## PAIGE RANA KARADAĞ

## PROFESSIONAL DOCTORATE IN HEALTH PSYCHOLOGY

## UNIVERSITY OF STAFFORDSHIRE

For you Nan, I know you would have been so proud.

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#### **Portfolio Abstract**

#### Paige Rana Karadag

#### Professional Doctorate in Health Psychology, 2024

This portfolio documents the work I have completed whilst undertaking the Professional Doctorate in Health Psychology at the University of Staffordshire (formerly Staffordshire University) between 2021-2024. The work was conducted within my two placements whereby I worked as a research assistant at the University of Warwick, and a Trainee Health Psychologist at Bristol ME Service, North Bristol NHS Trust. Opportunities external to these placements were also sought in order to fulfil the requirements of the programme.

This portfolio is divided into six chapters:

- 1. Professional Skills in Health Psychology
- 2. Systematic Review
- 3. Research from Design to Dissemination
- 4. Teaching and Training in Health Psychology
- 5. Consultancy in Health Psychology
- 6. Health Psychology Interventions

Within each of the chapters, I present evidence of my development in the form of research manuscripts, case studies and reflective commentaries. These outline the work I have completed, as well as the experience and skills that I have developed. Further details of the content of each chapter are provided in the introduction.

#### **Introduction**

In this portfolio, I present the work that I have conducted whilst undertaking the Professional Doctorate in Health Psychology at the University of Staffordshire (formerly Staffordshire University) between 2021-2024. During the Doctorate, I had two placements. In the first year of the Doctorate, I was employed as a research assistant at the University of Warwick. Within this placement I was at the forefront of a multimodal study which included a longitudinal questionnaire, a longitudinal sleep-tracking component, and an experimental phase. In years two and three of the Doctorate, I was employed as a Trainee Health Psychologist within Bristol ME Service, North Bristol NHS Trust. Within this role, I assessed and supported patients with Long Covid and Myalgia Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS). I therefore completed the five core competencies of health psychology across different areas of work, as detailed below.

#### **Chapter 1: Professional Skills in Health Psychology**

Chapter one of my portfolio focuses on the professional skills in health psychology. In this chapter I present a reflexive report of the professional competence and skills that I developed throughout my time on the Doctorate. This reflexive report is supported by excerpts from my reflexive diary that I kept during my training.

#### **Chapter 2: Systematic Review**

In chapter two I present my systematic review which explored whether age and sex/gender predicted psychological distress in patients awaiting an organ transplant. The systematic

review is accompanied by a reflective commentary which outlines my experiences of undertaking the review.

#### **Chapter 3: Research from Design to Dissemination**

Chapter three includes my qualitative research project which explored self-management and coping in young adults with chronic pain. This is accompanied by a reflective commentary which outlines my rational for decisions and my experiences of undertaking the research.

#### **Chapter 4: Teaching and Training in Health Psychology**

Chapter four comprises a teaching case study and evaluation of six teaching session which I developed and delivered. The teaching sessions focused on the theme of 'Long-Term Health Conditions'. I delivered a mixture of online, pre-recorded, and in-person sessions to undergraduate students, masters students and nurses undertaking additional training. The case study outlines processes and reflections on assessing student needs, identifying teaching content, selecting training materials and assessing learning outcomes. The teaching evaluation details different sources of feedback for my teaching sessions and outlines identified areas of strengths, challenges, and improvements.

#### **Chapter 5: Consultancy in Health Psychology**

Chapter five contains my consultancy case study, which I conducted for a public health team. I undertook a piece of work to develop, deliver and evaluate a group intervention to increase intentions to attend cervical screening. The case study outlines the process I followed: assessing the request, negotiating and planning, developing and maintaining client relationships, delivering the work, and evaluating the consultancy project. The case study is followed by a contract that I developed, which outlines the terms of the project.

#### **Chapter 6: Health Psychology Interventions**

The final chapter includes two different psychological interventions: a one-to-one face-toface intervention and a group, remotely delivered intervention. Both are detailed through case studies which outlines the assessment, formulation, delivery, and evaluation of the interventions. The case studies are then accompanied by a reflective commentary. For the one-to-one intervention, I worked with a client with Long Covid to improve their selfefficacy to manage their fatigue and increase their coping skills. The group intervention was linked with my consultancy work to design, deliver and evaluate a group intervention to increase the uptake of cervical screening.

# **Chapter 1: Professional Skills in Health Psychology**

#### **<u>1.1 Reflexive Report</u>**

#### Background

This reflexive report summarises my professional development whilst undertaking the Professional Doctorate in Health Psychology. It reports on my placements and the work I submitted from September 2021 to June 2024. The first section of the report discusses the five core competencies needed to become a health psychologist. The second section focuses on the professional skills that a health psychologist must possess, as outlined by the British Psychological Society (BPS, 2021) and the Health and Care Professions Council (HCPC, 2022).

I started my training in autumn 2021, towards the end of the COVID-19 pandemic. Although restrictions were easing, new remote ways of working had been adopted and this was reflected within my doctorate journey. In line with best practice guidance (Gibbs, 1988; Schon, 1983), I kept a reflective diary throughout the doctorate and reflected on my development. I applied Gibbs reflective cycle (1988) to ensure that I documented my experience, including my thoughts and feelings about what happened and what I had taken away from the experience.

#### **Placement Overview**

I had two placements throughout the doctorate. My first placement was as a research assistant at the University of Warwick. My workplace contact was a chartered health psychologist at the University of Warwick; however, she was external to the research study. Within this placement I was at the forefront of a multimodal study which included a longitudinal questionnaire, a longitudinal sleep-tracking component, and an experimental phase. This role included obtaining NHS ethical approval, setting up phases of the study, recruitment, data collection, testing participants, data cleaning, and manuscript write up. I gained valuable insights from participants living with chronic conditions such as fibromyalgia, arthritis, and complex regional pain syndrome. I completed this placement in November 2022 as it was a fixed term contract.

I decided that for my second placement, it would be beneficial to gain experience working in the NHS. Hence, my second placement was at Bristol ME Service within North Bristol NHS Trust. This service supports individuals living with Myalgia Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS) and post viral fatigue. The service helps patients to identify the condition and offers support to manage it effectively. Upon referral to Bristol ME Service, patients are assessed and a diagnosis of ME/CFS may be provided if appropriate. Following diagnosis, a management plan is agreed which can include individual appointments or referral to one of the service's multidisciplinary therapy groups. The service also supports patients with Long Covid and works in line with NICE guidelines for both ME/CFS and Long Covid. I was employed on a fixed term contract as there was short term funding for a psychologist to support patients with Long Covid. As I was undertaking the doctorate when I obtained the role, I was employed in the capacity of a trainee health psychologist. I started this role in November 2022 and originally the role was funded for five months. This has been extended several times and is currently funded until March 2025, which means that upon qualification I will progress to a band 7 health psychologist position.

#### **Section One: Core Competencies**

#### Teaching

It is important that health psychologists have a strong foundation to teach students, colleagues or other health professionals about relevant health psychology approaches and interventions to enhance their skills and knowledge in psychological principles (Anderson, 2019). I had some previous experience from working as a teaching assistant within a secondary school and I had taught English whilst on a psychology placement in Sri Lanka. However, I had not received any formal teacher training and I had not taught adults within higher education, so I was apprehensive about teaching university students and health professionals. I designed, delivered, and evaluated a series of six teaching sessions within my first year of the doctorate which focused on 'Long-Term Health Conditions' (LTHCs). These opportunities arose within my placement at the University of Warwick and externally at the University of Liverpool and Staffordshire University. I delivered a mixture of online, pre-recorded, and in-person sessions to undergraduate students, masters students and nurses undertaking additional training.

In my second year of the doctorate, I was invited back to deliver all sessions again, but this time as a paid guest lecturer. Some of the modules had changed slightly and one session that had been pre-recorded needed to be delivered in-person; therefore, I modified these sessions accordingly. I felt that this was an opportunity for me to improve my sessions further by reflecting on any constructive criticism that I previously received. The main observation I had from delivering these sessions was that my confidence grew throughout and in turn I became more comfortable at times of silence and facilitating group tasks and discussions. Additionally, at Bristol ME Service I was invited to deliver a teaching session to my colleagues which focused on applying the COM-B model of behaviour change (Michie et al.,

2011) to individuals with ME/CFS. Within this session I combined background information on the topic with an example case study of how to apply the model. Overall, this session received positive feedback from physiotherapists and clinical psychologists in the service.

I also obtained an additional paid teaching opportunity on a 'high-intensity therapists top up training course' for Cognitive Behavioural Therapy (CBT) for long term conditions. As I had completed a level two accreditation in CBT from the Association for Psychological Therapies (APT) and given that I applied CBT techniques within my role at Bristol ME Service, I felt that I would be a suitable candidate to deliver these sessions. These sessions differed to the ones I had delivered previously as they were full day sessions on Microsoft Teams to a large group of NHS therapists. During these sessions, I developed my ability to deliver engaging and interactive sessions online. However, I was asked some challenging questions which were beyond my expertise and experience, and I felt as though I was unable to answer the questions sufficiently. This is likely a challenge that I will encounter again in the future, but I think the best approach is to be honest with students and acknowledge when I do not know the answer. Overall, I received positive feedback for the additional sessions that I delivered.

Upon reflection, I felt that I agreed to deliver too many teaching sessions in my second year of the doctorate. This was an important learning experience as I did not want to turn down valuable opportunities but instead it resulted in me overextending myself. Therefore, in year three I turned down several opportunities and I just delivered one workshop. Nevertheless, these additional teaching opportunities have provided me with a deeper understanding of the theoretical elements required for effective teaching. All sessions highlighted the importance of completing needs assessments prior to the session and I became confident in completing assessments informed by Biggs (2003) 3P Learning Process Model. I also realised the

importance of meeting with the module lead to discuss the group dynamics. I have learnt how to reflect in action (Schon, 1991) to make judgements within the session based on the group and the timeframe available. Moreover, I have learnt how to integrate technology into sessions delivered in person or online, which adds another layer of interactivity. Before I started the doctorate, I would not have considered a career involving teaching. However, I have thoroughly enjoyed teaching university students and I hope that I have the opportunity to expand on this experience post-qualification.

#### Consultancy

Consultancy was the competency that I had the least experience in when I started the doctorate. However, the taught sessions at Staffordshire University helped develop my knowledge and understanding regarding how to successfully undertake a piece of consultancy work. I identified a consultancy opportunity by approaching a health psychologist within a public health team in a city council. Through initial meetings I outlined how my expertise and experience as a trainee health psychologist could be transferable to a public health setting. Following this, the client identified the need for a piece of work to develop, deliver and evaluate a group intervention to increase intentions to attend cervical screening. Throughout this piece of work, I learnt how to negotiate with the client so that both of our wants and needs were met. I was apprehensive about negotiating as I did not want to compromise the relationship with the client, however it became clear that it is a crucial aspect that contributes to the success of the consultancy (Block, 2011). For instance, I negotiated the intellectual property of the intervention with the client by using active and reflective listening skills (Roloff et al., 2003; Schultz, 1989). Through effective negotiation, it was decided that the intervention design and materials would be my property, but the use of these by the client was

not restricted. Development of the contract was also an important learning experience, particularly as it was a legally binding document which meant there was additional pressure for the contents regarding the deliverables to be realistic.

