, referring back to the influential research by Lorig et al., (1999 & 2001), their approach was transdiagnostic recognising that “patients with different chronic diseases have similar self-management problems and disease-related tasks” (Lorig et al., 1999, p.6). In addition, in other areas such as chronic pain management, it is commonplace to offer group therapy (Keefe et al., 2002) and for pain management group programmes to be delivered as a transdiagnostic approach (Wilson, 2017). Guidelines often recommend that “any chronic pain may be treatable by pain management methods” thus patients with a variety of diagnoses e.g., chronic lower back pain, fibromyalgia, or arthritis (The British Pain Society, 2018, p.22.), are treated in a mixed pain management programme. This is due to the focus of interventions being on enhancing self-management skills to manage chronic pain, and not on specific condition characteristics, thus skills can be applied across many diagnoses. However, new evidence to support single-issue pain management groups is emerging particularly in areas such as pelvic pain (Twiddy et al., 2015; Westbay et al., 2021), and facial pain (Tetlow et al., 2021).

Research has not yet established whether a transdiagnostic approach is superior to condition-specific approaches and comparative studies have been suggested both from a chronic pain (Tetlow et al., 2021) and LTCs perspective (Brassington et al., 2016).

The literature has used several terms for the different approaches interchangeably. For example, transdiagnostic has also been referred to as cross-condition, and specific approaches have been referred to as specific-disease, condition-specific, single-issue and diagnosis-specific. In this thesis the terms mixed-diagnosis and specific-diagnosis are used to simplify the language since this study took place in an NHS clinical setting, where layman’s terms were deemed most appropriate.

1.9 Current study

A previous study (Brassington et al., 2016) developed an ACT-based group intervention called ‘Better Living with Illness’ and applied it transdiagnostically. The intervention consisted of six, weekly, group sessions plus two follow-up sessions at 1 and 3 months. These authors developed a treatment manual and the content of this intervention is provided in appendix 1. This study measured anxiety, depression, quality of life, health perceptions, psychological flexibility and value orientated behaviour. They also included a within-participant control by collecting data at assessment and pre-intervention (i.e., participants served as their own control by providing outcomes assessed across different pre-intervention timepoints. Their primary outcome measured anxiety and depression using the Hospital Anxiety and Depression scale (HADS, Zigmund & Snaith 1983) and found significant reductions in HADS scores, with medium effect sizes (0.121 for depression and 0.105 for anxiety) that were maintained at 3-month follow-up. For their secondary analyses, no significant change was found in illness perceptions or health status however changes were seen relating to measure of quality of life suggesting patients became less limited by their long-term condition. Psychological flexibility improved during the intervention however reduced at follow-up. Overall, authors concluded that their “group-based ACT intervention may be beneficial for LTC’s and can be delivered transdiagnostically” (Brassington et al., 2016, p. 208. They also discussed theoretical and clinical implications of their study whereby they called for a comparative study to address the gap in the literature exploring the differences between mixed-diagnosis and specific-diagnosis approaches.

Therefore, a Northwest based Clinical Health Psychology service decided to develop an adapted version of the Brassington et al., intervention and explored implementing this in a process evaluation type study, comparing and assessing the feasibility and acceptability of the intervention, among patients and health professionals in specific-diagnosis versus mixed-diagnosis groups. Thus, this study differed from the Brassington et al., 2016 study which solely focussed on delivering the group intervention transdiagnostically.

It was considered important to assess acceptability given that this has been recognised as crucial when designing, evaluating and implementing healthcare interventions (Eldridge et al., 2016; Moore et al., 2015). Furthermore, it is important to take into consideration the acceptability of an intervention from the perspective of the recipient (patient), as well as other key stakeholders such as intervention deliverers and health professionals (Sekhon, Cartwright & Francis, 2017). As such, Sekhon, Cartwright & Francis (2017) developed a Theoretical Framework of Acceptability (TFA) which includes seven constructs described in table 1. Research has begun to use this framework to facilitate qualitative assessments of intervention acceptability. For example, Murphy and Gardner (2019a) assessed the acceptability of a men's mental health promotion program in pharmacists using the TFA. They found that applying the TFA to qualitative data was helpful for identifying potential changes to the interventions design. Furthermore, a study that assessed the acceptability of a postnatal walking group, using the TFA, made conclusions on key factors that affected acceptability to inform future research and recommendations (Pavlova, Teychenne & Olander, 2020).

Table 1 Theoretical Framework of Acceptability (Sekhon, Cartwright & Francis, 2017, p.8).

Construct	Definition
Affective Attitude	how an individual feels about the intervention
Burden	the perceived amount of effort that is required to participate in the intervention
Ethicality	the extent to which the intervention has a good fit with an individual's values system
Intervention coherence	the extent to which the participant understands the intervention and how it works
Opportunity Costs	the extent to which benefits, profits or values must be given up to engage in the intervention
Perceived Effectiveness	the extent to which the intervention is perceived as likely to achieve its purpose
Self-efficacy	the participant's confidence that they can perform the behaviour(s) required to participate in the intervention

1.10 Feasibility or pilot study?

The terms feasibility and pilot are often used synonymously (Arain et al., 2010), with no clear consensus on the difference between them. Arnold et al., (2009) define a pilot study as a small study for helping to design a further confirmatory study. The National Institute for Health Research (NIHR) recommends the following definitions:

A **feasibility study** as a way of asking "whether something can be done, whether it should be proceeded with and if so how".

A **pilot study** asks the same questions but "also has a specific design feature: where in a pilot study a future study is conducted on a smaller scale" (NIHR, 2021, paragraph 5).

It was decided, based on the NIHR definition, that the current study presented in this thesis was a mixed method (i.e., quantitative, and qualitative) pilot and feasibility study. The pilot part assessed the ‘promise of the intervention’, in other words, the preliminary effectiveness of the intervention (and checked that the study processes, such as recruitment and treatment, all ran smoothly) to inform the potential of a larger scale research study. The feasibility element assessed several uncertainties such as the:

- Acceptability of the intervention to the service users (patients of the Clinical Health Psychology service) and health professionals
- Recruitment procedures
- Adherence to the intervention
- Variation in use of the intervention and delivery of the intervention

1.11 Aims and format of thesis

Overall, the research described in this thesis aimed to compare the feasibility, acceptability, and preliminary effectiveness of an ACT group intervention, for specific-diagnosis versus mixed-diagnosis groups, to inform a clinical health psychology service how NHS resources can be best used to meet the needs of service users. An overview of the methodology follows with three sequential chapters presented as publishable papers each with their own research question that relate to the overall aim. These chapters are titled:

> Chapter 3. Quantitative evaluation of outcomes comparing an online acceptance and commitment therapy intervention for long-term conditions in specific-diagnosis versus mixed-diagnosis groups.
>
> Chapter 4. Eligibility, retention and acceptability of an online acceptance and commitment therapy intervention delivered to specific-diagnosis versus mixed-diagnosis groups.
>
> Chapter 5. Health professional views on the acceptability and feasibility of an online acceptance and commitment therapy intervention for specific-diagnosis versus mixed-diagnosis groups.

Overall conclusions are presented in chapter 6. An overview of my learning and development as a reflective practitioner is included in appendix 2.

Chapter 2 Overview of methodology

2.1 Introduction and context to the methodology

This top-up professional doctorate was started in September 2019, roughly 3 months prior to the onset of the COVID-19 pandemic. The ethics application and Research Ethics Committee meeting was attended 11 days prior to the first national lockdown in England. Ethical approval of the original methodology was granted on 14th April 2020. However, at this stage there was uncertainty as to when face-to-face working would return, thus a major revision to the design and protocol was required, to change the delivery format of the group intervention to an online intervention. An overview of the methodology used in this study is presented. Any differences to the original methodology are highlighted, followed by sections explaining the challenges and implications of the study context. It is acknowledged that some information is repeated in chapters 3-5. Given the complexity of this study, an overview is provided to give further detail and aid the reader's understanding.

2.1.1. Research design

A mixed methods pilot and feasibility study was selected and applied. Mixed methods were selected as it integrates rich and comprehensive data from a quantitative and qualitative approach, to answer the overall studies research questions:

1. Is there a difference in feasibility and acceptability of an online ACT intervention between specific-diagnosis versus mixed-diagnosis groups?
2. What are health professionals' views on the acceptability and feasibility of specific-diagnosis versus mixed-diagnosis groups and their experiences of working with patients who have attended such groups?
3. Do the results of this small pilot and feasibility study suggest similar effectiveness in health-related quality of life, illness beliefs and psychological distress in specific-diagnosis versus mixed-diagnosis groups?

We delivered online groups (described below in section 2.1.3.1). Quantitative data collected from attendance records, and qualitative data collected from qualitative interviews with participants who took part in the intervention, addressed research question 1. Qualitative data collected from qualitative interviews with health professionals who facilitated the intervention, and health professionals who referred patients to the intervention, addressed research question 2. Finally, quantitative data collected from psychometric measures (summarised in section 2.1.3.3.) addressed the third research question.

2.1.2. Study participants

2.1.2.1. Patient participants

Patient participants were recruited from the Clinical Health Psychology GM team waiting list, or by being made aware of the groups by health professionals working within specialities covered by the GM team (described in chapter 1, section 1.3). As per routine clinical practice, patients on the waiting list were invited to attend the group intervention via letter or during a routine waiting list check-in review. The waiting list was regularly reviewed so for each scheduled group, only new appropriate patients on the waiting list were sent invites (i.e., each patient only received one invite to respect their choice not to participate).

We had planned for potential patient participants to be able to self-refer to the clinical team. Self-referrals were expected from patients who saw an advertising poster placed in the waiting rooms of the hospital specialities the GM team covered. Since face-to-face healthcare was extremely limited during the recruitment period, posters were not used.

All interested participants received a telephone screening consultation, including a brief psychological assessment, to check each participant was suitable and that they met inclusion criteria (described in section 2.1.2.2). This assessment informed patients about the research study in line with details provided in the participant information sheet (see appendix 3).

If after this telephone screening assessment with a clinical team member a participant met the inclusion criteria, and wished to continue, they were allocated to the intervention and invited into one of the group conditions, dependent on their diagnosis (described in chapter 3). Written consent was obtained at the start of the intervention (see appendix 4for consent form).

The group intervention was still offered to any patient who did not want to take part in the research. If a patient was not suitable, they were offered appropriate alternative treatment as deemed necessary by the assessing clinician.

At the last session of the intervention, patient participants recruited to the research were invited via email to take part in a qualitative interview to explore their views and experiences (further detail provided in section 2.1.3.4)

2.1.2.2. Inclusion criteria

Patient participants needed a diagnosis of:

a) A long-term condition relating to one of the four specific-diagnosis specialities (dermatology, rheumatology, diabetes, or cardiology) for the specific-diagnosis group
b) A long-term condition (from any of the hospital specialities that the GM team covered) for the mixed-diagnosis group (including any of the specific-diagnosis specialities; dermatology, rheumatology, diabetes or cardiology)

Patient participants were also required to be 18 or over, English speaking, able to give informed consent, with access to a laptop/mobile/tablet and good internet connection to participate. These inclusion criteria were assessed through record checking.

2.1.2.3. Exclusion criteria

Patient participants were excluded if:

- they were actively engaged with another psychological therapy or receiving active input from a secondary mental health service
- they had significant substance abuse difficulties
- they had severe and/or chronic mental health problems, such as personality disorder where the interpersonal difficulties themselves are the required focus of an intervention
- they had a learning disability, at such a level that specialist skills would be required to deliver an intervention

These exclusion criteria were assessed via self-report as access to this information was not readily available on hospital records.

2.1.2.4. Health professional participants

Two types of health professional participants were recruited:

(A) Those who **facilitated/delivered** the intervention
(B) Those who **referred** patients to the intervention

Facilitators were invited via email to take part in an online focus group, and referrers were invited via email to take part in online individual interviews. These explored health professional participants views of the intervention and experiences of working with patients in relation to the groups. The only facilitator who was excluded from participating was the main researcher due to potential researcher bias. All health professional participants were informed about the research study and given a participant information sheet (see appendix 5), prior to consenting to take part.

2.1.3. Procedure

2.1.3.1. Intervention procedure

The online ACT group intervention was delivered to two group conditions, specific-diagnosis and mixed-diagnosis. Each group condition had four intervention group programmes (the intervention is described in section 2.1.3.2.), totalling eight groups overall. Group allocation is described in chapter 3. Prior to the COVID-19 pandemic it was standard practice to deliver groups face-to-face, however, government enforced restrictions meant that this was not allowed particularly during national lockdowns. Hence the delivery format was changed to online.

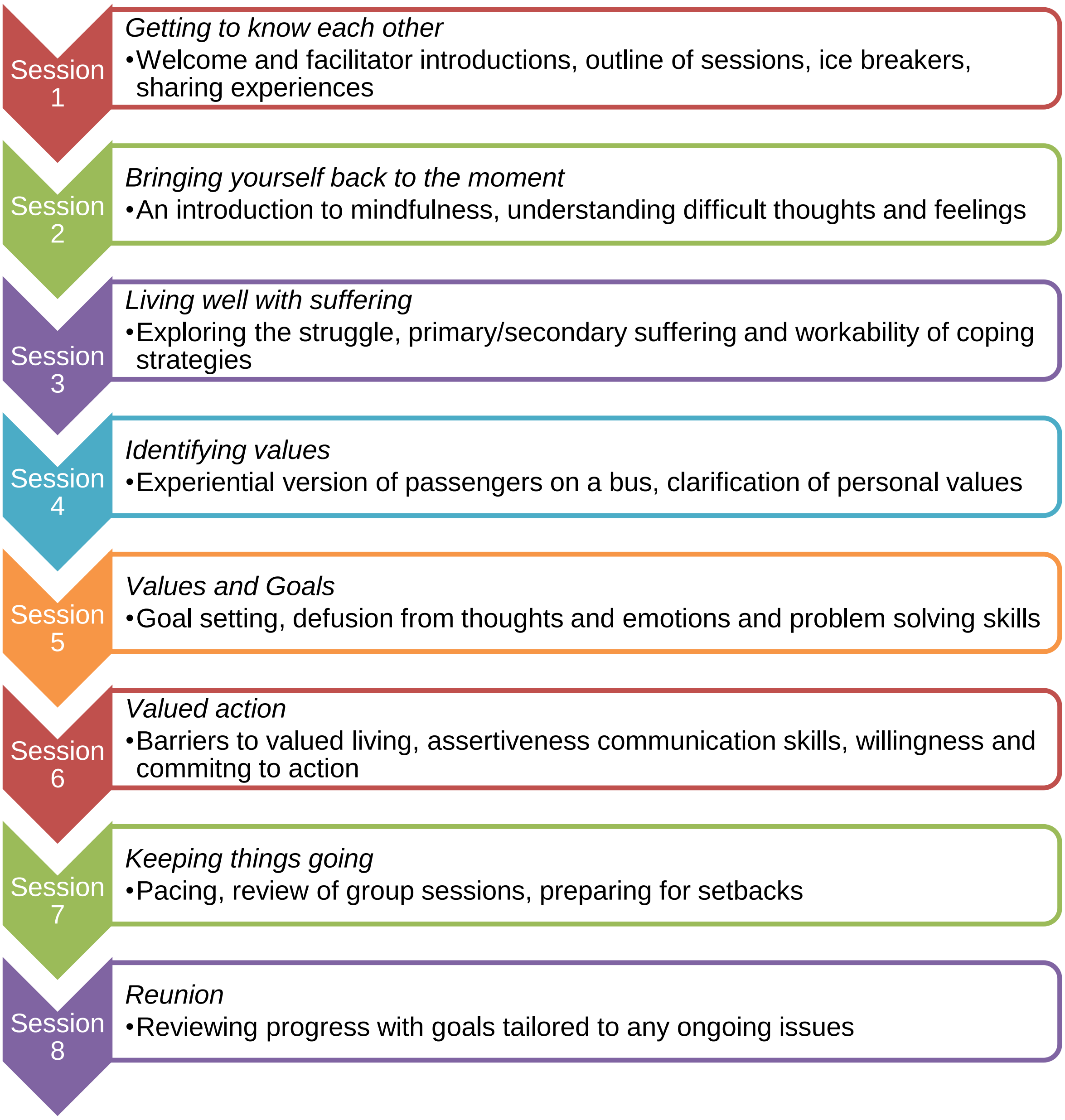
2.1.3.2. Intervention description

The ACT group intervention was called ‘Living Well with a Long-Term Condition’ and was adapted from the Brassington et al., (2016) ‘Better Living with Illness’ protocol. A clinician handbook, and participant workbook (see appendix 6 & 7), was developed that could be used for both group conditions. These materials were adapted by the researcher and other members of the GM team, all of whom had received specialist training in ACT. Each group was delivered online using a platform called ‘Microsoft Teams’. The intervention was facilitated by two qualified clinicians. The intervention consisted of 8, 2-hour sessions. Sessions 1-7 were delivered on a weekly basis, followed by a gap of 8 weeks, before the final ‘reunion’ session. Figure 2 describes the content for each session. An overview of the intervention compared with the original ‘Better Living with Illness’ intervention is provided in appendix 1. In summary the sessions covered the six core processes of ACT (as described in chapter 1, section 1.7), included experiential exercises, and allowed for group discussions to share experiences and learning between participants.

Online ‘screen share’ materials were developed so that facilitators could guide participants through the session content. Microsoft teams had features that were utilised to support the group sessions such as camera, mute, raise hand, text chat and share screen functions. Participants were encouraged to have their camera on during group sessions, but it was not mandatory (to respect privacy and confidentiality). At the end of the sessions, facilitators remained logged into the meeting for 15 minutes, to allow for any participants to answer questions privately. Telephone calls were also offered, should any participants have any questions which could be requested via email. Summary emails were sent following each session which included links to access any exercises as part of their home-practice between sessions.

Participants who missed sessions were signposted to read through information provided in their participant workbook and offered a telephone consultation to talk through any missed content. It was decided that if anyone missed the first two sessions consecutively, they were transferred to the next mixed-diagnosis group available or returned to the waiting list. This decision was based on the potential to cause disruption to the group dynamics, whereby social relationships would likely have already been established, making it difficult for a new person to interact with the group and feel part of the 'group spirit', which may also negatively impact a patient's own wellbeing. Unfortunately, resources did not allow multiple specific-diagnosis groups to run hence the option to transfer to another specific-diagnosis group was not possible.

Figure 2: Session content of group (adapted from Brassington et al., 2016)



Session 1

Getting to know each other

- Welcome and facilitator introductions, outline of sessions, ice breakers, sharing experiences

Session 2

Bringing yourself back to the moment

- An introduction to mindfulness, understanding difficult thoughts and feelings

Session 3

Living well with suffering

- Exploring the struggle, primary/secondary suffering and workability of coping strategies

Session 4

Identifying values

- Experiential version of passengers on a bus, clarification of personal values

Session 5

Values and Goals

- Goal setting, defusion from thoughts and emotions and problem solving skills

Session 6

Valued action

- Barriers to valued living, assertiveness communication skills, willingness and commitng to action

Session 7

Keeping things going

- Pacing, review of group sessions, preparing for setbacks

Session 8

Reunion

- Reviewing progress with goals tailored to any ongoing issues

2.1.3.3. Quantitative measures

The following psychometric questionnaires were completed by patient participants to assess psychological distress, illness perceptions and health-related quality of life at three different timepoints, baseline (pre-treatment), session 7 (post-treatment) and session 8 (8-week follow-up).

- The Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer & Williams, 2001) measured self-reported depression
- The General Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006) measured self-reported anxiety
- The Brief Illness Perception Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) measured self-reported illness perceptions
- The RAND 36-item Health Survey 1.0 (SF-36; Ware & Shelbourne, 1992) measured self-reported health-related quality of life

A full description of these measures is provided in chapter 3. The measures were collected online. Emails asking participants to complete the questionnaires were sent 1-2 days prior to the first group session (baseline- T1), immediately after the seventh group session (post-treatment, T2) and immediately after the 8-week follow-up session, T3). One reminder email was sent to those participants who had not completed the questionnaires one week after T2 or T3.

Other quantitative measures to assess the feasibility and acceptability of the intervention to the patient participants included eligibility, recruitment, retention, true completion, and intervention adherence rates. Definitions for these outcomes are described in chapter 4.

2.1.3.4. Qualitative procedure

We collected qualitative data with patient participants and health professional participants.

Patient qualitative interviews

Patient participants who had consented to take part in the research were invited via email to take part in online focus groups and individual interviews using microsoft teams. These were moderated by a research assistant who had an honorary contract as a volunteer assistant psychologist with the Clinical Health Psychology service. The research assistant was provided with training on how to conduct focus groups and individual interviews, and was supervised by the main researcher, who had prior qualitative research experience. Originally four focus groups were planned, two for each of the group conditions. To improve recruitment an amendment to the ethics was approved (20/NW/0125/AM01), to include individual interviews as well as focus groups to collect qualitative data from any participants who had been unable to take part in focus groups. Both interviews and focus groups are an evidenced based method of data collection for qualitative studies (Harrell & Bradley, 2009), the pros and cons for both were considered, and it was concluded that this additional alternative method of data collection allowed for greater flexibility to arrange interviews at times to suit all participants busy schedules.

Participants were invited via email by the researcher and were given a participant information sheet (see appendix 8). Those who took part provided written consent (see appendix 9 for consent forms). All qualitative interviews were audio-recorded, focus groups lasted no longer than 2 hours and individual interviews lasted no longer than 30 minutes. A topic guide (appendix 10) was used to elicit participants views and experiences of taking part in the intervention, as well as thoughts on the intervention being delivered to the two group conditions. More detail on the aims of the patient qualitative interviews is included in chapter 4.

Health professional interviews

One focus group was conducted with the facilitators of the intervention. Individual interviews were conducted with the referrers. All qualitative interviews were held online using microsoft teams and moderated by the same research assistant as above. All health professionals were invited via email and given participant information sheets explaining that the focus group would last no longer than one hour and individual interviews no longer than 30 minutes. Two topic guides were developed (see appendix 11), to gather the views and experiences of health professionals including their thoughts on the two group conditions. All health professionals who agreed to take part provided written consent (see appendix 12 for consent forms) and all qualitative interviews were audio-recorded.

2.1.4. Sample size

Prior to the pandemic the aim was to run each group with 6-10 participants totalling 24-40 participants for each group condition, giving 48-80 participants overall. These numbers were guided by a preliminary power calculation during the development of the study protocol. Further detail on the power calculation is provided in chapter 3. It is acknowledged that a power calculation was not strictly appropriate for a pilot study (Fox, Hunn & Mathers, 2009) and this study was not designed to test effectiveness, however, it was useful to estimate effect sizes that could potentially inform a subsequent study. Owing to the changes enforced by the COVID-19 pandemic and the practicalities of running a group online, the maximum number of participants recruited to each group was reduced to 6. This decision was made based on several factors. Firstly, limitations of the online platform meant that only 8 participants in a video call could be visible on the screen at any one time, accounting for the 2 facilitators this left opportunity for 6 further participants. This was important for managing risk. Secondly as the facilitators lacked experience of running an online group, this number of participants was deemed most appropriate by the Clinical Health Psychology service. Finally, a review of the literature was conducted and found that group interaction and cohesion is an important component to consider, particularly online, thus smaller numbers are recommended (Lopez et al., 2020; Weinberg, 2020).

For the qualitative data, we aimed to include up to 6 patient participants in each focus group and a total of 12 patient participants overall. The planned target for the number of health professional participants was also 12. These qualitative interview sample sizes were estimated to be small enough to manage the material, and large enough to provide new and rich information, to understand experiences in relation to the research questions.

2.1.5. Analysis

2.1.5.1. Quantitative data

A mixed 2 by 3 ANOVA analysis was used, to compare the mean differences between groups on the outcome measures. These were split on a between subjects' factors (group condition), and a within subjects' factor (time, with three timepoints; T1-baseline, T2-post treatment and T3-8 weeks follow-up), with data assessed for homogeneity, normality and sphericity, and appropriate adjustments made when assumptions were violated.

Descriptive statistics reported eligibility, recruitment, retention, true completion, and intervention adherence rates.

2.1.5.2. Qualitative data

Qualitative data was analysed aligned to a deductive and inductive, reflexive thematic analysis approach (Braun & Clarke, 2006; 2019, 2020). This commonly used hybrid approach was deemed appropriate, to best meet the aims of the study and answer research questions. Initially a theory-driven concept, the TFA (previously described in chapter 1), was applied for the process of deductive thematic analysis. Following this an inductive approach allowed the development of themes from the data and allowed for a broader understanding of the data. Further detail on the analysis of qualitative data is provided in chapters 4 and 5.

It is acknowledged that the coding approach was collaborative (as it involved multiple researchers) and reflexive whereby researchers' 'read' the data based on personal theoretical assumptions, analytic resources and skill. Thus, interpretations reflect those of the researchers' own experiences, beliefs and biases which will have affected the development and generation of themes and inferences.

2.1.6. Ethical considerations

This study was designed with the British Psychological Society's Codes of Ethics and Conduct (BPS, 2018) and the appropriate NHS Foundation Trusts guidance taken into consideration. The original methodology was approved by the NHS Research Ethics Committee in April 2020 (approval code 20/NW/0125; see appendix 13 for approval letter). It was sponsored by the University of Stirling and approved by the appropriate NHS Trust Research and Development team. Health Research Authority (HRA) guidance meant that any changes to reduce the risk of potential exposure to COVID-19 to participants, could be handled as a 'non-substantial amendment' and thus, could be approved by the sponsor. The methodology described above fit within this remit and was approved by the sponsor. The amendment described in section 2.3.1.4. was classed as substantial and required review by the HRA. Approval was granted on 11th August 2021 (approval code 20/NW/0125/AM03).

2.2. Challenges

Changing the delivery format of the group intervention was not without its challenges. Firstly, the NHS trust had to approve an online platform to use with patients. There were significant delays to this, owing to difficulties finding a platform that was fit for purpose in its functionality, whilst meeting several security standards. This delayed the delivery of the group interventions and data collection. Secondly, the intervention was reviewed and updated to be delivered online, which required the development of online resources. These materials took into consideration several factors to make them interactive, engaging, and accessible. Furthermore, the facilitators had minimal experience of working therapeutically online, thus quickly adapted to a new way of working, which required developing both clinical and technology skills. Some facilitators attended webinars and training, which provided some guidance to help foster proficiency and build confidence in these new skills. Thirdly, challenges for participants to access the intervention were explored. Most notably, participants were unfamiliar with accessing online services, particularly since it was uncommon to participate in online healthcare prior to the COVID-19 pandemic, thus required support. An 'online group guide' (see appendix 14) was designed and sent to all participants, practice sessions and on the day phone calls were also offered throughout the intervention period, to support them with accessing the technology.

2.3. Implications of context

The project was originally developed pre-pandemic and so the introduction presented in chapter 1 reflects background evidence mostly prior to the pandemic. However, emerging evidence demonstrates that the impact of the COVID-19 pandemic for people with LTCs has been significant and is predicted to be long-lasting. For example, a qualitative study by Fisher et al., (2021) found that living with an LTC through the pandemic had negative consequences on mental health and wellbeing and caused interruptions to healthcare. Furthermore, for those who contracted COVID-19, some individuals who have recovered from the acute illness, have reported long-COVID symptoms including fatigue, muscle pain, cognitive impairment and anxiety, which have negatively impaired quality of life and led to employment issues (Aiyegbusi et al., 2021). Long- COVID refers to the “illness in people who have either recovered from COVID-19 but are still reporting lasting effects of the infections, or have had the usual symptoms for far longer than would be expected” (Mahase, 2020, p.1). Long-COVID had not been widely recognised until after our recruitment period, thus we do not have data on whether our participants had been affected, but in the future, it is likely the demand on health services will increase substantially, in an already over-stretched and struggling healthcare system (British Medical Association, 2020). Furthermore, a recent study published in April 2021 has already found that NHS waiting lists for all treatment had hit a record high of 4.7 million people (O’Dowd, 2021). This is also reflected in the Clinical Health Psychology service (where this study took place), whereby the number of people waiting for therapy on the GM waiting list increased from 122 in December 2019, to 188 in January 2022. It is therefore even more imperative that healthcare interventions:

- are evidence-based
- implemented into practice with the engagement of key stakeholders
- efficiently use resources whilst meeting the needs of service users
- improve and sustain patient outcomes reducing the need for further medical intervention

The conclusions of this project are therefore highly relevant and clinically important for the current and future regional context, and provide the foundations for important further research, to provide the best care for patients based on evidence.

Chapter 3 Quantitative evaluation of outcomes comparing an online acceptance and commitment therapy intervention for long-term conditions in specific-diagnosis versus mixed-diagnosis groups

Abstract

Background

Links between LTCs and poorer mental health increases demand on psychological services. Group programmes use resources efficiently and have been applied across a range of medical specialities. A group programme based on ACT compared whether similar outcomes can be achieved with specific-diagnosis versus mixed-diagnosis groups.

Methods

Participants with an LTC were allocated to attend one of four specific-diagnosis groups or four mixed-diagnosis groups using an ACT intervention. Measures included health-related quality of life, illness perceptions, depression, and anxiety, completed at baseline, post intervention and 8-week follow-up.

Results

Both group conditions showed improvements across time for psychological distress, energy, emotions and general health. There was no overall differential effect of group, or group by time interaction.

Conclusions

Both group conditions showed similar improvements in psychological distress, illness perceptions and health-related quality of life. A fully powered RCT is now required to test differential effectiveness.

3.1 Introduction

Background evidence for this chapter has been comprehensively provided in chapter 1. Here I provide a brief summary to avoid unnecessary repetition.

Many people live with LTC's and struggle with the impact this has on their psychological wellbeing. NHS services are struggling to meet the demand to provide psychological support. Clinical health psychology services are attempting to implement evidence-based initiatives that can help address long waiting times and increase access to help for patients who are suffering. Amongst many strategies, group programmes are growing a body of evidence, particularly those based on a therapeutic approach called ACT. ACT has been used transdiagnostically however, it is unclear whether this is superior to using it within a single health condition approach, thus future comparative studies have been recommended (Brassington et al., 2016).

Therefore, a Clinical Health Psychology service in Northwest England, wanted to implement an ACT-based group approach to address long waiting times, whilst also exploring how best to meet the needs of patients. A previous intervention called 'Better Living with Illness' (Brassington et al., 2016), was delivered as a mixed-diagnosis group and had positive outcomes for participants. The current study adapted this intervention, by making changes to the order and content based on clinician experience and expertise, and developed a new programme named, 'Living Well with a Long-Term Condition', with the following aims:

- To assist people with LTCs to attain a richer, values driven life, despite the impact of their condition, thus improving their quality of life
- To help people learn to live with difficulties presented by LTCs (both physical and emotional) by providing an opportunity to learn new coping strategies, in a supportive small group environment

This study compared the difference between delivering this to groups of patients with mixed-diagnoses to those with specific-diagnoses to inform how best to use resources.

3.2 Methodology

3.2.1 Research design

This research is part of a mixed methods pilot and feasibility study.

Quantitative data collected from questionnaires (described in section 3.2.4.) were analysed and addressed the research question:

> Do the results of a small pilot and feasibility study suggest similar effectiveness in health-related quality of life, illness beliefs and psychological distress in specific-diagnosis versus mixed-diagnosis groups?

Patient acceptability and health professional views were investigated using qualitative interviews, and these are reported in chapters 4 and 5.

3.2.2 Intervention participants

Detail on the recruitment of participants was provided in chapter 2, section 2.1.2.1, page 21. Sixty-four participants were telephone-assessed for eligibility according to the inclusion and exclusion criteria (see table 2).

Table 2: Study inclusion/exclusion criteria

Inclusion Criteria	Exclusion criteria
- ≥ 18 years - English speaking - diagnosed with a LTC for the mixed-diagnosis group and diagnosed with a specific condition relating to one of the four specific-diagnosis specialities (dermatology, rheumatology, diabetes, and cardiology) for the specific-diagnosis group - access to online resources (e.g., laptop/mobile/tablet) and good internet connection	- actively engaged with another psychological therapy - in receipt of on-going input from secondary mental health services - significant substance abuse difficulties - severe and/or chronic mental health problems - a learning disability, at such a level that specialist skills would be required to deliver the intervention

Prior to the impact of the COVID-19 pandemic, sample size was calculated using G*Power[2] (Mayr et al., 2007) which indicated a sample size of 44 group completers ($\alpha \leq 0.05$, $\beta \geq 0.80$)

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[2] As stated in chapter 1, a power calculation is not strictly appropriate for a pilot study (Fox, Hunn & Mathers., 2009) and we did not design this study to test effectiveness however it was useful to estimate effect sizes that could potentially inform a subsequent study.

for a conservative medium effect size (f=0.25) for a mixed ANOVA analysis (described in section 3.2.6.). However, owing to the practicalities of running an online group during a global pandemic, this sample size was not achieved, and we provide further comment in the discussion.

3.2.3 Procedure

3.2.3.1. Group allocation:

Participants who met the inclusion criteria were invited into one of the group conditions:

1. Specific-diagnosis

Four specific-diagnosis groups covered four specialities: dermatology, rheumatology, diabetes, and cardiology. These specialities were chosen due to the number of usual referrals received. Participants were categorised into these groups dependent on the speciality from where the referral originated, or the participant's primary condition. Participants who attended the specific-diagnosis group were required to have a diagnosis relating to that speciality.

2. Mixed-diagnosis

Four mixed-diagnosis groups included participants who did not fall into the above specialities, or had co-morbid[3] conditions, or who were unable to attend the specified dates for any of the four specific-diagnosis groups.

Participants who were eligible for either group condition were not allocated randomly. They were offered a specific-diagnosis group first, and if they were unable to attend this, they were then offered a mixed-diagnosis group. It was not possible to randomly allocate these participants owing to conducting the research in real-life practice where resources were limited. Thus, recruiting patients to the specific-diagnosis groups was prioritised during the recruitment period.

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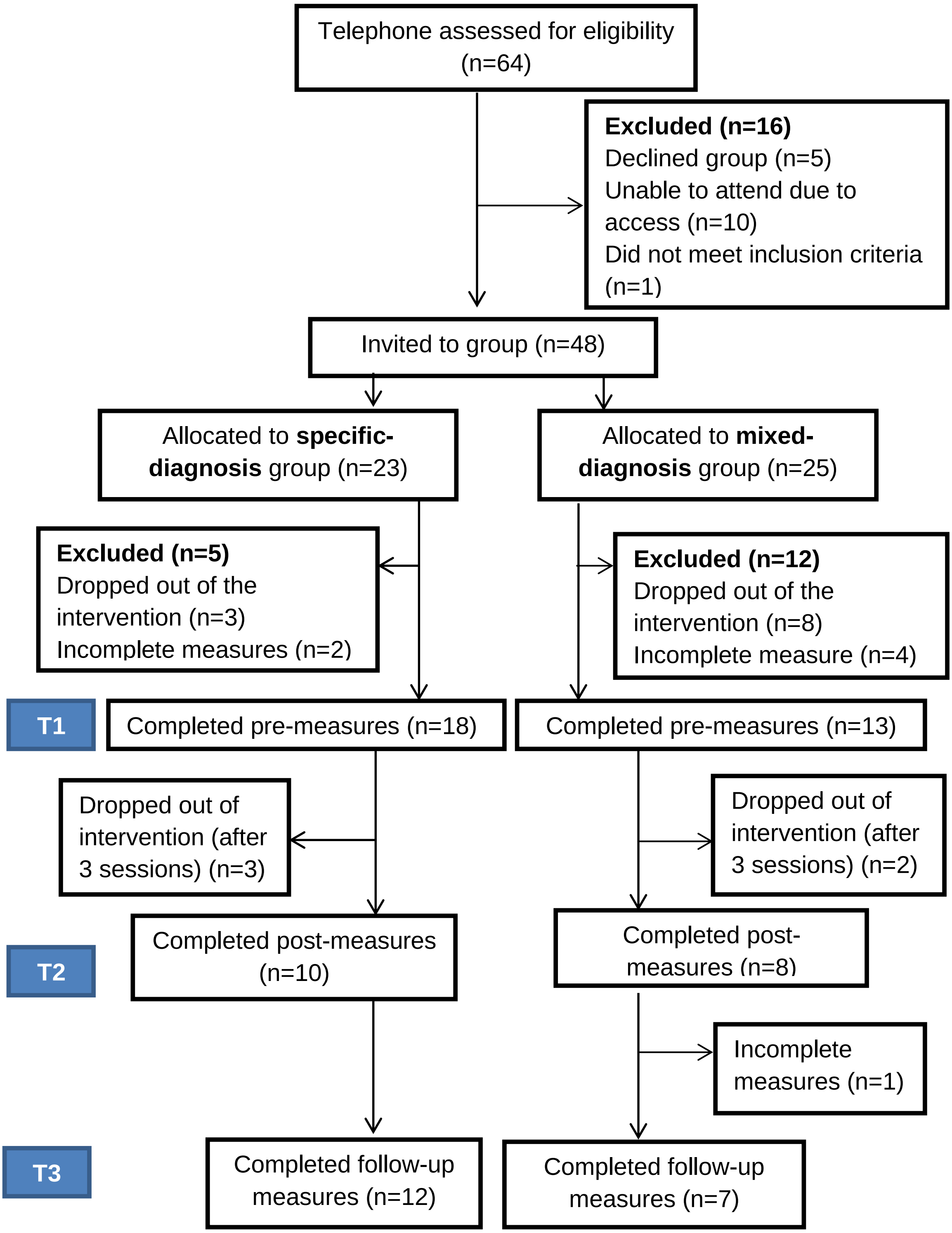
[3] Co-morbid was defined as having two or more long-term conditions at the same time in this study.

A repeated measures design was used, and measures were taken at baseline (T1); session 7 (post-treatment-T2), and 8 weeks follow-up (T3), see figure 3 for consort flow diagram.

Figure 3: Consort Flow diagram



Participants who attended less than 3 out of the 8 total sessions were considered 'non-completers'. Participants who attended 3 or more sessions were considered 'completers' as they received at least one third of the intervention in line with other studies (Brassington et al., 2016). 'True completers' were those who attended all 8 sessions.

Participants gave informed consent, and approval for this study was received from NHS Research Ethics Committee (approval code (20/NW/0125).

3.2.4 Measures

Psychological Distress

1) The Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer & Williams, 2001) was used to measure depression. It is a 9-item self-report questionnaire designed for use in medical settings (Levis, Benedetti & Thombs, 2019), and respondents indicate frequency of depression symptoms over the previous seven days. Scores range from 0-27, the clinical range is indicated at 10 or above, with higher scores indicating increased severity of depression. The PHQ-9 has been validated to detect depression in a range of chronic health conditions (Gillbody et al., 2007).

2) The General Anxiety Disorder Scale (GAD-7) (Spitzer et al., 2006) was used to measure anxiety. It is a 7-item self-report questionnaire with good validation data (Plummer et al., 2016), commonly used in secondary care and respondents indicate frequency of generalised anxiety symptoms over the previous seven days. Scores range from 0-21, the clinical range is indicated at 8 or above, with higher scores indicating increased severity of anxiety.

Illness Perceptions

3) The Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006) measures self-reported perceptions of health using 8 items. These items cover cognitive perceptions such as symptom experience, control over illness, duration of illness, and beliefs about treatment. Items were computed to form an overall composite score used in the analysis. This was computed by reverse scoring items 3,4 and 7, and adding these to items 1, 2, 5, 6 and 8. Higher scores represented a more negative perception of illness. This overall score has been widely used and shown good psychometric properties, including reliability and validity (Broadbent et al., 2015).

Health-Related Quality of Life

4) The RAND 36-item Health Survey 1.0 (SF-36) (Ware & Shelbourne, 1992) measures self-reported health-related quality of life. It covers eight domains: physical functioning, physical role limitations, emotional role limitations, energy/fatigue, emotional wellbeing, social functioning, bodily pain, and general health perceptions. Higher scores represent better quality of life in each domain. It is a widely used instrument with good reliability and validity across several health conditions (Vander Zee et al., 1996). All domains of the SF-36 were included in the analysis.

3.2.5 Intervention

Details of the intervention were provided in chapter 2, section 2.1.3.2. To recap, the intervention comprised of 7, two-hour weekly sessions with a follow up 'reunion' session at 8 weeks. An intervention handbook was developed by making small modifications to the 'Better Living with Illness' protocol by clinicians including the main researcher who had received specialist training in ACT. Each session utilised experiential exercises and metaphors to cover core ACT processes. Worksheets and guided mindfulness meditation exercises were recommended to facilitate learning and encourage home practice. The intervention also covered problem solving skills, pacing, assertiveness skills and goal setting as they are important features of living with an LTC. An overview of the content of group sessions was provided in figure 2 (in chapter 2). The intervention was facilitated by two qualified Psychologists as part of their clinical role in the Clinical Health Psychology service. A Health Psychologist (the main researcher) with experience working with people with LTCs, delivering group psychological interventions and training in ACT, facilitated all 8 groups, to ensure consistency and reliability of the groups. Four other qualified Psychologists worked with the main researcher to facilitate the groups, all of whom had experience of working with people with LTCs and training in ACT.