Overall, I received positive feedback from the client, and they were pleased with the deliverables and output. However, I was informed that at times my work was very academic which made it difficult for some of the clients to understand. This underlined the importance of considering the audience when conveying information. Additionally, this was a very large piece of consultancy work which I completed alongside my full-time job. At the start of the consultancy, I had not fully considered the implications of the workload, but it further highlighted the need to negotiate the deliverables with the client. Following completion of the consultancy, I continued working with the client to write a short communication which outlined the group intervention, to disseminate the piece of work. This was published by the Behavioural Science and Public Health Network. I have not had any further consultancy opportunities; however, this is something that I would like to pursue in the future.

#### Health Psychology Interventions

Health psychology interventions form an important part of a trainee health psychologists' journey, as a key focus within health psychology is behaviour change and the link between physical and mental health (Anderson, 2019; Ogden, 2012). When I started this module, I had no experience of delivering psychological interventions. As my first placement was as a research assistant, I sought external opportunities to be able to fulfil this competency. Subsequently, I linked the group intervention with my consultancy work to design, deliver and evaluate a group intervention using the COM-B model (Michie et al., 2011) to increase the uptake of cervical screening. Since completing this intervention, I have supported with the development and delivery of an online group self-management programme for young people with ME/CFS in my placement at Bristol ME Service. This has allowed me to understand the logistics of designing and delivering an online group intervention within the NHS. It also highlighted potential challenges of working with young people, including a lack of interaction within online sessions and the need to think of more creative methods (Nakarada-Kordic et al., 2017). Moreover, it has underlined possible confidentiality issues when delivering group programmes remotely. I was surprised that the format and delivery of these two group interventions was very similar, despite one being within a public health setting and the other being in a specialist NHS service. This has reinforced that I have the transferable skills required to effectively deliver an online group intervention in a variety of settings. Furthermore, I am going to continue to be involved with the delivery of future group programmes for young people with ME/CFS, allowing me to develop these skills further.

I had the opportunity to design and deliver a face-to-face intervention within my placement at Bristol ME Service. However, I encountered some challenges when trying to identify a suitable candidate for this intervention. This was because most service users opt for remote appointments, as they can be easier to attend with the fatigue. Nevertheless, I was able to identify a suitable patient who preferred in-person appointments. The intervention aimed to improve the client's self-efficacy to manage their fatigue and increase their coping skills. I used a CBT approach paired with the British Association of Clinicians in ME/CFS (BACME) therapy guide for fatigue management to inform the design of the intervention. Despite the initial challenges, I developed a range of skills through this opportunity. It differed in many ways to the online group intervention which utilised the use of technology, especially for the assessment of the group via online forms, and the delivery which incorporated videos and quizzes. I found that the in-person intervention relied a lot more on communication skills and developing the therapeutic relationship.

Since completing the competency, I have continued to develop my intervention skills within my role at Bristol ME Service, and I have delivered a variety of 1:1 interventions. Often, 1:1 interventions have focused on fatigue management and have been delivered remotely. This has enabled me to improve my ability to conduct assessments, formulations and deliver interventions via telephone and video appointments. I feel that my communication skills have improved by conducting interventions remotely as I need to be more attentive in these appointments given that I am often unable to detect body language cues (Kilvert et al., 2020). I have also had the opportunity to conduct interventions with patients who were referred for psychological support within Bristol ME Service. These interventions have often been with patients whereby a psychological barrier, such as lack of acceptance or high self-criticism, was preventing them from effectively engaging with self-management skills. This provided me with the opportunity to apply CBT or Acceptance and Commitment Therapy (ACT) techniques and broadened my knowledge and application of psychological techniques.

#### Research

Research is imperative in health psychology as it is required to provide evidence for policy, interventions and treatment pathways and inform best practice (Kaplan, 2009). I had previous experience of conducting research from my undergraduate degree, master's degree, and my role as research assistant. For the empirical research, I decided to undertake a qualitative study as the research conducted for my placement had used quantitative methods. Additionally, qualitative research is my preferred methodology as I feel more confident in the

data collection and analysis, and I have previously published a qualitative study (Karadag et al., 2020).

The study focused on self-management and coping in young adults with chronic pain. I conducted this study external to my placement, providing me with the skills to independently conduct a piece of qualitative research. This research experience was mostly positive; however, I did encounter issues when using NVivo software which resulted in delays during data analysis. I used problem solving skills to overcome these issues, but it has made me apprehensive about using the software again in the future. The manuscript was formatted for the British Journal of Health Psychology and was submitted for review, but unfortunately it was not accepted. This was disappointing; however, I plan to consider the reviewers' comments and will re-submit to another journal. As a large amount of data was collected, I decided to focus on two of the research questions and I plan to answer the remaining research questions by writing a second article at a later stage.

I have also gained valuable experimental and quantitative research experience from my placement at the University of Warwick. I became familiar with NHS ethics procedures and the challenges of submitting ethical amendments. My role also included testing participants with chronic pain using experimental methods. One of the main challenges that I faced within my role was recruitment for the lab-based component as participants needed to have chronic pain and be able to travel to the University of Warwick, which meant that the pool of potential participants was reduced. This role also enabled me to gain understanding of funded research and the procedures for reimbursing participants, which required stringent record keeping. I also supported with data organisation and was involved with several publications

from the University of Warwick. Alongside this, I continued working on a project from my master's degree. Recent publications are shown in Table 1.

Title	Authors	Type of	Publication
		Publication	Date
Investigating mental defeat	Jenna Gillett*, Paige	Protocol paper	February 2023
in individuals with chronic	Karadag*, Kristy Themelis,	BMJ Open	
pain: Protocol for a	Yu-Mei Li, Sakari Lemola,		
longitudinal experience	Shyam Balasubramanian,		
sampling study	Swaran Preet Singh, Nicole		
	Tang		
	*Joint first author.		
Mental defeat and	Kristy Themelis, Jenna	Journal article	November
suicidality in chronic pain:	Gillett, Paige Karadag,	The Journal of	2023
a prospective analysis	Martin Cheatle, Nicholas	Pain	
	Giordano, Shyam		
	Balasubramanian, Swaran		
	Preet Singh, Nicole Tang		
Narrative bias ("spin") is	Andrew Moore, Paige	Journal article	January 2024
common in randomised	Karadag, Emma Fisher,	PAIN	
trials and systematic	Geert Crombez, Sebastian		

#### **Table 1.** Publications gained throughout the doctorate

reviews of cannabinoids	Straube, Christopher		
for pain	Eccleston		
Self-Compassion in	Jenna Gillett, Arman	Journal article	Accepted for
Chronic Pain: Validating	Rakhimov, Paige Karadag,	British Journal	publication in
the Self-Compassion Scale	Kristy Themelis, Ji Chen,	of Pain	May 2024
Short-Form and Exploring	Nicole Tang		
Initial Relationships with			
Pain Outcomes			

#### Systematic Review

I had not previously conducted a systematic review from start to finish, so I was worried about this competency. The first challenge that I encountered was identifying a suitable review topic, as I struggled to find a gap within the literature in the same field as my placement. Subsequently, I decided to broaden my search beyond ME/CFS, and I used this as an opportunity to research a different LTHC to expand my knowledge further. Therefore, I conducted a systematic review to explore whether age and sex/gender predicted psychological distress in patients awaiting an organ transplant. I had intended to conduct a meta-analysis, however due to high levels of heterogeneity of the measures used, this was not feasible.

Despite initial challenges, I completed the systematic review and produced a narrative synthesis of the findings. Throughout the systematic review process, I have gained skills and experience in writing a protocol and submitting it to PROSPERO. I decided to use Rayyan to manage the papers and conduct the screening. Although I was wary of using technology

given the challenges that I encountered with using NVivo software for the qualitative study, I found that Rayyan helped to keep the papers organised and facilitated the screening process. Therefore, I would use this software again if I was to conduct a systematic review in the future. I also learnt how to extract data, conduct a narrative synthesis, and write a systematic review manuscript for a target journal.

#### **Professional Skills**

Throughout the doctorate, I have developed a variety of professional skills in line with the BPS (2021) and the HCPC (2022). To monitor this, I engaged with self-reflection and completed a weekly diary which included both long and short reflections that were in action or on action (Schon, 1991). I tried where possible to apply Gibbs Reflective Cycle (1988) but I found this challenging at the beginning of the doctorate journey because I was not always sure what I could do differently in the future. Additionally, for some reflections rather than detailing what I would do differently, I outlined what I planned to do next. Although these were still useful reflections, it might have been beneficial for me to discuss alternative ways of managing situations. Moreover, I initially reflected on situations where things had gone wrong or challenges that I faced, but I later learnt to reflect on positive experiences as this is also important when developing professional skills (Janssen et al., 2008). I found that monthly progress reports and annual reports were also a good opportunity for reflection and feedback from my supervisors and workplace contacts.

#### Section Two: General Professional Competencies

Legal, ethical and professional standards

To maintain integrity as a trainee health psychologist, it was essential to uphold ethical and legal standards as highlighted by the BPS (2021). Throughout the doctorate I had several opportunities to develop the necessary skills to uphold ethical and legal standards within my placements. As part of my placement at the University of Warwick I was responsible for setting up and maintaining databases to record questionnaire data, sleep tracking data and participant contact details. There was also a distress protocol in place whereby I was required to follow-up with all participants that were at high risk of suicidality as identified by the questionnaire. In line with ethical approval, I could only signpost these participants to appropriate organisations or service, as it was beyond the scope of my role to offer support. I also had to complete NHS ethical amendments within my placement at the University of Warwick and a Staffordshire University ethics application for my qualitative study. This required an understanding of adhering to the ethical standards that are upheld by both the NHS and universities when conducting research involving individuals with a long-term health condition.

Within my role at Bristol ME Service, I have documented clinical sessions within NHS online systems in a timely manner. I have also had to assess and report level of risk with every patient, and I have managed a situation whereby a patient was deemed at high risk of suicide. Additionally, I have frequently written assessment report letters for General Practitioners which include confidential information regarding patients' health and wellbeing. Similarly, I have provided medical reports for ill-health retirement applications and support letters for Personal Independence Payment (PIP) and Blue Badge applications. This required me to provide an account of the patients' level of function, but it was important that I disclosed within these letters that all accounts were based on self-report by the patient. There

were also two incidents whereby I experienced safeguarding concerns which meant that I had to contact the safeguarding team. On both occasions, I was supported by my supervisor and line manager to go through the appropriate organisations, ensuring that I had taken the necessary steps outlined by the safeguarding team.

#### Health psychology advice and guidance to others

I found it particularly challenging to offer health psychology guidance to others as I worked with qualified psychologists in both of my placements, so initially I did not think that I had valuable advice to offer as a trainee. However, an opportunity did arise in my placement at Bristol ME Service when I was asked to provide guidance on how to apply the COM-B model to self-management interventions for fatigue. I provided this guidance through an online training session, as requested by the service lead. Here I was able to reflect on my knowledge and experiences of applying the COM-B model in a behaviour change intervention and transfer it to a chronic fatigue population.

I also offered health psychology advice regarding the development of a young people's group self-management programme. My supervisor on placement was aware that I had been undertaking a qualitative research study to explore the experiences of young adults with chronic pain. Therefore, she asked for my advice when considering the age range and content for the group. Moreover, an assistant psychologist asked me for some guidance regarding how to conduct review appointments for patients who have completed the Long Covid selfmanagement group. I felt that I gave appropriate advice as I explained how I usually format these sessions and I provided example questions that I might ask to prompt the patient. Lastly, I have given advice to senior clinicians when they have asked about the suitability of patients for group interventions. In these instances, I have considered the patients level of function and psychological suitability to determine whether a group setting would be appropriate.

Furthermore, I had the opportunity to offer guidance to my buddy for the doctorate as they asked for my advice regarding starting the various competencies and completing the learning plan. I reflected on my own experience and considered the nature of my buddy's placement setting within the NHS. As I had successfully delivered a teaching session to educate nurses about behaviour change interventions, I suggested that they could deliver a similar teaching session to other health professionals within their placement.

#### Communicating skills in different contexts

Written and verbal communication skills play a pivotal role in the work of health psychologists when working with colleagues, patients, and stakeholders (O'Daniel & Rosenstein; Sharkiya, 2023). I helped to develop participant resources at the University of Warwick which included information leaflets, webpages and newsletters; all of which used a variety of communication skills. Within this placement, I was also interviewed for a podcast with Pain Concern which provided an alternative platform to communicate to a variety of stakeholders. Furthermore, open and consistent communication during the consultancy work with the council's public health team was essential to meet deliverables. This communication often took place via email and Microsoft Teams meetings with the client. I have further developed written communication skills in my placement at Bristol ME Service by writing patient assessment letters, medical reports, and support letters. I have learnt that it is particularly important to consider the language used when writing letters for financial aid or

employers to ensure that the recipient understands the nature and impact of Long Covid or ME/CFS on daily life.

I further developed my communication skills via conference presentations. I completed an oral presentation at Staffordshire University in 2022 and was pleasantly surprised to be awarded 'best oral presentation'. Through my placement at the University of Warwick, I also presented a poster at the 'International Association for the Study of Pain' (IASP) world congress conference in Toronto, Canada. This was my first in-person conference external to Staffordshire University, and it was also my first international conference. I had originally prepared a script for my poster presentation, however I quickly learnt that you cannot script a poster presentation, as you cannot predict what questions someone may ask. Nevertheless, it was helpful to have an 'elevator pitch' to summarise the poster if needed. I also took some smaller printed versions of the poster which were a huge success and a great way of measuring how many people displayed an interest in the poster throughout the day. I thoroughly enjoyed talking about the poster to a broader audience including medical doctors and researchers, as it was great to discuss the concept of mental defeat in chronic pain and highlight how health psychology applies to the field.

#### Service user and carer involvement

Patient and public involvement (PPI) is imperative to promote patient centred research (Brett et al., 2014). Involving service users in every aspect of research adds valuable insights which improve the quality of research from design through to dissemination (Arumugam et al., 2023). By engaging with PPI, it also shifts research so that it is conducted 'with' or 'by' service users, rather than it being 'about' them (Biggane et al., 2019). Part of my role at the University of Warwick was working with PPI advisors to review and contribute to participant materials. Moreover, for my qualitative study, I piloted the interview schedule with a friend who had lived experience of chronic pain to ensure that I included appropriate questions for young adults with chronic pain.

Service users were also involved in the development of the young people's group programme at Bristol ME Service. When patients were invited to attend, they were informed that this was our first time delivering a programme specifically for young people, so it would be treated as a 'pilot', and we would be obtaining feedback to improve the content and delivery of the group going forward. We asked attendees for verbal feedback throughout sessions to find out what aspects they were finding helpful or unhelpful so that we could consider this ahead of the next session. We also obtained feedback at the end of the group programme which will be used to improve the next young people's group programme.

#### Teamwork and leadership

Teamwork was essential within both of my placements, and I was able to experience working in two different types of teams. At the University of Warwick, I was part of a very small research team which involved just four core team members. As a team, we met for a weekly meeting to review research targets. Working in a small team had many benefits, including collaboration opportunities and the autonomy to manage my own schedule. However, I found it challenging to maintain boundaries regarding my workload within a small team. I was also part of a wider laboratory at the University of Warwick, whereby I collaborated with PhD students to share advice and guidance regarding data organisation and analysis. Additionally, I supervised a group of three undergraduate psychology students who were undertaking an internship on the research study at the University of Warwick. This provided me with an understanding of team leadership as I was required to identify and delegate suitable tasks, alongside providing supervision which often required: training, offering support with tasks and providing constructive feedback. This experience provided me with the opportunity to reflect on the leadership qualities that I hoped to demonstrate.

In my placement at Bristol ME Service, I am part of quite a large team with a range of clinicians including clinical and counselling psychologists, occupational therapists, and physiotherapists. Teamwork is particularly important within healthcare services to deliver the continuity of care (Chandrashekar & Mohan, 2019; O'Daniel & Rosenstein). I have frequently attended and presented at case review meetings to discuss complex cases and cross referrals with my colleagues. This has been an invaluable experience as it has allowed me to develop the way that I present the key aspects of a case to seek guidance from my colleagues. I have also worked in a smaller team with senior clinicians in the service to deliver a group programme. Additionally, I have attended and presented at multidisciplinary team meetings with practitioners from a Long Covid service to discuss physical health symptoms for further investigations. Moreover, I am part of a team of psychologists who work across the hospital trust. I have attended psychology team training days whereby we have worked in small groups to share ideas to improve our clinical practice. For instance, at one training day I was in a group with psychologists from the cancer services. As a group, we drew on our experiences of neurodivergence in our individual services and discussed ways to adapt sessions to meet the needs of individuals who are neurodivergent.

#### Understanding around organisational and systemic issues

Through having different placements, I have been able to experience the ways in which health psychology fits within different organisations. For instance, at the University of Warwick there were opportunities to apply health psychology in a teaching and research capacity. As it was a large university organisation, there was also the opportunity to network with other health psychologists who worked in departments such as the medical school. In comparison, in the NHS I applied health psychology by incorporating behaviour change techniques in self-management interventions. One systemic issue that I noticed within the NHS was that there was only one other trainee health psychologist within the hospital trust, as other psychologists had a clinical or counselling background. In many ways it has felt as though I have had to introduce the concept of health psychology, particularly to explain how it differs to clinical health psychology.

Through my consultancy work I also gained insights regarding how health psychologists work within public health organisations. Aside from the health psychologist overseeing the consultancy project, nobody else within the public health team had a background in health psychology. This reflects recent findings that there is a lack of understanding by clinical psychologists and public health practitioners regarding how health psychologists fit within organisations (Hart et al., 2023). Subsequently, there needs to be more awareness of how health psychology can be applied within the NHS and public health settings.

Another organisational issue that I faced during the doctorate was that COVID-19 caused significant challenges when I worked as a research assistant. The restrictions regarding working on campus meant that the experiment and sleep-tracking component were both postponed until restrictions had eased. Despite these delays, the funding was not extended for the project which meant that my contract ended before the project was complete.

Additionally, within both of my placements I have been on a fixed-term contract which reflects organisational issues in research posts and the NHS. This made it difficult to plan for my future involvement, as there was always some uncertainty regarding the duration of my role.

#### Equality, diversity and inclusion

Within my role at Bristol ME Service, I have offered patients the option of telephone, video or in-person appointments to accommodate their needs. One service-user also required a foreign language interpreter as their spoken English was limited. The service user opted for sessions to be via telephone, which meant that I was reliant on the interpreter's translation as there were no body language prompts. Another challenge was that the interpreter service could not guarantee that it would be the same interpreter for each session, which made it difficult to build a relationship or maintain the flow of sessions (Frandsen et al., 2019). It was also not possible to have materials or resources translated into the appropriate language which meant that information had to be communicated verbally. Additionally, I have worked with a service user that was Deaf and required a British sign language interpreter. To ensure there was adequate time to assess the patient with the interpreter I blocked out two clinic slots. I also made sure that that the room was set up appropriately.

#### Need for engagement in continuing professional development (CPD)

I engaged in a variety of short and longer-term CPD activities throughout my training. I completed 18 hours of CPD by undertaking a level two accredited CBT training course with the APT. Similarly, I completed a three-hour pre-recorded training session delivered by

Contextual Consulting which focused on ACT for young people. I have also attended various training days within my placement at Bristol ME Service which covered topics such as trauma informed care and somatic practice. Additionally, I completed further training on neurodivergence as I attended a session on Attention Deficit Hyperactivity Disorder (ADHD), which was delivered by a consultant psychiatrist and clinical psychologist. Nevertheless, I feel as though there are still areas for further development. I think it would be particularly valuable to complete training to provide supervision. I also think it would be beneficial to undertake more training in psychological therapies such as ACT or compassion focused therapy so that I am more equipped to apply these techniques when working with individuals with LTHCs.

#### Developing as a professional health psychologist

I started my journey as a trainee health psychologist with no clinical experience, yet throughout the doctorate I have had the opportunity to work in an academic setting, a public health setting and in an NHS specialist service, enabling me to gain a wide range of skills and exposure. As I have progressed through the doctorate, I have developed as an independent and autonomous clinician with my own caseload, and I have seen my own confidence grow when working with a variety of patients with various complexities. Within my role at Bristol ME Service, I have recently progressed to be able to assess and diagnose patients with ME/CFS if I feel that they sufficiently meet the criteria. This requires a huge amount of autonomy to make these decisions based on the information provided. It also means that I am accountable for the decision made regarding diagnosis, which is why it often requires a lot of deliberation. However, I do not feel pressured to able to make these decisions alone and if I do have a complex case or unclear diagnosis then I always have the option to discuss it with my colleagues at a case review meeting. Upon qualification, I will have the opportunity to practice as a qualified health psychologist within Bristol ME Service and I look forward to developing further.

#### Conclusion

Completing the doctorate has been invaluable as it has provided me with the skills and experience to practice as a health psychologist in a range of settings. I have learnt that selfreflection is paramount to be able to develop as a health psychologist, not only by learning from mistakes but also carrying forward the successes too. The opportunities that I had within placements and externally have been crucial to my professional development and I feel equipped to start my journey as a qualified health psychologist. Overall, I am excited to see what my future will bring as a health psychologist and I look forward to continuing to support individuals with long-term health conditions.

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# **Chapter 2: Systematic Review**

# 2.1. Systematic Review Manuscript

# Age and sex/gender as predictors of psychological distress in patients awaiting an organ transplant: A systematic review.

Short title: Distress in organ transplant candidates.

Paige Karadag<sup>\*1</sup>, Kerry Lum<sup>1</sup>, Richard Cooke<sup>1</sup>, Amy Burton<sup>1</sup>

<sup>1</sup> Staffordshire University

\*Corresponding author information: Paige Karadag, School of Health, Education, Policing and Sciences, Science Centre, Staffordshire University, Stoke-on-Trent, UK, (e-mail: <u>paige.karadag@research.staffs.ac.uk</u>).