3.2.6. Analysis

A two-way mixed ANOVA analysis was used to compare the mean differences between groups, split on two factors, where the within subjects' factor equalled time (T1- baseline, T2- post-treatment, T3- 8-week follow-up), and the between-subjects factor equalled group condition (specific-diagnosis versus mixed-diagnosis). Last observation carried forward (LOCF), intention to treat (ITT) for all 'completers' (those who attended three or more of the sessions), was used, where previous timepoint scores were entered for participants who discontinued or didn't complete measures. A secondary analysis of 'true completers' i.e., those who attended all 8 sessions, was also conducted (N=18, specific=10 and mixed=8). Post hoc Bonferroni & Fishers least significant difference adjusted pairwise comparisons were used to analyse the results. Assumptions of outliers, normality, homogeneity of variances and covariances and sphericity were assessed, and are discussed in further detail in the results section below. Significance levels are not the focus of this pilot and feasibility study. However, effect sizes are useful to give an indication of differences in effectiveness. The effect sizes used in this analysis were small =0.01; medium =0.06 and large =0.14.

3.3. Results

3.3.1. Overview of results

There were no outliers, as assessed by examination of studentized residuals, for values greater than ±3. Most variables were found to have normal distributions (assessed by Shapiro-Wilk's test (p>.05)), except for physical functioning, physical limitations, emotional limitations, energy, and social functioning subscales of the SF-36. Attempts to transform non-normal data were unsuccessful, however, normality was further assessed by normal Q-Q plots, and all variables were normally distributed. Given the robustness of the two-way mixed ANOVA analysis, non-normality was ignored. There was homogeneity of variances (p>.05) and covariances (p>.001), as assessed by Levene's test of homogeneity of variances and Box's M test, respectively. Where Mauchly's test of sphericity was violated, Huynh-Feldt (if ε >0.75) or Greenhouse-Geiser (if ε<0.75) corrections were used.

All 31 participants included in the analysis were considered 'completers' i.e., they attended at least 3 intervention sessions. There were 18 completers in the specific-diagnosis group and 13 completers in the mixed-diagnosis group. There were no participants considered 'non-completers'. Specific-diagnosis and mixed-diagnosis groups did not differ significantly at baseline in terms of demographic characteristics (see table 3). Further quantitative measures to assess the feasibility of the intervention in both group conditions are described in chapter 4.

Table 3: Participant demographic characteristics

Characteristic		Specific (n=18)	Mixed (n=13)	*p*
Mean age in years (SD)		46.05 (16.14)	47.94 (13.89)	$.154^{t}$
Gender (%)	**Female**	11 (61.1%)	10 (76.9%)	$.583^{PC}$
	Male	7 (38.9%)	3 (23.1%)	
Ethnic (%)				$.288^{PC}$
	White	18 (100%)	11 (84.7%)	
	Mixed	0 (0%)	1 (7.7%)	
	Missing	0 (0%)	1 (7.7%)	

T = t test
PC = Pearson Chi-Square

3.3.2. ANOVA analyses

3.3.2.1. Effect of group

The overall main effect of group condition showed only one subscale variable of the SF-36 had a statistically significant difference (p<.05), and medium-large effect (η^2=.133). The mixed-diagnosis group had an overall physical functioning score 21.67 (95% CI, .655-42.755) points higher than the specific-diagnosis group, but there was no differential effect of the intervention. Other effects of group revealed small effects for illness perceptions (η^2=.026), and emotions subscales of the SF-36 (η^2=.017); a small to medium effect for the social functioning and general health subscales of the SF-36 (η^2=.057 & η^2= .046 respectively) and a medium effect for the emotional limitations subscale of the SF-35 (η^2=.070). However, none of these differences were statistically significant.

3.3.2.2. Effect of time

Across the three timepoints there was a statistically significant effect of time for depression, anxiety and three subscales of the SF-36; energy, emotions, and general health (*p*<.05) with medium effect sizes (see figure 4). The full data for all measures is provided in table 4. Post hoc pairwise comparisons (table 5), indicated significant reductions in scores for depression (PHQ9) and anxiety (GAD7) between baseline and post-treatment (T1-T2), baseline and follow-up (T1-T3), but no change from post-treatment to follow-up (T2-T3). This suggests that psychological distress reduced following the intervention, although the significance was not maintained at the 8-week follow-up. Post hoc comparisons also indicated improvements in energy and emotions between baseline and follow-up (T1-T3), and general health between baseline and post-treatment (T1-T2), suggesting some improvements to aspects of their health-related quality of life. No significant change was found in overall illness perceptions (BIPQ).

3.3.2.3. Group by time interaction

The results of the two-way mixed ANOVA showed that there was no statistically significant interaction between the group conditions (specific-diagnosis versus mixed-diagnosis) and time on any of the outcomes.

For the secondary analysis of ‘true completers’, there was no difference found for the main effect of group, or group by time interaction. Across the three timepoints, there was only a statistically significant effect of time for depression (see appendix 15 for the full data for this analysis).

Overall, these results suggest that both group conditions had similar improvements in psychological distress, illness perceptions and health-related quality of life.

Figure 4: Changes in average scores across time for key variables: PHQ9, GAD7, energy, emotions, and general health for specific-diagnosis and mixed-diagnosis groups

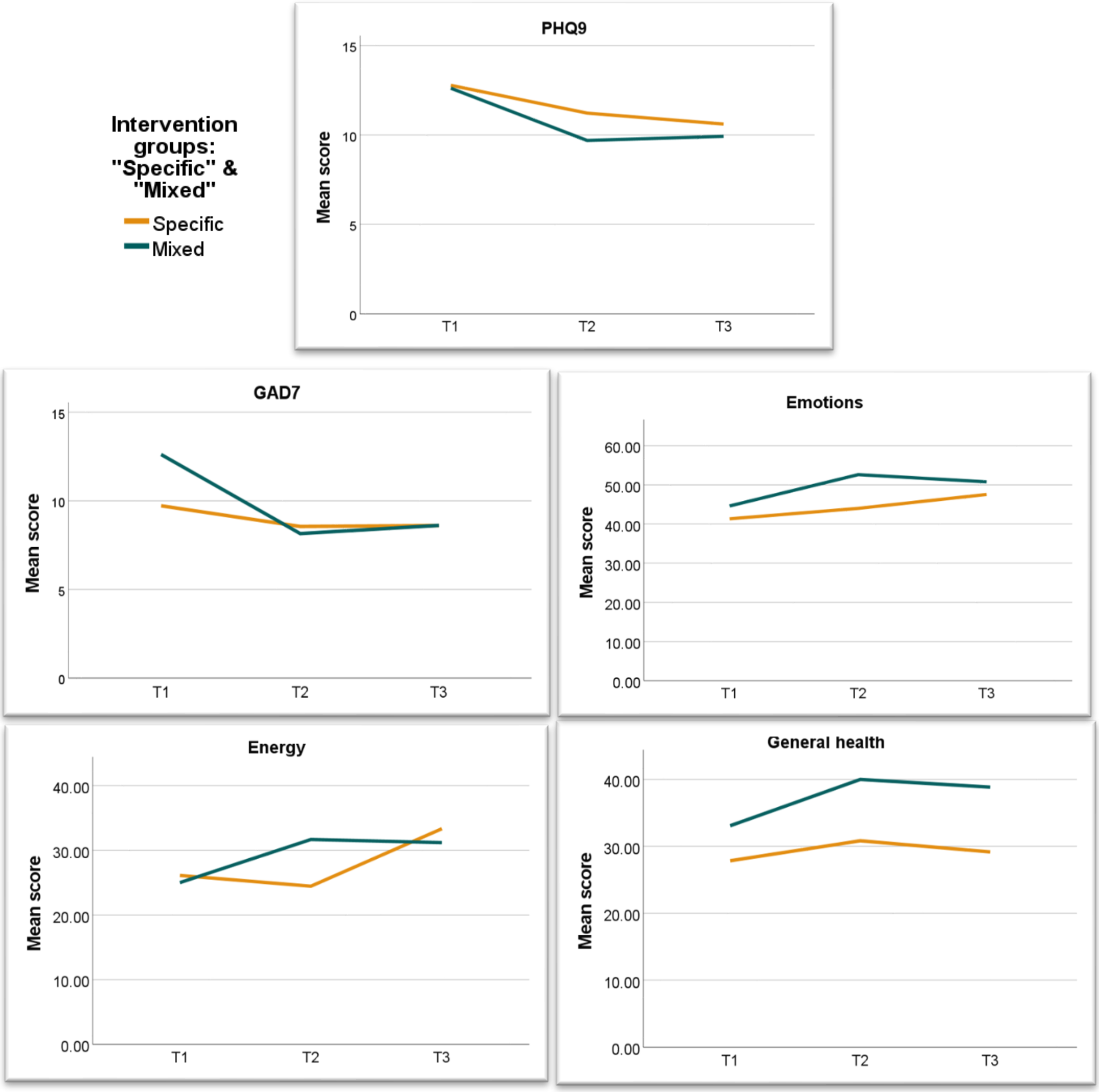


Table 4: Two-way Mixed ANOVA (LOCF)

			T1	T2	T3	**Effect of time**			**Effect of group**			**Group*time interaction**		
N= 31 **Specific (n=18)** **Mixed (n=13)**		**Intervention group**	**Baseline mean (SD)**	**Post-Treatment mean (SD)**	**Follow-up mean (SD)**	***F***	***p***	**Effect size (η^2)**	***F***	***p***	**Effect size (η^2)**	***F***	***p***	**Effect size (η^2)**
PHQ9		**Specific**	12.78 (7.14)	11.22 (7.18)	10.61 (7.43)	11.852	.000	.290	.117	.734	.004	.772	.467	.026
		Mixed	12.62 (4.98)	9.69 (5.74)	9.92 (5.94)									
GAD7		**Specific**	9.72 (6.67)	8.56 (5.35)	8.61 (5.48)	7.696	.002[a]	.210	.214	.647	.007	2.567	.094[a]	.081
		Mixed	12.62 (5.08)	8.15 (5.03)	8.362 (5.23)									
BIPQ		**Specific**	48.89 (7.39)	48.50 (7.23)	50.94 (9.73)	.675	.498[a]	.023	.782	.384	.026	.380	.662[a]	.013
		Mixed	52.15 (10.18)	52.00 (11.85)	52.38 (10.77)									
SF-36	**Physical functioning**	**Specific**	49.17 (29.17)	49.17 (30.45)	48.89 (34.75)	.758	.457[a]	.025	4.448	.044	.133	.717	.475[a]	.024
		Mixed	68.46 (25.69)	73.85 (23.29)	70.00 (27.23)									
	Physical limitations	**Specific**	37.50 (42.23)	33.33 (41.12)	38.89 (43.91)	.059	.923[a]	.002	.104	.749	.004	.994	.368[a]	.033
		Mixed	38.46 (44.04)	46.15 (36.58)	38.46 (37.66)									
	Emotional limitations	**Specific**	38.89 (44.65)	40.74 (43.61)	53.70 (44.49)	.873	.409[a]	.029	2.171	.151	.070	1.347	.267[a]	.044
		Mixed	20.51 (37.36)	33.33 (38.49)	23.08 (35.98)									

	Energy	**Specific**	26.11 (23.11)	24.44 (21.69)	33.33 (26.35)	4.709	.013	.140	.028	.869	.001	2.706	.075	.085
		Mixed	25.00 (23.11)	31.67 (22.73)	31.19 (23.08)									
	Emotions	**Specific**	41.33 (22.88)	44.00 (21.08)	47.56 (27.61)	3.361	.042	.104	.491	.489	.017	.718	.492	.024
		Mixed	44.62 (14.32)	52.62 (19.73)	50.77 (16.44_									
	Social functioning	**Specific**	36.11 (26.39)	38.89 (28.08)	47.92 (36.19)	1.576	.215	.052	1.737	.198	.057	2.142	.127	.069
		Mixed	47.69 (19.16)	60.19 (28.44)	49.61 (26.94)									
	Pain	**Specific**	42.22 (28.14)	45.28 (27.78)	50.14 (33.04)	1.178	.315	.039	.049	.827	.002	1.968	.149	.064
		Mixed	42.50 (29.05)	46.73 (26.82)	41. 74 (28.16)									
	General health	**Specific**	27.85 (19.88)	30.83 (20.45)	29.44 (20.21)	3.586	.050[b]	.110	1.404	.246	.046	.744	.441[b]	.025
		Mixed	33.08 (16.53)	40.00 (18.48)	38.85 (19.38)									

[a] Huyhn-Felder adjusted significance levels used due to sphericity violation where epsilon >0.75.

[b] Greenhouse-geisser adjusted significance levels used due to sphericity violation, where epsilon < 0.75.

Table 5: Post hoc comparisons (LOCF)

N= 31 **Specific (n=18)** **Mixed (n=13)**		**Pre vs Post-treatment (T1vsT2)**		**Post-treatment vs Follow-up (T2vsT3)**		**Pre vs follow-up (T1vsT3)**	
		MDiff	*p*	MDiff	*p*	MDiff	*p*
PHQ9[a]		2.239	.005	.190	1.000	2.429	.000
GAD7[a]		2.814	.018	-.259	1.000	2.556	.010
BIPQ[a]		.271	1.000	-1.415	.725	-1.143	1.000
SF-36	**Physical functioning**[a]	-2.692	.327	2.062	1.000	-.630	1.000
	Physical limitations[a]	-1.763	1.000	1.068	1.000	-.694	1.000
	Emotional limitations[a]	-7.336	1.000	-1.353	1.000	-8.689	.815
	Energy[a]	-2.500	.663	-4.204	.159	-6.704	.037
	Emotions[b]	-5.333	.056	-.855	-737	-6.188	.022
	Social functioning[a]	-7.639	.205	.775	1.000	-6.864	.622
	Pain[a]	-3.643	.352	.069	1.000	-3574	.770
	General health[b]	-4.955	.025	1.410	.267	-3.544	.128

[a] Post hoc Bonferroni least significant difference comparisons used

[b] Fishers least significant difference adjusted pairwise comparisons used.

3.4 Discussion

3.4.1. Discussion of results

The aim of this study was to conduct a pilot and feasibility test of whether an ACT group intervention would suggest similar effectiveness in health-related quality of life, illness beliefs and psychological distress, in specific-diagnosis versus mixed-diagnosis groups.

The results suggest that both group conditions resulted in improvements across time for psychological distress, energy, emotions, and general health, but there was no overall differential effects of the group. In a pilot and feasibility study like this, statistical significance is not the key outcome. However, effect sizes can help inform a subsequent randomised controlled trial (RCT). It is important to note that in this study, all the group by time interaction effect sizes were very small, i.e., less than 0.01. This suggests that both groups led to a similar degree of symptomatic improvement, with little evidence of a differential effectiveness between the conditions.

Therefore, although there is growing research for the use of mixed-diagnosis approaches, particularly from an ACT perspective (Brassington et al., 2016), the comparison of the two group conditions for people with LTCs is novel, and this study provides an initial and tentative finding. Several studies treating mental health disorders have conducted similar comparisons using CBT interventions and report similar results to the current study. For example, Norton and Barrera (2012, p.1) found “strong evidence for treatment equivalence across transdiagnostic and diagnosis-specific CBT conditions” for participants with panic disorder, social anxiety disorder and generalised anxiety disorder. Similarly, in a study for participants with major depressive disorder and comorbid anxiety disorders, there was no significant difference found between ‘disorder-specific’ and ‘transdiagnostic’ approaches (Titov et al., 2015). In addition, it is commonplace for transdiagnostic approaches to be offered in other physical health specialities such as pain management (Wilson, 2017), where pain management programmes are routinely offered to a range of chronic pain conditions. Therefore, further comparison studies are warranted to establish a firm conclusion for other LTC studies.

3.4.2. Limitations

This study has several important limitations. There was no control comparison, we do not know why people dropped out, the outcomes relied on self-report, baseline levels of the outcomes varied, and the sample size was small. There may have been a between-group difference in efficacy, but this study lacked the sample size to demonstrate this, and a pilot study is not designed to determine differential effectiveness. However, this study is part of larger project with further results on feasibility described in chapter 4. Furthermore, restrictions of the COVID-19 pandemic meant that the group had to be delivered online and the capacity of participants in each group was reduced, to allow for practical considerations such as online platform limitations, group interaction and safety.

Conventional statistical techniques were used testing for differences in analysing this data. It should be acknowledged that it has been argued that a more appropriate alternative way of dealing with this data, is to conduct non-inferiority statistical testing, to demonstrate that treatments or interventions are 'similar' to each other in terms of their clinical effectiveness (Walker, 2019). This form of analysis should be used in any subsequent, fully powered, RCT.

It is worth taking into consideration that this study defined 'specific-diagnosis' as diagnoses by medical speciality rather than single health conditions. There are a range of different health conditions/diagnoses that could fall under the speciality of 'rheumatology', 'dermatology' and 'cardiology' (particularly compared with diabetes); thus, we acknowledge that participants within these groups may not have shared the same specific condition diagnosis. However, this study was conducted in a naturalistic clinical setting, and it was a practical decision to be inclusive to meet the demands of the service users, whilst exploring a scientifically interesting research question.

The limitations highlighted mean that we need to be cautious about our findings, and about the extent to which they are generalisable.

3.4.3. Strengths

This study had some important strengths. First, this research provides initial findings to address the gap in literature which serves an important role in helping inform service planning in clinical health settings. Second, being conducted in a naturalistic clinical setting meant this study had high ecological validity which is often lacking in RCTs (Fagiolini et al., 2017). Third, the study included a wide range of outcomes (e.g., psychological distress, illness perceptions and health-related quality of life) and provided a good evaluation of the intervention on clinically meaningful outcomes.

3.4.4. Implications and future directions

This pilot and feasibility study shows that an online ACT group can be delivered to specific-diagnosis and mixed-diagnosis groups, with tentative initial findings suggesting that each is equally effective. The study demonstrates that it is feasible to conduct this type of comparative study, and that a full sized, adequately powered RCT is now justified. The finding of very small effect sizes for the group by time interaction is important, as it suggests that a subsequent definitive RCT testing for differential effectiveness should employ a sample size power calculation designed to test for a small effect size. This is important in clinical practice since groups are an efficient use of resources for patients to gain more timely access to psychological help (Davies, 2011), as well as being considered more cost effective (Biggs et al., 2020). Using a mixed-diagnosis approach could increase throughput of patients, as it is more inclusive, with increased flexibility around organising group programmes from referrals. More generally this study also adds to the growing body of evidence that ACT is an effective psychological approach to support people with LTCs, in a group format. For example, a systematic review conducted by Graham et al., (2016), described several ACT-based group interventions that provided evidence for; changing lifestyle behaviours for cardiac patients (Goodwin et al., 2012), improved diabetes self-management in patients with type 2 diabetes (Gregg et al., 2007), and reducing psychological distress in patients with multiple sclerosis (Nordin & Rorsman, 2012). This is unsurprising given that ACT is considered a flexible approach and has been effectively delivered in various formats (Ruiz, 2010). Furthermore, as previously discussed, ACT is considered an inherently transdiagnostic approach (applies to more than one condition) (Clarke et al., 2014; Dochat et al., 2021), and the current study also supports that it is applicable as a specific-diagnosis approach. In line with this, a published service evaluation (Hill et al., 2017), where the authors also adapted the original ‘Better Living with Illness’ group intervention (Brassington et al., 2016), for people with neurological conditions, found it was significantly effective in reducing psychological distress. This is a like finding to this study.

It is recognised that people living with LTCs share common struggles, such as lifestyle change, feelings of loss and changes in mood, that impact on many areas of life such as family, work, education, and finances. However, given the complex nature of many LTCs, there are intricacies to specific conditions that are not shared, such as the type of treatment or treatment burden, condition severity or stigma. We are unable to tell from this study whether the range of physical conditions had an impact on the group process or dynamics, thus further exploration is required. Furthermore, it is possible that comparisons between different diagnostic groups would be clinically important. Further research could test whether single-diagnosis groups may be differentially effective across different conditions, to explore when a mixed-diagnosis or specific-diagnosis approach may be indicated.

Although this study was originally designed to be delivered face-to-face, the study findings also support using an online (or internet-delivered) approach. This mode of intervention delivery has gained emerging evidence over the past 10 years, particularly in ACT interventions for; chronic pain (Buhrman et al., 2013; Hayes et al., 2014;); fibromyalgia (Simister et al., 2018), and diabetes (Kioskli et al., 2020). Furthermore, online interventions can overcome certain limitations of face-to-face approaches such as mobility and accessibility issues, long waiting lists, and direct and indirect costs (Slattery et al., 2019). This provides support for using online intervention methods in clinical settings, although does not suggest they should replace face-to-face methods. A further comparison study may help to further investigate this, taking into consideration patient preference, as some patients may prefer face-to-face working. Overall, it is likely that in a clinical setting, the ability to offer a range and choice of interventions, will best meet the needs of service users (Coulter, Roberts & Dixon, 2013) and best practice standards for psychological therapy services (CCIQ, 2020).

3.5 Conclusion

The group intervention showed similar effectiveness and no marked differences in the specific-diagnosis and mixed-diagnosis groups. The results are meaningful for services that are trying to prioritise resources and meet the needs of service users, but further research is required to confirm these tentative findings, thus an adequately powered RCT is indicated.

Chapter 4 Eligibility, retention and acceptability of an online acceptance and commitment therapy intervention delivered to specific-diagnosis versus mixed-diagnosis groups.

Abstract

Background

Including a stage of pilot and feasibility testing is recommended when developing interventions. Furthermore, the assessment of an intervention's 'acceptability' is considered particularly important for healthcare interventions. In this study, the feasibility and acceptability of a group intervention called 'Living Well with a Long-Term Condition' was compared between specific-diagnosis and mixed-diagnosis groups.

Methods

Participants either attended an online specific-diagnosis or mixed-diagnosis group in a clinical health psychology service. Quantitative data from attendance records, and qualitative data from online focus groups and interviews with participants, assessed feasibility and acceptability. Quantitative outcomes included eligibility and recruitment rates of the overall intervention plus, retention (attended 3 or more sessions), true completion (attended all 8 sessions), and mean intervention adherence rates, for the specific-diagnosis and mixed-diagnosis groups. Qualitative data was analysed using a combination of inductive and deductive thematic analysis, informed by the TFA.

Results

Quantitative data:

Eligibility rate was 98% (63/64) and recruitment rate 75% (48/63), for the overall intervention. For specific-diagnosis groups, retention and true completion rates were 83% (15/18), 56% (10/18) respectively, and the mean intervention adherence rate was 6.72 sessions. For mixed-diagnosis groups, retention and true completion rates were, 85% (11/13) and 62% (8/13) respectively, and the mean intervention adherence rate was 6.78 sessions. Intervention adherence was not found to be significantly different between groups.

Qualitative data:

Six patients who attended a specific-diagnosis group and 3 patients who attended a mixed-diagnosis group participated. All seven constructs of the TFA were coded, and inductive themes included; Group Relationships/Dynamics, Perceived Need, Feedback and Views and Expectations. Overall, the intervention was found to be acceptable in both group conditions.

Conclusions

Retention, true completion, and adherence rates were high and comparable, suggesting that both group conditions were feasible to patients. Acceptability of the intervention was high, and no apparent difference found between group conditions.

4.1. Introduction

When developing interventions such as the one described in chapters 1-3, there has been guidance published, with recommendations to include a stage of pilot and feasibility testing (Craig et al., 2013). Pilot and feasibility studies are important for assessing the feasibility of an intervention, which is defined as "whether something can be done, whether it should be proceeded with and if so how" (NIHR, 2021 paragraph 5). Thabane et al., (2010) also suggested that pilot and feasibility testing is important to assess the preliminary clinical effectiveness of an intervention. These studies are often considered preparatory research, necessary to address uncertainties including "the acceptability of an intervention to the user" (NIHR, 2021, paragraph 10). Furthermore, 'acceptability' has become acknowledged to be important when designing and successfully implementing healthcare interventions (Sekhon, Cartwright & Francis, 2017). For example, evidence has shown that interventions considered acceptable, have improved patient outcomes and adherence to treatment recommendations (Reupert et al., 2020).

Therefore, the current study sought to establish whether there is a difference in the feasibility and acceptability of the 'Living Well with a Long-Term Condition' group intervention (described in chapters 1 - 3), delivered to specific-diagnosis versus mixed-diagnosis groups. As far as we know, this study is novel in conducting such a comparison.

We undertook preliminary testing of the group intervention on patient outcomes (reported in chapter 3) and here report eligibility, recruitment, retention, true completion, and intervention adherence rates. We also report on the qualitative findings of the two different groups to understand perceptions of acceptability in each group. Health professional perspectives are explored in chapter 5.

Operationalising and defining acceptability is challenging, because there is no shared understanding of what acceptability refers to, or how it is to be assessed, particularly in healthcare literature (Sekhon, Cartwright & Francis, 2017). In addition, measuring the acceptability of interventions has historically focused purely on specific behaviours, such as degree of uptake, adherence, engagement and extent of retention or dropout. These measures have ignored participant reported cognitions and affective evaluations of acceptability, which could be viewed as reductionist (Sekhon, Cartwright & Francis, 2017). Thus Sekhon, Cartwright & Francis (2017) developed a multi-faceted Theoretical Framework of Acceptability (TFA, described in chapter 1, section 1.9), to assess the acceptability of an intervention from the perspective of recipients who have experienced an intervention.

Authors have acknowledged that using the TFA enables “comparisons of acceptability between alternative or competing interventions” (Sekhon, Cartwright & Francis, 2018, p.8), providing further rationale for its application in this study.

4.2. Quantitative Methodology

4.2.1. Design & setting

This study was part of a mixed methods pilot and feasibility research project, comparing an online ACT group intervention delivered to two group conditions (specific-diagnosis versus mixed-diagnosis groups). A full description of the intervention methods and the comparison of group outcomes was described in chapters 1-3.

This study used quantitative data collected from attendance records (detailed below), and qualitative data from online focus groups and individual interviews with patient participants, and addressed the following research questions:

> Is there a difference in feasibility and acceptability of an online ACT intervention between specific-diagnosis versus mixed-diagnosis groups?

4.2.2. Outcomes to assess the feasibility and acceptability of the intervention

Eligibility rate

The number of people who responded to an invite (via letter or waiting list check-in) to the group intervention during the recruitment period (June 2020-January 2021), who were assessed as eligible using the inclusion/exclusion criteria.

Recruitment rate

The number of participants recruited and allocated to each group condition.

Retention rate

The number of participants who remained in the intervention i.e., those who did not drop out of the intervention, and completed 3 or more sessions. This equated to completing at least one third of the intervention which is in line with how Brassington et al., (2016) defined ‘completers’.

True completion rate

The number of participants who completed the whole intervention i.e., all 8 sessions.

Intervention adherence

This was measured by calculating the average number of intervention sessions attended for each group condition.

4.2.3. Analysis

Descriptive statistics were used to summarise the eligibility, recruitment, retention, true completion, and intervention adherence rates.

4.3. Quantitative Results

The flow of intervention participants is presented in figure 5.

Eligibility rate

Of the 118 patients referred to the Clinical Health Psychology service over the 8-month recruitment period, 64 (53%) responded to an invite to the group intervention. Sixty-three (98%) of these were assessed as eligible by the clinicians of the Clinical Health Psychology team.

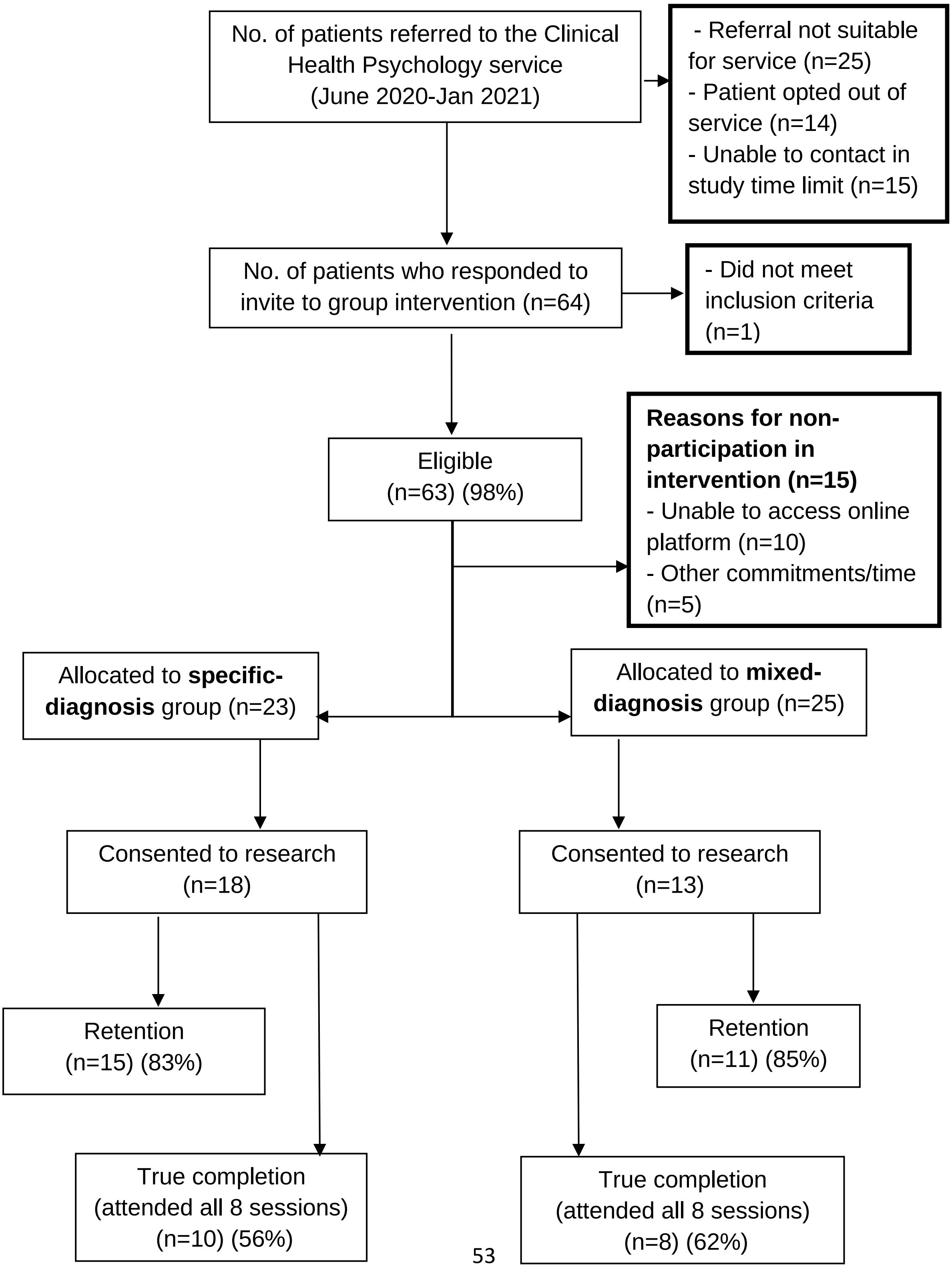
Recruitment rate

In total 48 out of 63 (75%) eligible participants agreed to take part in a group. Out of these, 31 (65%) gave their written consent to take part in the research. Twenty-three patients overall were allocated to the specific-diagnosis group, and 18 of these consented to the research. Twenty-five patients overall were allocated to the mixed-diagnosis group, and 13 of these consented to the research. Reasons for non-participation in the intervention included access difficulties, and other commitments such as childcare and work. Reasons for non-participation in the research were not collected.

Retention rate

The retention rate (attended 3 or more sessions) for specific-diagnosis groups was 83% (15/18) and 85% (11/13) for mixed-diagnosis groups. The percentage of participants who dropped out of the intervention was 17% (3/18) and 15% (2/13) for the specific-diagnosis and mixed-diagnosis groups respectively.

Figure 5: Flowchart of participation



True completion rate

The true completion rate (attended all 8 sessions) was 56% (10/18) and 62% (8/13) for specific-diagnosis and mixed-diagnosis groups respectively. Using Chi squared tests there was no statistically significant association between the group conditions and true completers of the intervention ($\chi^2(1)$ =.111, *p*=.739).

Intervention adherence

The average number of sessions attended by participants in the specific-diagnosis group was 6.61 (SD=2.03) and in the mixed-diagnosis group was 6.69 (SD=2.10), and this difference was not significant (*t* (29) = -.070, *p*=.944).

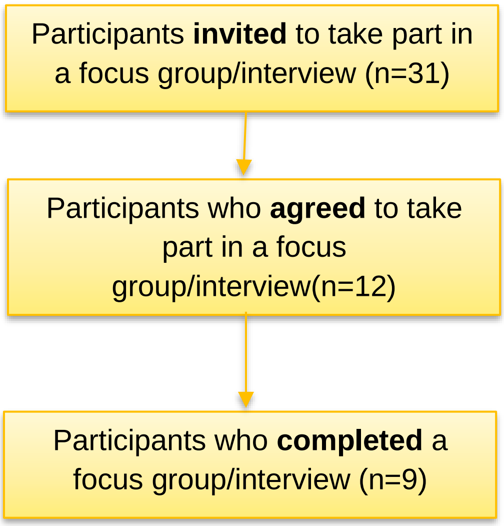
4.4. Qualitative methods

4.4.1. Participants

Qualitative data was collected via online focus groups and individual interviews with participants who had completed the online group intervention.

Participants were recruited from those who had consented to the study and completed at least 3 sessions of the intervention (see figure 6). These participants had consented to be contacted with an email invitation from the researcher to take part in a focus group or interview. Prior to taking part, all participants were provided with an information sheet and signed written informed consent electronically.

Figure 6: Flow diagram of patient participants



The focus groups were structured to allow a small number of patients (up to 6), to share their perceptions and experiences of the group intervention. Individual interviews were offered to those who were interested in taking part, but unable to attend the arranged focus groups. See table 6 for the number of participants involved in a focus group or interview from each intervention group.

Ethical approval was gained from the NHS Research Ethics Committee (approval code 20/NW/0125).

Table 6: Patient participants involved in qualitative interviews

	Number of participants included	Intervention group
Focus group 1 (Specific)	3	1 (Rheumatology)
	1	2 (Dermatology)
Focus group 2 (Mixed)	2	3 (Mixed)
	1	4 (Mixed)
Individual interviews (Specific)	1	5 (Cardiology)
	1	6 (Diabetes)
Focus group/interview	0 (no participants agreed to take part)	7 (Mixed)
	0 (no participants agreed to take part)	8 (Mixed)

4.4.2. Procedure

Focus groups and individual interviews were held between November 2020 and October 2021. There were two focus groups (one specific-diagnosis and one mixed-diagnosis) in total, and 2 individual interviews. Microsoft teams was used ensuring ease of access, as participants were familiar with the technology and its features. Focus groups lasted no more than 2 hours, and individual interviews lasted no longer than 30 minutes. A moderator, who had not been involved in the delivery of the online group intervention, conducted the online focus groups and interviews. Further detail on the moderator was provided in chapter 2 section 2.1.3.4.

A focus group and interview topic guide (see appendix 10) was developed informed by the TFA and aimed to elicit:

a) Views on the attractiveness, accessibility, and acceptability of the online ACT group intervention

b) Views on the group environment and attitudes towards being in a specific-diagnosis versus mixed-diagnosis group

The same guide was used for both focus groups and interviews. Probing questions were used to encourage participants to elaborate on their experiences.

4.4.3. Analysis

All recordings of the focus groups and interviews were transcribed verbatim (using microsoft teams in-built transcription function checked by the main researcher) and identifying information was removed to ensure anonymity. A hybrid approach of deductive and inductive reflexive thematic analysis (Braun and Clarke, 2019; 2020) was used to analyse the data, described previously in chapter 2 section 2.1.5.2.

Firstly, the TFA was used to form the basis of a deductive coding framework. The main researcher, and a second researcher (EC), independently coded the first transcript and five further inductive codes were constructed during the analysis of the data. These were called Group Relationships/Dynamics, Perceived Need, Feedback, Views on the Group Approach and Expectations. These new codes were added to the coding framework and applied to the remaining transcripts. Further refinement of the inductive codes was made following the initial analysis of health professional data (see chapter 5). It was decided that two of the newly identified inductive codes could be combined as they covered a similar theme. These were, Views of the Group Approach and Expectations, and were joined to form the code Views and Expectations. The coding framework was adjusted accordingly, and the transcripts reviewed to ensure no further refinements were necessary. See appendix 16 for the final coding framework applied. Once all data had been coded and reviewed, the construction of themes began relating to the acceptability and feasibility of the group intervention to specific-diagnosis and mixed-diagnosis groups.

4.5. Qualitative results:

Overall, participants perceived the group intervention to be acceptable. Findings are presented below for each of the codes included in the coding framework.

- ### 4.5.1. Deductive codes of the TFA

Affective Attitude

The affective attitudes of participants were explored in two parts, their anticipated affective attitudes and how they felt about the intervention *prior* to taking part, and their experienced affective attitudes and how they felt about the intervention *after* taking part. Overall, it was evident that some participants' attitudes changed over time where ultimately, they all shared favourable attitudes toward the group intervention.

> *Bearing in mind initial reservations, I would say you know wholeheartedly give it a go, stick with it, it's definitely worthwhile (Patient 1, specific-diagnosis group)*

Participants described elements that they liked about the intervention. For example, mindfulness was a specific strategy that was well liked, the facilitation of the intervention was highly commended, and the group format was regularly recognised as a positive as it fostered a sense of connection. This was evident for both specific-diagnosis groups and mixed-diagnosis groups.

> *Yeah, the togetherness of it was definitely an advantage, something I really liked. You know, being able to also see how other people dealt with things (Patient 4, specific-diagnosis group)*
>
> *It was really nice to just have a range of people, like we've come from very different backgrounds, our health conditions are different they manifest themselves in different ways, I liked that element of it (Patient 5, mixed-diagnosis group)*

Conversely, there were some dislikes mentioned. For example, some exercises were described as upsetting, technical difficulties were stress inducing, and it was suggested the intervention delivered face-to-face would have been preferred.

> *You know what I'd prefer other than this is face-to-face 'cause you can actually… to me… you can feel the other experiences of the other people - this is just a television isn't it (Patient 8, specific-diagnosis group)*

Dislikes of the intervention however, were not more notable in either of the specific-diagnosis or mixed-diagnosis groups.

Burden

This construct focused on the perceived amount of effort that was required to take part in the intervention. For most participants, accessing the intervention was easy once they had overcome any difficulties with technology.

> *It was easy for me to get into the group and work with it. Except for some of the early technology issues (Patient 3, specific-diagnosis group)*

For some, the intervention being online contributed to less effort and low burden, as it was less disruptive on their routine.

> *Yeah, because it was online that definitely helped with work. So obviously I didn't have to travel, at the time I was working from home, so that was good. If I'd have been in work then it would have been harder for me (Patient 9, specific-diagnosis group)*

For others, being online required more effort and made it difficult to get involved in discussions.

> *Yeah, and it [being online] was such a drawback you know I didn't partake as much, maybe as I might have done (Patient 1, specific-diagnosis group)*

Some participants recognised some personal factors that contributed to the increased effort required to take part in aspects of the intervention, but this did not appear to be linked to the group condition.

> *I have my own barriers, like mental barriers to do it, and I obviously had to pick myself up to be able to contribute to the group because of my own self-confidence (Patient 4, specific-diagnosis group)*
>
> *I struggled more with the motivation and doing the stuff at home 'cause I'm kind of a procrastinator…yes, so that kind of thing was tricky for me, but that's nothing to do with the group (Patient 6, mixed-diagnosis group)*

Ethicality

The intervention overall was perceived to be a good fit with participants' value systems. Participants recognised the group dynamics and the facilitation as important. This appeared to be similar in both specific-diagnosis and mixed-diagnosis groups.

> *I think everyone was respectful and kind to each other and that was important to me 'cause I try to not be judgemental (Patient 7, mixed-diagnosis group)*

> *My personal experience I thought [the facilitators] did a really good job of getting a professional balance with an open arms we're all friends here kind of approach (Patient 3, specific-diagnosis group)*

Intervention Coherence

Most participants reflected that they felt they had a good overall understanding of the intervention, its purpose and how it worked. They often noted that the participant workbook that accompanied the group sessions helped facilitate their understanding.

> *We got a booklet in advance of the course starting so that gave you some indication… because we had that it was very well understood, what we were trying to do and how it would work (Patient 2, specific-diagnosis group)*

Conversely, one participant who attended a mixed-diagnosis group was unclear about the aim of the group, although this did not appear to affect the interventions perceived effectiveness (as discussed below).