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# **ORCID ID:**

Paige Karadag: 0000-0003-2655-7109 Kerry Lum: 0000-0001-7413-0842 Richard Cooke: 0000-0003-0476-6284 Amy Burton: 0000-0002-3698-0712

X handle: @PaigeKaradag

#### Abstract

**Introduction:** Increased demand for organ transplants combined with lack of donor organs has resulted in significant wait times for organ transplantation. Psychological distress is common among patients awaiting an organ transplant yet there is little consensus regarding whether age and sex/gender influence psychological distress during this time. Therefore, this review aimed to identify whether age and/or sex/gender predicts psychological distress in patients awaiting an organ transplant.

**Methods:** A systematic search of APA Psychinfo, APA PsychARTCLES, CINAHL, MEDLINE and Scopus electronic databases was conducted in February 2024. The inclusion criteria included studies which reported the impact of age or sex/gender on anxiety and depression in adults awaiting an organ transplant. Following data extraction, quality appraisal was completed using the Quality of Survey Studies in Psychology checklist. Study findings were combined using a narrative synthesis.

**Results:** Nine studies met the inclusion criteria and were included within this review. Narrative synthesis showed that neither age nor sex/gender predicted anxiety or depression in patients awaiting an organ transplant.

**Discussion:** This was the first review to have explored whether age and sex/gender predicts psychological distress in patients awaiting an organ transplant. The findings of this review differ to research findings conducted within the general population and other patient populations, which have repeatedly identified that age and sex/gender predicts psychological distress. Therefore, further research is needed to determine the predictors of psychological distress within this population.

#### Introduction

According to the Global Observatory on Donation and Transplantation (GODT) it was reported that in 2022 there were over 157 thousand organ transplantations worldwide, which was a 9.1% increase compared to the data reported in 2021 (GODT, 2022). The most common organ transplants worldwide include the kidney (65%), liver (24%), heart (6%), lung (4%) and pancreas (1%) (Statista, 2022). Not only does organ transplantation increase life expectancies and improve quality of life, but it also remains the best treatment for terminal and irreversible organ failure (Grinyo, 2013).

Due to advancements in surgical techniques, there has been an increase in demand for organ transplants, yet there are limited numbers of donor organs available (Andrews, 2002). This situation has resulted in a significant increase in wait times for organ transplantation. In 2005 an organ transplant candidate in the United States would wait approximately five years for transplantation to take place (Matas, 2008). However, it was recently reported that because of the shortage of organs that are suitable for donation, only slightly more than 50% of people on the waiting list will receive a transplant within five years (United Network for Organ Sharing, 2024). Similarly, despite a fall in the number of patients awaiting organ transplant in the United Kingdom (Johnson et al., 2014), there are still significant disparities between the demand for transplantation and the number of organs available from donors (Bastani, 2020; Johnson et al., 2014). Not only does this result in an increase in the number of patients waiting several years for an organ transplant, but it also means that thousands of candidates are removed from the transplant waiting list because of death or being too unwell for transplantation (Bastani, 2020).

Given the challenges of living with organ failure, psychological distress is common among patients awaiting an organ transplant (Chilcot et al., 2014; Costa-Requena et al., 2017). Psychological distress can be described as a state of emotional suffering characterised by symptoms of anxiety and depression (American Psychiatric Association, 2013). Anxiety is defined as excessive fear or worry about a specific situation or about a broad range of everyday situations (World Health Organisation, 2014<sup>a</sup>). Symptoms of anxiety include difficulty concentrating, irritability, nausea or abdominal distress, heart palpitations, sweating and having trouble sleeping (World Health Organisation, 2014<sup>a</sup>). Depression is characterised by low mood or loss of pleasure or interest in activities for long periods of time (World Health Organisation, 2014<sup>b</sup>). Symptoms of depression can also include disturbed sleep and changes to appetite. Individuals might have additional feelings of low self-worth, thoughts about dying and hopelessness about the future (World Health Organisation, 2014<sup>b</sup>).

The uncertainty around waiting for an organ transplant includes unpredictability of when the transplant will take place and whether it will arrive in time, which places a large amount of stress on patients, alongside their physical health deteriorating (Haugh & Salyer, 2007; Martin et al., 2010; Toimamueang et al., 2003). Therefore, it is unsurprising that anxiety and depression are particularly prevalent during the waitlist period for transplant candidates (Corruble et al., 2010; Stewart et al., 2014; van Sandwijk et al., 2019). Research has found that psychological distress prior to transplantation was associated with poor psychological wellbeing after transplantation, which was further linked with poorer medication adherence after transplantation (Reber et al., 2016; Scheel et al., 2018). Similarly, literature has identified that depression during the waitlist period can increase the odds of posttransplant mortality (Dew et al., 2016). Given the detrimental effect that psychological distress may have on physical health outcomes after transplantation, it is important to understand the

factors which may influence anxiety and depression during the waitlist period. Currently, there is little consensus regarding which factors may contribute to an increase in psychological distress during this time.

Two factors which may influence psychological distress in organ transplant candidates are sex/gender and age. This is because research in the general population has consistently shown that females are significantly more likely to develop an anxiety disorder compared to males (Bruce et al., 2005; Christiansen, 2015; Regier et al., 1990). Similarly, it has been reported that depression is approximately 50% more common among females compared to males (Girgus & Yang, 2015; World Health Organisation, 2024<sup>b</sup>). Literature has also demonstrated that age plays an important role in predicting psychological distress in the general population (Bell, 2014; Blanchflower & Oswald, 2008). However, there has been a lack of consistent results regarding how age affects anxiety and depression. For instance, it was found that younger adults (16-29 years) were more likely to be affected by depression and severe anxiety than the older adults in Sweden (Statista, 2023). Similarly, a large-scale study involving 7485 participants living in Canberra, Australia found that psychological distress declined across the age range of 20-64 (Jorm et al., 2005). On the other hand, some research has highlighted that psychological distress increases in middle-aged adults (Blanchflower & Oswold, 2008). Whereas other research found that older adults are at an increased risk of depression and anxiety because of poor physical health, poor living conditions and a lack of access to quality support (World Health Organisation, 2023).

More specifically, there is evidence that sex/gender and age influence psychological distress in a range of patient populations. Research has highlighted that sex/gender predicted anxiety and depression in patients with chronic obstructive pulmonary disease, as females had higher

levels of anxiety and depression (Di Marco et al., 2006). This finding was mirrored in individuals with cystic fibrosis, as women reported more symptoms of anxiety than men (Goldbeck et al., 2010). Similarly, a systematic review found that women with inflammatory bowel disease were at higher risk of developing anxiety or depression compared to men (Fracas et al., 2023).

Research has also highlighted that age negatively correlated with depression in adults aged 21 to 87 years old with rheumatoid arthritis (Hughes et al., 2021). However, in patients with cystic fibrosis, younger patients reported fewer symptoms of anxiety and depression than older patients (Goldbeck et al., 2010). Furthermore, research found that anxiety and depression increased with age in patients with heart failure (Aburuz, 2018). Given the evidence that age and sex/gender influence psychological distress in the general population and among individuals with long-term health conditions, it is important to identify whether these findings would apply to individuals awaiting an organ transplant.

#### Current Systematic Review

The current systematic review aims to investigate whether age and/or sex/gender predict psychological distress in individuals who are on the waiting list for an organ transplant. For the purpose of this review, the terms 'sex' and 'gender' will be used together. This is not to suggest that these terms are interchangeable, as there are distinctions between them: sex typically refers to biological and physiological processes whereas gender refers to the roles, relationships and behaviours ascribed to different gender identities (Puil et al., 2014). However, attributes of sex and gender are multidimensional, dynamic, interactive and are not easily separable. Therefore, in recognition of this theoretical and empirical entanglement, it has been recommended that the term sex/gender is used within research (Kaiser et al., 2009; Springer et al., 2011; Tudiver et al., 2012).

There are several studies which have explored predictors of anxiety and depression in patients awaiting specific organ transplants (Corruble et al., 2010; Stewart et al., 2014; Vermeulen et al., 2005). Nevertheless, there is yet to be a review which has collated the results. Therefore, this systematic review will combine data from papers investigating psychological distress across different types of organ transplants. The current systematic review aimed to answer the following research question: Does age and/or sex/gender predict psychological distress in patients awaiting an organ transplant?

# Methods

This systematic review was conducted and is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2015) and was registered with 'PROSPERO before searches began (PROSPERO 2024 CRD42024486065).

# Study Inclusion Criteria and Search Strategy

In February 2024, the first author searched the following electronic databases: APA Psychinfo, APA PsychARTCLES, CINAHL, MEDLINE, and Scopus. This selection of databases was to provide good coverage of health and social sciences related research on the review topic (Petticrew & Roberts, 2008). The Population, Intervention, Comparison, Outcome and Study type (PICOS) tool guided the development of search terms and inclusion criteria (Methley et al., 2014). As this systematic review did not focus on an intervention or comparison group, these components were not used. The study population includes adults (aged  $\geq 18$  years of age) awaiting an organ transplant. This includes adults awaiting a: heart, lung, liver, kidney, pancreas, stomach, intestine or multi organ transplant. The outcome is to identify whether age and/or sex/gender are predictors of psychological distress (anxiety or depression), through use of a validated screening tool, in patients awaiting an organ transplant. A range of screening tools for psychological distress will be included such as Beck Depression Inventory (BDI), Hospital Anxiety and Depression Scale (HADs) and the DSM Criteria for anxiety and depression. Quantitative studies including cross-sectional studies or baseline cross sectional data from longitudinal (cohort) studies will be included in the review. Studies that were interventional in nature were excluded, as an intervention may influence the levels of psychological distress. Similarly, baseline measures from interventional studies were not included as the experiences of individuals anticipating an intervention whilst on the waiting list for an organ transplant may not be the same as those who are not expecting an intervention.

Databases were searched using the search terms: ("psychological distress" OR "anxiety" OR "depression") AND ("organ transplant" OR "heart transplant" OR "kidney transplant" OR "liver transplant" OR "lung transplant" OR "pancreas transplant" OR "stomach transplant" OR "intestine transplant" OR "multi organ transplant"). Studies published between 2003 and February 2024 were included within the review. The baseline of 2003 was selected as a previous review conducted in 2002 covered the psychological assessment of transplant candidates (Olbrisch et al., 2002). Study inclusion criteria are presented in Table 1.

#### \*INSERT TABLE 1 HERE\*

Once all potentially relevant studies were identified, duplicates were removed, and titles and abstracts were screened by the first author (PK) against the inclusion and exclusion criteria. The second author (KL) independently screened 10% of the abstracts. Where there was a difference in rating, discussions were had to reach 100% agreement and refine and affirm inclusion as necessary.

# Data extraction

The first author (PK) developed a data extraction form which facilitated extraction of general information, study characteristics, methods used, participant information, outcome measures, statistical analyses conducted, findings and conclusions drawn. The first author completed data extraction for all papers.

# Quality assessment

The quality of included papers was assessed using the Quality of Survey Studies in Psychology (Q-SSP) (Protogerou & Hagger, 2020). The Q-SSP has been found to have face and content validity (Protogerou & Hagger, 2020). Additionally, in a pilot test of its application, the Q-SSP also demonstrated good inter-rater reliability (Protogerou & Hagger, 2020). Each study was entered into a table and the answers to each of the questions on the Q-SSP were provided which enabled a quality rating to be established. The second author (KL) completed a quality assessment on 10% of the included full texts (final selection).