> *No, I suppose I didn't really know what the goal was at the end…but it still helped (Patient 5, mixed-diagnosis group)*

Opportunity Costs

This theme was least present in the transcripts. This suggests that few benefits, profits, or values had to be given up to engage in the intervention. Evidence described above, that also contributed to low burden, was the lack of travel required to take part, thus participants were able to engage, with limited impact on their day-to-day lives.

> *It's really good that I didn't have to travel for it, I could just stay at home…it was easy to fit into my day. (Patient 5, mixed-diagnosis group)*

Perceived Effectiveness

Overall participants perceived the intervention to be effective. Some participants were able to indicate certain strategies, such as mindfulness that were perceived the most effective.

> *Some of the techniques you know I'm aware of mindfulness and aware of meditation…I still think about and practice from time to time. So yeah, I found that useful (Patient 2, specific-diagnosis group)*

Whilst other participants gave a more general sense of the way in which they perceived it to be effective.

> *It's definitely improved my confidence as a whole just for general life as well as during these sessions (Patient 4, specific-diagnosis group)*

The extent to which the intervention was perceived to be effective in helping participants manage their LTC was varied, however, this did not appear to be more pronounced in either of the group conditions.

> *It's definitely helped, obviously the condition hasn't gone away I'm probably better at managing it…just a little bit more accepting of it and just trying to be a bit kinder to myself…I think it's definitely helped and given me more tools in the toolbox (Patient 6, mixed-diagnosis group)*

> *It was effective in terms of just learning some of the mindfulness and the way I deal with things… but I can't really say in terms of my condition I felt the therapy particularly improved anything specific (Patient 9, specific-diagnosis group)*

The extent to which the intervention was perceived to be effective long-term was also varied.

> *It's had some lasting benefits for me, certainly (Patient 2, specific-diagnosis group)*

> *Throughout the period of the treatment, the therapy was really good, afterwards I do feel a little bit, not quite lost at sea, but a bit kind of drifting (Patient 5, mixed-diagnosis group)*

Difficulties with implementing strategies in the long-term was recognised by the participants of the mixed-diagnosis group. Conversely the only participant to perceive that the intervention was not effective was from a specific-diagnosis group and this conflicted with his overall positive affective attitude.

> *No, like I say you've gotta try all this stuff. But I'll tell you it didn't work for me…But it was still great I'd do it again tomorrow (Patient 8, specific-diagnosis group)*

Self-Efficacy

Most participants remarked that their confidence to take part in the intervention grew over time, especially in group discussions.

> *So actually, for me there was quite a difference between beginning the course and I consider myself quite confident person, but I still had reservations and sometimes felt a bit uncomfortable, whereas by the end I was much more comfortable (Patient 1, specific-diagnosis group)*

The confidence of participants to engage in some of the tasks, such as home practice varied, although this appeared to be linked to individual factors such as personality traits. However, one participant did comment that being in a group with people who had the same condition (specific-diagnosis) improved their confidence.

> *Yeah I found it easier to talk about my condition to people who actually experienced what I'm going through (Patient 9, specific-diagnosis)*

4.5.2. Inductive codes

Group Relationships/Dynamics

This code was generated inductively, as group dynamics and the relationships between group participants was discussed throughout all focus groups and interviews. It was evidently very important to all participants.

Several factors such as personalities, group numbers and humour appeared to positively affect group dynamics and the ability for participants to form good relationships through a sense of social support.

> *The fact it was a small group made me feel really comfortable…I could say how I was feeling, that really helped (Patient 6, mixed-diagnosis group)*
>
> *We had a lot of banter. It flowed well. Everyone had their say and the atmosphere was great...everybody had a laugh and a joke, it was good (Patient 8, specific-diagnosis group)*

Factors that negatively affected participants also related to changes in group dynamics, such as when participants discontinued the intervention.

> *When one [member] of our group dropped out I don't know why, it just kind of got to me a bit and I thought oh, that's sad we're not going to see them again (Patient 5, mixed-diagnosis group)*

The group relationships formed did not appear to be affected by the group condition, although it was evident to one participant that meeting someone with the same condition was very meaningful.

> *For the first time I've met somebody with a condition the same as mine and that is quite goose bumpy, it's really quite something (Patient 1, specific-diagnosis)*

Perceived Need

This construct was identified inductively, as it was evident from participants that many of them felt they needed some form of intervention to meet their needs.

> *It was quite refreshing to actually be heard. You know, when you're fighting for some sort of support alongside my doctor who had recommended that I should get some*

> *sort of psychological support over three years ago (Patient 2, specific-diagnosis group)*

However, none of the comments referred to needing a specific-diagnosis group format. Furthermore, one participant suggested that their needs were still met, even in a mixed-diagnosis group, relating back to the group dynamic code.

> *I think I needed something in my life at that point because it can sometimes be quite a slow process to get help…and I hadn't met anybody else that had something similar to me. Since the group I have found somebody that has something sort of vaguely similar and even that's helped (Patient 5, mixed-diagnosis group)*

Feedback

This code was generated inductively, as participants gave feedback on what to retain, improve and change relating to the intervention.

In general participants did not suggest that any major changes to the intervention, its structure, or content were required. Some minor suggestions included the addition of extra follow-up sessions and other strategies that could facilitate the implementation of key learning beyond the end of the intervention.

> *I think we all thought that there was some thought that perhaps needed to be given to ways of helping individuals to just keep the momentum of the practices that we were taught….maybe putting up some videos so that the patients could click into a web page that had the voices of the facilitators that we experienced (Patient 3, specific-diagnosis group)*

Views and Expectations

This code was also identified inductively and purely focused on the views and expectations of the two different group conditions, to allow for a greater exploration of the patient perspective beyond the constructs of the TFA described above.

Participants generally appeared to have low expectations of the group intervention, which changed over time, and this was found in both group conditions.

> *I had very low expectations of this particular method of having group sessions. I really didn't think it was gonna work very well. I think it's proven me wrong. I think you know it's as good as, different but as good as face-to-face, real life group sessions (Patient 3, specific-diagnosis group)*

Views towards the two group conditions was diverse. Most of the participants who attended a specific-diagnosis group gave an indication that they would favour a specific-diagnosis group, suggesting that this was superior to them. However, their views did not dismiss the value of a mixed-diagnosis approach.

> *Same condition would be preferable for me, I'm not saying that there aren't some crossovers in terms of coping mechanisms etc., but yeah, my first thoughts on that question are that it was more beneficial to hear about specifics around some of the issues that we experienced, I would say not mixed for me, it's not something that I would find as attractive (Patient 2, specific-diagnosis group)*

Participants who attended a specific-diagnosis group provided a rationale which linked to the importance of group dynamics and relationships between participants.

> *Yeah, it's a shared connection, understanding, being through similar experiences, maybe even being on similar medication just understanding each other a little bit better compared to a mixed condition group (Patient 4, specific-diagnosis group)*

Although this was also evident in the mixed-diagnosis group.

> *I found that even though we are different conditions that we all had that understanding of each other and knew where we were coming from that was definitely an advantage for me (Patient 6, mixed-diagnosis group)*

Furthermore, for those in a mixed-diagnosis group, the range of conditions was seen as a specific advantage.

> *Everyone had different conditions…and so that was kind of a bit of a relief to think that it wasn't just me going through it and it wasn't just my specific condition and stuff like that…things affect other people similarly…so it made me feel not as isolated (Patient 7, mixed-diagnosis group)*

Conversely, some who attended a specific-diagnosis group, found it difficult to even comprehend a mixed-diagnosis approach.

> *I mean it's tricky, if you're gonna mix people, 'cause obviously everyone's condition…could be quite different to yours…I don't know if that would work…Yeah, I think it would be a lot more difficult to facilitate (Patient 8, specific-diagnosis group)*

Waiting time was also taken into consideration, as participants recognised accessing support would likely be quicker for a mixed-diagnosis group than specific-diagnosis group.

> *I feel that help as soon as possible is probably more beneficial than waiting for a group of people who all need help with a certain condition to come about (Patient 5, mixed-diagnosis group)*

Overall, participants could see advantages and disadvantages of both group conditions.

4.6. Discussion

4.6.1. Discussion of results

This study found no major difference in the feasibility and perceptions of acceptability of an ACT group intervention, in specific-diagnosis versus mixed-diagnosis groups. It is the first study to our knowledge to explore a preliminary comparison of feasibility and acceptability measures using a quantitative and qualitative approach, with the latter using the TFA.

Just over half the patients referred to the Clinical Health Psychology service responded to an invite to the group intervention. Although this is not particularly high, many of these were inappropriate referrals, or there were difficulties with contacting patients, which is common in psychological services (Haworth & Gallagher, 2005). The eligibility rate was 98%, indicating a very large proportion of interested patients were eligible according to the inclusion/exclusion criteria. This suggests that offering this type of group intervention overall is feasible. Furthermore, the recruitment rate of participants into either group condition did not differ substantially, although consent to take part in the research overall was lower in the mixed-diagnosis group. This imbalance was also present in the qualitative findings, where only 3 participants from a mixed-diagnosis group took part in a focus group or interview (versus 6 specific-diagnosis group participants), thus results are interpreted with caution and further research to represent a more balanced view is indicated.

While there were no significant differences in the average number of intervention sessions attended by the two different group conditions, or number of participants who dropped out (retention rate), a larger proportion of people completed the entire intervention (i.e., all 8 sessions) in the mixed-diagnosis group condition (62% versus 56%). It is hard to make comparisons with other studies, owing to the variability in how adherence is defined and measured. However, compared to other ACT group interventions, these completion and adherence rates appear to be slightly higher than rates reported elsewhere (Johns et al., 2016; Bendig et al., 2021). This could be due to the delivery format of the group intervention being online, where guided web-based interventions often out-perform automated web-based interventions (Brown et al., 2016) in terms of adherence, although differences in web-based versus face-to-face interventions are less marked (Van Ballegooijen et al., 2014). It is also worth considering the impact of the COVID-19 pandemic on intervention adherence and completion rates. Many of the group sessions were conducted during national lockdowns, where participants were likely to have been affected by changes to their employment status and social activities. Thus, attending group sessions offered an opportunity to reduce isolation or boredom, irrespective of having an LTC.

Compared to other studies that have explored two different group conditions, intervention adherence (again defined variably), has been found to be consistently slightly higher in specific-diagnosis groups than mixed-diagnosis groups for interventions using CBT (Titov et al., 2015 & Newby, Mewton & Andrews, 2017). This is perhaps unsurprising given that ACT is described as a transdiagnostic approach (Barnes-Holmes & Roche, 2001). Overall, there were no marked or consistent differences observed across the two group conditions in the quantitative measures of feasibility, suggesting that both approaches are equally feasible.

As stated, to our knowledge this is the first qualitative study to apply the TFA to explore patient perspectives on the acceptability of an ACT group intervention, to specific-and mixed-diagnosis groups. The application of this framework provided useful insights, whilst the hybrid of deductive and inductive thematic analysis, allowed for a thorough exploration of acceptability

Participants shared similar, positive, affective attitudes of the intervention across both group conditions. Similarly, it appeared that the intervention caused relatively low burden in both group conditions, although technical issues were equally highlighted. This is often cited as a drawback to online interventions (Chen et al., 2020). Some very minor differences in the perceived effectiveness of the intervention between the group conditions was found. One participant, from a specific-diagnosis group, reported the intervention was not effective, and mixed-diagnosis participants reported short-term perceived effectiveness but questioned long-term effects. Assessing the long-term outcomes of interventions is often uncommon in research. For example, in a systematic review of ACT interventions for people with LTCs, only 3 studies (of the 18 included), had a follow-up assessment of a long-term (i.e., 12 month) effect (Graham et al., 2016). Interestingly, participants readily gave feedback on ways to improve potential long-term effectiveness, including the idea of extra follow-up sessions, also known as ‘booster ‘sessions. This studies intervention included a follow-up session at 8-weeks. This interval length is comparable with other ACT group interventions with follow-up or ‘booster’ sessions, where length has varied from 2 weeks (Johns et al., 2016), 1 month (Eilenberg et al., 2016) and 3 months (Brassington et al., 2016).

Other very minor differences that were found in the acceptability of the intervention, between group conditions, were related to participants confidence to take part in and understanding of the intervention. Intervention coherence, described as the extent to which a participant understands the intervention and how it works, was developed into the TFA by Sekhon, Cartright and Francis (2017), in relation to their view that illness perceptions could influence perceptions of acceptability. Illness perceptions have been recognised as the thoughts and beliefs a person has about their illness (Petrie, Jaho & Devcich, 2007), where illness coherence ("the extent to which a patient's illness representation provided a coherent understanding of the illness" Moss-Morris et al., 2002, p.2), is one such perception. The extent to which intervention coherence influences acceptability is still unclear. Other studies have found variability in the construct intervention coherence (Pavlova, Teychenne & Olander, 2020). Where a low perception of coherence has been reported, it is thought to possibly affect the perceived effectiveness of an intervention (Murphy & Gardner, 2019b), thus more research to investigate how the constructs influence each other could be helpful.

Overall, using the TFA provided a helpful basis to assess and compare the acceptability of the group intervention in specific-versus mixed-diagnosis groups, where we conclude that generally there were no consistent differences found between group conditions.

The code Group Dynamics/Relationships was constructed inductively, and evidently contributed to the overall acceptability of the intervention. This code summarised how participants felt towards each other and suggested that a sense of sharing and connection was important. This is supported by group-based intervention research (Borek & Abraham, 2018), where studies have begun to explore how group interventions facilitate change, including the development of a 'mechanisms of action in group-based interventions' framework by Borek et al., (2019). This framework highlights several processes to facilitate change that were evident in this study, such as sharing of experiences, group cohesion and social support. Moreover, these processes were apparent in both group conditions, which could account for the lack of differences found. This is consistent with other qualitative studies that have explored CBT-based group interventions, where group cohesion was found to be important and prevalent in both group conditions (Christensen et al., 2021). The 'mechanisms of action in group-based interventions' framework includes a range of further comprehensive processes, which could be used to further understand or detect any differences, including advantages of the two different approaches and when either approach is superior and for whom (i.e., which specific LTC group).

4.6.2. Strengths

The studies' strengths related to the mixed method approaches used to explore the research question. Not only did it apply quantitative and qualitative methods, but within the latter it applied both an inductive and deductive approach, enabling data-driven and theory-driven analyses, to explore the acceptability of the group intervention and allowing for a more depth comparison to answer the research question.

4.6.3. Limitations

Conversely this study had several limitations. Firstly, it failed to get the opinions of the participants who dropped out of the intervention. It is possible that participants who dropped out may have provided very different perspectives on the acceptability of the group intervention and highlighted more differences between the group conditions, thus the results are somewhat biased. Secondly, the participants from a specific-diagnosis group were overrepresented, causing a skew in the results, making it difficult to make fair comparisons. Thirdly, as has been acknowledged by other studies using the TFA (Pavlova, Teychenne & Olander, 2020), some of the constructs are closely related, thus coding could have been influenced based upon interpretation. Studies have explored empirical measures of acceptability using the TFA (Renko et al., 2020), which could be combined with qualitative methods for a mixed methods approach, to further the rigor of findings. Though this study used mixed methods, the quantitative measures were more focused on the feasibility than acceptability and vice versa for qualitative methods. Finally, limitations of thematic analysis meant the focus group data was not analysed to account for the interaction between participants and between interviewees and moderators. However, interaction analyses could have important implications on the findings, such that interactions could shape participants' views based on the discussion, adding an extra layer of data to be explored (Morgan & Hoffman, 2018).

4.6.4. Implications and future directions

Overall, we found that the group intervention itself was feasible and acceptable to participants. Furthermore, the fact that participants reported a perceived need for an intervention (irrespective of the group condition), implies that services should continue to meet the needs of their service users, with groups being one option. We can tentatively conclude that there are no obvious differences between the group conditions, in terms of feasibility and acceptability in our sample. Therefore, it may be appropriate for clinical health psychology services to be flexible and offer both specific and mixed-diagnosis groups, dependent upon resources and demand. However, further research is required to test these tentative findings, whilst exploring other contributing factors such as patient choice, which has been recognised as a key principle for effective treatment in mental health services (National Collaborating Centre for Mental Health, 2019).

4.7. Conclusion

To conclude, findings from this study show that retention, true completion, and adherence rates were high and comparable in both group conditions, suggesting that both are feasible. The qualitative data shows that the intervention was acceptable to its attendees and that differences in acceptability between the group conditions were not obvious.

Chapter 5 Health professional views on the acceptability and feasibility of an online acceptance and commitment therapy intervention for specific-diagnosis versus mixed-diagnosis groups

Abstract

Background

Health professionals are key stakeholders to engage when attempting to implement new interventions into routine practice. In this study, the perspectives of health professionals involved in facilitating or referring patients to a group intervention are explored, with particular focus on the acceptability of specific-diagnosis versus mixed-diagnosis groups.

Methods

This was a qualitative study. Four health professionals who had facilitated the group intervention took part in a focus group, and 5 health professionals who had referred patients to the group intervention were interviewed individually. Deductive and inductive thematic analysis was used, informed by the TFA, and focused on the acceptability of the intervention in both group conditions.

Results

Five constructs of the TFA were coded, and inductive themes included Group Relationships/Dynamics, Perceived Need, Feedback and Views and Expectations. Overall, the intervention was found to be acceptable in both group conditions.

Conclusions

Acceptability of the intervention was high among health professionals, and no clear evidence of a difference found between group conditions.

5.1. Introduction

Increasingly, research evidence has highlighted the importance of implementing interventions into routine practice (Boaz, Baeza & Frazer, 2011; McMahon at al., 2015; Wensing & Grol, 2019). As such, this has become a new scientific discipline, known as implementation science (Bauer et al., 2015).

Stakeholder engagement has been recognised as a key factor to support the implementation of interventions (Boaz at el., 2018), with further evidence in its usefulness for assessing the acceptability and feasibility of interventions (Wuest et al., 2015). Health professionals have been recognised as key stakeholders (RAND, 2014) as their knowledge, insights and experiences are valued (Morton et al., 2017), and their ability to meet the needs of patients can be increased when there is appropriate access to evidence based interventions.

This study was part of a larger research project (described in chapters 1-4). We sought to build on traditional pilot and feasibility studies by not only including preliminary testing of an intervention on patient outcomes (chapter 3) but also exploring strategies to improve intervention implementation and impact by involving multiple stakeholders including service providers and health professionals. Acceptability and feasibility of an online ACT intervention from the patient perspective (using qualitative and quantitative data) was reported in chapter 4. This chapter focusses on health professional perspectives.

The aim of the current study is to describe health professionals' views on the acceptability and feasibility of the 'Living Well with a Long-Term Condition' group intervention for specific-diagnosis versus mixed-diagnosis groups

5.2. Methodology

5.2.1. Design

A qualitative design was used with online focus groups and individual interviews. This design was chosen to gather rich and meaningful perspectives from health professionals to answer the research question:

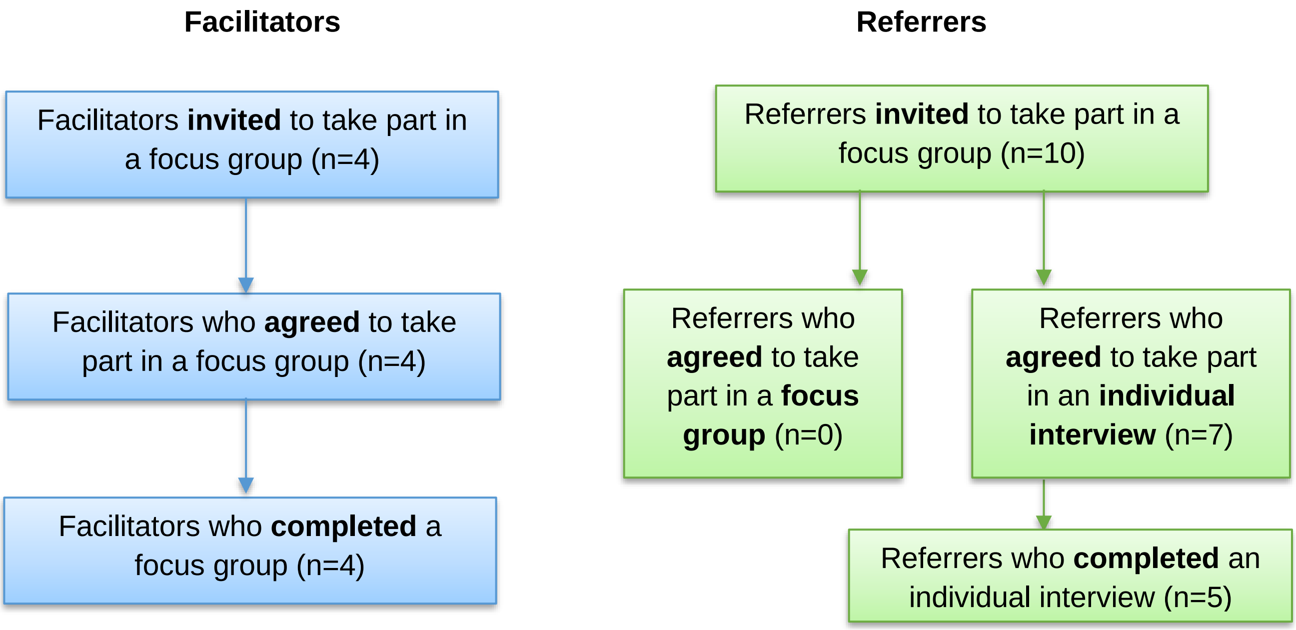
> What are health professionals' views on the acceptability and feasibility of specific-diagnosis versus mixed-diagnosis groups and their experiences of working with patients who have attended such groups?

5.2.2. Setting and sample

In this study, qualitative data was collected with health professional participants who had either (a) helped facilitate the online group intervention or (b) referred patients to the intervention.

Participants were recruited via purposive sampling, where all those who had facilitated the intervention (except the main researcher), or referred a patient to the intervention, were invited to take part. All participants were invited via email by the researcher to join a focus group or individual interview (see figure 7). All participants were also provided with a participant information sheet and written informed consent was collected electronically.

Figure 7: Flow diagram of health professional participants



Focus groups aimed to elicit participants' views, experiences, and feelings (including the perceived advantages and disadvantages) of facilitating the group intervention, to specific-diagnosis and mixed-diagnosis groups. Individual interviews of referrers also aimed to gather views, perceptions and feelings of the specific-diagnosis and mixed-diagnosis group intervention, including the perceived advantages and disadvantages and any changes noticed in patients that they had referred or worked with, who had completed the group intervention. The main researcher and author of this thesis did not take part in the facilitators focus group, to avoid influencing the discussion or findings. See table 7 for an overview of participants involved in the qualitative interviews.

Table 7: Health professional participants involved in qualitative interviews

Focus group- facilitators	**Individual interviews- referrers**	
Number of participants	*Interview number*	*Referrer speciality*
4	1	Diabetes
	2	Dermatology
	3	Dermatology
	4	Rheumatology
	5	Cardiology

An NHS Research Ethics Committee provided ethical approval for this study (approval code 20/NW/0125).

5.2.3. Procedure

The facilitators focus group was held in April 2021. A focus group for referrers was planned for June 2021, however no health professionals were able to attend due to work commitments. Since interviews and focus groups are an evidenced-based method of data collection for qualitative studies (Harrell & Bradley, 2009), an amendment to add individual interviews was approved by the HRA, allowing greater flexibility to arrange interviews at a time to suit health professionals' busy schedules. Subsequently, 5 individual interviews took place with referrers, between September and November 2021.

Microsoft teams, an online communication platform familiar to the health professionals was used which ensured accessibility. The focus group lasted 1.5 hours, to reduce burden to facilitator's time, and interviews lasted no longer than 30 minutes. The focus group and interviews were conducted by an impartial moderator i.e., someone who had not been involved in the delivery of the online ACT group. The moderator was a volunteer assistant psychologist, who received adequate training and supervision. Further details were provided in chapter 2 section 2.1.3.4.

Topic guides were designed to explore:

a) what views health professionals had regarding the feasibility and acceptability of the online ACT group intervention

b) what views health professionals had on the group environment and their thoughts of specific-diagnosis versus mixed-diagnosis groups

There was a guide for facilitators and a guide for referring health professionals (see appendix 11). Where it was deemed helpful for participants to expand on their views, probing questions were asked.

5.2.4. Analysis

The same analysis process as described in chapter 4, section 4.4.3 was applied to the health professional interview data.

First the coding framework was reviewed and 5 of the 7 constructs were deemed relevant for the analysis. A further 4 codes were added that were identified inductively during the analysis of patient data (see chapter 4; Views on the Group Approach, Expectations, Perceived Need and Feedback), as these were also deemed relevant to the analysis of the health professional data. A proportion of the transcripts were independently coded by the main researcher and a second researcher (GO). Discrepancies were discussed, and a proposal was made to combine the Views on the Group Approach and Expectations codes owing to an obvious crossover of coding. A new code ‘Views and Expectations’ was formed and implemented into the coding framework. Initial transcripts were reviewed, followed by the coding of remaining transcripts according to the updated coding framework, and no further changes were deemed necessary. See appendix 17 for the final coding framework applied to the health professional transcripts. After all data was coded according to the coding framework, themes were compiled that explored the experiences and attitudes of facilitating and referring health professionals, towards the acceptability and feasibility of the group intervention, to specific-diagnosis versus mixed-diagnosis groups.

5.3. Results

Overall, the group intervention was found to be acceptable to all health professionals. Findings are presented below for each of the codes included in the coding framework.

5.3.1. Deductive codes of the TFA

Affective Attitude

Overall health professionals expressed a favourable affective attitude towards the group intervention.

Facilitators reported very positive feelings about delivering the intervention in a group format and being able to witness the positive impact it might have on the participants of the intervention.

> *It was really good to do it in a group setting (Facilitator 1)*
>
> *I enjoyed sort of just seeing those light bulb moments for patients when they got something…you know a particular strategy, or even just a phrase…and they just really got it. That was lovely (Facilitator 3)*

It was evident that facilitators had a common liking of a specific strategy included in the intervention.

> *I particularly enjoyed the mindfulness elements of it…being able to see them do that [mindfulness] at the end and even continue doing that was really great to see. That's one of the things I particularly enjoyed about the group (Facilitator 2)*

On the other hand, there were aspects of the intervention that facilitators appeared to dislike, especially if the resulting affect was perceived to negatively impact participants of the intervention.

> *There was one exercise that we did that I didn't find as comfortable to do because it just didn't seem to always land very well with people, and they got upset (Facilitator 2)*

For another facilitator, their dislike pertained to the impact on group dynamics and fairness for all participants of the intervention:

> *I always dislike it when you've got somebody in the group [who] has not necessarily got that sort of self-awareness that they need to share the space and airtime, so I didn't really like having somebody in the group who was almost a bit of a wrecker (Facilitator 4)*

However, facilitators acknowledged some personal advantages to them as practitioners that contributed to a favourable attitude overall.

> *I think within the pandemic when you’re often by yourself and sometimes have limited contact with your colleagues, it's lovely to do some work with your colleague (Facilitator 3)*

Referrers did not have a direct experience of the intervention, thus their favourable affective attitudes were often implicit versus directly stated, through their willingness to recommend the intervention and desire for it to be offered in the future.

> *Yes I would definitely recommend this group to other health professionals as a source of support for patients (Referrer 2)*
>
> *I think it's all been very positive and I hope they do more (Referrer 5)*

Burden

Overall health professionals expressed that the burden to facilitate the intervention or refer patients to access the intervention was low.

Facilitators attributed this sense of low burden to the intervention materials, such as the handbook.

> *Overall, I thought it was easy to deliver because the handbook was very clear and well written and made a lot of sense (Facilitator 4)*

However, aspects of the intervention which made facilitation more challenging were ascribed to IT issues, administrative tasks, and group dynamics.

> *We found it quite difficult to be able to do all the IT stuff we couldn't get [videos] to play so that was a bit frustrating (Facilitator 3)*
>
> *[The group] was quite complicated at times because one of the guys expressed that he was very unhappy. So it really felt that we needed two clinicians there as well to help manage (Facilitator 1)*

Importantly, for the facilitators who had experience of delivering the intervention to both group conditions, it appeared the effort required was the same.

> *Actually, it [a mixed-diagnosis group] didn't make it any more difficult to run a group (Facilitator 2)*

Referrer’s comments suggested that there was minimal effort required for them to refer patients to the intervention.

> *Yeah, the referral process wasn't a problem…it's been very easy (Referrer 1)*

Perceived Effectiveness

It was evident that overall health professionals perceived the intervention as effective. Facilitators had direct experience of witnessing the perceived effectiveness of the groups and could comment on both group conditions. Alternatively, referrers commented on the perceived effectiveness based upon feedback from participants.

Several facilitators indicated that overall, the intervention was effective on important patient outcomes, like patient engagement (i.e., their attendance and involvement in group sessions).

> *I feel we got really good responses from patients in terms of their participation in group discussions* **(***Facilitator 2)*

Another example was perceived by some facilitators who shared how effective the intervention was for individual patients through their continued work with them.

> *I've worked with quite a few patients that continued with one-to-one therapy, two people in particular that really got a lot from the group and use the strategies especially the mindfulness exercises (Facilitator 3)*

Other benefits observed by facilitators did not relate directly to the content or strategies taught in the group sessions but were considered an important outcome.

> *They might not have done the exercise, but they said the only reason I'm coming back is because I felt understood and I made friends (Facilitator 1)*

Facilitators repeatedly indicated that being in a group contributed to the interventions perceived effectiveness, as it led to participants feeling connected, and this was demonstrated in both group conditions.

> *In both of them [specific vs mixed groups] people were really open about sharing the different ways their condition impacted them, and I think that was surprisingly quite helpful (Facilitator 2)*

Generally, facilitators perceived that both group conditions were effective.

> *I think there was benefits to both, so I think that there are lots of aspects to living with the long-term health conditions that are trans diagnostic and I think that the group works in both respects (Facilitator 4)*

One facilitator highlighted that there can be specific benefits to a specific-diagnosis approach, but this did not change the consensus of either approach overall.

> *I guess the other one benefit from it being specific is for example, I think if you've had a dermatology group, then often there is a lot of shared understanding and maybe around some of the treatments that you tried, but I don't think that made the mixed group any less beneficial (Facilitator 3)*

Referrers also commented on the perceived effectiveness of the intervention in relation to important patient outcomes relating to their LTC.

> *I just think it's helped their mental health. I think, the feedback I've had from patients when I've then seen them in clinic has been very positive and they all felt that they benefited from the course and gave very positive feedback about it…and they felt more able to manage their condition (Referrer 1)*

Furthermore, referrers reflected on some changes they had observed on patients' emotional wellbeing that suggest the intervention was perceived to be effective.

> *I think some people have become more confident… [and] happier within themselves and they're better able to deal with their problems (Referrer 2)*

One referrer shared some feedback relating to a patient who had attended a mixed-diagnosis group, suggesting that this approach is perceived effective owing to the group aspect.

> *It helped them enormously that they were sat next to other people and they didn't feel that they were alone you know…it wasn't just them, and some of the things that they were going through other people were experiencing as well and I mean, it definitely does help (Referrer 5)*

Self-Efficacy

Comments on health professionals' confidence to perform the behaviours required of them to refer or facilitate the intervention, was more prevalent in the facilitators than referrers.

Facilitators generally found the intervention easy to facilitate, as discussed above, which also indicated that they were confident in their competence to deliver it. However, certain aspects such as delivering the intervention online, appeared to account for any lack of confidence.

> *I think at first I was a bit nervous, probably about it being remote (Facilitator 2)*

Facilitators recognised that their clinical capabilities allowed them to feel confident to deliver the intervention to both group conditions.

> *I think for us as clinicians we work with so many different conditions, but you still have transferable skills, so there are also lots of similar experiences (Facilitator 1)*

One referrer indicated a lack of confidence in discussing the group with a patient prior to their referral, which relates to the intervention coherence construct discussed below.

> *I think, when I was asking patients if they would like a referral…and then sort of having to chat to the patients about the group, I think I found that was a bit harder because it was almost like I didn't know what to tell them to expect (Referrer 5)*

Intervention Coherence

Facilitators demonstrated a clarity on the purpose of the intervention and how the intervention worked. Facilitator 2 described their thoughts about the intervention and integrated their own personal summary of what the intervention did, and this was generalised rather than specific to either group condition.

> *I think it really provides a good kind of balance between opportunities to share people's experiences and what they've been through, and that shared experience of living with a long-term health condition, but also having strategies that people can take away and practice and think about (Facilitator 2)*

It was evident that some referrers were unclear as to what the intervention involved and thus their understanding was impaired.

> *No, I think I don't know enough about how it was run because obviously I wasn't there during the sessions and so I don't know the real details of it (Referrer 1)*

On the other hand, other referrers were able to give a general insight into the extent to which they understood the intervention.

> *I think the group is useful to patients knowing that they've got other people that are in the same boat and going through it, know the same issues and get a sense of support really and learning new ways of coping, strategies for managing (Referrer 3)*

However, despite any lack of understanding or confidence, the referrer's decision to invite participants to attend the intervention was unaffected and they appeared to trust in the clinical team responsible for delivering the intervention.

> *So I'm not a psychologist so I really have left that up to the capable team (Referrer 2)*

5.3.2. Inductive codes

Perceived Need

This code was identified inductively in the analysis of patient data as described in chapter 4. Overall, all health professionals identified the perceived need of the intervention as a source of support for patients.

Facilitators recognised that some patients need for the intervention was quite individual to their own agenda.

> *I would say for one of them it was giving themselves the time to actually dedicate to themselves…to somebody else I think it was having the support of others there to help them do the intervention because perhaps they weren't quite doing it by themselves (Facilitator 4)*

On the other hand, facilitators also recognised the perceived need of the intervention from a more generalised point of view, especially given the context in which the groups took place i.e., during a pandemic, where any support could be considered helpful regardless of the group conditions.

> *The pandemic could be quite lonely for people in general, and then any kind of contact would be beneficial so it then wouldn't be a problem if it's not exactly the same condition (Facilitator 1)*

Facilitator 3 provided a rationale as to their view why each approach would meet patient's needs.

> *People have, you know, the shared experiences of feeling isolated or feeling anxious or low mood, whatever their diagnosis (Facilitator 3)*

Referrers were very definitive in their expression of the patients' need for an intervention in general.

> *Some people who access my service were clearly in need of help other than medication and learning how to understand and treat their condition and to actually learn how to live with it and how to deal with that (Referrer 2)*

It appeared that referrers who worked with physical conditions that they considered 'rare', indicated that a specific-diagnosis approach was needed.

> *The conditions I treat are so rare that it's very unlikely they would have even heard of the condition before I give them the diagnosis, so they're not going to find that support but need it (Referrer 4)*

Feedback

This code was also generated inductively and allowed for feedback about aspects of the intervention health professionals would want to retain, improve, or suggest any changes.

Facilitators provided some minor suggestions, including the addition of specific strategies or techniques, and the use of multimodal approaches to teach such techniques, such as using recorded video clips. However, overall feedback suggested that even without these additions, the intervention was acceptable as it was.

> *We could put any number of other things into it, you know about behavioural activation or those sorts of things, but you know, I think it does what it says on the tin. You know it's an ACT intervention. I think it's pretty comprehensive (Facilitator 4)*

Furthermore, feedback from facilitators suggested that the intervention was easy to present to both group conditions.

> *I don't think there was any particular barriers because the content could be adapted to each group. So whether it's a specific or mixed (Facilitator 3)*

Some suggestions were made relating to ways to increase patient engagement, which one facilitator felt would increase the feasibility of running groups in the future.

> *Maybe something about the flexibility of being able to do an evening group so that we get good group numbers and can keep them going in the service (Facilitator 2)*

Referrers general feedback centred on the suggestion that it would be helpful for them to be provided with further information on patient attendance and outcomes.

> *So it would be nice to know that they've attended the course and when they attended it and it would also allow us to see, you know, has it helped them in improving their condition and things like that (Referrer 1)*

Views and Expectations

This code was also identified inductively during the analysis of patient data (discussed in chapter 4). It focused on the views and expectations of the two different group conditions, which allowed for further understanding, in addition to the TFA constructs described above.

In general, facilitators expressed an expectation that the specific-diagnosis group would be superior.

> *I thought going in that [the] specific group would be a lot better. I had in my mind that you know people have got the same condition that would be really helpful because*

> *they've got those shared experiences around maybe a particular treatment or the way their condition impacts them (Facilitator 2)*

However, it was evident that this expectation changed over time, and facilitators views transitioned to that of both group conditions being advantageous and suitable.

> *So actually now having done both, I actually think mixed is just as beneficial in my opinion, so it's really been a bit of a turnaround for me and how I thought it would go (Facilitator 2)*

> *I think it would be suitable for both, and I think it's acceptable for both (Facilitator 4)*

Facilitators acknowledged that certain practicalities would impact on patient access to the intervention, which would favour a mixed-diagnosis group.

> *With the mixed group that can be probably be quicker (Facilitator 1)*

Likewise, facilitators suggested other factors that would favour a specific-diagnosis group.

> *So it might be certain conditions that maybe do require, you know something a bit more specific because there is a very different way to maybe managing that condition and might come with some really specific difficulties for living with that condition (Facilitator 2)*

Ultimately, facilitators struggled to choose one group condition over the other suggesting that overall, both are acceptable.

> *That's a really hard question…do I have to pick one? (Facilitator 3)*

Within the referrers, the views of the two group conditions was more varied. Two out of the five referrers gave an overall preference to the specific-diagnosis group.

> *Specific disease. Yeah, I believe that's more beneficial for the patient (Referrer 1)*

> *I suppose that the straightforward answer would be any intervention is likely to benefit rather than no intervention, but I feel that [mixed] might not be the kind of best level of care we can provide (Referrer 4)*

Whereas the other three referrers felt that both group conditions were applicable suggesting both were acceptable.

> *I don't think it matters whether people have the same condition or a range of conditions…if you've got a range of conditions then people will be able to lend support they will still be able to empathise with other members of the group, even if they don't have exactly the same condition, even if they do have the same condition, they may be affected in different ways anyway…so I think both approaches will work and it doesn't really matter (Referrer 2)*

> *I think it's good to have them mixed (Referrer 5)*

Furthermore, as with facilitators, practical implications were recognised by referrers as important when considering which group condition to choose. For example, one referrer suggested the mixed-diagnosis group would be a more efficient use of resources.

> *You've got the capacity to see more patients haven't you and to offer more patients help at one time. So it would be a better use of resources (Referrer 3)*

However, the specific-diagnosis group was considered as potentially more appealing to patients, thus may impact on patient engagement.

> *I think it might engage patients more. Knowing that it was a group specifically that's gonna help them in their condition rather than it being broad and helping multiple people with different conditions (Referrer 4)*

Regarding referrers expectations, these related to a broader view of the two group conditions, with the expectation that a group provides support and understanding pertaining to its aims, i.e., to live well with an LTC.

> *You are expecting that they will be able to understand that it's a chronic condition…understand that it might be something they can control to a degree, but have to live with (Referrer 2)*

Overall, both group conditions appeared acceptable and feasible amongst health professionals' views and expectations.

5.4. Discussion

5.4.1. Discussion of results

This study is the first to assess the acceptability of an ACT group intervention, comparing specific-diagnosis versus mixed-diagnosis groups, with health professionals using the TFA. The findings help to understand health professionals' views of specific- diagnosis versus mixed-diagnosis groups with implications for future practice.

The findings overall suggested that health professionals found the intervention (in both group conditions) acceptable, as demonstrated by their positive attitude, confidence in their roles and low amount of effort required within their roles. Other studies have yet to explore the comparison between group conditions to support these findings. However, another study that has explored therapists' acceptability of an online ACT intervention, also found that personal advantages to the therapist/facilitator and their perceived benefit of the intervention to participants, contributed to their positive affective attitude and an overall sense of higher acceptability (Contreras et al., 2021).

A difference in the understanding of the intervention (intervention coherence) was observed between facilitators and referrers. This was to be expected, given that facilitators were involved in the delivery of the intervention, its structure, content, and format. Conversely, the referrer's role was simply to refer patients into the intervention. It is possible that referrers' lack of understanding of the intervention and how it worked, could have influenced their views towards the two group conditions, although it was not possible to detect this in the data. Instead, findings suggested that a higher sense of acceptability was related to the trust referrers had in the psychological service providing the intervention. Trust has been recognised as a key factor in the collaboration and co-operation of health professionals, particularly working in multidisciplinary teams (Roncaglia, 2016). Multidisciplinary working is known to improve patient outcomes (Taberna et al., 2020) and often relies on overcoming barriers such as communication (Doyle, 2008). In this study, feedback from referrers suggested that improved communication, for instance, letters detailing the attendance and outcomes of patient participation, would be beneficial, and this type of feedback has also been recognised in other studies (Lo et al., 2016). Despite this, findings from feedback on what to improve, retain or change (a theme that was identified inductively), gave no clear indication that either group condition was more, or less acceptable among health professionals.