#### Data Synthesis

Due to the substantial level of heterogeneity present in the included studies regarding the outcome measures used for psychological distress, it was not possible to use meta-analysis to pool results from included studies. Therefore, a narrative synthesis was conducted. The synthesis was conducted to understand any heterogeneity within the area being investigated and to combine information.

#### \*INSERT FIGURE 1 HERE\*

# Results

#### *Description of studies*

The descriptive data extracted from studies is summarised in table 2.

#### \*INSERT TABLE 2 HERE\*

#### Study Characteristics

Nine studies were included within this review, with a total of 1271 participants who were candidates on the waiting list for an organ transplant. Two studies were conducted in Turkey, two in Brazil, one in the Netherlands, one in China, one in the United Kingdom and one conducted in Germany and Austria. Studies included participants who were awaiting a liver (n=503), kidney (n=357), heart (n=227) or lung transplant (n=184).

# Quality of studies

Quality of the studies varied as k = 7 studies were determined to have 'questionable quality' (Annema et al., 2017; Fidan et al., 2021; Myaskovsky et al., 2003; Ni et al., 2020; Santos et al., 2010; Tavabie et al., 2020; Thomas & Castro, 2014), and k = 2 studies were rated as

having 'acceptable quality' (Erbay et al., 2021; Spaderna et al., 2014). A common strength among the papers was that they all reported that participants were asked to provide informed consent. Additionally, in all papers the problem and population under investigation was described, defined, and justified. Almost all papers provided definitions of study variables, described the recruitment strategy, and provided the context of data collection and duration. Further strengths were that all studies described key demographic characteristics and the discussion of findings was confided to the sample population. However, a common weakness among studies was that the majority did not specify research questions or a hypothesis. Moreover, none of the included studies provided a justification for the sample size and very few provided the attrition rate or a method for treating attrition. Another weakness was that few studies provided an adequate description of the measures in the report and none of the studies clearly stated whether participants were debriefed.

#### Design and Outcome Measures

Seven of the included studies were cross sectional (Erbay et al., 2021; Fidan et al., 2021; Myaskovsky et al., 2003; Ni et al., 2020; Santos et al., 2010; Tavabie et al., 2020; Thomas & Castro, 2014). Two studies were ongoing or longitudinal studies monitoring transplant candidates over time several time points, however only the baseline data was extracted from these studies (Annema et al., 2017; Spaderna et al., 2014).

Three studies used the Beck Depression Inventory (BDI) to measure depression (Erbay et al., 2021; Fidan et al., 2021; Thomas & Castro, 2014) and one study used the Beck Anxiety Inventory (BAI) to measure anxiety (Santos et al., 2010). Two studies used the Hospital Anxiety and Depression Scale (HADS) to measure anxiety and depression (Spaderna et al., 2014; Tavabie et al., 2020). One study used subscales of the Symptom Checklist-90 (SCL-90)

for anxiety and depression (Myaskovsky et al., 2003), one study used the State-Trait Anxiety Inventory (STAI-6) for Anxiety and the Dutch version of the Centre for Epidemiological Studies Depression scale (CES-D) (Annema et al., 2017) and one study used the Hamilton Rating Scale for Depression (HAMD-17) and the Hamilton Anxiety Rating Scale (HAM-A) for anxiety (Ni et al., 2020).

Eight studies reported the effects or association of age on psychological distress (anxiety or depression) in organ transplant candidates (Annema et al., 2017; Erbay et al., 2021; Fidan et al., 2021; Ni et al., 2020; Santos et al., 2010; Spaderna et al., 2014; Tavabie et al., 2020; Thomas & Castro, 2014). Five studies reported the effects or association of sex/gender on psychological distress in organ transplant candidates (Annema et al., 2017; Erbay et al., 2021; Fidan et al., 2021; Mayaskovsky et al., 2003; Tavabie et al., 2020).

#### Age and psychological distress

In total, eight studies explored whether age was associated with psychological distress (anxiety or depression). Specifically, seven studies explored whether age was associated with depression in patients awaiting an organ transplant (Annema et al., 2017; Erbay et al., 2021; Fidan et al., 2021; Ni et al., 2020; Spaderna et al., 2014; Tavabie et al., 2020; Thomas & Castro, 2014). Within these studies, several scales were used to measure depression including the CES-D (Annema et al., 2017), the HAMD-17 (Ni et al., 2020), the HADS (Spaderna et al., 2014; Tavabie et al., 2020) and the BDI (Erbay et al., 2021; Fidan et al., 2021; Thomas & Castro, 2014). None of these studies found age to be associated with depression in patients awaiting a liver, kidney, lung, or heart transplant (p > .05).

Five studies investigated whether age was associated with anxiety in patients awaiting an organ transplant (Annema et al., 2017; Ni et al., 2020; Santos et al., 2010; Spaderna et al., 2014; Tavabie et al., 2020). Several scales were used to measure anxiety including the STAI-6 (Annema et al., 2017), the HAM-A (Ni et al., 2020), the BAI (Santos et al., 2010), and the HADS (Spaderna et al., 2014; Tavabie et al., 2020). All five studies found that age was not significantly associated with anxiety in patients awaiting a liver or heart transplant (p > .05).

#### Sex/gender and psychological distress

Five studies investigated whether sex/gender was associated with depression in patients awaiting an organ transplant (Annema et al., 2017; Erbay et al., 2021; Fidan et a., 2021; Myaskovsky et al., 2003; Tavabie et al., 2020). Across these studies, several scales were used to measure depression. Measures included the CES-D (Annema et al., 2017), the SCL-90 (Myaskovsky et al., 2003), the HAMD-17 (Ni et al., 2020), the HADS (Spaderna et al., 2014; Tavabie et al., 2020) and the BDI (Erbay et al., 2021; Fidan et a., 202; Thomas & Castro, 2014). Three studies included liver transplant candidates (Annema et al., 2017; Fidan et al., 2021; Tavabie et al., 2020) one study included kidney transplant candidates (Erbay et al., 2021), and one study included lung transplant candidates (Myaskovsky et al., 2003).

Four studies found that sex/gender was not significantly associated with depression in patients awaiting a liver, kidney, or lung transplant (p > .05) (Annema et al., 2017; Erbay et al., 2021; Fidan et a., 2021; Myaskovsky et al., 2003). However, one study found that being female was significantly associated with an increased prevalence of abnormal depression scores in patients awaiting a liver transplant (p = 0.02) (Tavabie et al., 2020).

Three studies investigated whether sex/gender was associated with anxiety in patients awaiting an organ transplant (Annema et al., 2017; Myaskovsky et al., 2003; Tavabie et al.,

2020). Three different scales were used to measure anxiety including the STAI-6 (Annema et al., 2017), the anxiety subscale of SCL-90 (Myaskovsky et al., 2003) and the HADS (Tavabie et al., 2020). All studies found that sex/gender was not significantly associated with anxiety in patients awaiting a liver or lung transplant (p > .05).

#### Discussion

The aim of this review was to identify whether age and/or sex/gender predict psychological distress in patients awaiting an organ transplant. Nine studies were identified, and results indicated that age and sex/gender do not predict psychological distress in patients awaiting an organ transplant.

The findings of this review are inconsistent with research findings regarding sex/gender and psychological distress in the general population and other patient populations. Research conducted in the general population highlighted that psychological distress was consistently higher in females compared to males (Bruce et al., 2005; Regier et al., 1990). This finding has also been shown in patients with long term conditions (Di Marco et al., 2006; Fracas et al., 2023; Goldbeck et al., 2010). However, only one study included within this review found that there was a significant correlation between sex/gender and depression. This study only included 19 liver transplant patients which might explain why these results differ, as the more common finding was that sex/gender was not associated with depression or anxiety in patients awaiting an organ transplant.

Similarly, the review findings are also inconsistent with research regarding the effect of age on psychological distress in the general population. Literature has found that within the general population, age influences psychological distress (Bell, 2014; Blanchflower & Oswald, 2008; World Health Organisation, 2023). Age has also been found to impact psychological distress in patient populations too (Aburuz et al., 2018; Goldbeck et al., 2010; Hughes et al., 2021). Nevertheless, none of the studies included in the current review found age to be associated with anxiety or depression in patients awaiting an organ transplant.

One possible explanation as to why these results differ to wider populations could be because patients on the transplant list have already undergone rigorous psychological assessments prior to being accepted onto the waiting list. Subsequently, patients who are determined to have high levels of psychological distress during the assessment may be considered unsuitable for an organ transplant at that stage (Sarkar et al., 2022). There were ten studies identified which have investigated the effects of age and/or sex/gender on psychological distress in patients who were being evaluated for an organ transplant e.g. Burker et al., (2005), Phillips et al., (2011) and Soyseth et al., (2020). However, these studies were not included as this review focus was specifically on anxiety and depression in patients who were already on the waiting list. From an initial search, it is unclear whether the findings within this population would differ to the findings of this review. For instance, some studies found that among patients being evaluated for a lung transplant, neither age nor sex/gender correlated with emotional distress (Burker et al., 2005; Soyseth et al., 2020). However, Phillips et al (2011) identified that women reported significantly more symptoms of depression than men who were undergoing psychological evaluation for a lung transplant. Therefore, future research could explore the findings for this cohort, particularly to identify whether predictors of psychological distress differ between these groups.

Additionally, broader research regarding psychological distress in the general population is often conducted in Western countries such as North America, Europe and Australia and therefore reflects Western societies (Haroz et al. 2017). However, more than half of the studies included in this review (k = 5) were conducted in non-Western countries such as Turkey, China and Brazil. Therefore, the cultural and societal differences could provide an explanation as to why these findings regarding predictors of psychological distress differ. For instance, studies in China found that there were no significant sex/gender differences for depression (Gao et al., 2020; Lee et al., 2009). Nevertheless, research in Turkey and Brazil mirrored western findings that females experience higher rates of psychological distress compared to males (Carpena et al., 2020; Kose, 2020). Studies in Brazil found age to be associated with depression (Hintz et al., 2023). However, research is lacking regarding the impact of age on psychological distress in adults within China and Turkey. Therefore, further research is required to determine whether age affects psychological distress in these counties to fully compare the findings across western and non-western populations.

As most of the diagnostic tools for anxiety and depression were developed via research in Western populations, there may be features of anxiety or depression in non-western populations that are not captured via current measurement tools (Haroz et al., 2017). This suggests that further research is required in patients awaiting an organ transplant in both western and non-western countries. Furthermore, as the studies included in the review were of low quality, it is difficult to know whether their findings would be replicated in high quality studies. This may further explain why the findings of this review differ to previous findings in the general population and patient samples.

# Strengths and limitations

This review addressed a clear gap within the literature as it is the first review that has explored whether age and/or sex/gender predict psychological distress in patients awaiting an organ transplant. A comprehensive search strategy was used to review all available evidence so that it was combined accordingly. Subsequently, this review included a range of organ transplant candidates including liver, lung, kidney, and heart, which is representative of the four most common types of organ transplant. It also provided important insights that predictors of psychological distress may differ to the general population and other patient populations. Another strength of the review was that each stage was prespecified in the PROSPERO protocol, making it transparent and reproducible. Similarly, this review had a second reviewer which added to its reliability.