Another theme that was identified inductively and helped further understanding into the health professional's acceptability of the two group conditions, was Views and Expectations. Initial expectations from facilitators were that the specific-diagnosis group would be 'better', however, it was evident that the actual experience of delivering the intervention in both group conditions altered that view. Evidence relating to the use of ACT group interventions for people with LTCs, comparing specific-diagnosis versus mixed-diagnosis conditions, is sparse, however, research has explored the use of CBT to specific and mixed-diagnosis groups. Assumptions are often cited that specific-diagnosis approaches offer advantages over mixed-diagnosis approaches, such as higher completion rates and improved patient outcomes (Newby, Mewton & Andrews, 2017). However, in practice many studies do not find substantive differences between the two approaches (Titov et al., 2015; Dear et al., 2015). Thus, it is unsurprising that facilitator's views changed based on their experiences, particularly since the extent to which they perceived the intervention to be effective (which closely related to observed patient outcomes) was also high in both group conditions.

Reasons for using a mixed-diagnosis approach are often related to the ability to treat comorbid conditions concurrently, whilst reducing waiting times (Christian et al., 2021). One factor that health professionals acknowledged, that indicated an advantage of the mixed-diagnosis group, was the efficient use of resources. This finding is unsurprising, given that health professionals are working within the constraints of under-funded and over-stretched NHS services (Royal College of Physicians, 2016), where cost and equity is thought to be pivotal in addition to feasibility and acceptability, in the implementation of interventions (Pottie at al., 2021).

Overall, there did not appear to be any clear difference in acceptability between the two group conditions for health professionals. This is especially important, given that the health professionals are considered key stakeholders with the potential to increase the success of an intervention being implemented.

5.4.2. Strengths

This study is novel as it explored the perspectives of health professionals, in a comparison of acceptability for specific-versus mixed-diagnosis groups in a busy NHS environment. Furthermore, it used a combination of theory-driven and data-driven processes, to enable a detailed exploration of perceptions and views, which would not be achieved solely through quantitative approaches. The methodology of focus groups and individual interviews made it easy for health professionals, particularly referrers to take part and this is further discussed in chapter 6.

5.4.3. Limitations

A potential limitation of the current study is the relatively small sample size, particularly of referrers perspectives. Of the 10 referrers who responded to an invite to take part in an interview, only 5 consented and completed an interview. This was likely down to clinical workload and difficulties in scheduling time aside with competing demands, however, could also be indicative of participant bias towards those who favourably viewed the group intervention for their patients. Furthermore, the recruitment period for this study was relatively short and thus health professionals, particularly referrers, were often only able to give speculative opinions in relation to the topics discussed during their interview. As previously acknowledged in chapter 4, some of the constructs of the TFA are closely related, which increases the potential for coding to overlap and cause discrepancies, due to subjective interpretation. In addition, the topic guide for the focus group and individual interviews was not designed to target all seven of the constructs of the TFA. Although the questions or topics discussed ensured that participants were able to express their thoughts, views, and perceptions, some areas of acceptability were missing. Furthermore, some questions were quite leading in their nature, thus confirmation bias could have been present, particularly in explorations of the perceived effectiveness of the intervention. As acknowledged in the limitations of the patient data (chapter 4), interaction analyses of focus group data was not conducted, which may have influenced participant's views towards the acceptability of the intervention. Finally, this study focused mainly on exploring the acceptability of the group intervention amongst health professionals and so we are unable to make firm conclusions on their views about the feasibility.

5.4.4. Implications and future directions

This study aimed to fill in the gap exploring health professionals' views towards the acceptability of a group intervention. There is an abundance of literature that explores patient perspectives, however a more comprehensive exploration of multiple key stakeholders (patients & providers) has the potential to gain a more in-depth understanding of research areas, in the field of implementation science. Alongside other qualitative studies (Sekhon & van der Straten, 2021; Pavlova, Teychenne & Olander, 2020; Murphy & Gardner, 2019a; Murphy & Gardner, 2019b; Contreas et al., 2021), this study highlighted that the TFA is helpful to explore the acceptability of interventions, using theoretically driven processes. Given that acceptability has been defined so widely in the literature, it is helpful to use a framework, which can standardise the way in which it is explored and reported, to aid the implementation of interventions. Future qualitative acceptability research should therefore continue to use this framework in combination with a mixed method approach, to allow for meaningful concepts to derive from the data. Conducting the intervention online did not appear to affect the overall acceptability of the intervention from a health professional perspective and overcoming barriers such as technical issues was possible. However, given that this research was conducted during the COVID-19 pandemic, health professionals were aware of restrictions that meant delivery of the intervention was limited to online. Thus, health professionals may have had stronger opinions on the web-based approach, and it is possible to have impacted their view of the two different group conditions overall. Future research could therefore compare online versus face-to-face delivery to specific and mixed-diagnosis groups.

5.5. Conclusion

There was no clear evidence of a difference in acceptability for either group condition, meaning we are unable to confidently conclude which group condition was preferred by health professionals. Given this and similar findings from chapter 4, we found no clear advantage for specific-diagnosis versus mixed-diagnosis groups, and we can tentatively suggest that services can make a choice on the approach they use. This is an important finding, as services are often competing with meeting the needs of service users and limited resources. Having the choice gives services greater flexibility to prioritise resources and patient needs, however, further research is required to test these preliminary findings in a robust trial.

Chapter 6 Conclusions

This research set out to compare the feasibility, acceptability, and preliminary effectiveness of an online ACT group intervention for specific-diagnosis versus mixed-diagnosis groups. This chapter will attempt to expand on some of the novel or interesting findings, whilst drawing together the results from the quantitative and qualitative studies.

The most important finding of this mixed methods research is there was no clear difference detected in the feasibility, acceptability, and preliminary effectiveness of the 'Living Well with a Long-Term Condition' group intervention, in specific-diagnosis compared with mixed-diagnosis groups. The feasibility and effectiveness were assessed using quantitative measures, which overall suggested that both group conditions were feasible and showed promise in improving outcome measures. The acceptability was assessed in patients and health professionals using qualitative methods and suggested that both group conditions were acceptable.

It is perhaps unsurprising that the two group conditions showed no marked differences in the specific-diagnosis and mixed-diagnosis iterations, given that other research in the field of mental health disorders, using CBT, also found no major differences when comparing a specific and mixed approach (Dear et al., 2015; Titov et al., 2015; Newby, Mewton & Andrews, 2017; Chritiensen et al., 2021). In LTC research, ACT group interventions usually use a specific-diagnosis approach, for example in oncology (Arch & Micthell, 2016); diabetes (Amsberg et al., 2018), and HIV (Skinta et al., 2015). Conversely, a mixed-diagnosis approach is commonplace in pain management programmes (Wilson, 2017), where groups are offered to patients with a variety of health complaints. For example, in a recent systematic review of online ACT-based interventions for chronic pain, only 3 (of the 14 included) were for specific-diagnosis groups (van de Graaf et al., 2021). Comparison studies of the two approaches are also lacking in chronic pain research. Although one recent study, within the field of occupational rehabilitation, investigated the feasibility of mixed-diagnosis approaches across physical and mental health disorders, with some promising results (Hara et al., 2018). They concluded that a mixed-diagnosis approach was acceptable to participants and that different diagnostic groups can benefit.

The comorbidity rate of physical and mental health conditions is rising (Daré et al., 2019), which is further exacerbated by the recent context of the COVID-19 pandemic, adding further pressure onto physical and mental health services in England, with the onset of 'Long-COVID' (Aiyegbusi et al., 2021). According to recently published data, in January

2022, 2% of the UK population self-reported long-COVID symptoms (Office for National Statistics., 2022). In June 2021, NHS England set up 89 specialist clinics, comprising of multidisciplinary health professionals, to address the physical and psychological needs of those with long-COVID, with a range of services in primary and secondary care now under development (NHS England and NHS Improvement, 2021). Long-COVID adds a new complexity to clinical health psychology services and thus, it may be necessary to plan interventions that offer the most flexibility, such as mixed-diagnosis approaches.

Despite findings showing no marked difference between the group conditions, there was one minor finding that appeared somewhat unusual. The mixed-diagnosis group had an overall SF-36 quality of life physical functioning score 21.67 points higher at baseline than the specific-diagnosis group - a difference which persisted across follow-up. The physical functioning scale is one of eight included in the SF-36 that explores self-reported health-related quality of life (Ware & Shelbourne, 1992). The physical functioning scale comprises of 10 items, that cover a hierarchical range of activities (for example., bathing, walking, climbing the stairs, running) that scorer's rate on how limited their ability to perform the behaviour is. The items are scored, summed, and re-coded according to a scoring system, to obtain a score between 0-100, where a high score defines a more favourable health state i.e., good physical functioning. Therefore, it appears that the mixed-diagnosis group overall had a better baseline level of physical functioning, compared to the specific-diagnosis group. In this research we did not record participant characteristics on their physical health conditions. Therefore, we are unable to explain whether this difference was due to the different physical health conditions present in the mixed-diagnosis groups compared with specific-diagnosis groups, or whether this difference is due to chance. However, despite this baseline difference in physical functioning, there was no differential effect of treatment group.

Although the intervention was found to be acceptable (in both group conditions), this research did obtain some suggestions for ways in which the intervention could be modified and adapted. The inclusion of different therapeutic techniques was suggested by facilitators, whilst referrers suggested improved communication through fuller details of the intervention and outcome letters. Patient summary outcome letters are (and were in this study) routinely sent to GP's and referrers as per standard practice within the Clinical Health Psychology service. This mismatch in referrers perspective and practice identifies a problem in the communication regarding patient care, and since inter-professional communication can impact patient outcomes (Franz et al., 2020), this should be addressed. Patients suggested that repeated follow-up sessions and access to audio-recordings from practices included in the intervention would be useful. Some of these suggestions have practical implications on demand and service resources, however, where possible these suggestions could be implemented to improve the quality of the intervention – which may improve outcomes and acceptability.

One of the strengths of this research was the use of mixed methods, as it allowed for a comprehensive exploration of the research aims. Furthermore, guidance recommends that the use of mixed methods is important during the initial development of complex interventions (O'Caithain et al., 2019). Given that the intervention used in this research was a complex intervention, an evaluation of the feasibility, acceptability and preliminary effectiveness using mixed methods was highly appropriate.

Furthermore, a mixed methodology was used for the qualitative part of this research, that is, a combination of focus groups and individual interviews. The decision to use both these methods was driven by difficulties in recruitment, whereby some participants struggled to attend focus groups due to time constraints. Thus, individual interviews offered increased flexibility, making it easier for participants to take part. Implications for combining qualitative methods within a single study has been recognised and referred to as triangulation (Flick et al., 2018). Triangulation increases the potential of further understanding of a phenomenon according to Lambert & Loisella (2008). Individual interviews are useful to collect in depth accounts of an individual's perspective, whereas focus groups have the bonus of interaction data (Morgan & Hoffman, 2018). It is thought that the group interaction between members of a focus group can emphasise similarities and differences in perspectives and experiences. It is possible that this could have influenced the findings in this research, but interaction analyses were not included owing to limitations of the thematic analysis approach (Braun & Clarke, 2006).

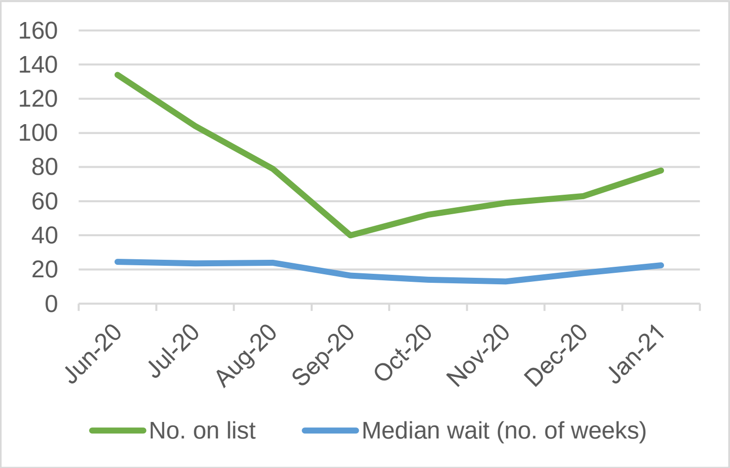
Overall, this research is a pilot and feasibility study and as such all the results should be interpreted with caution. However, early piloting and development work of interventions has often been overlooked, and longstanding recommendations have been made to give this phase of intervention development more attention (Lowe, 2019). Therefore, despite the numerous limitations, this research does add value and make initial steps towards addressing a gap in the literature.

This research was largely based upon a previous study by Brassington et al., (2016) that used an ACT group intervention for people with LTCs, delivered to mixed-diagnosis groups.

They found that their intervention, ‘Better Living With Illness’, was effective at reducing psychological distress, reducing physical limitations, and increasing valued behaviour for people living with LTCs. Owing to these results, many of the components were adopted into the ‘Living Well with a Long-Term Condition’ intervention. However, since the focus of this research was to conduct a pilot and feasibility study, mainly to assess the feasibility and acceptability of the two group conditions (specific-diagnosis versus mixed-diagnosis), only some of the outcome measures used in the Brassington et al., (2016) study were included in this research, namely psychological distress, illness perceptions and health-related quality of life. Measures of psychological flexibility and valued living, specific ACT measures, were not included, as these were not deemed relevant to the research aims. This is supported by literature warning that too many primary and secondary study outcomes can “a) lead to an unfocused research question and study, and b) present problems with interpretation if the treatment effect differed across the outcomes” (Vetter & Mascha, 2017, p.680).

This research was designed and developed due to the long waiting times that patients experience when trying to access mental health support in NHS services, such as the Northwest based Clinical Health Psychology service. Owing to this research being a pilot and feasibility study, the impact of the group intervention on waiting times was not explored. A brief analysis of the waiting list data between June 2020 and January 2021 (the 8-month recruitment period), reveals that the number of patients on the waiting list reduced and the median number of weeks waiting also reduced (see figure 8).

Figure 8: GM waiting list figures between June 2020-January 2021



However, it is hard to make even tentative conclusions from this data given the large number of variables that could have influenced the waiting list, such as staffing levels and the

COVID-19 pandemic. At any given time, there are several initiatives being implemented to address the waiting list and without conducting a controlled trial, it would be difficult to attribute any changes to one intervention. It is likely that initiatives would work in combination to meet service users' needs. This research shows that the 'Living Well with a Long-Term Condition' group is one such initiative, that can be delivered to specific-diagnosis and mixed-diagnosis groups, online and with the likelihood to improve patient outcomes.

This research has provided helpful indications for future research. First and foremost is the indication for an adequately powered RCT, to robustly assess the effectiveness of the intervention and compare results between both group conditions. Secondly, further comparison research could explore delivery of the intervention online versus face-to-face in both approaches, and could explore which single-diagnosis groups may be differentially effective across different conditions, to explore when a mixed-diagnosis or specific-diagnosis approach may be indicated.

Weighing up the results of the research overall, it is imperative that patients are at the heart of clinical service planning decisions. This thesis concludes with a final recommendation. This recommendation is based on the findings of this research, supported by other research evidence (Newby, Mewton & Andrews, 2017), and takes into consideration the increased throughput of patients and easiest most efficient way to recruit patients for a group intervention to run. If one approach had to be cautiously chosen, the recommended approach would be mixed-diagnosis.

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Appendices

APPENDIX 1: Overview of 'Better Living with Illness' Intervention compared to the Living Well with a Long-Term Condition' Intervention

Better Living with Illness (Brassington et al., 2016)	
Session 1	*Introduction to the group* Introductions and treatment rationale. Creative hopelessness exercises, including primary/secondary suffering and workability of coping strategies
Session 2	*Where do we go from here* Getting stuck with symptoms, thoughts, and feelings versus moving forward from them using an experiential version of passengers on a bus metaphor. An introduction to mindfulness
Session 3	*Thoughts and values* Clarification of personal values
Session 4	*Values and goals* Goal setting, defusion from thoughts and emotions, and problem-solving skills. Self as context and perspective taking processes included throughout the intervention from this point
Session 5	*Valued action* Assertive communication skills, willingness, and committing to action
Session 6	*Keeping things going* Pacing as committed action, review of intervention and setback preparation

Living Well with a Long-Term Condition	
Session 1	*Getting to know each other* Welcome and facilitator introductions, outline of sessions, ice breakers, sharing experiences
Session 2	*Bringing yourself back to the moment* An introduction to mindfulness, understanding difficult thoughts and feeling
Session 3	*Living well with suffering* Exploring the struggle, primary/secondary suffering, and workability of coping strategies
Session 4	*Identifying values* Experiential version of passengers on a bus, clarification of personal values
Session 5	*Values and Goals* Goal setting, defusion from thoughts and emotions and problem-solving skills
Session 6	*Valued action* Barriers to valued living, assertiveness communication skills, willingness and committing to action
Session 7	*Keeping things going* Pacing, review of group sessions, preparing for setbacks
Reunion session	*Reunion* Reviewing progress with goals tailored to any ongoing issues

APPENDIX 2: Learning and development as a reflective practitioner

Being a reflective practitioner is an important part of being a Psychologist and was an integral part of the Stage 2 Qualification in Health Psychology which I completed in 2017. As this top-up professional doctorate is an extension of my qualification and I value being an effective, ethical, and reflective practitioner, I wanted to include this brief reflective section.

Undertaking any type of study is a potentially daunting task but doing a top-up professional doctorate alongside a full-time job, I was somewhat apprehensive. Whilst I had covered research skills during my stage 2 training, 2 years had passed since my qualification and the focus of my role had been developing my clinical skills in assessment, formulation, and intervention, to be an effective practitioner. I had some exposure to audit work, but my role had a limited research focus, thus I knew that I would need to revisit, re-learn, and develop new skills to conduct this pilot and feasibility project. For example, I had not previously conducted a piece of research that required review by an NHS Research Ethics Committee, and this process was more time-consuming and difficult than I had anticipated. However, the unexpected addition of conducting this research during a global pandemic was by far the biggest challenge on both a professional and personal level. My role within the Clinical Health Psychology service changed somewhat dramatically at the onset of the pandemic, all contact with patients was transferred to initially just telephone delivery, with the addition of video consultations after a few months. Furthermore, our service was asked to provide psychological support to inpatient services including patients, families, and staff. I volunteered to work part-time in Theatres and the Intensive Care Unit (ICU) between March-June 2020, and owing to demand, again in ICU, October 2020-April 2021. I had no prior experience of working in this setting and it was both stimulating and challenging simultaneously. I found it rewarding to be ‘doing my bit’, but I had rarely worked with death and dying before working in the ICU. Peer support was in abundance at this time, alongside supervision which allowed me to manage many of the difficult experiences.

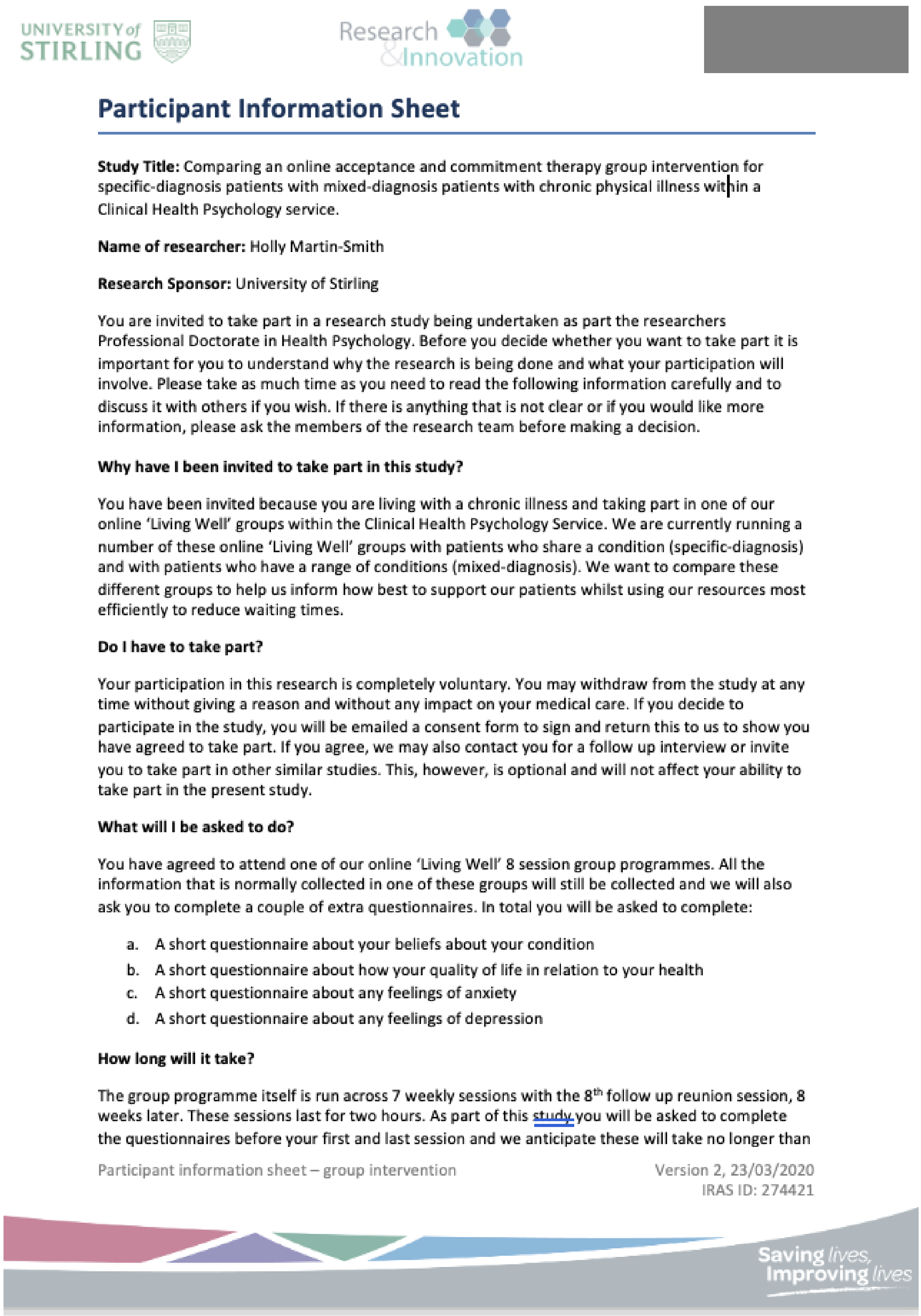
At times, I found it beneficial to be doing this research project amid the pandemic, it was something different to focus on and work towards, which once amendments had been made, had set tasks to be completed over a timeline. Furthermore, the group intervention allowed me to work closely with my colleagues in facilitating the groups at a time when we were all feeling isolated, working from home had with limited contact with each other. We overcame the anxiety and challenge of learning ‘remote’ delivery together and I was proud of how quickly as a team we adjusted and supported each other. I was also delighted at how well it worked with patients.

Another big challenge of this project was the change in my supervision just 2 months before my second provisional submission deadline. I had been granted an extension by the University due to the pandemic but had not foreseen the need to extend this again. Whilst this was hugely disappointing, events were out of my control and the need for flexibility was again necessary. I was hugely grateful to my supervisor who stepped in and was relieved when we agreed that a 'third opinion' would not result in any drastic changes being introduced. I had completely underestimated how hard writing up my thesis would be, particularly how much time it would take whilst juggling a full-time job. I feel lucky to have had supportive, efficient, and skilled supervisors to guide me through the last few months. I learnt to be disciplined, to try and 'practice what I preach' as a clinician by being compassionate towards myself and my work-life balance but this was often a challenge. I recognise that achieving this doctorate is hugely important to me, and in many ways I had to adopt some of the acceptance and commitment therapy strategies from the group intervention, to help me manage the difficult thoughts and feelings that arose along the way.

Owing to all the above I have developed a number of skills. Firstly, research skills such as being able to conceptualise, design, sample, implement data collection, carry out data analysis, evaluate methods (both quantitative and qualitative) and critically reflect on results and implications. Secondly, professional skills such as interpersonal skills like collaboration to ensure good working relationships with health professional colleagues and research supervisors, leadership and practicing ethically and with accountability. Thirdly, online therapeutic skills of which were unexpected such as building rapport and maintaining engagement in the online therapeutic environment and keeping clients safe by understanding and managing risks when working online. Finally, personal skills such as perseverance, independence, attentiveness, and above all organisation.

I am fortunate to take with me these skills and experiences, and know that they have made me a better practitioner and overall Health Psychologist, as I continue my career.

APPENDIX 3: Intervention participant information sheet



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Participant Information Sheet

Study Title: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of researcher: Holly Martin-Smith

Research Sponsor: University of Stirling

You are invited to take part in a research study being undertaken as part the researchers Professional Doctorate in Health Psychology. Before you decide whether you want to take part it is important for you to understand why the research is being done and what your participation will involve. Please take as much time as you need to read the following information carefully and to discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask the members of the research team before making a decision.

Why have I been invited to take part in this study?

You have been invited because you are living with a chronic illness and taking part in one of our online 'Living Well' groups within the Clinical Health Psychology Service. We are currently running a number of these online 'Living Well' groups with patients who share a condition (specific-diagnosis) and with patients who have a range of conditions (mixed-diagnosis). We want to compare these different groups to help us inform how best to support our patients whilst using our resources most efficiently to reduce waiting times.

Do I have to take part?

Your participation in this research is completely voluntary. You may withdraw from the study at any time without giving a reason and without any impact on your medical care. If you decide to participate in the study, you will be emailed a consent form to sign and return this to us to show you have agreed to take part. If you agree, we may also contact you for a follow up interview or invite you to take part in other similar studies. This, however, is optional and will not affect your ability to take part in the present study.

What will I be asked to do?

You have agreed to attend one of our online 'Living Well' 8 session group programmes. All the information that is normally collected in one of these groups will still be collected and we will also ask you to complete a couple of extra questionnaires. In total you will be asked to complete:

a. A short questionnaire about your beliefs about your condition
b. A short questionnaire about how your quality of life in relation to your health
c. A short questionnaire about any feelings of anxiety
d. A short questionnaire about any feelings of depression

How long will it take?

The group programme itself is run across 7 weekly sessions with the 8th follow up reunion session, 8 weeks later. These sessions last for two hours. As part of this study you will be asked to complete the questionnaires before your first and last session and we anticipate these will take no longer than

15 minutes to complete. We will ask you to complete these at a time convenient for you prior to the first and last session.

Is there anything I need to do before the group programme?

You will be asked to complete the questionnaires but otherwise all materials as part of the group programme as usual will be sent to you via post or email. With your consent we will also write to your GP informing them of your participation in the online group programme and research.

What are the possible benefits with taking part in this study?

The information you provide will be beneficial in helping to improve understanding of service provision within the Clinical Health Psychology service. Whilst this may not benefit you directly, it may help us to support future patients in a more timely and efficient way.

Are there any risks associated with taking part in this study?

This is not a clinical trial and there are no risks associated with the group programme however discussing your experiences of living with a chronic condition may bring up some uncomfortable thoughts and feelings. The qualified psychologists leading the group programme will be able to offer you appropriate support and you can of course withdraw at any time.

How will we use information about you?

We will need to use information from you for this research project.

This information (personally identifiable data) will include your:

- Initials
- NHS number/Hospital ID
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. This personally identifiable data will be retained until the lasts data collection point and then deleted.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking on of the research team
- by sending an email to [redacted]
- by ringing us on [redacted]

What will happen to the results of the study?

The results of the study will help inform the Clinical Health Psychology service of the feasibility and acceptability of group programmes and how we can best support patients. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. The study results will be disseminated to relevant service providers and academics. The information obtained in this study will be used as data for the researcher's doctoral thesis and may be published in academic journals or presented at academic conferences.

If you wish to receive more information and/or a summary of the anonymised results of the study, please feel free to contact the researcher at [redacted]

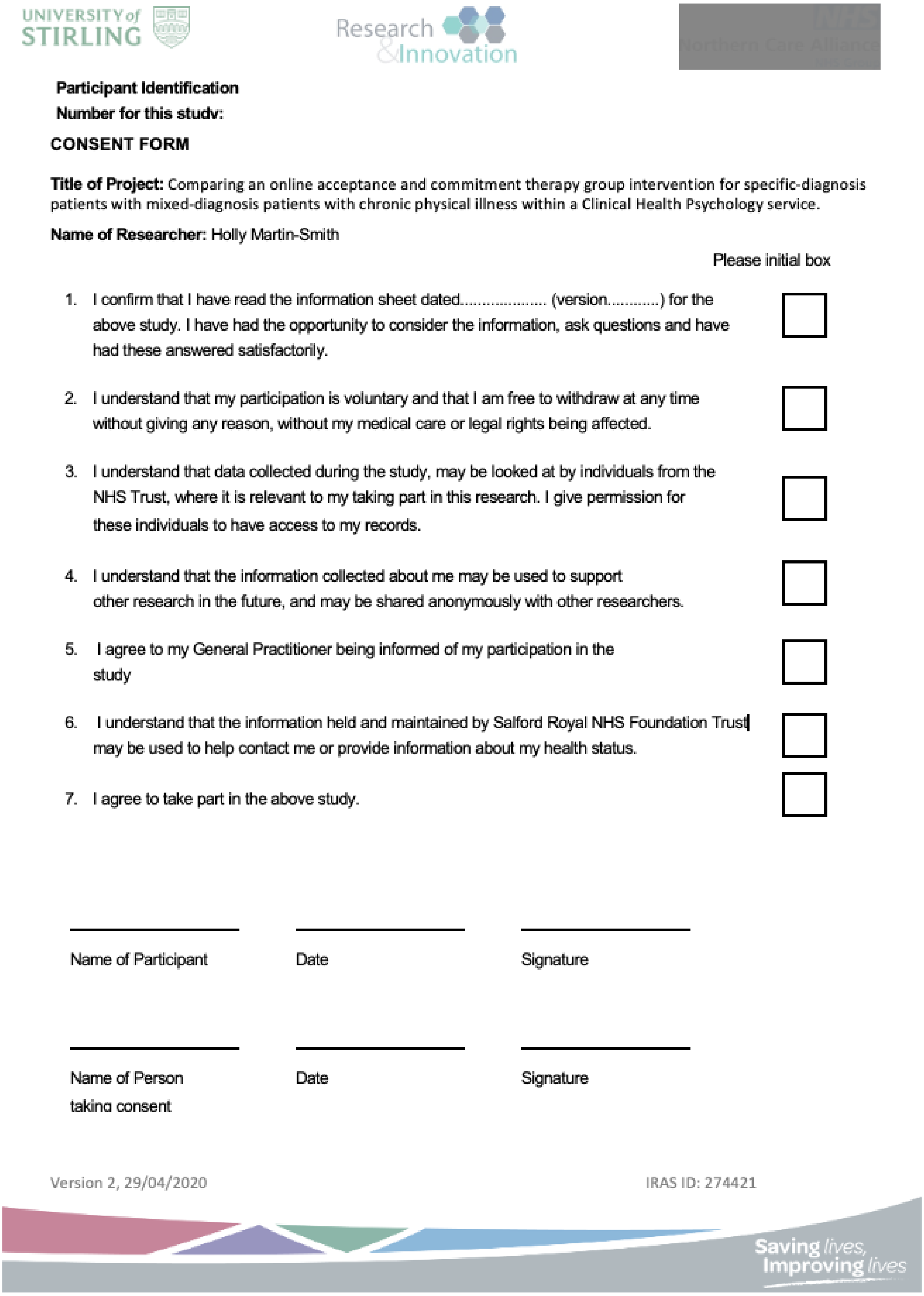
If I have some more questions who should I contact?

Holly Martin-Smith, [redacted] or [redacted]

What if I am not happy with how the research was conducted?

Please contact the above named researcher. If you wish to discuss this research with a more senior member of staff, please contact [redacted], [redacted] at [redacted] or on [redacted].

APPENDIX 4: Intervention consent form



UNIVERSITY of STIRLING

Research &Innovation

[redacted]

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of Researcher: Holly Martin-Smith

Please initial box

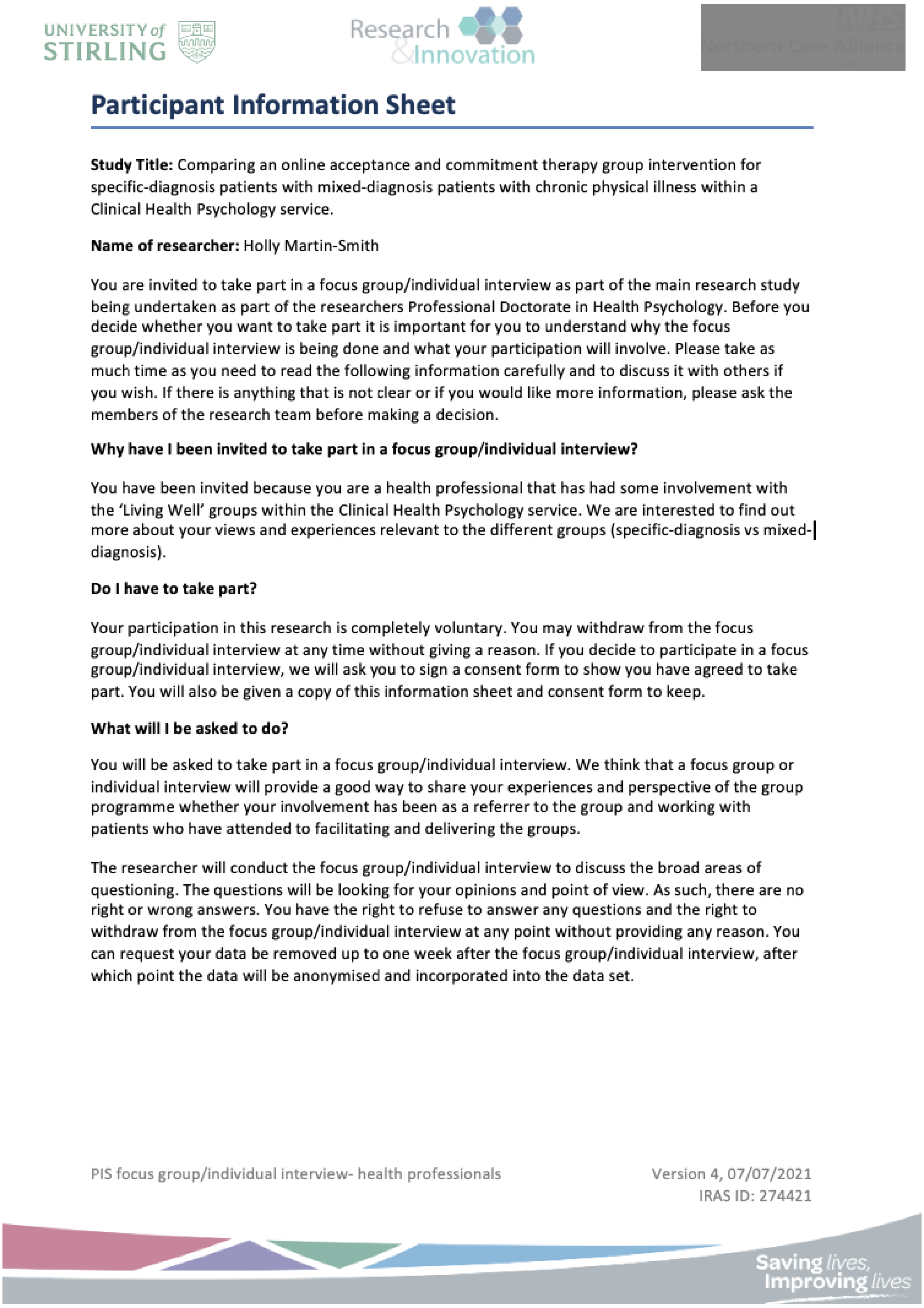
1. I confirm that I have read the information sheet dated.................... (version...........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data collected during the study, may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐
5. I agree to my General Practitioner being informed of my participation in the study ☐
6. I understand that the information held and maintained by Salford Royal NHS Foundation Trust may be used to help contact me or provide information about my health status. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Version 2, 29/04/2020 IRAS ID: 274421

Saving lives, Improving lives

APPENDIX 5: Health professional participant information sheet



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Research & Innovation

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Participant Information Sheet

Study Title: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of researcher: Holly Martin-Smith

You are invited to take part in a focus group/individual interview as part of the main research study being undertaken as part of the researchers Professional Doctorate in Health Psychology. Before you decide whether you want to take part it is important for you to understand why the focus group/individual interview is being done and what your participation will involve. Please take as much time as you need to read the following information carefully and to discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask the members of the research team before making a decision.

Why have I been invited to take part in a focus group/individual interview?

You have been invited because you are a health professional that has had some involvement with the 'Living Well' groups within the Clinical Health Psychology service. We are interested to find out more about your views and experiences relevant to the different groups (specific-diagnosis vs mixed-diagnosis).

Do I have to take part?

Your participation in this research is completely voluntary. You may withdraw from the focus group/individual interview at any time without giving a reason. If you decide to participate in a focus group/individual interview, we will ask you to sign a consent form to show you have agreed to take part. You will also be given a copy of this information sheet and consent form to keep.

What will I be asked to do?

You will be asked to take part in a focus group/individual interview. We think that a focus group or individual interview will provide a good way to share your experiences and perspective of the group programme whether your involvement has been as a referrer to the group and working with patients who have attended to facilitating and delivering the groups.

The researcher will conduct the focus group/individual interview to discuss the broad areas of questioning. The questions will be looking for your opinions and point of view. As such, there are no right or wrong answers. You have the right to refuse to answer any questions and the right to withdraw from the focus group/individual interview at any point without providing any reason. You can request your data be removed up to one week after the focus group/individual interview, after which point the data will be anonymised and incorporated into the data set.

Saving lives, Improving lives

How long will it take?

We anticipate the focus group will last no longer than 60 minutes. individual interview will last no longer than 30 minutes.

Is there anything I need to do before the focus group/individual interview?

No, you will not need to do anything prior to the focus group/individual interview. The moderator will discuss what is going to happen in the group/individual interview and you will be given an opportunity to ask any questions that you might have. If you are in a focus group the moderator will then ask everyone to agree on some ground rules for the group (e.g., avoiding speaking over other people, being respectful and considerate of other people's feelings). Once everyone is happy for the group or interview to begin, the moderator will switch on the recording devices and ask the first question. You will be given another opportunity to ask questions at the end of the group/individual interview.

What are the possible benefits with taking part in this focus group/individual interview?

As a result of participating in a focus group/individual interview, you may feel as if you have contributed to improving the services provided by the Clinical Health Psychology department which may improve patient care in the future.

Are there any risks associated with taking part in this focus group/individual interview?

There are minimal risks to participating in this focus group/individual interview. You may be uncomfortable sharing your experiences but you will only be asked to share what you are comfortable sharing and you are free to omit any questions that you would prefer not to answer. You are free to opt out of the discussion/interview at any time and provision will be made for you to take breaks and pauses as necessary. If you need assistance or would like to speak with someone after taking part in the focus group/individual interview, a member of the psychology team will be able to contact you for any further support.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Initials
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is use?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking on of the research team
- by sending an email to [redacted]
- by ringing us on [redacted]

What will happen to the results of the study?

The results of the study will help inform the Clinical Health Psychology service of the feasibility and acceptability of group programmes and how we can best support patients. The study results will be disseminated to relevant service providers and academics. The information obtained in this study will be used as data for the researcher's doctoral thesis and may be published in academic journals or presented at academic conferences.

If you wish to receive more information and/or a summary of the anonymised results of the study, please feel free to contact the researcher at [redacted]

If I have some more questions who should I contact?

Holly Martin-Smith, [redacted] or [redacted]

What if I am not happy with how the research was conducted?

Please contact the above named researcher. If you wish to discuss this research with a more senior member of staff, please contact [redacted], [redacted] at [redacted] or on [redacted].

APPENDIX 6: Clinician Handbook

Living Well with a Long-Term Condition

2020

Clinician Handbook

Acknowledgements:

This handbook was developed using the following protocols:

- Better Living with Illness Protocol (Brassington, L., Ferreira, N. B., Yates, S., Fearn, J., Lanza, P., Kemp, K., & Gillanders, D. (2016). Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioural Science*, *5*(4), 208-214)

- Living Well with Neurological Conditions Hill, G., Hynd, N., Wheeler, M., Tarran-Jones, A., Carrabine, H., & Evans, S. (2017). Living well with neurological conditions: Evaluation of an ACT-informed group intervention for psychological adjustment in outpatients with neurological problems. *The Neuropsychologist*, *3*, 58-63.

We thank the authors for their generosity in sharing their resources and allowing us to adapt them to our physical health population.

Session one: Getting to know each other

0-15 minutes

- Welcome & facilitator introductions -

- Provide a brief outline of group sessions–
    - Week 1: **Introduction-** getting to know each other
    - Week 2: **Bringing Yourself Back To The Moment -** introducing mindfulness and exploring difficult thoughts and feelings
    - Week 3: **Living Well With Suffering** – how do we struggle and cope with difficulties and exploring the illusion of control
    - Week 4: **Identifying Values -** what are they and what are our own values? Learning to step back from thoughts.
    - Week 5: **Values and Goals** – choosing goals based on our values and learning about problem solving
    - Week 6: **Valued Action-** learning to communicate assertively, practicing mindful acceptance to facilitate moving towards our goals
    - Week 7: **Keeping Things Going-** how pacing can be helpful, preparing for setbacks and reviewing the group.

- Foster self-compassion i.e., share with group ideas that no matter what your experience to date has been like, what your pain and suffering is like, you are a person in your own right; you are fine, right here right now. You don't have to do anything or be anywhere else but here at this moment. That is enough. We look forward to getting to know you over the next weeks

- Foster a sense of belonging- sharing that everyone in the room might not have exactly the same condition/problems/struggles and we often make comparisons with each other but to know that everyone belongs here and has a right to be here

- Ground rules- agree on some ground rules with participants. For example:
    - confidentiality
    - use of mobiles
    - respect
    - listening
    - sharing
    - quiet space
    - undisturbed
    - eating
    - recommendation that participants refrain from sharing contact information until after the group has finished to protect group dynamics

- Interacting with Microsoft teams- explaining about the different functions
    - chat function- emoji's
    - raise hand
    - sharing screen

- Having a play – inviting participants to use the different functions

20 – 30 minutes

- Ice breakers: -
    - introducing ourselves - e.g., giving name, one fact, & reason they wanted to come to the group.
    - video of Shelley- if audio fails, send to participants via email.

30-55 minutes-

- Explore experiences of living with a long-term condition- invite participants to share their story, emphasising that this is optional but an opportunity to share how they are feeling in a safe space.

55-65 minutes **COMFORT BREAK**

65-95 minutes

- Continue to invite participants to share their stories of living with a long-term condition.

95-105 minutes-

  - Previous participant feedback- read out the letters written by previous participants of the group.

105-120 minutes -

Ending session 1:

- Provide a summary
- Answer any questions
- Discuss home practice using participant workbook
- Explore any reflections

Session two: Bringing yourself back to the moment

0 -15 minutes

- Welcomes, teas and coffees, acquainting -
- Reminder of names. If new members present, facilitator introduces new member by first name, and invites opportunity to share their story, explicitly inviting the group to respect their experiences if they choose to share as the group progresses.

15-25 minutes

- What is mindfulness? (Info in workbook)
-

25-55 minutes

- Mindfulness practices:

55-65 minutes **COMFORT BREAK**

65-110 minutes

- Group exercise: “Understanding your thoughts and feelings about your condition. Using flipchart/whiteboard. (20 mins)
- Each person invited to write down some of the difficult thoughts and feelings that they notice they have in relation to their condition (My Experiences handout page 9 of participant handbook). (10 mins)
- Feedback to group (15 mins)

110-120 minutes

- Summary, questions, home practice. Reflections.

WHAT IS MINDFULNESS?

- Facilitators guide the group to consider what they think mindfulness means. Use flipchart/ whiteboard to brainstorm what mindfulness is and what it isn't. You can use the 'What is mindfulness' handout provided in the participant workbook on page 4.
- Reinforce the idea that mindfulness can only ever really be understood experientially through the practices, but that the written handout can be helpful.

MINDFULNESS PRACTICES:

- Facilitators invite the group to participate in some experiential mindfulness practices
  - Start with introduction to Mindfulness script
  - Follow with leaves on a stream script

Introduction to Mindfulness- Script

Find a comfortable place to sit with your back straight if it's comfortable to do that: we're trying to stay alert and aware during this exercise. If you're willing, you can close your eyes, or otherwise maybe focus on a spot on the wall.

Start by just bringing your awareness to the noises that you can hear in the room around you. [Pause] Notice where the noise is coming from. [Pause] If a thought comes into your mind, notice the thought, and try to let it go, gently bringing your attention back to what you can hear in the room. [Pause] You might find your mind trying to take your attention away from the noises in the room, maybe telling you that this is boring, that it won't help, or some other judgement. When it does this, just notice what your mind is saying, and gently bring your attention back to the room, noticing the noises that you can hear. [Pause]. And when you're ready, open your eyes.

Ask for feedback on what people found happened. Would anyone like to share any thoughts that came up? What did they do when that happened? What was this like? Was there anything that kept coming up? Anything they found difficult?
OK, I'd like us to try this exercise again, this time bringing our awareness to our breath, if you're willing.

Find a comfortable position with your back straight if it's comfortable to do that, trying to stay alert and aware with your eyes closed or defocused. Normalise being distracted by thoughts and praise noticing (effort), rather than achieving.

For the next few breaths, try to notice the feeling of your breath, as your lungs empty and refill automatically [pause]. Try to observe it like you're a curious scientist who has never come across breathing before. [Pause] Notice the air as it flows in through your nostrils and down into your lungs [pause]. Feel the warm air as it leaves your body, going up your throat and back out again [pause]. Notice how your body rises up when you breathe in ... your chest... your shoulders... your rib cage... your abdomen [pause]. And how it comes back down as your breath leaves your body [pause]. When thoughts come into your head, try to notice the thought and bring your attention gently back to your breath [pause]. Explore the feeling of your breath in your mouth... your nose... your throat... and as it goes down into your body [pause]. And when your mind naturally tries to take your attention on to something else - maybe with thoughts of when will this end, or what you need to do later, just gently acknowledge the thought, and return your attention and awareness back to exploring and noticing your breath [pause]. And when you're ready, open your eyes.

Ask for feedback again, with a focus on getting the participants just to notice their experience and steering away from trying to make sense of what thoughts may have come up, instead just noticing that the mind may have wondered that they might have a certain feeling towards one practice or the other. Next move onto a visualization mindfulness exercise.

Leaves on a Stream Script

In this exercise, we are going to imagine sitting by a stream, and as thoughts come to our head, we'll try to see if we can let them go using the stream to help us. As always, start by finding a comfortable position and remember that we're trying to become more aware of the here and now in this exercise, a bit like we're trying to 'fall awake'.

When you're ready, take a few deep breaths to help you settle into this exercise. Let the air fill your lungs, your tummy expanding to make room for this, and then letting the air empty from your body.

And now imagine that you are sitting beside a stream that is flowing gently by you. Take a look around you and let your imagination fill in the details of the scene. Notice the stream, and perhaps some trees around you. Bring your awareness to some leaves that are floating down the stream.

For the next few minutes, we're going to focus our attention on the stream. And whenever a thought comes into your head, whatever it's about, we're going to notice the thought, place it on the leaf and let it float away down the stream. We're going to do this for all of your thoughts – pleasant and unpleasant – whatever comes up is ok.

Just keep watching the stream, and noticing what comes into your mind. And when you notice something, place it on a leaf and let it float away. We're not trying to get rid of these thoughts, rather just let them float on by us at their own speed. Some people find it helpful to have a kind, smiling facial expression when they're placing their thoughts on a leaf. Perhaps try this and see how it works for you.

You might get thoughts about being bored, or not doing this right. Just try to notice these thoughts if they come up, gently and kindly place them on a leaf and let them float away.

Sometimes you might get hooked into your thoughts before noticing what's happened. Don't worry if this happens, it's completely normal. When you notice that it's happened, just notice your thoughts, and gently out them on a leaf and let them float away.

No matter how many thoughts come up, try to notice them, place them on a leaf and let them float away.

If a feeling comes up, maybe frustration or tiredness, simply notice it, saying "here's a feeling of frustration" or "here's a feeling of tiredness", and then place those words on a leaf and let them float away.

Whenever thoughts come up for you, try to just notice them, gently and kindly place them on a leaf and let them float away.

And when you're ready, try to bring your attention away from the stream and back to the room around you – noticing the sounds, the feeling of contact with the floor and the chair – and then open your eyes.

COMFORT BREAK

GROUP EXERCISE: UNDERSTANDING YOUR THOUGHTS AND FEELINGS ABOUT YOUR CONDITION

1. Guide the group to first consider some common distressing emotions? (Guiding to focus on fear, anger, sadness).

2. Invite the group to consider that each difficult feeling has a function, a purpose, otherwise evolution, like a proud housekeeper that is unwilling to put up with anything that isn't essential in the house, would have thrown these out a long

time ago. We have shared these feelings with other animals for centuries because they work well to help us to do something!?

3. Cautioning to the group that figuring out the usefulness of a feeling can appear easy but can be quite hard (use example of happiness or contentedness? What is the function? Propose to the group that this feeling tells us that all is well and that we don't need to change anything drastically right now).

4. Inviting the group to consider Fear? First fleshing out the shared experience/meaning of fear in the group using the whiteboard/flipchart and heading Thoughts, Bodily Sensations, & Behaviour / Actions). Guiding the group with an example if required such as how a mouse would act if eating from a bowl and then surprised by a cat. Emphasising the association between fear and flight behaviour.

5. Inviting the group to consider what would happen if we didn't feel fear? If required, what would happen to the mouse if it didn't and it was surprised by the cat? If it remained completely, and quite bizarrely content? It wouldn't end well. Fear enters our life as it thinks that there is a problem, a threat to our safety. It tells us that if we do not act then something bad will happen. Fear can be very useful. It can be a friend who keeps us alive. However, it may also tell us there's a problem when there isn't, or it might keep coming back when we can't actually do anything more about the problem.

6. Moving on to consider anger. Again inviting description of anger using the same headings as was done with consideration of fear, emphasising the association with the fight response. Drawing on example of mouse and the cat if required. What if the mouse was backed into a corner and couldn't run past the cat? What might happen? It might try to bite the cat to get past it, to survive. Ask the group if they can think of a time when being angry gave them something useful in the moment? If not, use the example of calling up to complain about an inaccurate utility bill. Anger comes along to give us the energy to fight back, to try to solve the problem and to stop what is happening to us, to keep things going as well as possible and us alive. Anger might shout out strong opinions about the injustice that's happening. Without it, we might passively sit back and never protect or defend ourselves or those we care about. Of course, like fear, it might come along at an unhelpful time, or when we really can't do anything about what has happened or is happening to us.

7. What about sadness? Why do we still have such a painful emotion? Why hasn't this been left out of the revised edition of human nature? Writing out using the same experiential headings as did for fear and anger. Inviting the group to

consider examples of when we might feel sad, perhaps even using the example of the mouse again, and the freeze response. Such as if it was trapped by the cat for a very long time and began to experience learned helplessness. So, what does sadness tell us then when it shows up in our lives?

8. Supporting the group to arrive at the conclusion that sadness tells us that something is wrong, but that it may not be a snarling beast chasing us, or something in our way, but that it could be a lost loved one, or something else we have lost, or are losing. When sadness comes along it forces us to focus on the thing we have lost or are losing, at the expense of seeing the things that are going well. It makes us have sad, concerned thoughts, which can be useful. But again, these might not be helpful in some circumstances such as if we are doing something that we know to be right for us, or if we have done all we can in a situation to solve the problem that's making us sad.

9. So, fear, anger and sadness can be really useful types of feelings that our minds have used for thousands of years to tell us when something is wrong or affecting our chances of living our life. We would really struggle without these characters in our lives. You could imagine these feelings to be a bit like lights on the dashboard of a car that flicker on to tell us something we need to know. Some are really important to act upon, and others less important if we know we have done what we can about the problem they represent.

Ask participants to write down some of the difficult thoughts and feelings that have come into their life since having a long term condition, using page 8 in participant workbook

FEEDBACK TO GROUP:

1. Would anyone feel able and open enough to share some of the difficult thoughts and feelings that come up for them related to their condition? Facilitate discussion and sharing if appropriate in that moment.

2. So your difficult thoughts and feelings are entirely normal, and as you agreed earlier if we stopped having fear, anger or sadness, things similarly might not turn out well for us. So we wouldn't want them to completely go away. However, it's entirely acceptable to not want these thoughts or strong feelings to get in the way of you doing what gives you pleasure and meaning in your life. The things that you value.

3. So, based on what we've discussed, would anyone like to try to make sense of why it's healthy to have difficult thoughts or feelings enter our lives related to a long-term condition?

4. Guiding the group to consider that long term conditions have a major impact on the person. You may go through many losses, such as losing the ability to do certain things with your body, or mind. Your mind in turn tries to help by bringing feelings like fear, anger, and sadness into your life to try to make you aware that something is wrong and that something needs to change.

5. Anyone would feel similar to you. And I imagine that despite there being problems related to different conditions in the group, that there are many similarities in how people feel towards their condition and the thoughts they find themselves having. I'm sure there are also many differences too.

6. So, our minds are a bit like storytellers, constantly making sense of what we're going through. You might notice your mind weaving elaborate stories related to your condition such as because you've had one flare up/heart attack (adapt as appropriate) that you will definitely have another, or that because you can't walk like you used to that everyone is looking at you when you go to the shops, or maybe, that you'll never be happy again now you have this condition (adapt to the context for the diversity of conditions affecting the group).

7. Your mind may tell this story to you so often, and so convincingly, through your thoughts that you begin to believe these strong opinions of your mind and start to act like the stories and opinions are facts. Certainties.

8. But whether these thoughts or opinions of your mind are facts or not is almost beside the point.

9. It may be more important to appreciate that some thoughts and feelings are helpful and others unhelpful for you and your goals in life.

10. You might unintentionally find yourself all wrapped up and hooked into your thoughts. They might come in very close to the point where they get in the way of you living the type of life that you want to live, even with the impact of your condition. You might start saying 'No' to things you know you need to start saying 'Yes' to.

11. The mindfulness exercises are one step towards spotting what your mind is up to, so that you can best use the good things it can do to get the most out of life. The mindfulness exercises may start to help you to see and respect the opinions of your mind coming in, and helping you to know which ones to follow, and which ones to let go on their way more. Not battling with the mind but noticing its pull and push in different directions. However, the benefits of practicing mindfulness only come after regular practice. It's a bit like planting a seed when you first practice. You need to spend time regularly watering and providing light for the plant to grow and emerge. Similarly, bringing mindfulness into your life takes effort, patience, and kindness for good things to come out of it.

12. Next session will focus much more on how to cope with the push and pull of the mind, by helping you to spot the battle that can happen between us and our minds, towards a more valued life, even with your condition.

Ending session 2:

- Provide a summary
- Ask for any questions
- Discuss home practice using participant workbook
- Explore any reflections.

Session three: Living well with suffering

0 -15 minutes

- Welcomes, teas and coffees, acquainting
- Recap of last week – reflecting on homework

15-55 minutes

- The struggle
- Primary vs secondary suffering

55-65 minutes

COMFORT BREAK

65-100 minutes

- Feedback – sharing with the group on suffering/primary and secondary struggling
- ACT in a nutshell
- Illusion of control
- Walking in the rain metaphor

100-110 minutes

- Mindfulness practice- breathing anchor

110-120 minutes

- Summary, questions, home practice. Reflections.

THE STRUGGLE

Open up a discussion about 'the struggle'. Ask participants:

What kind of things do you do to try and cope with or control your long-term condition and everything that comes with it?

What have you done to avoid or get rid of problematic symptoms/sensations, thoughts, feelings, memories, emotions?

Share screen and type up.
Possible examples:

- Avoiding social situations
- Treatments
- Equipment
- Limiting activity/ resting
- Stop work or sports

Note reflect that it sounds like they have been working hard to control their long-term condition and everything that comes with it.

What results have these strategies had in the short term for your long-term condition?

Did your difficult thoughts and feelings go away?

How does it make us feel when the thoughts, feelings, and sensations we have been trying to control return?

What about in the long term - in terms of your long-term condition? And in terms of your quality of life?

What has this cost you in terms of wasted time, energy, or money: or negative effects on health, well-being, work, leisure, or relationships?

Are there similarities between some of the strategies? [Try to separate out control and non-control based strategies]

Thinking about this, what does your experience tell you? What effect does trying to control your long-term condition, and how you feel about it, have on your life - does it make your life and long-term condition better? Or does it reduce your quality of life and make it harder to live with your long-term condition?

Looking for control / solution finding being the problem (but if this doesn't come, wait until after next bit). Stress that control can be a helpful strategy, but that sometimes it can become the problem.

Metaphor: Struggling in Quicksand

Opportunity to use this metaphor to illustrate struggling.

Y*ou're walking along and suddenly end up in quicksand and you may not necessarily know how you got there but you find yourself in this sticky situation.*

What instinctively do we do? (Cue for struggle)

And what happens when we struggle in quicksand (cue for sink deeper)

What is the advice if you get caught in quicksand? (Cue for increase surface area, lie back into quicksand, keep still).

This is very tricky; because every instinct in your body tells you to do is struggle, but you do what comes naturally you will become more stuck. Psychologically it is a leap to lay back but notice it is a lot less physical effort than struggling.

Moving participants to think more about struggling and control in the context of primary and secondary suffering.

PRIMARY AND SECONDARY SUFFERING

Talk participants through the following points. It can be helpful to type up into screen share document of primary and secondary suffering as per diagram on page12 of participant workbook

- *When you have a long-term health condition, the obvious problems come from your symptoms, for example pain, fatigue, itching, palpitations etc - these can be described as **primary suffering**.*

- *However, living with a long-term condition can bring other difficulties, including stress, worry and low mood. These are overlaid on top of the primary suffering. Your health may stop you doing things you want or need to do, or you may not see as much of your friends and family. Treatments you try may have unpleasant side-effects, or may not help as much as you hoped, leading to disappointment. All these additional difficulties can be described as **secondary suffering**. Some people find that these secondary* *difficulties can make their symptoms worse, for example being stressed and worried means that pain increases, and so a vicious cycle develops.*

- It’s a bit like having to carry a cushion everywhere you go - it makes it difficult to go about your life. But when we start adding more and more cushions to a pile in your arms, life becomes increasingly difficult. Your symptoms are like the first cushion, but your secondary suffering is the additional cushions piled on top. If we could find a way to put down *some* of the cushions, wouldn't life feel a little bit easier?

- *Although we don't mean it to,* ***how we respond*** *can add to the suffering we are experiencing overall. Whilst we may not be able to completely get rid of the symptoms, we can think about how we respond to it. These sessions will focus on ways which you can* ***manage*** *and* ***start to reduce*** *your secondary suffering.*

- The diagram (on page 13 of participant workbook) gives us a way of organising our primary and secondary suffering so that we can see how different areas link together. Thoughts, emotions, behaviours and physical sensations are tightly linked together and difficulties in one area often lead to difficulties in another. For instance, as in the example provided, a person experiencing persistent pain or fatigue may respond by doing less and resting more. This can lead to thoughts such as “I’m no use – everyone else has to do things that I should be doing”, which can then lead to feelings of anxiety and frustration. Anxiety and frustration can then lead to further physical sensations such as increased tension and therefore increased pain and fatigue.

- By identifying how this process impacts our own lives, we can begin to figure out ways to make changes. Take some time to fill in your own Primary and Secondary Suffering using the diagram on page 13 of the participant workbook.

- Then ask participants to complete ’How do you try to cope with your suffering’ - table on page 14.

FEEDBACK

- Invite the group to talk about and share examples of their suffering that they have written down. Supporting them to identify particular thoughts, feelings, bodily sensations and actions (writing these up on a screen share document if appropriate.

- Mental and physical suffering is painful, and upsetting and so we can feel driven to try to stop it, to avoid it, to control it. How do people try to cope or manage their suffering? Validating and normalising that people are doing the best they can with the strategies they have. Guiding the group to explore and consider some of the strategies as either (emotional) control, or (experiential) avoidance if appropriate.

- Finally, inviting the group to share the unintentional consequences of these strategies. For example, yes, avoiding people makes them feel less uncomfortable about their forgetting but does it result in increased loneliness? Does trying to block out thoughts to avoid the misery of the pain they feel work to bring about a more meaningful life? Or does it just distract them from time with their loved ones? Working to highlight that emotional control and experiential avoidance strategies bring short-term relief but over the long-term add to the suffering from the condition, and actually make things worse. Shaping the discussion towards the suggestion for the need for a new way of coping with the suffering?

COMFORT BREAK

ACT IN NUTSHELL METAPHOR

To prepare for this exercise, provide each participant with a blank piece of paper and pen. Alternatively blank pages are provided in the participant workbook or ask people to use their hands.

- Inviting the group to undertake the ACT in the nutshell metaphor to cultivate further creative hopelessness. So, I'd like to invite you to try a brief exercise on ways of coping with suffering. Please bring openness as this exercise is a little different. Are you willing to explore this?

- So, each of you have a blank piece of paper in front of you, if you don't you can use your hands. I'd like you to pick one difficult thought that often pops up, perhaps one of the strongest opinions that your mind tells you. Write this down on the paper (you won't have to share this) or just imagine it written in your hands.

- Now choose one difficult feeling that commonly turns up since your diagnosis, like an uninvited visitor. Write this down/imagine it written in your hands. Everyone have something?

- Now, if you'll indulge me, I'd like you to look at what you've wrote there, or what you have imagined, these forms of suffering. Now, I'd like you to look towards a blank wall in the room you are in (just a wall if you don't have a blank one) and imagine that on it is everything that you value. This could be family, a pet, your work, a certain someone, hobby or something else entirely. On here is everything important to you in the world. The stuff that gives your life meaning to you.

- Now if this feels OK for you and your body, I'd like you to hold that paper up in front of your face with two hands, facing you, so that the thought and feeling you wrote there come in real close to you (masking view of wall). Are you able to see the wall and connect with what matters? Can you have a relationship with that which is important over here? No, the suffering has got completely in the way, to the point where all your attention is shining on that. There's no room for anything else in this moment.

- So something needs to change. What can you do with it? Could you just throw away the paper, completely get rid of the suffering? The thoughts, the feelings? No, you would have done that long ago if you could. Unfortunately, we aren't able to get rid of some types of suffering.

- Of course you could try to push it away. Hold both arms out if it's comfortable, getting those thoughts and feelings as far away from you as possible, really pushing them away. How are your arms feeling as you do this? Tired? Are you able to connect with the things that you value when you're locked in this struggle with the suffering? Maybe for a moment, but not for long, before your energy runs out, or you suffer even more as your arms begin to weaken.

- And so, you may be using this valuably energy, trying to push it all away what could you do to cope with this suffering? To cope with that which you can't control?

- You could try letting go, gently bringing a willingness. You can’t change the suffering, but can choose not to waste your energy battling against it. You could choose to lay the paper or your hands on your lap. Pausing, how do your shoulders feel now? And are you able to now connect with the things that make your life important to you? They’ve been here the whole time whilst you were in the ‘struggle’ with your suffering. Has your suffering gone anywhere? Have you gotten rid of it?

- What have we showed there do you think? About you and your suffering? Guiding towards ideas of suffering often being out of our control but how we react to suffering being in our control.

The next section aims to explore the idea that control doesn’t always work.

THE ILLUSION OF CONTROL

So we’re all walking around trying to control our suffering, discomfort and how we feel but it doesn’t work in the long term.

The human mind has given us an extraordinary advantage – it allows us to make plans, invent things, co-ordinate actions, analyse problems, share knowledge, learn from our experiences and imagine our future. It allows us to shape the world around us and as a result of our ability to control our environment we develop an expectation that we should be able to control other aspects of our experience also. How much control can we have over our internal world?

Exercise: Suppressing thoughts: pink elephant

For the next 30 seconds, think about anything you want to think about. You can think about what you did yesterday, a conversation you had with a friend or what you’re having for dinner tonight but whatever you do don’t think about a pink elephant. You mustn’t imagine what shade of pink it is or how big it is just think of anything else but a pink elephant.

Exercise: Suppressing feelings

Imagine you're wired up to a polygraph, a lie detector. You're told that you must not, under any circumstances, get anxious. Not even a tiny bit. If you do, the polygraph will pick it up - that's what it's designed to do. And if it detects you being anxious, then an alarm bell will go off and you will get an electric shock. What would happen? [Get shocked!] So even though something horrible would happen that you really want to avoid, you can't control or eliminate your emotions for that?

Ask participants what can we learn from those two exercises? Look for how control doesn't work. Reflecting on Where do we learn about control from? Particularly in relation to thoughts, feelings and our health. Family, friends, school, society:

- don't cry
- there's nothing to be afraid of
- get over it/move on
- put on a brave face
- stop feeling sorry for yourself
- stiff upper lip

WALKING IN THE RAIN METAPHOR:

Introduce the Walking in the Rain Metaphor to illustrate how adopting an accepting, mindful approach to suffering can practically lead to a different outcome.

- So perhaps let's look at the same from a different angle. Say you're on your way to a close friend's birthday party, it begins to rain, no, pour down, you have a couple of streets to go, and it's raining cats and dogs. You have no umbrella, and you really weren't dressed for the rain. It was a sunny day. It's cold, and before you know it you're utterly soaking, your shoulders tense up, head and neck droops down, and you hurry your way there as quickly as possible, noticing more and more negative thoughts about the situation. Your mind shouting "You've gone and done it, you're soaked now", "As if this has happened", your mood becomes lower, and angrier "You should have brought an umbrella" your mind utters. You get to the door of her house, mind busying itself again with its stories, and predictions "You should just go home now, no one will like you there anyway". You drop your head again and walk away from the house, to call a taxi to go back home. You get home, feel warmer and dry, but lonely and left out.

- Here's a same scenario but see if you can notice where it begins to differ. You're on your way to a close friend's birthday party, it begins to rain, no, pour down, you have a couple of streets to go, and it's raining cats and dogs. You have no umbrella, and you really weren't dressed for the rain. It's cold, and before you know it you're utterly soaking wet, so you accept this, saying to yourself "Oh well, there's nothing I can do about getting wet, I may as well just continue to gradually make my way there". You notice the impulse to drop your head and neck, but you choose to turn towards the rain, looking up into the sky. You're getting wet, but you notice that you've started to smile. Your notice your mind saying "Hopefully, my friend will let me shower and loan me some dry clothes for the party". Your mind becomes quite quiet and you start to find that you've become interested in the sound of the rain drops, how they splash across the pavement. You arrive at your friends, uncomfortable, soaked, yet you feel at least a little content. You go in, feel grateful towards your friend for the shower and change of clothes, and enjoy the party. You look back the next day and realise that if you hadn't gone to the party you would have missed out on a lot that matters to you. Even things you didn't expect, such as some concert tickets given to you for free as your friend couldn't go.

- To use as a summary at the end of the session. So from a mindfulness perspective, some suffering in our lives is inevitable. However, tragically for some much more than others, including those with neurological conditions. There is suffering that can be changed and some that cannot.

- Trying to fight, control, or stop suffering that is unstoppable may be noble, yet actually leads to more suffering, and wastes valuable energy. Energy that can be used learning to gradually accept and work with your suffering, towards your goals, a valued life where you connect with the things that are important to you, and deal better with your suffering.

MINDFULNESS EXERCISE

The last task for session three is a mindfulness exercise. You can link in the themes from today to the idea that with practice mindfulness can help us to accept the things we cannot change i.e., the primary suffering and reducing or overcoming the things we can i.e., secondary suffering.

Ask for feedback (one by one if time allows). Normalise being distracted by thoughts and praise noticing (effort), rather than achieving.

Ending session 3:
- Provide a summary
- Ask for any questions
- Discuss home practice using participant workbook
- Explore any reflections.

Session four: Identifying values

0-10 minutes

- Welcomes, teas and coffees, acquainting
- Recap of last week, review homework

10- 30 minutes

- Passengers on a bus (script then video)

30-55 minutes

- What is a value

55-65 minutes

COMFORT BREAK

65-100 minutes

- Photos/object exercise
- Special event exercise
- Values and commitments

100-110 minutes

- Mindfulness practice- body scan

110-120 minutes

- Summary, questions, home practice. Reflections.

PASSENGERS ON A BUS

Introduce passengers on a bus:

One of the things that we've agreed over the sessions is that suffering from your condition gets in the way of some of the things you do in your life, actions that are important and meaningful to you. In doing this, making you suffer more and potentially causing a struggle between you and the suffering, such as fighting with difficult thoughts and feelings.

It's maybe a bit like fighting back against quicksand, sinking more and more, the harder you fight. Does anyone know what they say to do if you fall into quicksand? Exactly, accept that it has happened, relax into it and slowly make careful, planned movements.

So, we've agreed in previous sessions that what you do with your time has a major impact on how easy it is to cope with the condition and related suffering.

Passengers on a bus script

- I'd like to invite you to explore an exercise called 'Passengers on the Bus'.
- So, I'd like you to adopt a comfortable posture, close your eyes, and turn your attention to the fact that you're breathing in this moment.
- Now imagine that each of us has a bus, and that we are each the driver. Everyone's bus is different, different colours, different shapes and sizes. I'd like you to imagine your bus in this moment. To see it in your mind's eye.
- Now on each of our buses we have our own passengers. There are helpful passengers and unhelpful passengers. Unfortunately, the unhelpful passengers are the concern here. These are the difficult thoughts, feelings, memories, losses, pains, sensations, diagnoses that make up your suffering. Try to see your own difficult passengers if you can. Perhaps pain could be there, perhaps depression, fear.
- So, after some struggling once they first got aboard, you've made a deal with them that as long as they stay behind the line and don't bother you up front in your seat, that you'll drive anywhere they want to go, maybe even if you'd rather not.
- So, this has been just about bearable for a while. Perhaps you are driving

aimlessly into the distance. You keep driving where the passengers tell you to go to try to cope with them.

- But enough's enough. One day you decide to turn the bus around, and drive in the direction of what's important, your family. But as soon as you turn, the passengers rush up to the front and crowd you, shouting right up in your face. "*You dare keep driving this way, go on, we dare you, just see what happens", "We're really going to hurt you".*

- It's too much. They're too demanding, too intimidating. You swing your bus around back in the direction you were driving, the way they want you to go, keeping you by yourself, away from people. One of the more helpful passengers comes forward to the front of the bus and whispers quietly *"I don't think you should do that again. That was dangerous".*

- Now here's the thing. All the unhelpful passengers did was intimate you. Sure, it was intense, and hard! And painful. But remember that they can never, ever, harm you. Even though they may threaten it. But as long as you believe them, they have complete control over your life and the directions you are headed.

- So now you know this, if the other directions really do matter to you. What's your options? You could keep driving further and further away from where you know you need to be, becoming further away from what you want and deserve in your life.

- Or you could begin to face up to the passengers, and show them that you're going to try make more room for whatever they try to do to you, because there are some places you must go that are just too important to you. Much more important than the suffering from their threats, and bullying. So important to you that they're worth the hardship! You turn the bus around.

- The passengers do the same. They rush to the front, and gather around you. But you expect this. You turn towards them, and bravely allow them just to be there. Inviting them to do whatever they feel they need to do. You sit there, resilient, and weathering their storm as you drive towards the direction of something else important, meeting a friend whom who haven't seen for years, something you know you can do, even with the passengers on board!

- As you drive towards your goal you notice that it's really draining. The unhelpful passengers just keep coming at you.

- But finally you arrive and meet your friend, and it feels good. You get a sense of energy in your body and feel more connected. The unhelpful passengers keep shouting, but some of them now seem a little quieter. You sit there, focused on being with your friend. You're curious about what the passengers have to say but you're not letting them take over the moment. It doesn't feel amazing, yet there is a sense of wholeness as you bravely face your experiences.

Show participants the passengers on a bus video, participants may want to jot down what showed up for them in the space provided on page 20 of the participant workbook.

WHAT IS A VALUE

If we're going to get behind the wheel and take our bus in the direction that's most important to us, we need to know where we're going. Sometimes it can be unclear what direction this is though. We're going to be spending today talking about our values to help us understand and connect with which directions are important to you and where you want to take your bus.

Ask the group - what is a value? Possible screen share task, looking for:

- What you want to live by and for
- Personal
- Chosen freely
- Give life direction and meaning
- Values can never be achieved – that would be a goal
- Something that is very important to you

So values are different to goals, how? Goals can be something you complete in the direction of your value (e.g., person aims to spend time with their brother over the weekend who was recently moved to a new job, because they value 'being supportive' amongst other values). Goals are about something we aim to do in the future. Something that we have either done or not done.

Values are something that we can do right now in any given moment. For example, goals could be to start to eat your five-a-day, to stick to recommended alcohol limits, or to exercise three times a week, but the value, behaving healthily can be done in any moment. For example if a tray of biscuits were suddenly to appear, you might find yourself considering how healthy it would be to eat one and any related goals. And you might make a decision either way to live in line with this value.

Most people have more than one value in life. Values can be in a number of areas, for example:

Family

- *Friends*
- *Partner*
- *Work*
- *Self-care*
- *Personal growth and development*

We’re going to think ab ,
across our life as a whole, thinking about: What do you want your life to be about? What sort of person do you want to be? What kind of things would you be doing if you were living that value?

It can be quite challenging to think about these things. It can raise difficult issues and feelings about how we are not doing what is important to us, or how our conditions tell us we can't do these things. Sometimes our mind can tell us that our values are “impossible” or “unrealistic” or “not really important enough”. As we’re thinking about our values today and these thoughts come up, try to notice when they do and gently let these thoughts go.

COMFORT BREAK

PHOTOS/OBJECT EXERCISE

Ask group to share object or photo that they brought along with them, starting with facilitators. Encourage the sharing of why and what is important to them- i.e. their values within the object or photo.

SPECIAL EVENT EXERCISE

Use the following script

- Let’s try an exercise to help us get in touch with our values.
- We’re going to imagine we’re at a special event, this could be a birthday party or celebration for you.

- Two people are going to give a speech at the special event about what you mean to them, what you stand for in life, what role you might have played in their life. While you're imagining this, people often find that their mind suggests things like "that person wouldn't really say that", or something similar – try to notice when thoughts like this come into your mind and gently bring your attention back to the exercise.

- So, we're going to start with mindful breathing, and then go on to imagine your special event. When you're ready, find a comfortable position with your feet firmly on the floor and close your eyes. For the next few breaths, notice the air as it fills your lungs, and how they automatically empty with no effort from you. Bring your awareness to the sensation of the air coming into your body and observing it as it leaves again.

- Imagine you have arrived at your special event. Look around you at where you are. You might be in a room at home, somewhere you are comfortable, or perhaps in a big function room somewhere. Look round the room taking in the guests that are there at the event. You may only have 1 or two, or hundreds. Whatever you imagine is fine.

- Imagine that one of your guests stands to give a speech about what you have meant to them and what you've stood for in your life, what qualities you have and things you have managed to do in your life even with your condition. If thoughts come into your mind about how the event wouldn't really be like this (e.g. I haven't achieved anything), notice these thoughts and gently bring your attention back to what the person is saying and what you'd like them to be saying.

- Imagine a second guest standing to give a speech about what you have meant to them and what you've stood for in your life. Again, when thoughts come into your mind, maybe about how the party wouldn't really be like this (e.g. would never say these things), notice these thoughts and gently bring your attention back to what the person is saying.

Debrief – ask if there is anyone who would like to share any part of their speeches. Encourage people to share the values that this excise has identified around the domains listed above. Look out for possible problems with identified values, such as is it a goal or a process rather than a value? What if no one knew that was your value; would it still be important to you? Is it a goal about other people? Give participants an opportunity to write down any values they have noticed from the above exercises in the space provided on page 23, they may also wish to refer to list of values below (and in participant workbook page 24).

List of Values

Honour
Wisdom
Integrity
Peace
Beauty
Nesting
Nurturance
Balance
Faith
Spirituality
Love
Strength
Communication
Self-expression
Imagination
Creativity
Forgiveness
Intuition
Compassion
Diversity

Experience
Learning
Loyalty
Reliability
Order
Respect
Thoughtfulness
Patience
Tolerance
Serenity
Attentiveness
Equality
Caring
Intimacy
Sensuality
Play
Fun
Effort
Productivity
Health

Freedom
Curiosity
Openness
Perseverance
Calm
Wonder
Humour
Organisation
Stability
Security
Meaning
Understanding
Intelligence
Adventure
Risk
Courage
Power
Connectedness
Citizenship
Belonging

Flow
Structure
Rhythm
Excitement
Wit
Sustainability
Self sufficiency
Independence
Leadership
Kindness
Expansiveness
Simplicity
Conservation
Spontaneity
Comfort
Warmth
Discipline
Justice
Detachment

VALUES AND COMMITMENTS

Think about one of the values that you have identified that you'd like to work on right now, perhaps one that you feel isn't in your life as much as you'd like. When you're ready, close your eyes and try to settle in to the here and now. And without needing to commit to any action, or deciding you're going to do something, imagine one large commitment and one small commitment, possibly the smallest one that you can think of, that you could do that would be in line with your values today. Notice what shows up in your mind as you think about these commitments. Remember, we're not thinking about DOING these commitments, just trying to identify what these would be. When you've identified what they are, open your eyes and write them down.

Look at your small commitment. Are you willing to do that today?

Ask participants to use the space on page 23 of the participant workbook to write down any commitments.

MINDFULNESS EXERCISE

The last task for session four is a mindfulness exercise. Mention to patients that this exercise is a body scan and often people with physical discomfort or pain can find it quite helpful. However, any change in tension or pain isn't the goal with this exercise. What we're focusing on is becoming more aware of our bodies and what is happening in them. As we're scanning round our bodies, our focus will be on noticing and observing, rather than trying to change any sensations that we find.

Ask for feedback (one by one if time allows). Normalise being distracted by thoughts and praise noticing (effort), rather than achieving.

Ending session 4:

- Provide a summary
- Ask for any questions
- Discuss home practice using participant workbook
- Explore any reflections.

Session five: Values and Goals

0-10 minutes

- Welcomes, teas and coffees, acquainting
- Recap of last week, review homework

10- 30 minutes

- Developing SMART goals

30-55 minutes

- Values and goals worksheet – group and individual

55-65 minutes **COMFORT BREAK**

65-90 minutes

- Problem solving (group then individual)

90-110 minutes

- Mindfulness practice- sounds

110-120 minutes

- Summary, questions, home practice. Reflections.

DEVELOPING SMART GOALS

- Ask participants to think back to last session and the difference between values and goals. Reiterating that we may have many goals that are in the direction of a value. They're a bit like stepping stones as you move in the direction of what's important to you. There can also be barriers to work around. Things that can block you from getting to your next stepping stone.

- Perhaps considering that someone has the value of '*being supportive'*

- What could they do right now, as an immediate goal? (e.g., calling a friend right now who they know has been struggling and arranging to do something that will be good for both of them, such as going to the park).

- What could the person do in the short-term? What goals could they set? (e.g., meeting a friend on Fridays for coffee, making sure they reply to their messages by Sunday each week).

- What could they do in the long term? (e.g., arrange to go on holiday with a friend next year, make sure they go to their friend's wedding).

- There can be barriers along the way? For all its usefulness, the mind is also a fabulous reason-giving machine. It can reason that it's OK not to act to achieve our goals or live in line with our values.

    - What reasons or excuses could the mind give this person as they try to be a supportive friend? (e.g., other people can take care of themselves without you, they don't need you, why do you bother putting yourself through more pain just to meet up with them? they don't really like you anyway, they just say that they do to make you feel better. Besides you're too tired to meet up with them aren't you?)

- Any of these sound familiar? They're powerful opinions and stories that can be painful when they come up. But they're just that, just opinions, just stories.

- Regardless of any truth to them, it's important to consider if they are helping us to do what's important? Or taking us away from a valued direction?

- So we can set immediate, short, medium and long-term goals that can help us to move in the direction of our values. Barriers will come up from our minds, which is entirely fine.

- Practicing mindfulness can help us to spot some of the unhelpful stories the mind can dish out, which can help us to make wise decisions to not let these thoughts in the way of our goals.

- Another way is make sure that our goals are **SMART** – screen share document if needed

Specific – Well defined, not vague, can clearly be seen to be met.

Meaningful – Genuinely guided by your values (e.g., not to just please others).

Adaptive – Goals that help to enrich your life. Is it in the right direction?

Realistic – Can be done with the available resources the person has.

Time-framed – Has a set time frame within which to get there.

- So using what we've looked at there, we're going to support you to set some SMART goals towards an important value using the values and goals worksheet. Now we are going to take our time with this so like every other session, there is no rush.

Guide the group to make their way through the values and goals worksheet

- Support willing participants to share and commit to their goals with the group, emphasising that public commitments often have more gravitas than those made purely with our minds. Homework to act on their commitments that they made during the session.

- Reinforce the importance of what they have just done with the group. They have begun to set goals for living a better, richer, and more fulfilling life, even with their neurological condition. They are making steps to deal better with their suffering, through efforts to make room for the difficulty in their lives.

COMFORT BREAK

PROBLEM SOLVING

- Share with the group that it is common for there to be many barriers/problems that can get in the way of achieving goals. It can be helpful to try and pre-empt these and put in place strategies to overcome them.