Nevertheless, there were several limitations of the studies included within this review. There was a large amount of variation in the sample sizes for the included studies as samples ranged from 19 participants to 292 participants. Moreover, four out of the nine included studies had fewer than 100 participants. Although there are challenges associated with conducting research within this population, these small sample sizes are not reflective of the number of patients awaiting an organ transplant, given that there are more than 7000 currently on the waiting list in England alone (NHS England, 2023). Additionally, small sample sizes could have impacted the results of the studies and thus the overall results of the review.

Another limitation was high levels of heterogeneity across studies in how psychological distress was measured. This meant it was not possible to pool results across studies using meta-analysis, which would have been one way to assess the small sample sizes. Moreover, quality assessment for most studies included in this review were poor, with seven out of the nine included studies having 'questionable quality' and just two had 'acceptable quality'.

Thus, future research needs to be more robust in its design and reporting to improve the quality of the published literature (Petticrew & Roberts, 2008).

# Conclusion

Overall, the findings demonstrated that neither age nor sex/gender predicted psychological distress in patients awaiting an organ transplant. This finding suggests that predictors of psychological distress in this population differ to predictors in the general population. Due to limitations with studies included in this review, further high-quality research is required to better determine whether age and sex/gender do play a role in predicting anxiety and depression within this population.

# **Conflict of interest statement**

The authors declare no conflicts of interest.

# Data availability statement

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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*Please note: References marked with an asterisk (\*) were the included studies within the review.* 

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topics/depression#tab=tab\_1

Inclusion	Exclusion
Organ transplant candidates who completed	Organ transplant recipients
measures whilst on waitlist/ pre-transplant	
Adults (age > = 18)	Children (age <18)
Quantitative studies including cross-	Qualitative studies
Quantitative studies including closs-	Quantative studies
sectional study or baseline cross sectional	Interventional in nature
data from a longitudinal (cohort) study.	
	Case study
Results reported in English	Results reported in other languages
Anxiety or depression level is reported	Anxiety or depression is not reported using
using reliable and validated measures such	an established measure
as Beck Depression Inventory, Hospital	
Anxiety and Depression Scale, DSM	
Criteria for anxiety and depression.	
Impact of age or sex/gender of participants	Impact of age or sex/gender of participants
reported for anxiety or depression	not reported for anxiety or depression

Figure 1: PRISMA Diagram demonstrating search and study selection process.



Authors Year	Country	Aim	Design	Sample and Sample	Outcome Measure	Analysis and Results (age)	Analysis and Results (sex/gender)
				Size			
Annema et al., (2017)	The Netherlands	To explore whether distinct trajectories of anxiety and depression are present in liver transplant candidates, how these trajectories evolve over time, and to identify which demographic, clinical, and individual characteristics are related with these trajectories.	Prospective longitudinal cohort study. (baseline data extracted)	N= 216 Liver transplant candidates on waitlist Males = 144 (66.7%) Age (18+) mean (SD). 51.6 (11.3)	State-Trait Anxiety Inventory (STAI-6) Dutch version of the Center for Epidemiological Studies Depression scale (CES-D)	Univariate ordinal logistic regression analyses Anxiety: Found no relations between age and anxiety. Age mean (SD): Anxiety below clinical level: 51.9 (11.3) Anxiety slightly above clinical level: 51.1 (11.7) Anxiety high above clinical level: 51.8 (11.0) p = .79 Depression: Found no relations between age and depression	Univariate ordinal logistic regression analyses <b>Anxiety:</b> Found no relations between sex and the trajectories of anxiety. Gender: male n (%) Anxiety below clinical level: 78 (66.1) Anxiety slightly above clinical level: 46 (68.7) Anxiety high above clinical level: 20 (64.5) p = .94 <b>Depression:</b>

**Table 2:** Descriptive information and results of included studies

						Age mean (SD):	Found no relations between sex and the
						Depression below clinical	trajectories of
						level: 50.6 (11.2)	depression
						Depression slightly below clinical level: 52.2 (12.0) Depression slightly above clinical level: 50.9 (11.1) Depression high above clinical level: 54.2 (5.7)	<ul> <li>p = .40</li> <li>Gender: male n(%)</li> <li>Depression below clinical level: 21 (58.3)</li> <li>Depression slightly below clinical level: 71</li> </ul>
						p = .89	(68.3)
							Depression slightly above clinical level: 45 (68.2)
							Depression high above clinical level: 7 (70.0)
							Correlations between depression and gender were not statistically significant.
							r = .046, p > .05
Erbay et al., (2021)	Turkey	To determine the factors affecting the	Cross- sectional	N = 292	Beck depression inventory (BDI)	Hierarchical multiple regression analyses	Hierarchical multiple regression analyses

		quality of life of	Ouantitative	Patients		Depression	Depression
		patients who are	study	registered			1
		undergoing		on kidnev		Correlations between	Correlations between
		haemodialysis		transplant		depression and age were not	depression and sex
		treatment with		list		statistically significant	were not statistically
		chronic kidney				statistically significant	significant
		failure and		130		r = 060	Significant.
		awaiting kidney		females.		1 1000	r = .046
		transplantation.		162 males		p > 05	
		and to measure		102		p >	n > 05
		the association		Age range			
		of depression		18-83.			
		levels and		mean (SD)			
		coping styles on		= 51.99			
		the quality of		(14.00)			
		life of		(			
		individuals					
		awaiting kidney					
		transplantation.					
Fidan et al.,	Turkey	To analyse life	Cross	N= 56	Beck depression	Pearson's correlation	Pearson's correlation
(2021)	•	quality,	sectional	patients	invention (BDI)	coefficient/Spearman's rank	coefficient/Spearman's
		depression		registered		correlation coefficient.	rank correlation
		symptoms and	Mixed	for a lung			coefficient
		existence of	methods	transplant		Depression	
		sexual		included			Depression
		functional	(quantitative	in the		There were no relationships	
		disorders of	measures	study		among patient age and BDI	Moderate depression
		patients waiting	were			score.	was detected in 7
		for liver	completed	64.3%			females (35.0%) and 14
		transplantation.	via interview)	males		p > .05	males (38.9%); 25.0%
							had mild depression
							symptom and 14.3%
				Aged 18- 64 Mean age males = $46.6 \pm$ 13.6 years. Mean age females = $46.6 \pm$ 14.2 years			showed signs of severe depression. There were no differences between female and male BDI results ( $p > .05$ ) $X^2 = 0.291$ p = 1.000
------------------------------	--------------------------------	--	--	---	--	---	--
Myaskovsky et al., (2003)	United States of America	To describe the strategies lung transplant candidates use to cope with stressors related to their health. To examine how lung transplant candidates' coping styles were related to quality of life controlling for other variables that might be important to their quality of life.	Cross sectional Mixed methods (quantitative measures were completed via interview)	N= 128 lung transplant candidates 57.8% female Age ≤ 50: 49.2%	Subscales of the Symptom Checklist-90 (SCL-90) for anxiety and depression	-	Regression analysis. Anxiety Gender and anxiety $R^2=$ 17 (not significant) p > .05 Depression Gender and depression $R^2=13$ (not significant) p > .05

Ni et al., (2020)	China	To assess the affective status, sleep quality, and daily living abilities of candidates on the orthotopic liver transplant waiting list at a single center in China and to identify the association between these factors and disease severity as represented by the MELD score.	Cross- sectional, single-centre study Quantitative	N = 53 liver waiting list candidates 41 (77.4%) men and 12 (22.6%) women. Age range = 21-84 Average = $52.2\pm12.6$ 7 years	Hamilton Rating Scale for Depression (HAMD-17) Hamilton Anxiety Rating Scale (HAM-A)	A non- parametric Mann- Whitney U-test) was used. Anxiety: Age was not correlated with the scores on the HAM-A Depression: Age was not correlated with the scores on the HAMD-17	-
Santos et al., (2010)	Brazil	To evaluate the degree of anxiety related to the completion of orthotopic liver transplant and the possible correlation between anxiety	Prospective study Cross sectional, quantitative	N= 215 patients on waiting list for liver transplant; 165 (76.7%) were male and 50 (23.3%)	Beck Anxiety Inventory (BAI)	Nonparametric Mann- Whitney (for comparison of 2 levels) and Kruskal-Wallis (for comparison of 4 levels). <b>Anxiety:</b> There was no statistically significant difference between age and level of anxiety.	-

		and etiologic diagnosis.		were female. Age range 18-72. Average = 49.5 years.			
Spaderna et al., (2014)	Germany and Austria	To prospectively evaluate the association of everyday physical activity with event-free survival in ambulatory patients enrolled in the Waiting for a New Heart Study, while considering objectively assessed medical risk, depression, and anxiety.	Ongoing prospective multisite observational study. Cross sectional quantitative data extracted.	N= 227 Adult patients newly listed for heart transplant. Women N (%) = 42 (18.5) Age mean (SD) = 53.5 (10.3)	German translation of the Hospital Anxiety and Depression Scale (HADS)	T tests and chi-square tests as appropriate Anxiety: Anxious and non-anxious patients did not differ in age. (p's > .33; data not shown). Depressed and nondepressed patients did not differ in age. p's >.15; data not shown).	-
Tabavie et al., (2020)	United Kingdom	To understand the prevalence of anxiety and depression among patients on the liver	Cross sectional Quantitative	N= 19 Patients attending the liver transplant waiting list clinic	Hospital Anxiety and Depression Scale (HADS)	Continuous variables were analysed with Mann- Whitney U or Student t- tests. Categorical variables were analysed with the chi- square test.	Categorical variables were analysed with the chi-square test. <b>Anxiety</b>

		transplant				Anxiety:	Female sex was not
		waiting list.		Male = 7		v	significantly associated
		0		(37%)		Although not reaching	with increased anxiety.
				Female =		statistical significance, there	
				12 (63%)		was a trend that suggested	p = 0.51
				12 (00 / 0)		that patients with abnormal	
				Age range		HADS scores for anxiety	Depression
				20-61		were vounger	
				Mean $= 44$		were younger.	Female sex was
						p = 0.12	significantly associated
						p = 0.12	with an increased
						Depression:	prevalence of abnormal
						- · F · · · · · · · · · · · · · · · · ·	HADS scores for
						There was no association	depression.
						with age and HADS scores	1
						for depression	OR=12.5
						1 I	95% CI=1.47-84.6
						p =0.72	
						1	p = 0.02*
Thomas, C.	Brazil	To assess the	Ex post facto	N= 65	Beck	Pearson's correlations	
V., & de		relationship	study	patients on	Depression		
Castro, E. K.		between		kidney	Inventory -	Depression:	-
(2014)		personality, self-	Cross-	transplant	(BDI)		
		efficacy and	sectional	waiting		Correlation between age and	
		depression	quantitative	list		depression	
		factors in					
		Brazilian		female =		r = -0.038	
		patients on the		26 (40%)			
		kidney		and male		p > 0.05	
		transplant		=39 (60%)			
		waiting list.					