- Ask the group if anyone is willing to work through one of the goals they identified on their values and goals worksheet. If someone is willing, use the problem-solving worksheet (page 32 in the participant workbook) and write up their example on the screen share document if needed. If no one is willing, guide all participants to use their problem-solving worksheet to think through any barriers they may have to achieving their goals. They may like to focus on their immediate or short-term goal. Remind participants that often difficult passengers on our bus might crop up as problematic and encourage them to think of possible solutions to handling these passengers that they have learnt from previous sessions.

MINDFULNESS EXERCISE

The last task for session five is a mindfulness exercise. This exercise will ask participants to focus on tuning into thoughts and sounds.

Ask for feedback (one by one if time allows). Normalise being distracted by thoughts and praise noticing (effort), rather than achieving.

Ending session 5:

- Provide a summary
- Ask for any questions
- Discuss home practice using participant workbook
- Explore any reflections.

Session six: Valued action

0-10 minutes

- Welcomes, teas and coffees, acquainting
- Recap of last week, review homework

10- 55 minutes

- Barriers to valued living and assertiveness task
- Assertiveness techniques

55-65 minutes

COMFORT BREAK

65-85 minutes

- Skills practice: Assertive communication role play (if time)
- Stepping stones metaphor

85-110 minutes

- Mindfulness practice- mindful acceptance

110-120 minutes

- Summary, questions, home practice. Reflections.

BARRIERS TO VALUED LIVING

- Today is about paying attention to the things that are truly important to you. We've been talking for the last 2 weeks about personal values, and what we can do to live our values. Sometimes this can feel really difficult though. What kind of things can get in the way of us living our values?

Look for thoughts and feelings and health symptoms / pain.

- Remember how we talked about passengers on a bus? And how our thoughts, symptoms, feelings, sensations, urges, memories, etc. are like our passengers. They often try to tell us that what you're doing is dangerous, scary, silly, difficult, or worthless. That's their job to do that. Your job is to drive the bus in the direction that you've chosen. But those passengers can make it really difficult.

ASSERTIVENESS TASK

- One thing our "passengers" can affect is how we communicate with others. Some people find that the significant changes that happen to a person's life when they have a long-term condition can make it harder for them to communicate with others. People sometimes find that they feel less confident asserting their needs. Some people talk about how they have a lot of thoughts about how they are a nuisance to others and difficult feelings of guilt that lead them to put the needs of others before their own. This is what we call being passive and is characterised by not expressing your thoughts and feelings in the way you want to and being submissive towards others.

- Other people, however, might find that they start to communicate in a more aggressive way, perhaps getting caught up with thoughts about how unfair the situation is and experiencing difficult feelings of anger and frustration. This aggressive style of communication involves expressing your own thoughts and feelings but doing this in a way that is at the expense of others, maybe by shouting or arguing.

- Another way of communicating is to be what we call assertive, which involves expressing thoughts and feelings in a calm, confident way while listening and respecting the person that you are communicating with.

- We're going to do a small task now. Share assertiveness task screen share document. We are going to go through the behaviours on the screen and decide which of the 3 circles each behaviour belongs in. We'd like you to work together and decide whether you think that behaviour is assertive, aggressive or passive, and we will place it under the correct heading, and then we'll discuss each as a group afterwards.

After the task, facilitate a discussion about each of the categories.

- Which behaviours were easy to categorise? Which were harder? What information would have made it easier to decide which category to place it in? What advantages are there to communicating in each of the styles? What about costs or disadvantages? What does your experience tell you about which communication styles work best?

- Communicating assertively can give us a choice about how we behave and communicate with other people. It has the advantages of being able to express ourselves and our needs while doing this in a way that strengthens our relationships with others and helps us to live our lives in line with our values.

- When we're trying to be assertive, there are some things that it can be helpful to bear in mind:

- Try to be clear and succinct
- Be polite but firm
- Try to keep a calm voice and body
- Use good eye contact
- Listen carefully to what the other person is saying

ASSERTIVENESS TECHNIQUES

- There are also a couple of techniques that can be very helpful in doing this. The first is called I-messages. This involves trying to start each sentence with 'I'. So, instead of saying 'You are always taking advantage of me like this', you could try 'I feel like I'm being taken advantage of'.

- One other technique that can be really helpful is the broken record technique. This involves being persistent and calmly repeating the same statement. For example, if someone stopped you in the shopping centre and tried to sell you a new Sky package, you could state, 'Thank you, but I'm not interested'. They may well say something else in reply as part of their sales pitch, to which you can calmly and politely repeat 'Thank you, but I'm not interested'.

COMFORT BREAK

ASSERTIVE COMMUNICATION DEMONSTRATION

- Facilitator's role play the following scenarios to demonstrate the use of the above techniques. Each scenario is played twice, the first time with ineffective communication and the second moving to more assertive communication. Ask participants to reflect on what the notice after each round encouraging and prompting to recognise assertiveness and the techniques.
    - Scenario:

A consultation between a medical professional and patient. The patient is unsure about taking more medication and would like to discuss other options. The medical professional feels that the medication is the best way forward and tries to insist the patient agrees to taking as prescribed.

1) Patient is passive- reluctantly agrees to go along with medical professionals' advice, knowing full well that they won't be taking the medication

2) Patient is assertive – uses the broken record technique to say thank you to the medical professional but calmly explain that they are not comfortable with taking more medication and would prefer to discuss other options.

    - Scenario:

A phone call between a person and friend/family member. The friend/family member asks the person to complete another task after they have just finished helping them for a while.

1) Person is aggressive – uses language such as 'you always expect me to do everything' and gets annoyed about them asking again when all they want to do is rest

2) Person is assertive, uses the I messages technique to say how they are feel, when, why and what they want e.g. I feel overwhelmed when you ask me to do this extra task because I have already helped quite a lot today and I need to go home and rest.

STEPPING STONES METAPHOR

- Skills like assertive communication can be really helpful in moving us towards living our values. But taking steps in the direction of our values involves making a commitment to do something. It's a bit like crossing a river to get somewhere really amazing and important to you using stepping stones. How might you go about this? You could practice first maybe, by putting some stones on the grass that you're standing on and stepping from one to another. You could maybe ask someone to demonstrate how to do it while you watch them. Are there any other ways you would go about it? [Pause] You could also try to step to the first stone by stretching out your leg [demonstrate]. But while we're trying like this, are we actually making steps towards the other side, the place that's really important to us? Notice how it looks and maybe feels a bit strange, just trying.

- What if we actually take the step forward? Stand on a bank and ask ourselves if we are completely 100% ready to commit to stepping onto the stone. And if we are, go ahead and take the step.

- What would happen if I asked you to step to a stone that's 4 feet away? Or a high boulder? Or a pebble? [Pause] Notice that we can choose to be willing to do something like stepping in some situations, like from one stone to another stone that's close by and looks stable, and not in others, such as a stone that's far away. There might be reasons for you not stepping onto the far away stone. Perhaps it's too risky for you. Or maybe it's just not important enough to you and doesn't fit in with your values. But what's clear about the stepping here is that it is all-or-nothing. You either do it or you don't. I can't stick my toes off the edge of the stone and say 'look, I'm jumping!' We can choose which situations we're going to be willing to do something in, but we can't be half-willing. Willingness is something you either do or don't have.

- What we've been trying here in this group is to start setting goals that are stepping stones to living our values every day.

- Discussion around what their experience is of setting goals – looking for avoidance (e.g., "after the group has finished" or "next year") or fusion (confidence, motivation).

MINDFULNESS EXERCISE

The last task for session six is a mindfulness exercise called mindful acceptance. This practice can take up to 20 minutes so it is a longer practice than in previous sessions. It asks participants to try to be mindful of how they are feeling emotionally and understanding where we feel that emotion in our bodies.

Ask for feedback (one by one if time allows). Normalise being distracted by thoughts and praise noticing (effort), rather than achieving.

Ending session 6:

- Provide a summary
- Ask for any questions
- Discuss home practice using participant workbook
- Explore any reflections.

Session seven: keeping things going

0-10 minutes

- Welcomes, teas and coffees, acquainting
- Recap of last week, review homework

10- 55 minutes

- Pacing: To learn about how pacing can be helpful in doing more of the things we value

- Preparing for setbacks & exercise

55-65 minutes **COMFORT BREAK**

65-85 minutes

- Moving on: To refresh what we've learned in the group - consider any thoughts or feelings as the sessions comes to an end, preparing for endings and new beginnings. Reflect upon what has been most meaningful and important to them from the sessions

85-100 minutes

- Mindfulness practice- body scan

100-120 minutes
- Goodbyes & outcomes & plan reunion

PACING

- Sometimes it can feel as though our health symptoms are very unpredictable and get in the way of us living our values. Maybe you feel better on some days, and feel like you can do the things that are important to you, but then when you do, you feel floored afterwards, maybe for days, and then miss out on things that are even more important to you. You maybe feel as though you really pay for the times when you do manage to do things. It can be hard to understand why this is happening.

- An alternative approach is to pace activities. Pacing is trying to keep doing the things you want to do, but taking regular breaks to avoid overdoing things. It's trying to pause and rest before our symptoms kick in and stop us doing more of what is important to us. Life is a marathon, not a sprint, and pacing is something that can be useful in helping us do more of the things that are important to us.

    - Imagine you have 9 things you want to get done and you are having a good day so you blast along and get 5 of them done and find that night your symptoms are really difficult and you find you can't manage anything for the next two days.

    - Now go back in time, it's that first day and you choose to do only 3 things and stop.

    - The next day you are not flared up, so you do three that day too, and stop.

    - Then on the third day you finish jobs 7, 8 and 9. After 3 days you have had your usual level of symptoms, and you have got all the things done you want to get done and not been floored by your symptoms.

- Pacing can be applied to any activity. It might mean spreading the ironing out over the course of a week, rather than trying to blast through it one day. Or perhaps buying only a few things at the supermarket every 2 or 3 days, instead of one large shop weekly shop.

- What kind of ways have you tried to pace in the past? How have you found it? What kinds of things stop you from pacing?

- When we talk about pacing, we're not talking about doing it to try to reduce, control or get rid of your symptoms. Rather, pacing can be used to do more of the things that are important to you with the symptoms that you have by taking control of behaviour, rather than letting behaviour be dictated by symptoms.

PREPARING FOR SETBACKS

- We've talked about a lot of skills that you hopefully find helpful in moving your life forward in the direction that you want to take it. However, the path ahead isn't likely to be smooth. In fact, we can probably guarantee that there will be some potholes ahead, and so we'd like to spend some time with you thinking about preparing for the potholes and punctures that lie ahead of you.

Tools metaphor

- The things that we've learned are like tools that helped you to live a more meaningful life with your health condition. And we have a great tool bag to store all of the tools in. Now you could take your toolkit and put it in your store cupboard at home, the one that's rammed full of stuff already, but you can squeeze one more thing in. And you get on with living your life.

- While you're doing that, what's happening to the tools? Maybe they're getting a bit rusty. Or maybe you're forgetting how you turn them on and operate them. You might find it hard to remember where on earth they actually are in that cupboard, and even if that is where you actually put them. So, when you hit difficulties, as is likely to happen, what do you do? You maybe spend a lot of time looking for the toolkit in a panic, feeling like you're getting nowhere, before you give up. Or maybe you find the bag and try to use the tools but can't quite remember how to use them.

- What else could we maybe do with this toolkit that we've been working on over the last six weeks? Perhaps we could leave it lying on the living room coffee table. Or beside the kettle in the kitchen. Somewhere that would keep the bag in our sight and encourage us to keep checking on the tools. We could dip into the bag regularly and use the tools to make sure they're still working ok. That way, when things are difficult, everything's to hand and we don't have to spend lots of time and energy finding the tools at a time when that feels a very difficult thing to do.

  - You could choose to take some time off from doing the hard stuff that you've been learning in this group. But there are costs or risks to this. This treatment that you've been doing for the last six weeks isn't like other treatments where you attend the hospital for treatment, and then stop. Perhaps a better way to think of this approach is that it is ongoing, and might require you to keep tinkering at these techniques, keep dipping in to them and using them regularly, to help keep you on the path that you choose to be on.

- What kind of setbacks do you think you might encounter in the days, weeks and months ahead? Often, setbacks happen at times when there are things that get in the way of us using the skills and techniques that you've been learning here. What kind of things have you faced in the past that have helped you with difficulties?

- There's a range of different things that could result in a setback, and so what you do when you're faced with this could be very different depending on your circumstances. It can be useful, though, to take some specific steps to get yourself back on track. Here are some things that you can work though when you hit a pothole.

Step 1: Stop what you are doing and notice that a setback is occurring.

Step 2: Take a moment to gather your thoughts (perhaps by practicing some mindfulness).

Step 3: Review the situation leading up to the setback. Try asking yourself:

- Where were you when it started?

-What was going on in your immediate environment?

- Who was with you?

-Was there an identified trigger?

-Did you have any particular thoughts, feelings or physical responses that were associated with the setback?

Step 4: Establish an immediate plan for action to allow your actions to remain in line with your personally chosen values and goals. This might include taking a few minutes to go for a walk, being mindful, or calling a friend for support. The plan should be quick and easy to use in the moment that you are having a setback.

- Having these kind of plans on hand and ready can help with riding out the setback. You know what will help you best to do prepare for setbacks. Take some time to write some things down below that would be helpful for you to remember to draw on if you find yourself in a setback. These could be the kind of plans we've mentioned above, or different skills that you've learned. Whatever is most meaningful to you.

Ask participants to turn to page 41 in their workbook. They may like to jot a few ideas down in the table of setbacks they think they might face in the near future and things you could try to help you to get back on your valued path. Ask if any participants are willing to share what they have written and get any feedback.

COMFORT BREAK

MOVING ON

Spend some the remainder of the session considering any thoughts or feelings as the sessions come to an end, preparing for endings and new beginnings. Reflect upon what has been most meaningful and important to them from the sessions. This is chance to recap over anything participants would find helpful to revisit and encourage participants to take things forward between now and the reunion session in 8 weeks' time.

MINDFULNESS EXERCISE

If time finish with a brief mindfulness practice.

GOODBYES AND OUTCOMES

Ask participants to complete the outcome measures. Discuss any plans for the reunion session.

Thank participants for coming along to the group. Allow participants to take some time to say goodbye to the people that they met on their journey through the group, and to share thoughts with each other on being part of the group.

Session eight: Reunion

0-20 minutes

- Welcomes, teas and coffees, reacquainting
- Provide a recap/summary of the sessions
  - Week 1: **Introduction-** getting to know each other
  - Week 2: **Bringing yourself back to the moment -** introducing mindfulness and exploring difficult thoughts and feelings
  - Week 3: **Living well with suffering** – how do we struggle and cope with difficulties and exploring the illusion of control
    - struggling in quicksand metaphor
    - primary and secondary suffering
    - ACT in a nutshell
    - Walking in the rain metaphor
  - Week 4: **Identifying values** - what are they and what are our own values? Learning to step back from thoughts.
    - passengers on a bus metaphor
    - object/photo exercise
    - speeches at a special event exercise
    - values and commitments
  - Week 5: **Values and Goals** – choosing goals based on our values and learning about problem solving
    - values worksheet
    - problem solving worksheet
  - Week 6: **Valued Action-** learning to communicate assertively, practicing mindful acceptance to facilitate moving towards our goals
    - assertiveness sort task
    - facilitator demonstration of I message and broken record

        - Week 7: **Keeping Things Going-** how pacing can be helpful, preparing for setbacks and reviewing the group.

20- 55 minutes

- ➢ Facilitate a discussion around
  - What's not gone so well in the past 2 months
  - What's gone well in the past 2 months

55-65 minutes **COMFORT BREAK**

65-85 minutes

- ➢ Obstacles – facilitate a discussion with participants to find out what obstacles have got in the way of achieving any goals and what tools/techniques they might be able to remind themselves of:
  - goal setting
  - mindfulness
  - reviewing values
  - using metaphors
  - pacing
  - problem solving

85-95 minutes

- ➢ Mindfulness practice – facilitator choice based on experiences during the main sessions

95-110 minutes

- ➢ Developing compassion for others- connectedness
  - ask participants to write down pieces of compassionate advice for the next group, use the chat function on MS teams (if they consent to do so in a shared environment) and we can make a note of any advice and share this at the beginning of the next group.

100-120 minutes
- ➢ Goodbyes & outcomes

APPENDIX 7: Participant workbook

[redacted]

Living Well with a Long Term Condition

Participant Workbook

Clinical Health Psychology Service

Week 1: Introduction to the group

Welcome to the group, this group is for people living with a long-term condition. We hope that by participating in this group, you will learn more about your problems and manage your life to the best of your abilities even though you have a long-term condition.

Our goals for this week are:

- Introductions and a chance to get to know each other.
- Guidelines for the group.
- Understand what the group is about and what to expect.

Why we are all here

Everyone in this group is here because they are living with a long-term condition. Although there are differences in your conditions and the particular problems that you face, you all have this in common. And for all of you, your long-term condition may be getting in the way of you leading the kind of life you'd like to live. Take a moment to think about why you've come along to this group and list a few reasons for this below. Then think about what you'd like to get out of the group and write this down as well.

Why am I participating in the group?	**What would I like to learn from the group?**
______________________________	______________________________
______________________________	______________________________
______________________________	______________________________

Getting to know me

We're going to spend some time getting to know each other by taking turns to introduce ourselves. Some ideas for what you could share with the group: -

1. Your name
2. Where you are from and grew up
3. How you spend your time
4. Hobbies or interests you enjoy
5. Personal goals you have in life
6. What you've written about why you're here and what you'd like to learn from the group

Overview of the group

This group is an 8-session programme (7 weekly sessions followed by an 8th reunion session roughly 2 months later). Each session includes learning new information and practicing skills as well as group discussion. Joining in all of these things as much as you are able will help you get the most out of this group.

Your long term condition

We'd like to understand a bit more about what it's like for you to live with your long-term condition. If it helps, you can use this space to write a bit about your experiences, and the impact your condition(s) has on your life now.

Week 2: Bringing yourself back to the moment

Welcome back to the group. This week we will be learning about:

- Mindfulness

- What it's like having difficult thoughts and emotions about our long-term condition

- What we do with them

What is mindfulness?

> "*The clock is running. Make the most of today. Time waits for no man. Yesterday is history. Tomorrow is a mystery. Today is a gift. That's why they call it the present*" Alice Morse Earle.

What is mindfulness?

- It is a way of living life that came from ancient Eastern spiritual practices, that centres on the present moment. That the past has happened, and the future has yet to come, and that the only place where we can truly live our lives is in the here and now.

- It is choosing to 'be' open and present in the moment, just noticing, and exploring what is happening, with the only aim of becoming more aware. Sometimes what we learn at these times can lead to us making wiser decisions about our lives.

- It is the view that everyone goes through some form of suffering in their life, but that some people go through much more suffering than others.

- It is the view that trying to get rid of suffering which cannot be changed, such as what has happened in the past, or what has been lost, can actually cause more suffering in itself.

- It is the view that if we work to make more room for the suffering that can't be changed, with greater willingness to live our lives anyway, instead of fighting it, that we can make more room for what's actually important in our lives.

- It is being aware of when, like everyone else (even mindfulness meditators), your wandering mind takes you away from the moment.
- It is being interested about where the mind, like a restless, energetic puppy, has taken us, even if we find ourselves with something painful (e.g., a distressing thought or sensation).
- It is shining a spotlight on our minds and bodies, wherein we may discover difficult things that regularly pay us a visit, such as;

  - Upsetting **thoughts**, about the past, or future.
  - Strong **feelings** such as sadness, anger, or fear.
  - Painful or unwanted **bodily sensations**
  - Unhelpful things you might do (**your behaviours**), such as trying to hide from thoughts by trying to block them out.

- It is working towards kindly allowing difficult things to be there, and accepting that if they are, then they are already part of the moment.
- It is practicing mindfulness exercises to become more aware of when your mind takes you away, in doing this, learning to gently let go of things more easily, and more able to bring your attention back to the here and now.
- It is learning to use sitting, body, movement, or other *mindfulness meditations.*
- It is learning to draw on all our senses to more fully appreciate the moment as we go about our daily lives (e.g., focusing on the colours, smells, textures, tastes and sounds around you as you mindfully eat a meal) using *mindfulness skills*.
- It is being more caring and compassionate to yourself, your situation and your difficulties. Difficulties that you did not choose, yet that which are still part of your life.
- It is being more curious, and more open about what you can do to live your life in a way that is meaningful and important to you, even with this suffering.

> *"Mindfulness means paying attention in a particular way, on purpose, in the present moment, and non-judgmentally",* Jon Kabat-Zinn.

What mindfulness is not

- Mindfulness is not a religion.

- It is not ‘auto-pilot’, going from one thing to another, in a ‘doing mode’. It is carefully making choices based on what is happening in the moment, and what is valuable to you.

- It is not a way to try to ‘control’ your feelings. Some mindfulness exercises may seem to make sadness disappear at times. Yet this is not always the case. It is a way to face your feelings, become more aware, and live your life in a valued way even with them.

- It is not giving yourself a hard time or judging yourself for the pain that you are going through. It is being kind to yourself and all that each new moment brings.

- It is not a way to distract yourself or to escape. Every realistic goal must first start from accepting the here and now. Mindfulness focuses the mind on the moment. You are not trying to get anywhere else when you do a mindfulness exercise.

- It is not a way to stop thoughts or difficult feelings from happening. They can be like trains arriving to the station. Mindfulness is a way of learning how not to jump aboard and get taken away with each passing train. That you can let some go by, and remain where you have chosen to be.

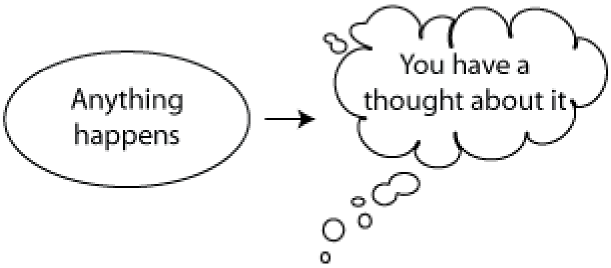
- It is not a set of relaxation exercises. The practices can be relaxing, yet in some moments they may be stressful if you are turning towards a difficult thought, feeling or bodily sensation. Each mindfulness practice is equal no matter what feelings you notice. Sometimes, mindfulness exercises can feel very hard.

- It is not an approach that can just be taught out of a manual, the teacher needs to have made a dedicated commitment to their own mindfulness practice and development.

- It is not something that you can try once or twice and hope for lasting benefits. You lay the foundations for the potential benefits by committing yourself to the practice of the meditations and mindfulness skills, daily if this is possible. Those that do this have been shown to gain the greatest benefit. Beginning to learn mindfulness is like planting a seed, it takes regularly nourishment to allow the

Understanding your thoughts and feelings about your condition

Human beings are thinking creatures. We think, plan, worry, and fantasise all the time – we can't help it! We can have thousands of thoughts per day. Anything that happens to us, or in the world around us, can lead to a thought.



Some thoughts are intentional, like when we deliberately try to remember where we left our keys, or decide what we want to eat.

Other thoughts are automatic, like when we instinctively make a snap judgement ("That's ugly"), or when we judge other people ("They're horrible"), or ourselves ("I'm useless", "I shouldn't have done that").

The Upsides and Downsides Of Thinking

Thinking is what makes humans special: it means that we can plan, imagine, and fantasize. This is tremendously useful and is why we are so capable and ingenious. It means we can make complicated decisions, solve difficult problems, live together in groups, cooperate, and help one another. But thinking comes with costs too: we can also worry, ruminate, and criticise ourselves. Sometimes our thoughts can be overwhelming and we wish we could turn them off.

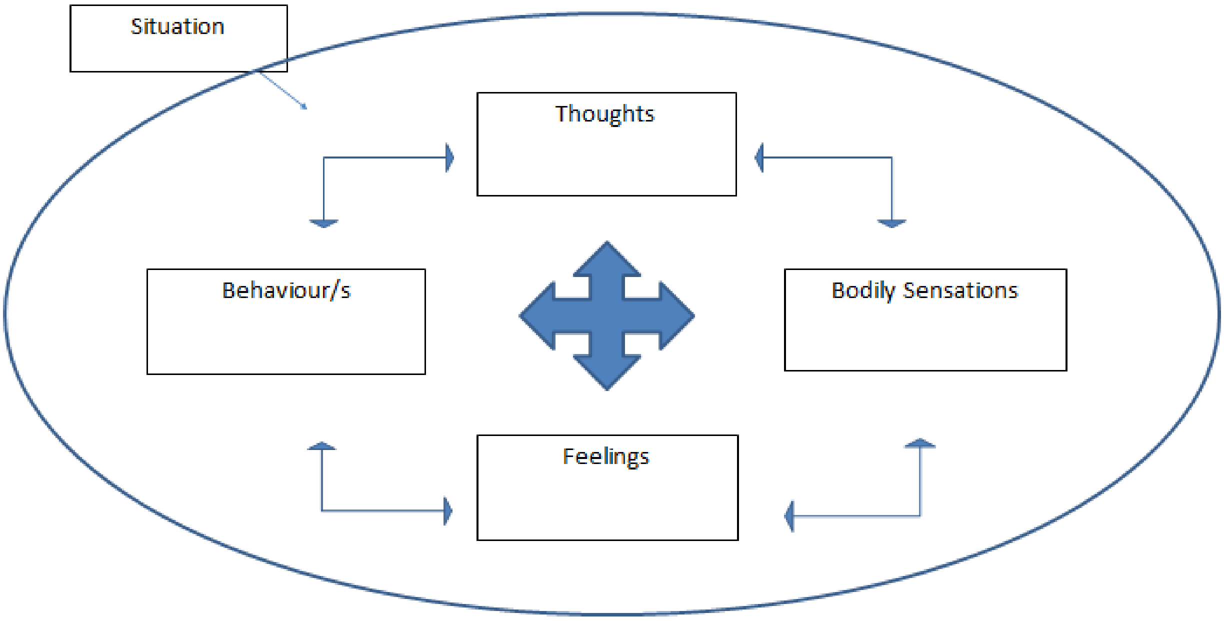
In any chronic illness, it can be hard to keep a positive outlook. The unpredictability of symptoms and the limitations they bring to so many everyday activities can make life very difficult. It is not surprising that at times people can feel demoralised, helpless and worried about the future.

The Thought-Feeling Link

It is often assumed that a situation or event produces a feeling or reaction. However, it is not that simple. Events or situations do not 'make' us react in a certain way. Rather, there is an intervening step that affects how we feel and what we do. The intervening step is our thoughts. Our thoughts occur automatically, often without our being aware of them. They are shaped by our beliefs and values and they help us to make sense of our world. We do this by making ‘interpretations’ about the events that happen around us. It is these interpretations (our thoughts) of an event or situation that can affect the way we feel which in turn may affect the way we behave.

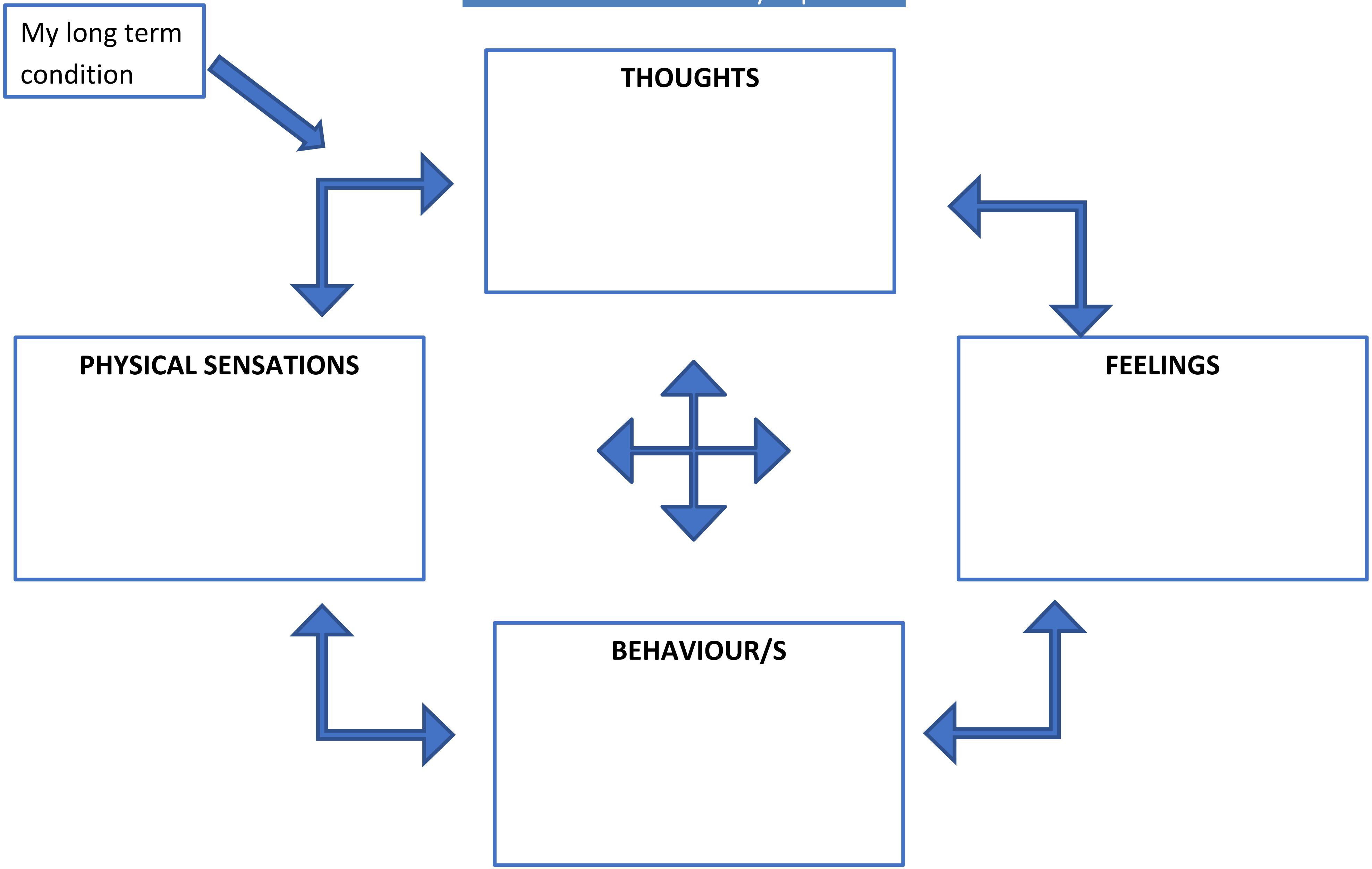
Thought – Feeling Cycle

Humans are very complex beings, so the cycle goes both ways. In addition to how we think affecting our feelings and actions, our feelings and actions can influence how we think. Our thoughts, feelings and actions are always interlinked, with arrows going in all directions.



In addition to this, we often experience physical sensations connected with anxiety and feeling low. These are a natural stress response. With anxiety these include tense, tight muscles, increased heart rate, sweating and shallow breathing. For low mood they can include increased lethargy, fatigue and pain.

Session two handout: My Experience



My long term condition

THOUGHTS

PHYSICAL SENSATIONS

FEELINGS

BEHAVIOUR/S

Home commitments for session two

1. Take a look at the ‘What is mindfulness’ handout

2. Listen to a mindfulness practice (either ‘Leaves on a stream’ or ‘Breathing anchor’) on YouTube for 5 days out of 7 between now and next session

Breathing anchor

Mindfulness Meditation Breathing anchor
Teik Yen Ko • 410K views • 3 years ago
Guided mindfulness meditation

https://www.youtube.com/watch?v=fUeEnkjKyDs

Leaves on a stream

Leaves on a stream
Guernsey Health and Social Care -

https://www.youtube.com/watch?v=yIlZHoiOb0s

3. What happened in session two? What was important to you?

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4. Thinking back on what we discussed on how common it is to have difficult thoughts and feelings about long term conditions, please write down any difficult thoughts that come to mind

1. ……………………………………………………………………………

2. ……………………………………………………………………………

Remembering that these are opinions of the mind.

Week 3: Living well with suffering

This week we will be learning about:

- The struggle - primary and secondary suffering

Primary and secondary suffering

When you have a long-term health condition, the obvious problems come from your symptoms, for example pain, fatigue, and itching, palpitations, balance problems etc symptoms - these can be described as ***primary suffering***. However, living with a long-term condition can bring other difficulties, including stress, worry and low mood. Your health may stop you doing things you want or need to do, or you may not see as much of your friends and family. Treatments you try may have unpleasant side-effects, or may not help as much as you hoped, leading to disappointment. All these additional difficulties can be described as ***secondary suffering***. Some people find that these secondary difficulties can make their symptoms worse, for example being stressed and worried means that pain increases, and so a vicious cycle develops.

It's a bit like having to carry a cushion everywhere you go - it makes it difficult to go about your life. But when we start adding more and more cushions to a pile in your arms, life becomes increasingly difficult. Your symptoms are like the first cushion, but your secondary suffering is the additional cushions piled on top. If we could find a way to put down some of the cushions, wouldn't life feel a little bit easier?

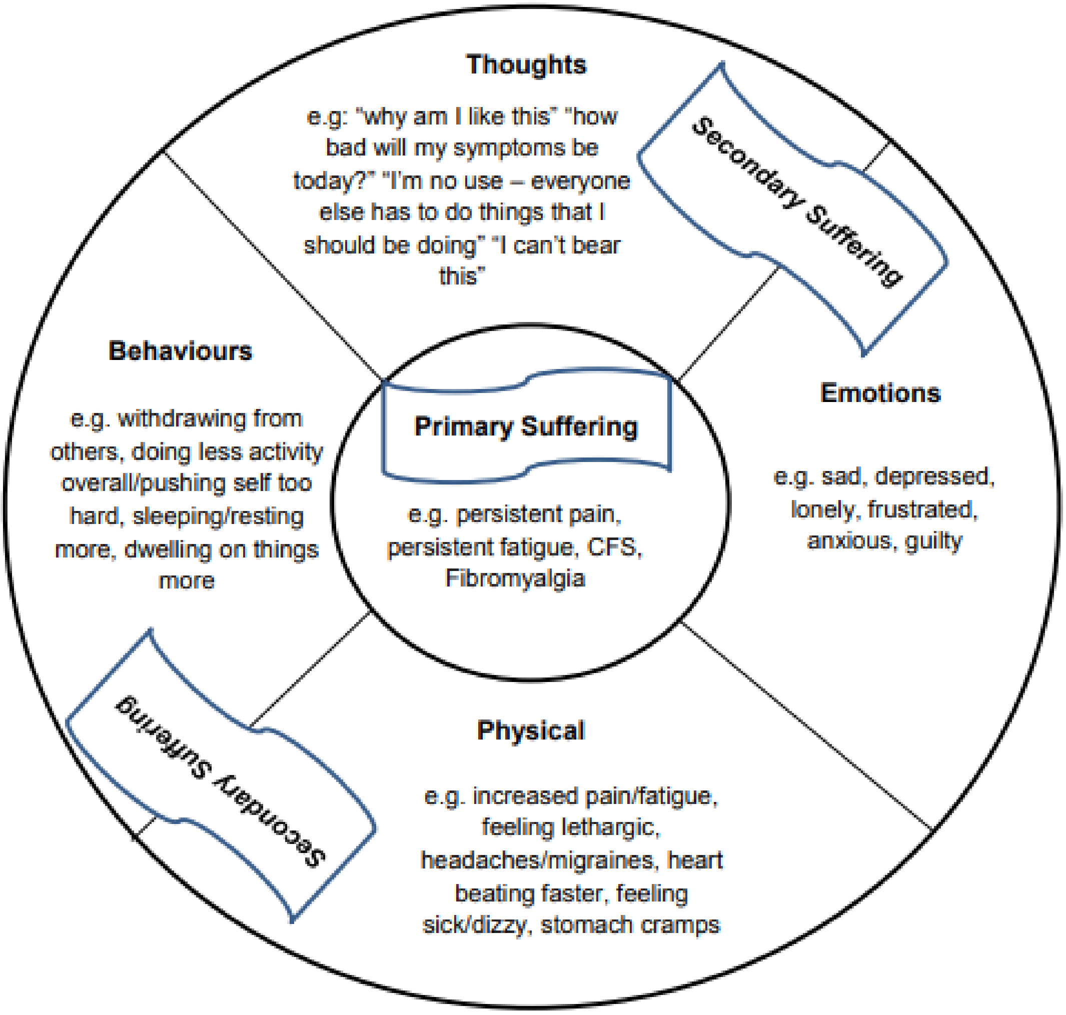
Although we don't mean it to, ***how we respond*** can add to the suffering we are experiencing overall. Whilst we may not be able to completely get rid of the symptoms, we can think about how we respond to it. These sessions will focus on ways which you can ***manage*** and ***start to reduce*** your secondary suffering.

These worksheets might help you to think about your primary and secondary suffering, and the impact they have on your life. You may also find it useful to think about things you have tried to help manage your symptoms and the ways in which these may have been helpful and unhelpful.

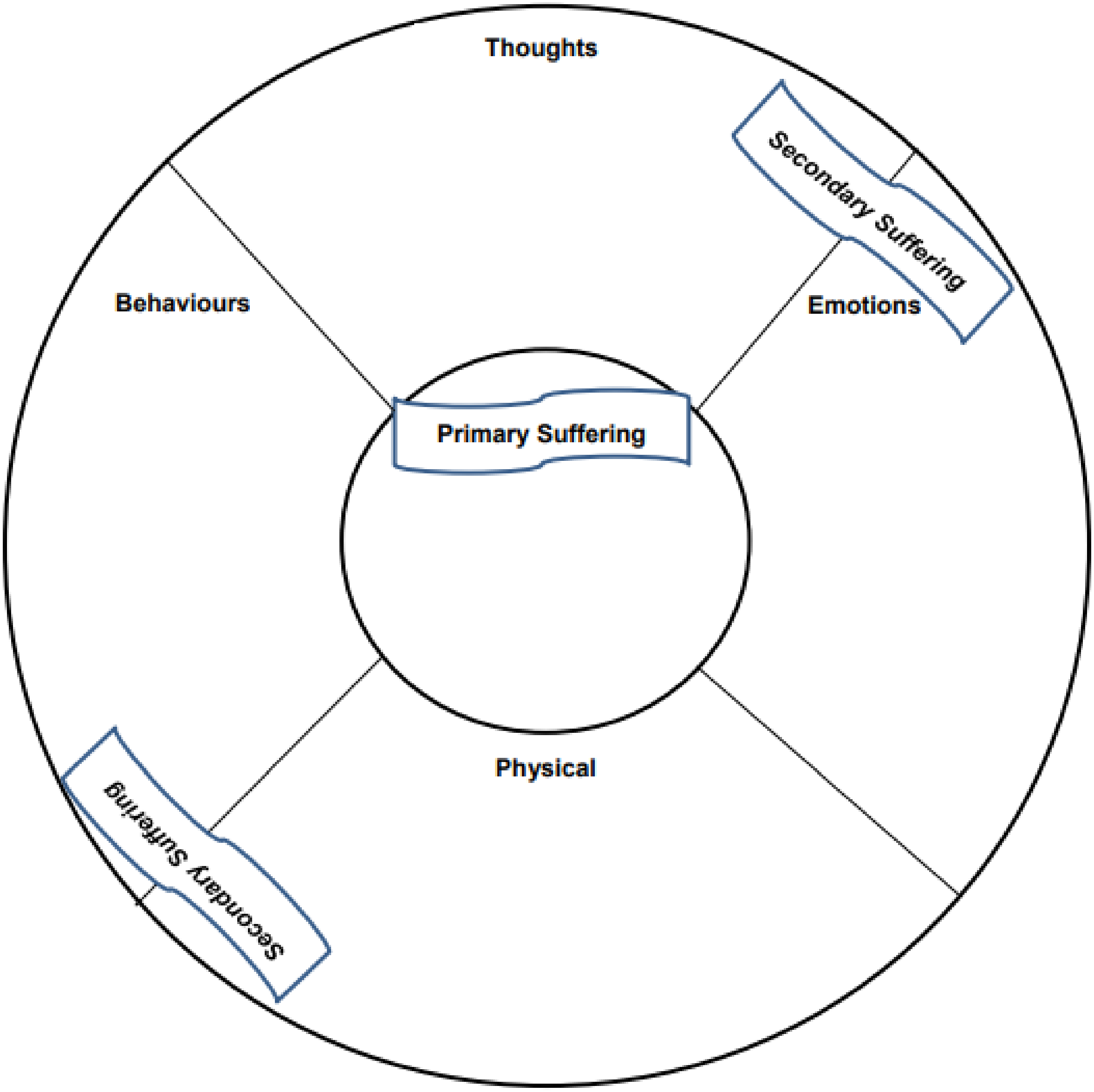
Primary and Secondary suffering

The diagram below gives us a way of organising our primary and secondary suffering so that we can see how different areas link together. Thoughts, emotions, behaviours and physical sensations are tightly linked together and difficulties in one area often lead to difficulties in another. For instance, as in the example below, a person experiencing persistent pain or fatigue may respond by doing less and resting more. This can lead to thoughts such as “I’m no use – everyone else has to do things that I should be doing”, which can then lead to feelings of anxiety and frustration. Anxiety and frustration can then lead to further physical sensations such as increased tension and therefore increased pain and fatigue.