		Age range 25 – 72		
		mean =		
		49.11		
		(SD=		
		11.58)		

#### 2.2. Systematic Review Commentary

#### Introduction

Systematic reviews are important as they help researchers and practitioners to keep up with relevant literature by providing access to all available evidence on a specific topic (Cook et al., 1997; Owens, 2021). Initially, I found it quite difficult to find a suitable review topic, despite identifying a range of potential areas of focus. From my experience of working in Bristol ME Service, I thought that it would be beneficial to focus on health anxiety within Myalgic Encephalomyelitis (ME)/ Chronic Fatigue Syndrome (CFS). However, through a scoping review it became clear that there was not enough research regarding health anxiety in individuals with ME/CFS to conduct a systematic review. Subsequently, I decided to broaden the review to health anxiety in chronic pain populations, but unfortunately a review in this area had already been conducted. As the theme of my portfolio is long-term conditions (LTCs), I decided to expand the search to investigate an area that I have not covered within my training so far. Therefore, I decided to focus on patients awaiting an organ transplant. This population appealed to me as it would allow me the opportunity to investigate a range of LTCs which face the additional challenge of needing an organ transplant. Specifically, I decided to investigate whether age and/ or sex/gender predicted psychological distress in individuals who are on the waiting list for an organ transplant.

#### **Protocol and PROSPERO**

I had some previous experience of pre-registering a study on the open science framework within my placement at Bath Centre for Pain Research during my master's degree. However, I had not previously written a protocol for a systematic review or registered one on PROSPERO. Due to this lack of experience, I felt apprehensive about this task, and I was unsure where to start. I particularly struggled when writing the 'data analysis' section as I did not know what the analysis would be at the stage of writing the protocol and I did not fully understand the determinants of a meta-analysis or narrative synthesis. Therefore, I sought guidance from my supervisor and the module lead who helped to clarify the level of detail that was required for this section of the protocol.

Upon submitting the protocol to PROSPERO, it was returned to me with feedback that I needed to add more information for the 'intervention, exposures' section. When I originally wrote the protocol, I did not think that there were any interventions or exposures so I thought it would be appropriate to leave these sections blank. However, the PROSPERO reviewers explained that age and sex/gender would be considered as the 'exposures' within this context and therefore sufficient detail needed to be added to these sections. The same applied to the 'comparators/ control' section of the protocol. Once I had added this information, the protocol was accepted and published.

Overall, I found the protocol to be a valuable exercise as it outlined my research questions, data extraction and analysis plan. For future protocols, I would add more detail to the inclusion and exclusion criteria. This was because I encountered several challenges associated with the definition of 'transplant candidate' during the screening phase and if it has been more clearly defined in the protocol, I may have avoided some of these obstacles.

#### Ethics

To comply with Staffordshire University research ethical review policy (2019) and to adhere to the General Data Protection Regulation (2018) I completed an ethics disclaimer. This differed to the types of ethics applications that I was used to, and I found it to be a relatively straight forward process.

#### Search terms and searches

I used the PICOS (Population, Intervention, Comparison, Outcome, study type) tool to guide my search and this helped me to consider any key concepts which needed to be included in the search strategy. As I was not reviewing an intervention or comparison group, I did find the tool slightly confusing to apply at times. Alternatively, the SPIDER tool might have been more suitable as it includes the following components: sample, phenomenon of interest, design, evaluation and research type (Cooke et al., 2012). Although the SPIDER tool is often applied to qualitative or mixed method research (Cooke et al., 2012), it may have been more applicable to my research question as it does not require the details of an intervention or comparison group. Nevertheless, I would use PICOS again for future reviews that include an intervention and comparison group.

I feel that I learnt a lot during this stage of the review about how to combine search terms, as this was not something that I had done previously. Although I searched a range of databases, I did not search the grey literature for this review. This was due to the time constraints that I faced, as I was conducting the review on my own outside of my placement, and I did not think that I had the capacity to search the grey literature in time. Nevertheless, searching grey literature is an important aspect of systematic reviewing as it minimises publication bias (Blackhall, 2007). Therefore, for future reviews I will aim to search the grey literature too.

#### **Data screening**

Upon completion of the database searches, I began the data screening phase. I had initially planned to use the referencing software Mendeley to facilitate with the data screening; however, I encountered challenges when trying to upload the references. Therefore, I decided to use 'Rayyan' software as it has been found to be an effective tool which allows screening to be completed efficiently (Ouzzani et al., 2016). I extracted the articles identified in the database searches into a Microsoft Excel spreadsheet and uploaded the files to Rayyan. Rayyan identified potential duplicates which I then had to manually filter through before removing. This was time-consuming and there may be a more streamlined way of doing this in the future. For instance, Endnote has been found to be efficient for de-duplication as it can automatically detect duplicate citations and remove them without additional manual checking, whilst maintaining 100% specificity (Jubb et al., 2020; Lorezertti & Ghali, 2013). Therefore, next time I would consider using a referencing software such as Endnote for the de-duplication stage before uploading the references to Rayyan for screening.

After removing the duplicate entries, I was left with 2122 articles for screening. I first screened the titles, followed by the abstracts and full texts. At each stage, I used Rayyan to organise the articles into three categories: 'include', 'exclude' and 'maybe'. When I excluded articles, Rayyan allowed me to add a label to explain why it did not meet the inclusion criteria. Similarly, I was able to add a comment to refer to at a later stage if needed. I found that the comment function was particularly useful for articles that I was unsure about and categorised as 'maybe'.

It is recommended that data screening is completed by two individuals independently which helps to ensure reliability (Kitchenham, 2004). Using a second reviewer throughout the entire study screening process is considered best practice, however this requires significant resources (Stoll et al., 2019) and was not possible for this review. Therefore, a second reviewer independently screened 59 abstracts (10% of total abstracts), which were selected at random using a random number generator. I created an excel table which included the necessary details for the second reviewer to complete the screening.

Any papers that we disagreed on were discussed until 100% agreement was reached. However, this process highlighted to me how two reviewers can interpret the information in an abstract differently. I realised that I had been too cautious within the abstract screening as I included several studies that probably could have been excluded at this stage. I think that this was due to my lack of confidence in screening and my limited experience within the organ transplant literature, as I was not as familiar with the terminology used. This resulted in 340 full texts for me to screen which was both time consuming and tedious. Nevertheless, I was able to quickly get into a pattern of reviewing the method section to assess eligibility using my inclusion and exclusion criteria. One barrier that I encountered at the full text screening stage was the 'maybe' category which involved studies that controlled for age and sex/gender or included it as a covariate. These studies required careful consideration as to whether they met the inclusion criteria. After deliberating, I decided that including age or sex/gender as a covariate was not sufficient to answer the research question and they were subsequently excluded. There were also some studies that I was unable to obtain the full text for, despite requesting them from Staffordshire University library. As I did not have the time to contact the authors to request the full text, I had to exclude these studies.

Once the screening had been complete, I calculated Cohens Kappa in Microsoft Excel to test interrater reliability (McHugh, 2012). I found this quite challenging as I had not done this before, and I was reliant on online instructions. Once I had calculated it correctly, Cohens Kappa was determined to be 0.22 which is considered 'fair agreement'. However, 0.40 to 0.60 is required for an acceptable level of agreement which suggests that there was low interrater reliability (McHugh, 2012). This was particularly disappointing, and I felt as though I had 'failed' this aspect of the systematic review. I discussed this statistic with the module lead, who highlighted that I may have calculated Cohen's Kappa prematurely, as often it would be used to show inter-rater reliability at the stage of full text screening, rather than at the abstract screening stage. I hope that the next time I conduct a systematic review I will have a second reviewer throughout the entire screening process, but if this is not possible, I will involve them at the point of full text screening rather than abstract screening.

#### **Data extraction**

Upon completion of the full text screening, there were 25 studies which I initially thought met the inclusion criteria. However, when I started the data extraction phase, I realised that six studies had included pre-transplant measures for transplant recipients. I met with the module lead to discuss these studies and we agreed that they should be excluded as they were too different to the other populations considering all participants had received a transplant.

I also realised that 'candidates' meant two different things in this context as it referred to patients that had been accepted onto the waiting list for a transplant and patients who were undergoing evaluation for a transplant. This meant that I had 9 studies which included patients who had been accepted onto the transplant waiting list and 10 studies that included patients who were being evaluated to see if they were suitable for an organ transplant. I decided to extract the data for all these studies as it helped me to gain a better understanding of the data. I then arranged a meeting with the module lead to discuss the possibility of including both sets of studies. We concluded that one option was for me to include the two populations, but I would need to review the groups separately and then compare the results. I would have liked to include both groups as this would have resulted in a more comprehensive systematic review of the literature. However, given the timeframe that I had available to complete the review, I felt that I only had the capacity to focus on one of these groups. I referred to the protocol, whereby I had specified that I would be investigating the impact of age and sex/gender on psychological distress in patients on the organ transplant list. Consequently, I felt that it was appropriate to focus on the group who had already been accepted onto the waiting list, opposed to those under evaluation as this would be deviating from the protocol.

Although I encountered some challenges within the data extraction phase, it highlighted the pivotal role of data extraction when conducting a systematic review, particularly as it determines the type of analysis that can be used. Going forward, I feel more equipped to conduct data extraction independently.

#### **Quality Assessment**

The quality assessment of papers included in a systematic review is essential (Higgins et al., 2019). I had some previous experience of using the Cochrane a risk of bias tool for a Cochrane review that I assisted with during my master's degree. However, I did not have any experience of using other quality assessment measures, so I did feel slightly apprehensive

when starting the quality assessment. I decided that the Quality of Survey Studies in Psychology (Q-SSP) (Protogerou & Hagger, 2020) would be a suitable measure to use given that all of the studies used questionnaires to measure psychological distress. The second reviewer completed the quality assessment for 10% of the included studies, which equated to 1 study. There was full agreement with the second reviewer for the quality assessment. Although the Q-SSP had detailed guidelines, I found it quite difficult to determine the quality of studies at times. However, I think that this may be because I lacked confidence with my judgements. I think that this is something that will improve with experience and I was reassured that there was agreement with the second reviewer.

#### Data analysis

If possible, a meta-analysis should be conducted as this provides a more accurate analysis of the measures than an individual study can alone (Haidich, 2010). I met with the module lead and my supervisor to discuss whether a meta-analysis would be feasible. I did not anticipate how complicated the inclusion criteria for data analysis or data synthesis would be and through discussions with the module lead, I learnt that there were lots of factors that I needed to account for. For instance, I needed to consider: the consistency of scales used; how many studies included anxiety or depression; and how many studies evaluated the impact of age or gender. During data extraction, I found that a variety of different scales were used within the two groups of studies. The Beck Depression Inventory was used most frequently as it was used in four of the studies. However, not all statistics were reported for each of these studies and on two occasions only age was included in the analysis.

Due to the high levels of heterogeneity of the measures used across the studies, it was agreed that a meta-analysis would not be possible. Therefore, a formal narrative synthesis of the findings of all included studies was conducted. This included a synthesis of methodology (design and sample characteristics), study quality and study findings. Prior to this, I had very limited knowledge about meta-analysis and narrative synthesis, so I feel as though I learnt a lot throughout this process. I was slightly disappointed that I was not able to conduct a meta-analysis for this review as it would have enabled me to develop my skill set further. Nevertheless, I may have the opportunity to conduct a meta-analysis in future endeavours.