By identifying how this process impacts our own lives, we can begin to figure out ways to make changes. Take some time to fill in your own Primary and Secondary Suffering using the diagram below.



My Primary and Secondary Suffering:



How do you try to cope with your suffering?

How do you suffer as a result of your condition? (remember that difficult thoughts and feelings can be part of suffering). ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… …………………………………
Do you try to control, or stop the suffering? If so, how? ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… …………………………………
Does what you do to try to cope make your life worse in any way? ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… ………………………………………………………………………… …………………………………………………………

Getting rid of thoughts and feelings

Trying to get rid of the difficult symptoms, thoughts and feelings that illness brings is very understandable. If we could just get rid of them, we'd be able to get on with things. But it doesn't usually work like that. If you try not to think about something, it usually ends up being in our thoughts. What does your experience tell you about trying to get rid of a sad feeling by telling ourselves to "Cheer up!"? Or how about stopping thinking about that worrying appointment we've got coming up?

Your experience is probably starting to suggest to you that trying to control or get rid of your thoughts and feelings doesn't work. We can put a lot of effort into trying to control our problems, but **the harder we try to quieten them down, the louder they seem to get.**

Walking in the rain

Imagine you're outside, walking somewhere that you need to go to, and it suddenly starts to rain. No, not rain, pour down. It's really bucketing and you're starting to get wet. You've got quite a long way to go and no umbrella on you. You're starting to feel fed up and cold and miserable. What would happen to your body and posture? Imagine it now and let your body sense it and change as it would if it were happening right now. Make some notes here about how your body has changed while you've been imagining walking in the rain.

OK, let's stick with the same scenario; you're still outside walking in the pouring rain and getting soaked, but this time try imagining that your attitude was "OK, I'm getting wet. I can't do anything about it. Wish I'd remembered my umbrella. Oh well, never mind. I'm still getting really wet!" Pay attention to how this feels in your body and what's happened to your posture with this. Write down how your body changed this time.

Think about the differences between these two scenarios. Which one do you get more wet in? What does this have to do with living with a long term condition?

Being **willing** to be wet while we walk where we want to go is a bit like **doing what's important to us even though we have a health problem**. We may not be able to change some things like rain, but if we can change how we react to it, it changes our experience. What we're going to be doing over the next few weeks is learning about how to live life in the presence of the difficulties that you have with your long term condition, while connecting to things that are important to you in the here and now.

Home Practice for Session Three

1. Listen to a mindfulness practice (either ‘Leaves on a stream’ or ‘Breathing anchor’) on YouTube for 5 days out of 7 between now and next session

Breathing anchor

Mindfulness Meditation Breathing anchor

Teik Yen Ko • 410K views • 3 years ago

Guided mindfulness meditation

https://www.youtube.com/watch?v=fUeEnkjKyDs

Leaves on a stream

Leaves on a stream

Guernsey Health and Social Care ·

https://www.youtube.com/watch?v=yIlZHoiOb0s

2. What happened in session three? What was important to you?

……………………………………………………………………………

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3. Thinking back on what we discussed about suffering, the struggle, and beginning to bring more willingness to be present even with the difficulties, write down one or two activities that are important to you, that you **CAN** do even with your condition (e.g., I can go for a coffee with a friend, even if I'm worried about the way I look)
    1. …………………………………………………………………… ……………………………………………………………………
    2. …………………………………………………………………… …………………………………………………………………..
    3. …………………………………………………………………… ………………………………………………………………

4. Bring a photo (or photos) or object to represent what is important to you. It is entirely up to you what you bring. What matters is that this photo or object in some way matters to you.

Week 4: Identifying values

This week in the group we will learn about:

- *Values and what they are*
- *What our own values are*

Difficult thoughts and emotions about our illness

Sometimes our symptoms, thoughts and feelings about our illness can get in the way of us doing what is important to us. One way to think of it is like you're the driver of a bus. As the driver, you know where this bus is going. Its somewhere you know you really want to go, somewhere really important to you. At the same time, there are some scary passengers on this bus. These passengers are like your thoughts, feelings, body sensations and memories. These passengers don't always want to go where you want to, and when you don't go their way, they let you know about it. So let's say you want to take this bus that is your life, in the direction of going out for a meal with someone you really care about. One of the passengers starts saying things like *"I wouldn't bother, you're just going to end up sore and uncomfortable."* Think about the kind of things your passengers sometimes say to you. Perhaps they tell you that you're stupid? Or a nuisance to your loved ones?

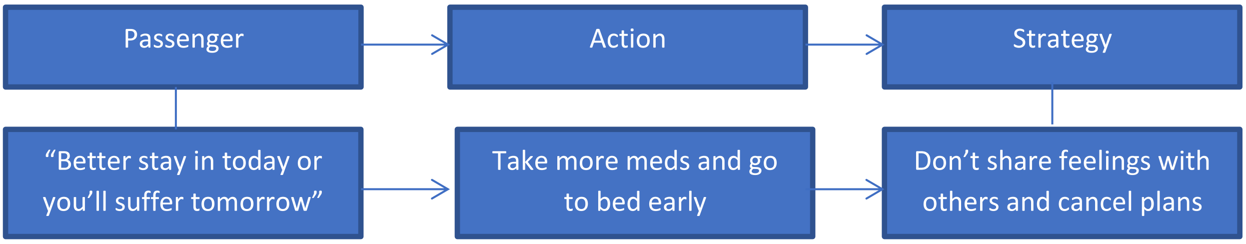
Make a note of what your passengers say, and perhaps what they look like, here.

These passengers might rush up behind you, shout in your face, threaten you – they're basically bullying you into doing what they say. So, understandably, you choose to do what they say, and not go where you want to go and they settle down, into the back of the bus and out of sight. Maybe you make a deal with them – "if you sit in the back and hide down behind the seats so I can't see you, I'll go wherever you want me to". In the meantime you're driving around in circles, and not going anywhere in particular, just driving aimlessly.

Now you may get fed up with this eventually. Maybe the next thing you try is getting rid of these nasty passengers. So to do that, you first stop the bus and then head up towards the passengers to confront them. But notice, the very first thing you had to do here was stop the bus. Where is your bus going right now? Is it going to that really important place you want it to go to? When you go to try to deal with the nasty passengers - and there are many of them – they look ready to fight you. You give it your best shot and wrestle with them. But ask yourself this – how well has it worked? And notice that all the time you fight them, ***the bus is not going anywhere.***

And so it's back to the old agreement, if they leave you alone, you will only go where they say and nowhere else. Pretty soon, they don't have to tell you where to go, you can predict it. You see the turn coming up and know as soon as you see it that they're going to start yelling "Turn right!" Over time you can maybe even pretend that you don't have any passengers any more. You maybe tell yourself that's where you just have to go. However, when they do show up, it's with the added power from the deals you've made with them before.

Notice this interesting part, the key thing - these passengers have never done you any physical harm. They cannot, and never will. What they're basically saying is "If you don't do what we say, we're going to come right up to you, and you're going to have to look at us". All they've got over you is the ability to intimidate. They do look really nasty, horrible and scary, there's no getting away from that. However, the only power they have over you is the power you give them. You are the driver and you trade your control over the bus to keep the passengers away. Your passengers are maybe telling you that what you're doing is dangerous, scary, silly, difficult, worthless. That's their job to do that. Your job is to drive the bus in the direction that you've chosen.



Passenger	Action	Strategy
"Better stay in today or you'll suffer tomorrow"	Take more meds and go to bed early	Don't share feelings with others and cancel plans

What are values?

Being able to step back from our thoughts can help us to be in charge of our bus and make sure we're heading in a direction that's valued and important to us. But what does that really mean? And how do you know which direction to take?

Values are…

- What you want to live by and for
- Personal
- Your choice
- Give life direction and meaning

Think of someone that you think of as inspirational, ideally not a family member. It could be someone famous, or someone you know. What do you think their values are? What's important to them? What do they stand for in life? Use this space to think about this.

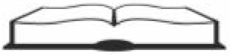
Values are a bit like a compass. They guide you as to the direction for your journey through life. We might pass landmarks on the way – perhaps a hill, a town or a tower – these are like goals, destinations. We might 'arrive' at these things, but we never arrive at our valued direction. Our track might waver from the direction that the compass guides us in, and we might feel a bit lost or confused, but our compass can guide us back to the path that's important to us.

You might have values for a number of areas of your life, such as:


Family


Work


Self-care


Personal growth


Leisure

During the exercises in the group, you will have thought about or talked about what kind of values are important to you. What you want to stand for in life? What you want to be remembered for? Make a note of the values that you connected with in the session here.

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________
7. ______________________________
8. ______________________________
9. ______________________________
10. ______________________________

Commitments

Make a note of any commitments you would like to work towards:

What are you willing to do today?

____
____
____
____

List of Values

Honour
Wisdom
Integrity
Peace
Beauty
Nesting
Nurturance
Balance
Faith
Spirituality
Love

Experience
Learning
Loyalty
Reliability
Order
Respect
Thoughtfulness
Patience
Tolerance
Serenity
Attentiveness

Freedom
Curiosity
Openness
Perseverance
Calm
Wonder
Humour
Organisation
Stability
Security
Meaning

Flow
Structure
Rhythm
Excitement
Wit
Sustainability
Self sufficiency
Independence
Leadership
Kindness
Expansiveness

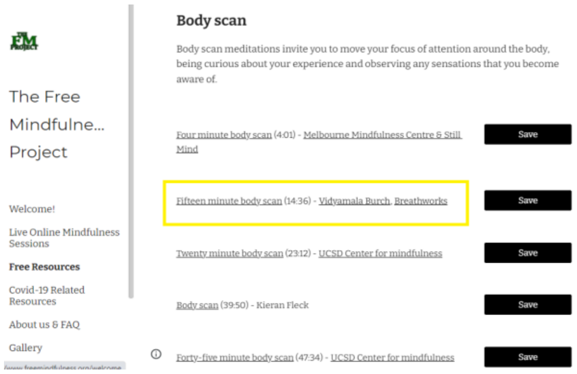
Strength
Communication
Self-expression
Imagination
Creativity
Forgiveness
Intuition
Compassion
Diversity
Equality
Caring
Intimacy
Sensuality
Play
Fun
Effort
Productivity
Health
Understanding
Intelligence
Adventure
Risk
Courage
Power
Connectedness
Citizenship
Belonging
Simplicity
Conservation
Spontaneity
Comfort
Warmth
Discipline
Justice
Detachment

Home practices for Session Four

1) Listen to a mindfulness practice (try the ‘Body Scan’) on YouTube for 5 days out of 7 between now and next session

http://www.freemindfulness.org/download

Scroll down to ‘Body scan’ and we recommend the ‘Fifteen-minute body scan’ practice by Vidyamala Burch.



Body scan

Body scan meditations invite you to move your focus of attention around the body, being curious about your experience and observing any sensations that you become aware of.

Four minute body scan (4:01) - Melbourne Mindfulness Centre & Still Mind

Fifteen minute body scan (14:36) - Vidyamala Burch, Breathworks

Twenty minute body scan (23:12) - UCSD Center for mindfulness

Body scan (39:50) - Kieran Fleck

Forty-five minute body scan (47:34) - UCSD Center for mindfulness

2) What happened in session four? What was important to you?

………………………………………………………………………………………

………………………………………………………………………………………

……………………………………………………………………………

3) Can you think of three of your most important values?

A) ……………………………………………………………………………

B) ……………………………………………………………………………

C) ……………………………………………………………………………

4) You are invited to make one small commitment today in line with one of your values by doing something that helpfully moves you towards this value.

Week 5: Values and Goals

The group will focus this week on:

- Choosing goals based on our values
- Stepping back from our thoughts
- Learning about solving problems

Goals based on our values

Last week we started to think about steps that we could take towards our valued direction in life. This week, we are going to take this further and talk about setting goals in line with our values. When you are thinking about goals, it can be helpful to follow four steps:

1) Choose one value to focus on.

2) Brainstorm goals in line with this value.

3) For each goal, think about small, immediate actions, as well as short, medium and long term ones that will help you to achieve your goal.

4) Finally, try to make sure your goals are SMART.

SMART goals for mindful valued living

Often we can have difficult thoughts, feelings or sensations that can cause us to veer off course in a direction away from where we were wanting to head. One way to try to work with the passengers on our buses is to make sure that all of our immediate, short- and long- term goals are SMART.

Specific – Define the goal well. Where? Who with? Exactly what you want to achieve? Make it something you can clearly see if you have done it or not.

Meaningful – Make sure it something that fits with one of your values, that you are not just aiming to get there to please someone else, or through purely trying to avoid unavoidable suffering for examples. It needs to be meaningful to you.

Adaptive – If you achieve the goal will it help you to live a more fulfilling, richer, life? Make sure that the goal will be of benefit.

Realistic – Is this an impossible goal? Make sure it is something you can achieve in your current situation.

Time-framed – Give yourself a time-frame to try to meet this goal. When will you do this? Day? Date? Time?

- It can also help to share your goal with another person close to you. This can make it more likely that you will achieve the goal you set yourself.

- Remember that the practice of mindfulness can continually support you to reach your goals.

Values and Goals Worksheet

Value that needs to be turned towards for my wellbeing.	Long term goal (e.g., How would I like things to be different in 6 months?)	Short term goal (e.g., What can I commit to do by next week, next month?)	Difficult thoughts, feelings, sensations that I'm willing to make room for to get there…	When it does get hard it would be useful to tell myself…	Immediate goal (what can I do right now, today, to live in service to this value?)

Barriers to achieving goals

Sometimes other things can get in the way of us working towards our values-based goals and living our life in line with our values. When this happens, the first step we need to take is to be clear about which value we are struggling with, and what it is that is getting in the way. This can help us to step back from the thoughts about the problem and in starting to look towards what we want to do about them. Once we have our problem written down, there are some steps that we can follow to take action and get us back on our valued path:

1) *Identify the problem*
2) *Brainstorm all the different solutions you could try.*
    - *It's helpful at this point to include absolutely anything, even impossible or silly options, as these can sometimes spark off a very useful option. It's also best to try to stick to thinking of as many options as possible without starting to think through the detail of any of them at this point.*
3) *Go through the list of possible solutions and select the top 3*
4) *Think about the pros and cons of each option.*
5) *Choose the option that makes the most sense for you in terms of living your values. Break your chosen option down into step-by-step actions.*

Using these kind of problem solving strategies can be very helpful in moving us towards doing more of what we value. But it's important that we are aware of when it's helping us to do this, and when it's not, so that we can make a choice about whether it is the right tool for us in that moment.

Problem Solving Worksheet

Identify any problems to achieving your goal:

Possible solutions:

List top 3 solutions:
1.

2.

3.

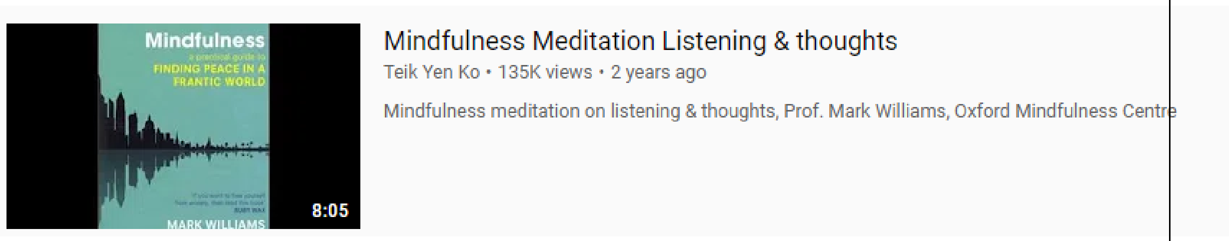
	Advantages	Disadvantages
Solution #1		
Solution #2		
Solution #3		

Decide on actions:

What might get in the way?

Home commitments for Session Five

1. Continue to practice mindfulness.



Mindfulness Meditation Listening & thoughts

Teik Yen Ko • 135K views • 2 years ago

Mindfulness meditation on listening & thoughts, Prof. Mark Williams, Oxford Mindfulness Centre

https://www.youtube.com/watch?v=OFeTTgl_wAI

2. What happened in session five? What was important to you?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

3. If you have not done so, complete the values and goals exercise that you started in the session. Remember what was said about how this can be a step towards living a richer, more fulfilling life even with your condition.

4. Work towards completing your immediate goals you set out. You may wish to have a think about breaking your short-term goals into even smaller steps.

Week 6: Valued Action

Our goals for this week are:-

- To learn about communicating assertively
- To practice mindful acceptance

Assertive communication

Remember how we talked about passengers on a bus? And how our thoughts, feelings, sensations, urges, memories, etc. are like our passengers? They often try to tell us that what you're doing is dangerous, scary, silly, difficult, or worthless. That's just what they do. Your job is to drive the bus in the direction that you've chosen. But those passengers can make it really difficult.

One way our "passengers" can make it difficult to go in our valued direction is by affecting how we communicate with others. Some people find that the significant changes that happen to a person's life when they have a health problem can make it harder for them to communicate with others. People sometimes find that they feel less confident asserting their needs. Some people talk about how they have a lot of thoughts about how they are a nuisance to others and difficult feelings of guilt that lead them to put the needs of others before their own. This is what we call being passive, and is characterised by not expressing your thoughts and feelings in the way you want to, and being submissive towards others.

Other people, however, might find that when they are struggling with their passengers, they start to communicate in a more aggressive way, perhaps getting caught up with thoughts about how unfair the situation is and experiencing difficult feelings of anger and frustration. This aggressive style of communication involves expressing your own thoughts and feelings, but doing this in a way that is at the expense of others, maybe by shouting or arguing.

Another way of communicating is to be what we call assertive. This involves expressing thoughts and feelings in a calm, confident way while listening and respecting the person that you are communicating with.

Communicating assertively has the advantages of being able to express ourselves and our needs while doing this in a way that strengthens our relationships with others and helps us to live our lives in line with our values.

When we're trying to be assertive, there are some things that it can be helpful to bear in mind:

- Try to be clear and succinct
- Be polite but firm
- Try to keep a calm voice and body

- Use good eye contact
- Listen carefully to what the other person is saying

There are also a couple of techniques that can be very helpful in doing this.

I-Messages: This involves trying to start each sentence with 'I'. So, instead of saying 'You are always taking advantage of me like this', you could try 'I feel like I'm being taken advantage of'.

See if you can practice converting these sentences into I-Messages:

You make me so angry!____

Why won't you just do what I ask!_______________________________________

You're not listening to me____

Broken Record: This involves being persistent and calmly repeating the same statement. For example, if someone stopped you in the shopping centre and tried to sell you a something, you could state, 'Thank you, but I'm not interested'. They may well say something else in reply as part of their sales pitch, to which you can calmly and politely repeat 'Thank you, but I'm not interested'.

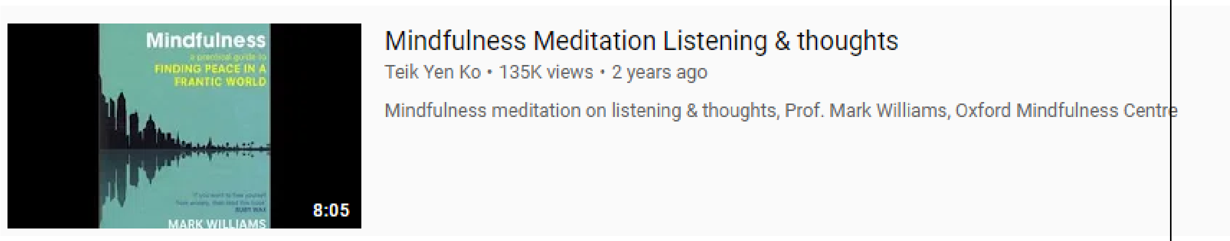
Stepping stones

Skills like communicating assertively can be really helpful in moving us towards living our values. But taking steps in the direction of our values involves making a commitment to do something. We can't just be a little bit committed to doing something. It's all-or-nothing.

Remember our task identifying values and goals? One of them was to invite a friend round for a catch-up. Often we might hear ourselves say that we're going to try to do goals like this. But being half-willing to carry out a goal doesn't work. You either invite your friend round or you don't, there's no half-way house. Willingness is something you either do or don't have. There might be reasons for you not inviting your friend round. Ask yourself: do you need to be completely free of barriers to your goals (or reasons not to do something) before you are willing to commit to them?

Home commitments for Session Six

1. Continue to practice mindfulness.



Mindfulness Meditation Listening & thoughts

Teik Yen Ko • 135K views • 2 years ago

Mindfulness meditation on listening & thoughts, Prof. Mark Williams, Oxford Mindfulness Centre

https://www.youtube.com/watch?v=OFeTTgl_wAI

2. What happened in session six? What was important to you?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

2. Try to make time regularly to consider your values and choose commitments to help you live your values. These could be things that you identified in last week's homework, or new goals and actions. Use the record sheet on the next page to write about your commitments and what resulted from them. We'll talk about this more at the group next week.

Commitments record sheet

Day	Commitment	Results

Week 7: Keeping Things Going

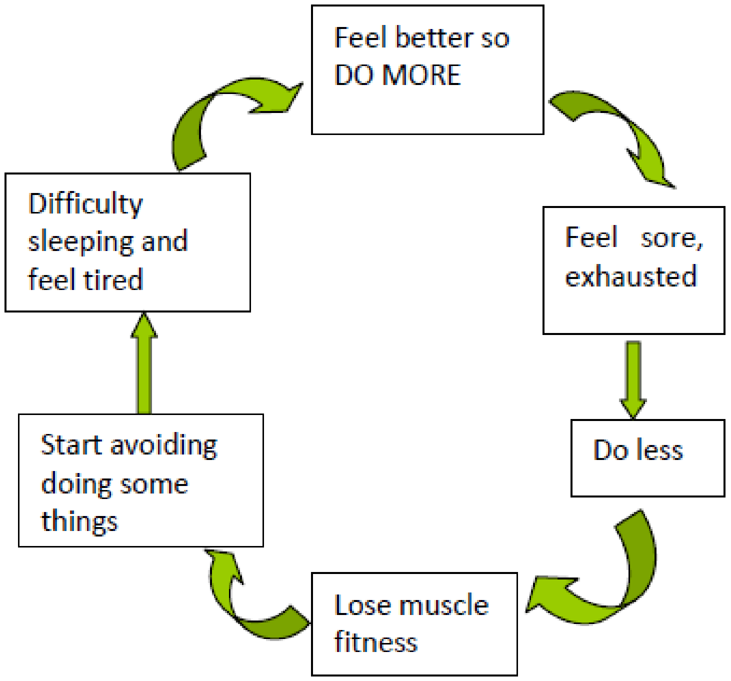
Our goals for this week are:

- To learn about how pacing can be helpful in doing more of the things we value
- To prepare for setbacks.
- To refresh what we've learned in the group.

Pacing

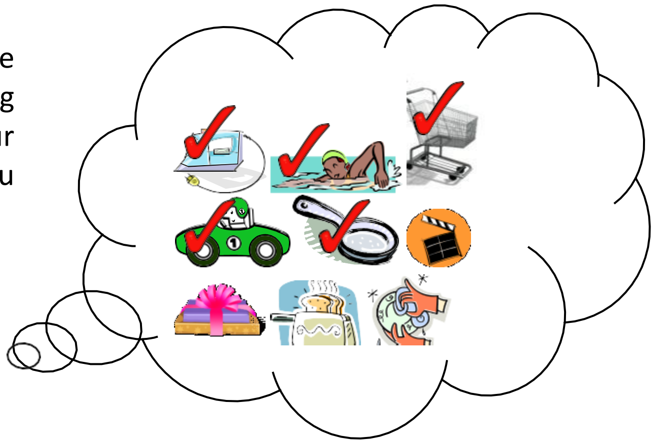
Sometimes it can feel as though our pain or health symptoms are very unpredictable and get in the way of us living our values. Maybe you feel better on some days, and feel like you can do the things that are important to you, but then when you do, you feel floored afterwards, maybe for days, and then miss out on things that are even more important to you. You maybe feel as though you really pay for the times when you do manage to do things. It can be hard to understand why this is happening.

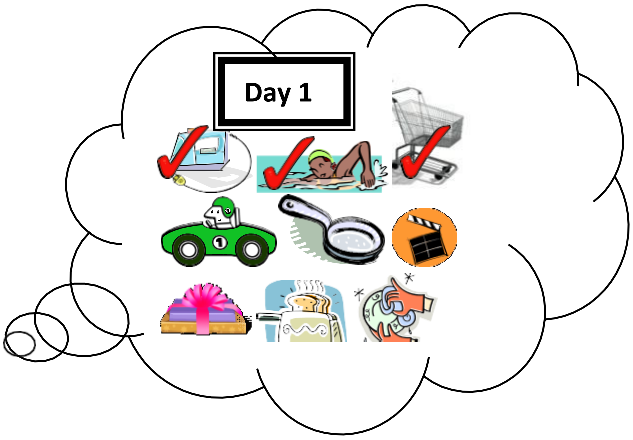
One way to think of it is:



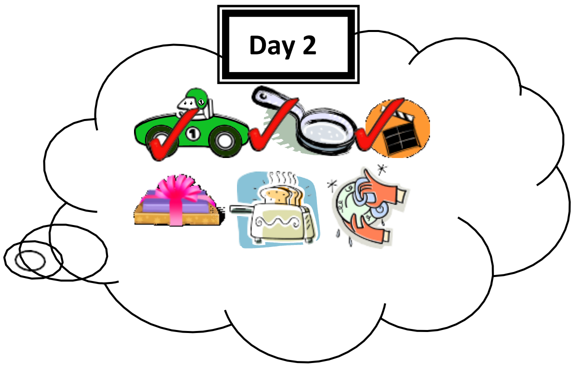
An alternative approach is to pace activities. Pacing is trying to keep doing the things you want to do, but taking regular breaks to avoid overdoing things. It's trying to pause and rest before our symptoms kick in and stop us doing more of what is important to us. Life is a marathon, not a sprint, and pacing is something that can be useful in helping us do more of the things that are important to us.

Imagine you have 9 things you want to get done and you are having a good day so you blast along and get 5 of them done and find that night your symptoms are really difficult and you find you can't manage anything for the next two days.

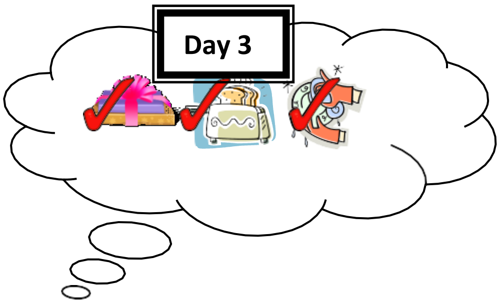




Now go back in time, it's that first day and you choose to do only 3 things and stop.



The next day you are not flared up, so you do three that day too, and stop.



Then on the third day you finish jobs 7, 8 and 9. After 3 days you have had your usual level of symptoms, and you have got all the things done you want to get done and not been floored by your symptoms.

Pacing can be applied to any activity. It might mean spreading the ironing out over the course of a week, rather than trying to blast through it one day. Or perhaps buying only a few things at the supermarket every 2 or 3 days, instead of one large shop weekly shop.

What kind of ways have you tried to pace in the past? How have you found it? What kinds of things stop you from pacing?

When we talk about pacing, we’re not talking about doing it to try to reduce, control or get rid of your symptoms. Rather, pacing can be used to do more of the things that are important to you with the symptoms that you have by taking control of behaviour, rather than letting behaviour be dictated by symptoms.

Preparing for setbacks

We’ve talked about a lot of skills that you hopefully find helpful in moving your life forward in the direction that you want to take it. However the path ahead isn’t likely to be smooth. In fact, we can probably guarantee that there will be some pot holes ahead, and so we’d like to spend some time with you thinking about preparing for the pot holes and punctures that lie ahead of you.

The things that we've learned are like tools that helped you to live a more meaningful life with your health condition. And we have a great toolbag to store all of the tools in. Now you could take your toolkit and put it in your store cupboard at home, the one that's rammed full of stuff already, but you can squeeze one more thing in. And you get on with living your life.

While you're doing that, what's happening to the tools? Maybe they're getting a bit rusty. Or maybe you're forgetting how you turn them on and operate them. You might find it hard to remember where on earth they actually are in that cupboard, and even if that is where you actually put them. So when you hit difficulties, as is likely to happen, what do you do? You maybe spend a lot of time looking for the toolkit in a panic, feeling like you’re getting nowhere, before you give up. Or maybe you find the bag and try to use the tools, but can't quite remember how to use them.

What else could we maybe do with this toolkit that we've been working on over the last seven weeks? Perhaps we could leave it lying on the living room coffee table. Or beside the kettle in the kitchen. Somewhere that would keep the bag in our sight and encourage us to keep checking on the tools. We could dip into the bag regularly and use the tools to make sure they're still working ok. That way, when things are difficult, everything's to hand and we don't have to spend lots of time and energy finding the tools at a time when that feels a very difficult thing to do.

You could choose to take some time off from doing the hard stuff that you've been learning in this group. But there are costs or risks to this. This treatment that you've been doing for the last seven weeks isn't like other treatments where you attend the hospital for treatment, and then stop. Perhaps a better way to think of this approach is that it is ongoing, and might require you to keep tinkering at these techniques, keep dipping in to them and using them regularly, to help keep you on the path that you choose to be on.

What kind of setbacks do you think you might encounter in the days, weeks and months ahead? Often, setbacks happen at times when there are things that get in the way of us using the skills and techniques that you've been learning here. What kind of things have you faced in the past that have helped you with difficulties?

Use this table to write about setbacks you think you might face in the near future and things you could try to help you to get back on your valued path.

Setback	Things I could try to get back on my path

There's a range of different things that could result in a setback, and so what you do when you're faced with this could be very different depending on your circumstances. It can be useful, though, to take some specific steps to get yourself back on track. Here are some things that you can work though when you hit a pot hole.

Step 1: *Stop what you are doing and notice that a setback is occurring.*

Step 2: *Take a moment to gather your thoughts (perhaps by practicing some mindfulness).*

Step 3: *Review the situation leading up to the setback. Try asking yourself:*

- Where were you when it started?

-What was going on in your immediate environment?

- Who was with you?
- Was there an identified trigger?

- Did you have any particular thoughts, feelings or physical responses that were associated with the setback?

Step 4: *Establish an immediate plan for action to allow your actions to remain in line with your personally chosen values and goals. This might include taking a few minutes to go for a walk, being mindful, or calling a friend for support. The plan should be quick and easy to use in the moment that you are having a setback.*

Having these kind of plans on hand and ready can help with riding out the setback. You know what will help you best to do prepare for setbacks. Take some time to write some things down below that would be helpful for you to remember to draw on if you find yourself in a setback. These could be the kind of plans we've mentioned above, or different skills that you've learned. Whatever is most meaningful to you.

Try writing these plans down on a small card and carrying it about with you, perhaps in your pocket, inside your phone case or in your wallet or purse.

Moving on

Thank you for coming along to the group. We hope you've found it helpful. This workbook is yours to keep. You might find it useful to dip into it regularly and remind yourself of the different things that you've learned, and the notes that you've made.

If you feel that you've not come as far as you had hoped, remember that you can continue to make progress over the coming weeks, months and even years. It can take time for new skills to be learned and consolidated so that they're part of our everyday life. The things that you have tried in this group have not been easy. Your experiences are always changing though. As you pass through challenging, or easier, times, remember that this will pass. Checking your compass regularly to move you towards your valued direction in life will help you with this.

You can use this space to leave yourself a message should you find yourself looking over this book in the future. Something that might help you to get back on track if you need to, telling yourself how you've been feeling when you've managed to live your life more as you would like.

Thank you for joining us and for everything you've brought along to the group. Take some time to say goodbye to the people that you have met on your journey through the group, and to share your thoughts with each other on being part of the group.

Very best wishes for your future

APPENDIX 8: Patient qualitative interview participant information sheets

UNIVERSITY of STIRLING

Research & Innovation

[redacted]

Participant Information Sheet

Study Title: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of researcher: Holly Martin-Smith

Research Sponsor: University of Stirling

You are invited to take part in a focus group as part of the main research study being undertaken as part the researchers Professional Doctorate in Health Psychology. Before you decide whether you want to take part it is important for you to understand why the focus group is being done and what your participation will involve. Please take as much time as you need to read the following information carefully and to discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask the members of the research team before making a decision.

Why have I been invited to take part in a focus group?

You have been invited because you have completed one of our 'Living Well' groups within the Clinical Health Psychology Service and we are interested to find out more about your thoughts, feelings and experiences of taking part.

Do I have to take part?

Your participation in this research is completely voluntary. You may withdraw from the focus group at any time without giving a reason and without any impact on your medical care. If you decide to participate in a focus group, we will ask you to sign a consent form to show you have agreed to take part. You will also be given a copy of this information sheet and consent form to keep.

What will I be asked to do?

You will be asked to take part in a focus group. A focus group is a small group of individuals (3-8) who share a similar experience. We think that a focus group will provide a good way to share your experiences and perspective of the group programme. Focus groups will be recorded and recordings will be shared with a transcription service holding data security policies compliant with NHS data security standards and the General Data Protection Regulation, and confidentiality agreements.

A moderator will facilitate the focus group to discuss the broad areas of questioning. The questions will be looking for your opinions and point of view. As such, there are no right or wrong answers. You have the right to refuse to answer any questions and the right to withdraw from the focus group at any point without providing any reason.

PIS Focus group- patients

Version 3, 14/04/2020
IRAS ID: 274421

Saving lives, Improving lives

How long will it take?

The focus group will be arranged subsequent to you attending the 8-session group and will last around 2 hours.

Is there anything I need to do before the focus group?

No, you will not need to anything prior to the focus group. On the day once everyone has logged in, the moderator will discuss what is going to happen in the group and you will be given an opportunity to ask any questions that you might have. The moderator will then ask everyone to agree on some ground rules for the group (e.g., avoiding speaking over other people, being respectful and considerate of other people's feelings). Once everyone is happy for the group to begin, the moderator will switch on the recording and ask the first question. You will be given another opportunity to ask questions at the end of the group.

What are the possible benefits with taking part in this focus group?

As a result of participating in a focus group, you may feel as if you have contributed to improving the services provided by the Clinical Health Psychology department which may improve care for future patients.

Are there any risks associated with taking part in this focus group?

There are minimal risks to participating in this focus group. You may be uncomfortable sharing your experiences in the group programme, but you will only be asked to share what you are comfortable sharing, and you are free to omit any questions that you would prefer not to answer. You are free to opt out of the discussion at any time and provision will be made for you to take breaks and pauses as necessary. If you need assistance or would like to speak with someone after taking part in the focus group, a member of the psychology team will be able to contact you for any further support.

How will we use information about you?

We will need to use information from you for this research project.

This information (personally identifiable data) will include your:

- Initials
- NHS number/Hospital ID
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. This personally identifiable data will be retained until the lasts data collection point and then deleted.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking on of the research team
- by sending an email to [redacted]
- by ringing us on [redacted]

What will happen to the results of the study?

The results of the study will help inform the Clinical Health Psychology service of the feasibility and acceptability of group programmes and how we can best support patients. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. The study results will be disseminated to relevant service providers and academics. The information obtained in this study will be used as data for the researcher's doctoral thesis and may be published in academic journals or presented at academic conferences.

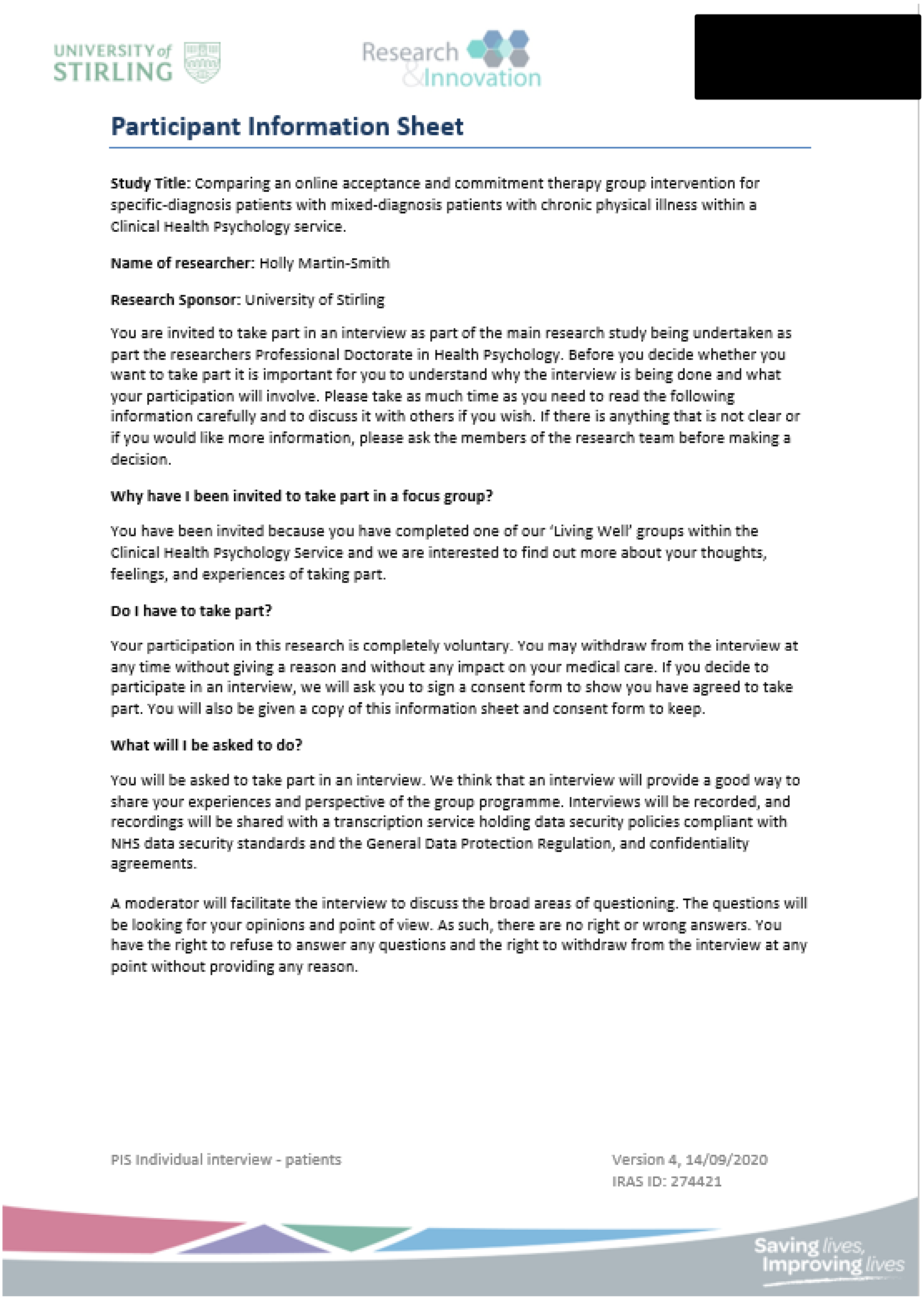
If you wish to receive more information and/or a summary of the anonymised results of the study, please feel free to contact the researcher at [redacted]

If I have some more questions, who should I contact?

Holly Martin-Smith, [redacted] or [redacted]

What if I am not happy with how the research was conducted?

Please contact the above-named researcher. If you wish to discuss this research with a more senior member of staff, please contact [redacted], [redacted] at e [redacted] or on [redacted]



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[redacted]

Participant Information Sheet

Study Title: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of researcher: Holly Martin-Smith

Research Sponsor: University of Stirling

You are invited to take part in an interview as part of the main research study being undertaken as part the researchers Professional Doctorate in Health Psychology. Before you decide whether you want to take part it is important for you to understand why the interview is being done and what your participation will involve. Please take as much time as you need to read the following information carefully and to discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask the members of the research team before making a decision.

Why have I been invited to take part in a focus group?

You have been invited because you have completed one of our 'Living Well' groups within the Clinical Health Psychology Service and we are interested to find out more about your thoughts, feelings, and experiences of taking part.

Do I have to take part?

Your participation in this research is completely voluntary. You may withdraw from the interview at any time without giving a reason and without any impact on your medical care. If you decide to participate in an interview, we will ask you to sign a consent form to show you have agreed to take part. You will also be given a copy of this information sheet and consent form to keep.

What will I be asked to do?

You will be asked to take part in an interview. We think that an interview will provide a good way to share your experiences and perspective of the group programme. Interviews will be recorded, and recordings will be shared with a transcription service holding data security policies compliant with NHS data security standards and the General Data Protection Regulation, and confidentiality agreements.

A moderator will facilitate the interview to discuss the broad areas of questioning. The questions will be looking for your opinions and point of view. As such, there are no right or wrong answers. You have the right to refuse to answer any questions and the right to withdraw from the interview at any point without providing any reason.

PIS Individual interview - patients

Version 4, 14/09/2020
IRAS ID: 274421

Saving *lives,*
Improving *lives*

How long will it take?

The interview will be arranged after you have attended the 8th session of the group and will last around 30 minutes.

Is there anything I need to do before the interview?

No, you will not need to anything prior to the interview. The moderator will discuss what is going to happen in the interview and you will be given an opportunity to ask any questions that you might have. Once you are happy for the interview to begin, the moderator will switch on the recording devices and ask the first question. You will be given another opportunity to ask questions at the end of the group.

What are the possible benefits with taking part in this interview?

As a result of participating in an interview, you may feel as if you have contributed to improving the services provided by the Clinical Health Psychology department which may improve care for future patients.

Are there any risks associated with taking part in this interview?

There are minimal risks to participating in this interview. You may be uncomfortable sharing your experiences in the group programme, but you will only be asked to share what you are comfortable sharing and you are free to omit any questions that you would prefer not to answer. You are free to opt out of the discussion at any time and provision will be made for you to take breaks and pauses as necessary. If you need assistance or would like to speak with someone after taking part in the interview, a member of the psychology team will be able to contact you for any further support.

How will we use information about you?

We will need to use information from you for this research project.

This information (personally identifiable data) will include your:

- Initials
- NHS number/Hospital ID
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. This personally identifiable data will be retained until the lasts data collection point and then deleted.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking on of the research team
- by sending an email to [redacted]
- by ringing us on [redacted]

What will happen to the results of the study?

The results of the study will help inform the Clinical Health Psychology service of the feasibility and acceptability of group programmes and how we can best support patients. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. The study results will be disseminated to relevant service providers and academics. The information obtained in this study will be used as data for the researcher's doctoral thesis and may be published in academic journals or presented at academic conferences.

If you wish to receive more information and/or a summary of the anonymised results of the study, please feel free to contact the researcher at [redacted]

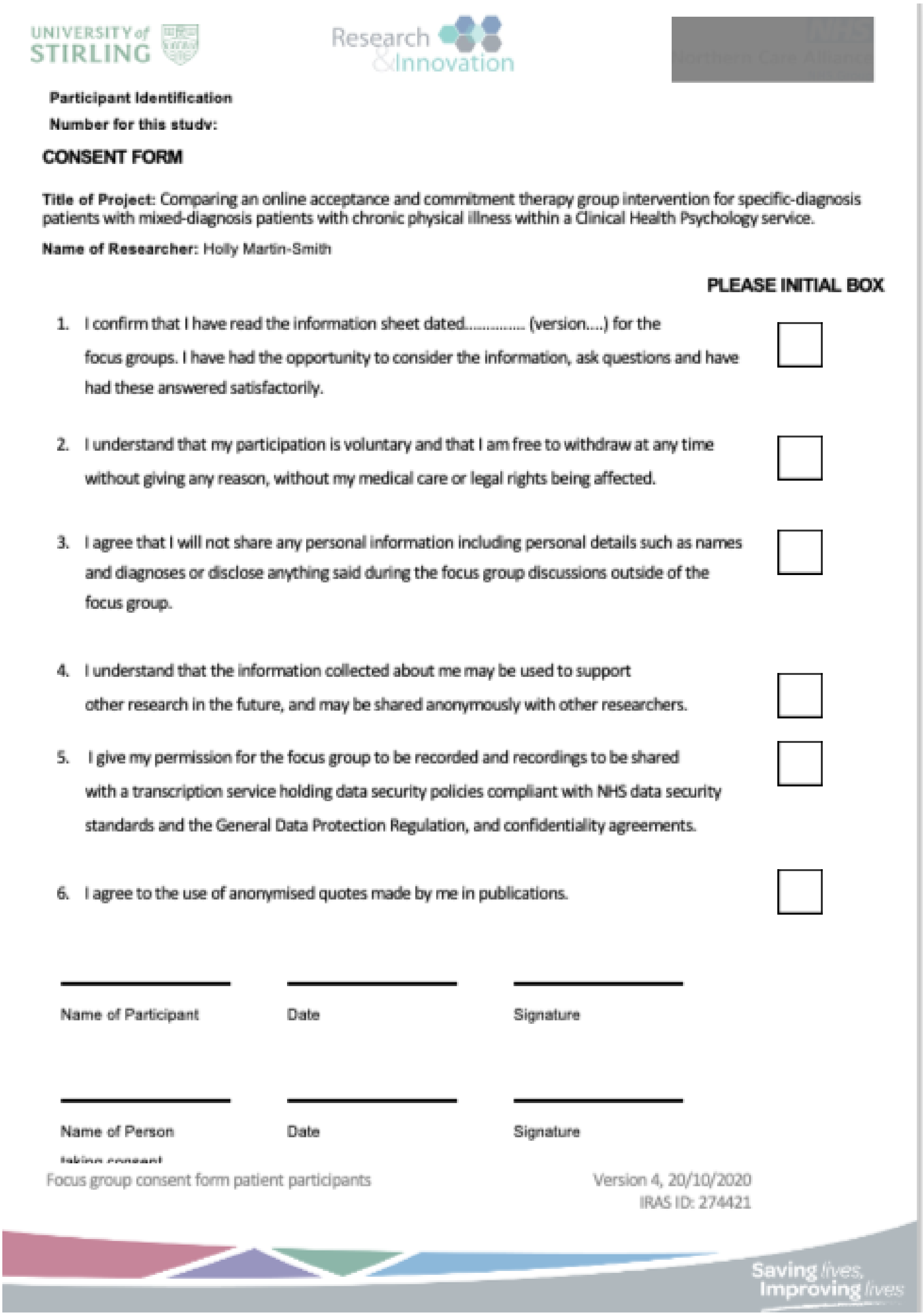
If I have some more questions who should I contact?

[redacted] or [redacted]

What if I am not happy with how the research was conducted?

Please contact the above-named researcher. If you wish to discuss this research with a more senior member of staff, please contact [redacted], [redacted] at [redacted] or on [redacted] [redacted].

APPENDIX 9: Patient qualitative interview consent forms



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[redacted]

Participant Identification
Number for this study:

CONSENT FORM

Title of Project: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of Researcher: Holly Martin-Smith

PLEASE INITIAL BOX

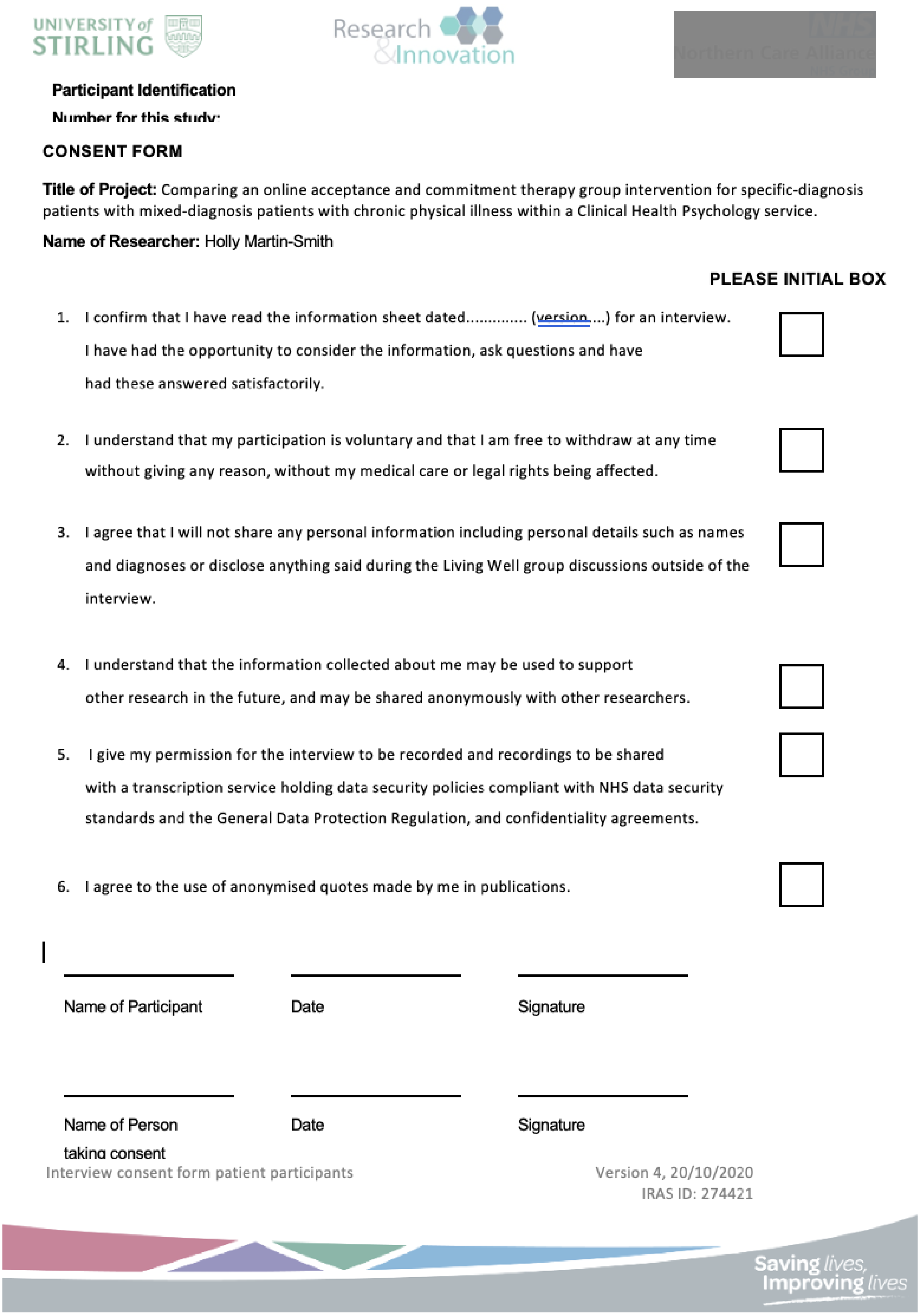
1. I confirm that I have read the information sheet dated.............. (version....) for the focus groups. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree that I will not share any personal information including personal details such as names and diagnoses or disclose anything said during the focus group discussions outside of the focus group. ☐
4. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐
5. I give my permission for the focus group to be recorded and recordings to be shared with a transcription service holding data security policies compliant with NHS data security standards and the General Data Protection Regulation, and confidentiality agreements. ☐
6. I agree to the use of anonymised quotes made by me in publications. ☐

____________	____________	____________
Name of Participant	Date	Signature
____________	____________	____________
Name of Person taking consent	Date	Signature

Focus group consent form patient participants

Version 4, 20/10/2020
IRAS ID: 274421

Saving lives, Improving lives



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Participant Identification Number for this study:

CONSENT FORM

Title of Project: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of Researcher: Holly Martin-Smith

PLEASE INITIAL BOX

1. I confirm that I have read the information sheet dated............. (version....) for an interview. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree that I will not share any personal information including personal details such as names and diagnoses or disclose anything said during the Living Well group discussions outside of the interview. ☐
4. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐
5. I give my permission for the interview to be recorded and recordings to be shared with a transcription service holding data security policies compliant with NHS data security standards and the General Data Protection Regulation, and confidentiality agreements. ☐
6. I agree to the use of anonymised quotes made by me in publications. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Interview consent form patient participants

Version 4, 20/10/2020
IRAS ID: 274421

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APPENDIX 10: Topic guide for patient qualitative interviews

Focus Group/Individual interview Topic guide – patient participants

Introduction to the focus group/individual interview

- Welcome to the focus group/individual interview
- We will discuss your experiences of taking part in the 'Living Well With a Long Term Condition' group.
- Introduce moderator
- Explanation of ethics, consent and confidentiality of focus group/interview and analysis.
- Ground rules for focus group (e.g., avoiding speaking over other people, being respectful and considerate of other people's feelings)
- Structure and duration of the focus group/individual interview.
- Any questions?

Focus group Ice breaker

- Introduce each other to the group. Moderator starts

Section one: Group experiences – feasibility/acceptability of intervention

- Can you tell me about your experiences while taking part in the group?
- What were your initial expectations of the group?
- What were the specific advantages of the group?
  Probe
    - Time commitments, timing of appointments, travel, meeting others etc.
- What were the specific advantages disadvantages of the group
  Probe
    - Time commitments, timing of appointments, travel, meeting others etc.
- What specifically did you like about the group?
  Probe
    - What did you think about being in a [specific/mixed condition] group?
    - What did you like about being in a [specific/mixed condition] group?
- What specifically did you dislike about the group?
    - Was there anything you didn't like about being in a [specific/mixed condition>] group?

- How well did you feel the group fit in with your values and principles?

- How easy was it for you to access the group?

- How much effort did it require to take part?
  Probe
  - To what extent was that manageable?

- How well did you feel you understood the purpose of the group therapy and how it works?

- In what ways do you feel that you have benefited from taking part in the group?

  Probe

  - Any specific benefits for living with your condition or other benefits for functioning (social, occupational/school, private, leisure, family relationships), mood/depression, anxiety, stress, the way you feel about yourself, your appearance?
  - What specific thing achieved change?

- How effective did you feel the group therapy was?

  Probe

  - (On improving quality of life, managing illness, emotional wellbeing?)
  - How much did the group help with these?

- How easy or difficult was it to take part in the group therapy?

- How confident were you that you could do the home practice

- How confident were you that you could do the set goals?

- How confident were you that you could take part in group discussions?

- To what extent would you recommend this group to other people with similar problems to your own?

  Probe

  - What specific thing would you recommend to someone about the group or is it the group as a whole?

- Is there anything that you would add to or change about the group?

Section two: Group environment – thoughts and perspectives

- What are your thoughts and feelings about being in a group with people who share your condition versus people who have a range of conditions?

  Probe

    - What do you think of the specific/mixed group approach?
    - How well does it fit with your values/principles?

- Do you think there are any advantages to being in a group with people who share your condition versus people who have a range of conditions?

  Probe

    - e.g. Shared understanding and connection
- Do you think there are any disadvantages to being in a group with people who share your condition versus people who have a range of conditions?

  Probe

    - e.g. lack of understanding and connection

Ending

- Thank you for participating in this focus group
- Quick summary of topics discussed
- Any questions/comments/changes to their thoughts after hearing what others have said?
- Offer of one page summary

APPENDIX 11: Topic guides for health professionals (facilitators and referrers)

Facilitators topic guide

Introduction to the focus group

- Welcome to the focus group
- This group will discuss your thoughts regarding the ‘Living Well With a Long Term Condition’ group run by the Clinical Health Psychology service.
- Introduce moderator
- Explanation of ethics, consent and confidentiality of focus group interview and analysis.
- Ground rules (e.g., avoiding speaking over other people, being respectful and considerate of other people’s feelings)
- Structure and duration of the focus group.
- Any questions?

Ice breaker

- Introduce each other to the group. Moderator starts

Section one: Group experiences – feasibility/acceptability of intervention- *For health professionals delivering group intervention:*

- Can you tell me about your experiences of delivering the group?
- What specifically did you like about delivering the group?
  Probe
    - What did you think about delivering the specific-diagnosis group?
    - What did you think about delivering the mixed-diagnosis group?
    - What did you like about delivering the specific-diagnosis group?
    - What did you like about delivering the mixed-diagnosis group?
- What specifically did you dislike about delivering the group?
  Probe
    - Was there anything you didn’t like about delivering the specific-diagnosis group?
    - Was there anything you didn’t like about delivering the mixed-diagnosis group?
- To what extent do you feel that patients have benefited from taking part in the group?

  Probe
- Is there anything that you would add to or change about the intervention?

Section two: Group environment – thoughts and perspectives- *For health professionals delivering group intervention:*

- What are your views about the group being delivered to patients who share a condition (specific-diagnosis group)?
- What are your views about the group being delivered to patients who have a range of conditions (mixed-diagnosis group)?
- What are your experiences of delivering the group to patients who share a condition (specific-diagnosis group)?

  Probe

  Did it work? Were there any barriers? How were these overcome?
- What are your experiences of delivering the group to patients who have a range of conditions (mixed-diagnosis group)?

  Probe

  Did it work? Were there any barriers? How were these overcome?
- Do you think there are any advantages to the group being delivered in these two different formats?
- Do you think there are any disadvantages to the group being delivered in these two different formats?
- How do you think we can best support patients with these groups in the future?

  Probe

  Perspectives on choosing one of the formats

Ending

- Thank you for participating in this focus group
- Quick summary of topics discussed
- Any questions/comments/changes to their thoughts after hearing what others have said?
- Offer of one page summary

Referrers topic guide

Introduction to the interview

- Welcome
- This interview will discuss your thoughts regarding the 'Living Well with a Long Term Condition' group run by the Clinical Health Psychology service.
- Introduce moderator
- Explanation of ethics, consent and confidentiality of interview and analysis.

- Any questions?

Section one: Group experiences – feasibility/acceptability of intervention

- How did you hear about the group?
- Can you tell me about your experiences of referring to the group?
- What were your initial expectations of the group for patients?

- What did **you** think would be the specific advantages of the group for patients?

- What did **you** think would be the specific disadvantages of the group for patients?
- How easy was it for you to refer to group?
- To what extent do **you** feel that patients have benefited from taking part in the group?
    - If so have you noticed any changes in supporting these patients?
    - Any specific benefits?
- To what extent would you recommend this group to other health professionals who would like to refer patients with similar problems to your patients?

  Probe

    - Yes/no answers on reasons for their response.
    - (What specific thing would you recommend to someone about the group or is it the group as a whole?)
- Is there anything that you would want to add or change to the group intervention or the way in which you refer patients?

Section two: Group environment – thoughts and perspectives- *For referring health professionals:*

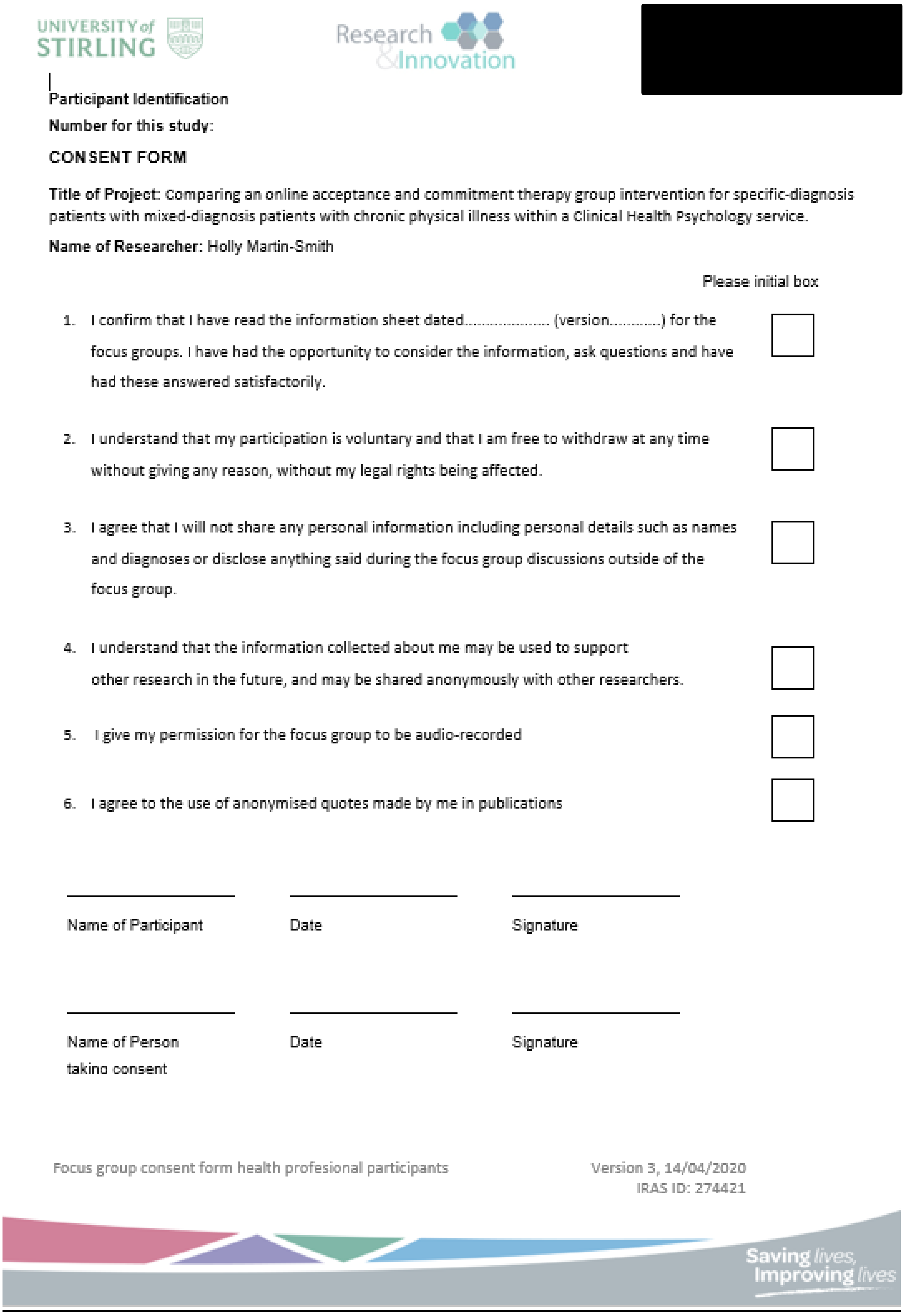
- What are your views about the group being delivered to patients who share a condition (specific-diagnosis group)?
- What are your views about the group being delivered to patients who have a range of conditions (mixed-diagnosis group)?

- Do you think there are any advantages to the group being delivered in these two different formats?
- Do you think there are any disadvantages to the group being delivered in these two different formats?
- If the group was to continue to be offered in which format would you think would be best for patients and why?

Ending

- Thank you for participating in this interview
- Offer of one page summary

APPENDIX 12: Health professional consent forms



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[redacted]

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of Researcher: Holly Martin-Smith

Please initial box

1. I confirm that I have read the information sheet dated.................... (version............) for the focus groups. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐
3. I agree that I will not share any personal information including personal details such as names and diagnoses or disclose anything said during the focus group discussions outside of the focus group. ☐
4. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers. ☐
5. I give my permission for the focus group to be audio-recorded ☐
6. I agree to the use of anonymised quotes made by me in publications ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Focus group consent form health profesional participants

Version 3, 14/04/2020
IRAS ID: 274421

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[redacted]

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Comparing an online acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.

Name of Researcher: Holly Martin-Smith

Please initial box

1. I confirm that I have read the information sheet dated ....version .... for the individual interview. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐
3. I will keep all discussions held in the interview confidential. ☐
4. I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers. ☐
5. I give my permission for the interview to be recorded. ☐
6. I agree to the use of anonymised quotes made by me in publications ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Consent form health profesional participants- interview

Version 4 07/07/2021
IRAS ID: 274421

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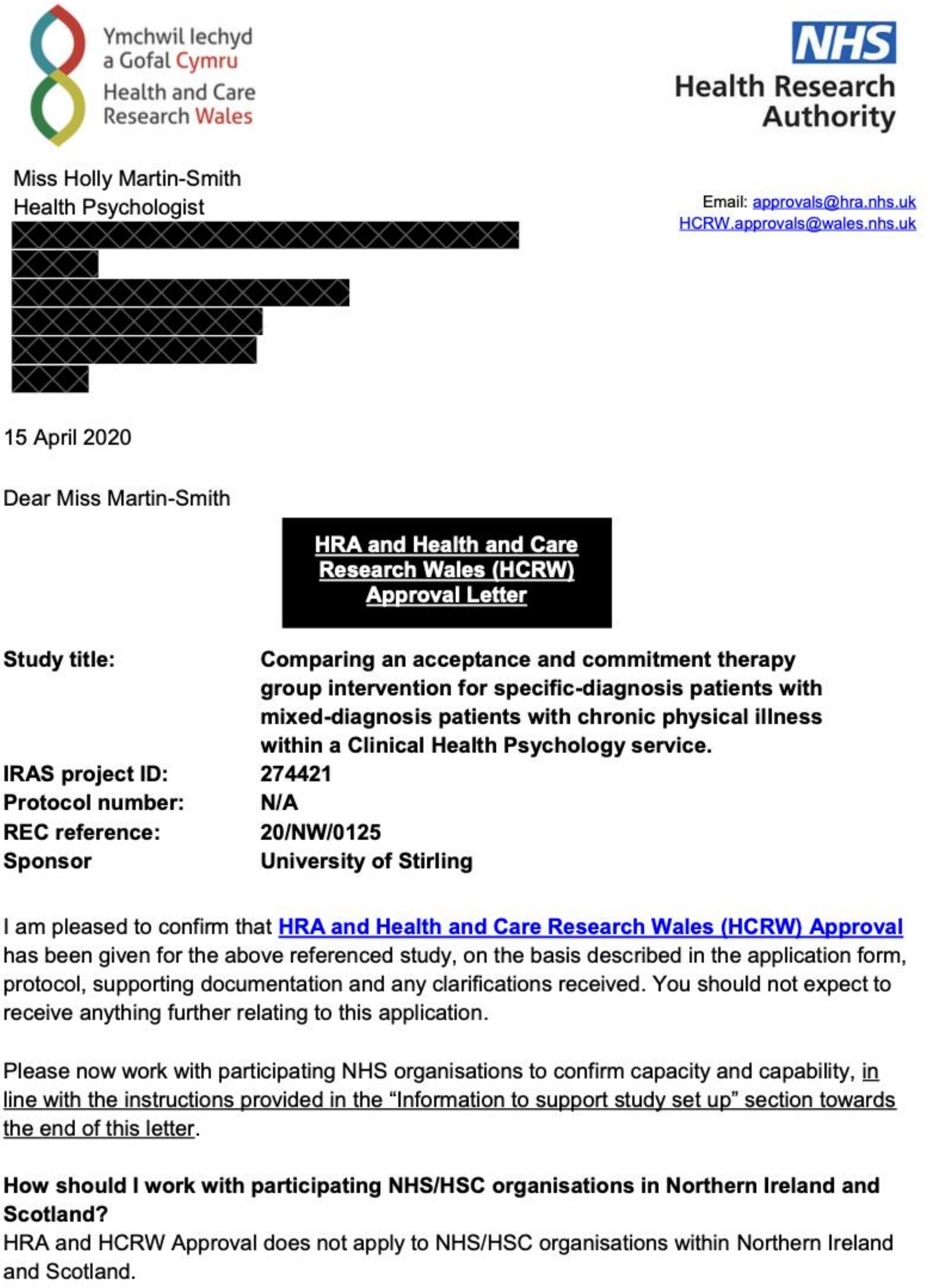
APPENDIX 13: Ethical approval letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Holly Martin-Smith
Health Psychologist
[redacted]

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

15 April 2020

Dear Miss Martin-Smith

HRA and Health and Care Research Wales (HCRW) Approval Letter

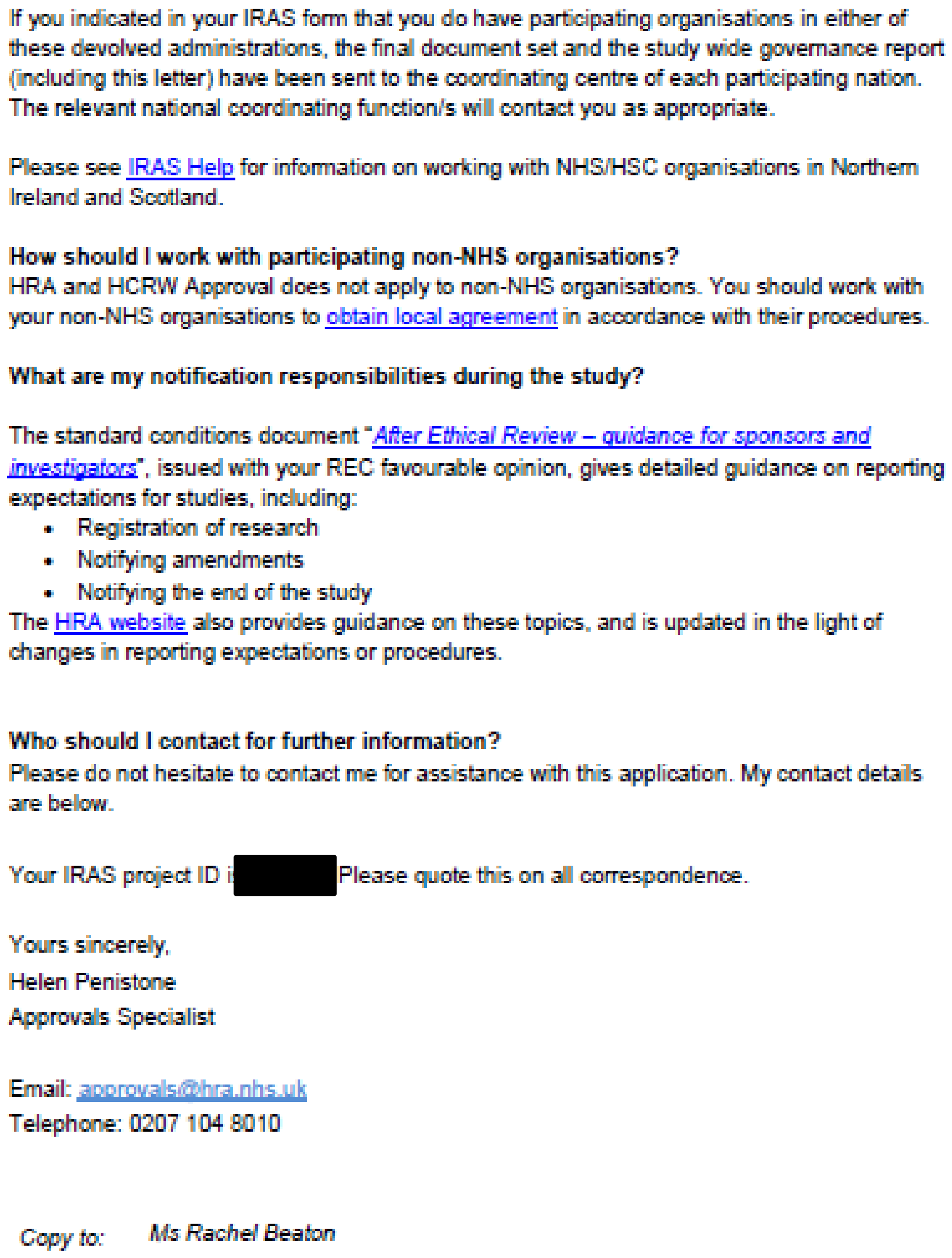
Study title:	**Comparing an acceptance and commitment therapy group intervention for specific-diagnosis patients with mixed-diagnosis patients with chronic physical illness within a Clinical Health Psychology service.**
IRAS project ID:	**274421**
Protocol number:	**N/A**
REC reference:	**20/NW/0125**
Sponsor	**University of Stirling**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.



If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID i[redacted]Please quote this on all correspondence.

Yours sincerely,
Helen Penistone
Approvals Specialist

Email: approvals@hra.nhs.uk
Telephone: 0207 104 8010

Copy to: *Ms Rachel Beaton*

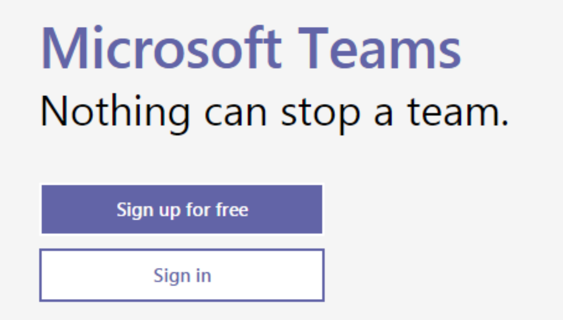
APPENDIX 14: Online group guide

Online Group Guide

What do I need to do?

Prior to the online group

- Access Microsoft teams- you may have an account already, if not you can sign up for free here:



Microsoft Teams

Nothing can stop a team.

https://www.microsoft.com/en-gb/microsoft-365/microsoft-teams/group-chat-software

- Once signed up you will have the option to download the software onto your laptop/computer – it is completely up to you whether you like to do this or not, it is not a necessity as the online group meetings can be accessed via the internet as well as the downloaded app.
- If you are having any problems, a member of our team can assist you, please email us on on <email address> or contact <contact number> and we can get back to you.

On the day of the online group

- We will send you an email with a link to our group meeting. To access the meeting all you need to do is click on the link and follow any instructions.
- Any problems – we have a member of staff to help you, you can email us on <email address> or contact <contact number>
- We would appreciate if you could try to connect into the call 15 minutes before we are due to start in case of any technical issues. That way we can make the most of the two hour session.

During the online group

- We will facilitate the online group. All you will need to do is take part as much as you feel able and comfortable. We will invite participants to join in with group discussions and activities however you do not have to speak if you do not want to. We will try to facilitate the discussions so that we don't talk over each other, this is sometimes inevitable though so we will all just do our best.

What if I'm having IT issues?

There will be a member of the team available to support anyone with IT issues. If you need to contact us you can email <email address> or phone <contact number> and someone will get back to you as soon as possible.

What do I do if I become upset or distressed?

Getting upset is normal, if you don't feel able to stay with the group, you can leave at any time. A member of the clinical team will give you a call to offer you any support that you may need. We will therefore need a number that we will be able to contact you on and an emergency contact in case we can't get hold of you.

What do I do if I want to leave/if I don't want to continue?

Of course there is no obligation for you to continue with the group if you decide it is not something you want to do. If you do want to leave there is a 'leave meeting' button on the screen. A member of the team will monitor who is in the online meeting at all times, if somebody drops out we will give you a quick call to check if you are having any technical issues, or whether you may have decided you no longer wish to participate.

What do I need to know about consent?

We will need your consent to contact you and an emergency contact if necessary. We will also need your consent to use Microsoft teams which will mean that your email address will be shared with other members of the group. We will of course ask that all participants do not share this and abide by the ground rules of confidentiality as discussed in the first session.

What do I need to know about security?

Obviously we want to make sure that these online group meetings are secure and confidential. The trust has reviewed Microsoft teams and approved this as an online platform to use for patient groups. This means that they are satisfied with the online security and confidentiality procedures. If you would like to discuss this further, a member of the team will be happy to so.

APPENDIX 15: Full data for secondary analysis of ‘true completers’

Mixed ANOVA (last observation carried forward, true completers)

						Effect of time			Effect of group			Group*Time interaction	
N= 13 Specific (n=9) Mixed (n=4)		**Intervention group**	**Baseline (pre-treatment) mean (SD)**	**Post Treatment mean (SD)**	**Follow up mean (SD)**	***F***	***p***	**Effect size**	***F***	***p***	**Effect size**	***F***	***p***	**Effect size**
PHQ9		**Specific**	9.56 (7.44)	7.67 (8.14)	6.78 (8.06)	3.757	.039	.255	18.334	.597	.625	1.313	.289	.107
		Mixed	11.75 (7.18)	8.50 (4.00)	10.75 (5.76)									
GAD7		**Specific**	6.33 (6.51)	5.44 (4.69)	5.44 (4.72)	2.530	.103	.187	1.458	.253	.117	1.295	.294	.105
		Mixed	12.25 (7.14)	6.50 (2.08)	8.25 (5.50)									
BIPQ		**Specific**	46.56 (8.40)	44.89 (7.04)	49.56 (13.10)	1.788	.191	.140	2.488	.143	.184	.873	.432	.073
		Mixed	52.50 (13.34)	56.20 (8.58)	57.50 (6.81)									
SF-36	**Physical functioning**	**Specific**	52.22 (29.91)	53.33 (32.21)	50.56 (36.78)	1.142	.337	.094	.002	.965	.000	.422	.661	.037
		Mixed	52.50 (35.24)	58.75 (33.76)	47.50 (36.17)									
	Physical limitations	**Specific**	36.11 (45.26)	38.89 (46.96)	47.22 (50.69)	.912	.416	.077	.431	.525	.038	.548	.586	.047
		Mixed	25.00 (50.00)	18.75 (23.94)	25.00 (50.00)									
	Emotional limitations	**Specific**	44.44 (47.14)	48.15 (44.45)	66.68 (44.09)	.264	.720[a]	.023	1.249	.288	.102	1.798	.198[a]	.141
		Mixed	20.51 (37.36)	33.33 (38.49)	23.08 (35.98)									

	Energy	**Specific**	33.89 (25.71)	27.22 (23.86)	40.56 (29.73)	1.526	.240	.122	2.976	.112	.213	2.876	.078	.207
		Mixed	7.50 (8.66)	13.75 (7.50)	11.25 (13.15)									
	Emotions	**Specific**	52.44 (23.19)	52.89 (21.14)	56.00 (32.00)	.580	.568	.050	.347	.568	.031	.611	.552	.053
		Mixed	41.00 (15.45)	52.00 (22.86)	45.00 (19.42)									
	Social functioning	**Specific**	45.83 (27.91)	50.00 (31.25)	68.05 (38.07)	.760	.480	.065	.470	.507	.041	3.998	.083	.267
		Mixed	43.75 (16.14)	62.50 (27.00)	28.23 (21.35)									
	Pain	**Specific**	36.39 (31.72)	45.00 (31.09)	52.22 (38.17)	2.782	.084	.202	.378	.551	.033	.726	.495	.062
		Mixed	28.12 (35.78)	36.25 (21.36)	33.75 (36.37)									
	General health	**Specific**	24.03 (23.46)	33.89 (27.58)	30.56 (28.11)	8.960	.001	.449	.022	.885	.002	.278	.760	.025
		Mixed	23.75 (16.01)	37.50 (21.01)	33.75 (25.29)									

[a] Huyhn-Felder adjusted significance levels used due to sphericity violation where epsilon >0.75.

[b] Greenhouse-geisser adjusted significance levels used due to sphericity violation, where epsilon < 0.75.

Post hoc comparisons

N= 13		Pre vs Post treatment (T1vsT2)		Post treatment vs Follow up (T2vs T3)		Pre vs follow up (T1 vs T3)	
		MDiff	***p***	**MDiff**	***p***	**MDiff**	***p***
PHQ9[a]		2.569	.149	-.681	1.000	1.889	.112
GAD7[a]		3.319	.291	-.875	1.000	2.444	.353
BIPQ		-1.167	1.000	-2.833	.571	-4.000	.455
SF36	**Physical functioning**	-3.681	.743	7.014	.718	3.333	1.000
	Physical limitations	1.736	1.000	-7.292	.723	-5.556	.773
	Emotional limitations	10.648	1.000	-5.093	1.000	5.556	1.000
	Energy	.208	1.000	-5.417	.462	-5.208	.743
	Emotions	-5.722	1.000	1.944	1.000	-3.778	1.000
	Social functioning	-11.458	.400	8.160	1.000	-3.299	1.000
	Pain	-8.368	.197	-2.361	1.000	-10.729	.176
	General health	-11.806	.083	3.542	.342	-8.264	.133

APPENDIX 16: Coding framework applied to patient data

Deductive codes of the Theoretical Framework of Acceptability	Definition	Code
Affective Attitude	Anticipated Affective Attitude: How an individual feels about the intervention, prior to taking part Experienced Affective Attitude: How an individual feels about the intervention, after taking part	**AAA** **EAA**
Burden	The amount of effort that was required to participate in the intervention	**B**
Ethicality	The extent to which the intervention has a good fit with an individual's value system	**E**
Intervention Coherence	The extent to which the participant understands the intervention and how it works	**IC**
Opportunity Costs	The benefits, profits or values that were given up to engage in the intervention	**OC**
Perceived effectiveness	The extent to which the intervention is perceived to have achieved its intended purpose	**PE**
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention	**SE**

Inductive codes	Definition	Code
Group relationships/dynamics	Any comments on the group dynamics or relationships between group participants	**GR**
Perceived Need	Any extent to which an individual perceives the need for the intervention	**PN**
Feedback	Any feedback on what to retain/improve in the intervention	**F**
Views & Expectations	Any views and/or expectations of the group approach and the two group conditions based on supposition and experience	**VE**

APPENDIX 17: Coding framework applied to health professional data

Deductive codes of the Theoretical Framework of acceptability	**Definition**	**Code**
Affective Attitude	How an individual feels about the intervention	**AA**
Burden	The amount of effort required to refer patients to the intervention/ facilitate the intervention	**B**
Perceived effectiveness	The extent to which the intervention is perceived to have achieved its intended purpose	**PE**
Self-efficacy	The individual's confidence that they can perform the behaviour(s) required to refer/facilitate the intervention	**SE**
Intervention Coherence	The extent to which the individual understands the intervention and how it works	**IC**
Inductive codes	**Definition**	**Code**
Perceived Need	Any extent to which an individual perceives the need for the intervention for patients	**PN**
Feedback	Any feedback on what to retain/improve in the intervention or any changes	**F**
Views and Expectations	Any views and/or expectations of the group approach and the two group conditions based on supposition and experience	**VE**