#### Manuscript write up and Dissemination

Alongside submitting this paper as part of my portfolio for the doctorate, I intend to submit it to Clinical Transplantation, The Journal of Clinical and Translational Research. I selected this journal as it is centred around organ transplants and has previously published studies that have investigated psychological distress in organ transplant candidates. When writing the manuscript, I ensured to follow their author guidelines. Overall, the guidelines helped to provide structure for the manuscript. However, I was confused by the guidance relating to the reference style and thought that I needed to change the references from APA 7 to AMA. The module lead clarified the journal guidance and explained that 'free-format submission' meant that I could use any referencing style in the manuscript. I had already started reformatting the references manually at this stage, however, I was not entirely confident that I had correctly formatted them in AMA style, therefore I reverted back to APA 7. This experience underlined the value in using a referencing software when formatting references for journal submissions, as it would save a lot of time. The reason why I had decided not to use a referencing software was because I have experienced issues in the past when trying to import references. However,

going forward I think it would be useful to invest some time to resolve these issues so that I can use the software in instances such as this. As Staffordshire University supports the use of RefWorks, I will consider this for future use.

Additionally, I followed the PRISMA guidelines as this is the standard format for reporting systematic reviews (Page et al., 2021). I found that the PRISMA guidelines were particularly helpful for the write up of the methods and results sections. However, I decided not to include a PICOS table within the manuscript as the intervention and comparison components did not apply to my systematic review. Although this varied to the protocol on PROSPERO, I did not perceive age or sex/gender to be an intervention or comparison and therefore it did not feel appropriate to include them as such. As mentioned, going forward I would consider using the SPIDER tool if the systematic review was not focusing on an intervention or comparator group.

#### Summary

Completing the systematic review has been one of the most challenging aspects of the doctorate. This was because it was the piece of work that I felt the least confident about and had very limited experience in. Despite it being a particularly daunting task, it has been rewarding as it allowed me to research an area I was not as familiar with, and it has enabled me to develop a variety of skills needed for completing a systematic review again in the future. I also enjoyed the systematic structured whilst completing the review as it provided direction throughout. Therefore, I am grateful for this experience, and I hope that I can develop these skills further in the future.

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# **Chapter 3: Research from Design to Dissemination**

#### 3.1. Qualitative Study Manuscript

# Self-management and coping in young adults with chronic pain: A reflexive thematic analysis.

Short title: Experiences of chronic pain in young adults

Paige Karadag\*1, Dr Jennifer Taylor1, and Dr Amy Burton1

<sup>1</sup> Staffordshire University

\*Corresponding author information: Paige Karadag, School of Health, Education, Policing and Sciences, Science Centre, Staffordshire University, Stoke-on-Trent, UK, (e-mail: paige.karadag@research.staffs.ac.uk).

ORCID ID: 0000-0003-2655-7109

#### Abstract:

**Objectives:** Few studies have explored experiences, self-management techniques and coping strategies used by young adults with chronic pain. Young adults may face specific contextual challenges, potentially impacting engagement with self-management and coping. This project aims to explore the experiences of living with chronic pain in young adulthood to determine facilitators and barriers to self-management and identify coping strategies. It also wanted to understand how these mapped onto the COM-B model of behaviour change.

**Design and methods:** A qualitative interview study including adults aged 19-30 who experienced chronic pain and met the inclusion criteria. Participants were recruited via social media and chronic pain charities. Semi-structured interviews took place online with the primary researcher and were recorded and transcribed verbatim. Interviews were analysed using reflexive thematic analysis.

**Results:** 14 participants (10 females, 4 males) aged between 19-30 took part. Three themes were developed though reflexive thematic analysis: 1) Pivotal role of self-advocacy and diagnosis; 2) Understanding of chronic pain in young adults; 3) The resilience and adaptability of young adults.

**Conclusions:** Young adults needed to self-advocate for a diagnosis to engage with selfmanagement techniques. Clear information is required from health care professionals for young adults to develop an understanding of their chronic pain. Support from employers for young adults must be improved to aid self-management. Coping strategies used by young adults are often facilitated by their resilience. This study has provided important insights regarding self-management and coping strategies that could apply to health care and employment settings.

Keywords: Chronic pain, Young adults, Health psychology, COM-B model, Qualitative study

#### Data availability statement:

The data that support the findings of this study are available from the corresponding author upon reasonable request. Some data is not available due to participants not providing consent for transcripts to be shared beyond the project team.

#### Acknowledgements:

The authors would like to thank all the participants who shared their experiences with us as their contribution to the research is invaluable. The authors are grateful to all the charities who helped with recruitment by sharing the social media advert. Lastly, we would like to thank Camilla Baker, for taking the time to pilot the interview schedule and providing feedback. The author(s) received no financial support for the research.

**Statement of contribution:** PK produced the research idea and developed the theory and plan for this study with support from AB. PK produced the study materials, recruited participants, conducted the interviewed and transcribed audio recordings. PK carried out the initial analysis and discussed theme development with AB. All authors contributed to the study development and reviewed and approved the manuscript.

#### Introduction

Chronic pain is defined as pain that persists for more than three months (Treede et al., 2019). It can be secondary to underlying health conditions such as rheumatoid arthritis or it can be primary, whereby there is no underlying cause (Treede et al., 2019). Examples of primary chronic pain include fibromyalgia and chronic primary headaches (World Health Organisation, 2019). Chronic pain is one of the leading causes of disability worldwide (Vos et al., 2012) and it affects between one-third and one-half of the UK population; corresponding to almost 28 million adults (Fayaz et al., 2016).

Most literature focuses on chronic pain in middle-aged to older adults due to the high prevalence of chronic pain (often due to general age-related health decline) recorded in this demographic (Larsson et al., 2017). Limited research has been conducted with younger adults (Brown et al., 2021; Hilton et al., 2017), yet the prevalence of chronic pain in younger adults aged 18-39 years could be as high as 30% (Fayaz et al., 2016). There is little consensus on the definition of 'young adults', but several studies define it as aged 18 – 30 years (Brown at al., 2021; Stinson et al., 2013; Twiddy et al., 2017).

Young adulthood is an important developmental stage, as neurological developments continue beyond the point of sexual or physiological maturity (which is considered to be reached between 16-18 years old) (Graber, 2023). Physical development and synaptic pruning in frontal brain regions which oversee cognitive functions, including decision making, continue into ages 20-30 (Scherf et al., 2006; Velanova et al., 2008). Young adults often experience life transitions such as attending university, living independently, pursing romantic relationships, and entering full-time employment (Arnett, 2011). Barriers to achieving these milestones can have long-term implications for health, wellbeing, and quality of life (Lewis & Rudolph, 2014). Previous qualitative studies in young adults with chronic pain have identified fewer education and employment opportunities, isolation from peers and increased dependence on parents and services in comparison to non-clinical samples (Brown et al., 2021; Stinson et al., 2013; Twiddy et al., 2017). Social consequences also exist, including impacting romantic relationships and activities (Stinson et al., 2013; Waldie & Poultron, 2002).

Young adults accessing treatments for chronic pain report difficulty relating to others in group therapy and express there is a "lack of understanding" which they attributed to their age (Stinson et al., 2013). Further barriers identified include difficulty adhering to a pain management plan due to the demands of exams and casual work (Stinson et al., 2013). Additionally, developmental changes could influence self-management and coping skills in some young adults, as the executive functioning skills needed for self-management tasks are not fully developed until mid-to-late twenties (Casey et al., 2008). Self-management techniques, such as activity pacing or stretching, are considered an appropriate strategy for symptom regulation as they have been found to significantly improve pain intensity, depression, and disability (Nicholas et al., 2012). However, given the reported lack of understanding and difficulty adhering to treatment plans (Stinson et al., 2013), more investigation is required to understand the potential barriers and facilitators to engagement in self-management strategies for young adults with chronic pain.

The COM-B model of behaviour change (Michie et al., 2011) has been used to design selfmanagement interventions in chronic pain populations (Mansell et al., 2016; Timmerman et al., 2017; Sandhu et al., 2022). The model proposes that there are three conditions required for behaviour change: capability, opportunity, and motivation (Michie et al., 2011). Currently, it has not been applied to chronic pain self-management in young adults. Moreover, little is known about the specific coping strategies used by young adults with chronic pain. This needs to be explored using qualitative methods to gain detailed insights into the barriers and facilitators to self-management and to explore what coping strategies are used by young adults with chronic pain (Hammarberg et al., 2016). Subsequently, this project aims to explore the experiences of living with chronic pain in young adulthood. It also plans to address the following research questions: 'what are the barriers and facilitators to selfmanagement for young adults with chronic pain?'; 'what techniques and coping strategies do young adults use to manage their chronic pain?'; 'how do these map onto the COM-B model?'.

#### **Materials & Methods**

#### Design

A qualitative interview study was conducted with young adults experiencing chronic pain. Semi-structured interviews were used as they allowed participants to provide in-depth accounts of their personal experiences with chronic pain (Jamshed, 2014; Smith, 2015). Ethical approval was received from the School of Health, Science and Wellbeing Ethics Committee at Staffordshire University.

#### Participants and Recruitment

14 participants (10 females and 4 males) aged between 19 and 30 (mean age = 26) took part (Table 1). All were UK based; however, one participant (Oona, aged 30) had recently moved to the UK from another part of Europe.

## Table 1. Participant Demographics

Pseudonym	Age	Sex	Level of education	Employment status	Ethnicity	Diagnosis	Age of
							onset
Emma	25	Female	Master's degree	Working full time	White	Seronegative Rheumatoid	22
						Arthritis	
Julia	25	Female	Bachelor's degree	Doctoral student	White	Ulcerative Colitis	24
Mia	25	Female	Master's degree	PhD Student	White	Irritable Bowel Syndrome and Cluster Headaches	14/15
Mark	30	Male	Secondary (GCSE's, O-Levels)	Working full time	White	Migraines/Cluster Headaches	15
Nadiya	26	Female	Bachelor's degree	Working full time	Asian/Asian	Fibromyalgia, Migraines, and	13/14
					British	Irritable Bowel Syndrome	

Liam	26	Male	Post-Secondary	Working full time	White	Migraine	
			(College, A-Levels,				16
			NVQ3 or equivalent				
Theo	30	Male	Post-Secondary	Unemployed, seeking	White	Axial Spondylitis	28
			(College, A-Levels,	opportunities			
			NVQ3 or equivalent				
Scarlet	30	Female	Master's degree	Working full time	Black/African/	Daily Persistent Headache	27
					Caribbean/		
					Black British		
Amelia	19	Female	Post-Secondary	Medical student	White	Ehlers Danlos syndrome and	9/10
			(College, A-Levels,			'Symmetrical Inflammatory	
			NVQ3 or equivalent			Arthropathy'	
Kelvin	28	Male	Master's degree	Working full time	Black/African/	Undiagnosed chronic pain	23
					Caribbean/	from injury	
					Black British		

Ava	20	Female	Post-Secondary	University student	White	Crohn's Disease	5
			(College, A-Levels,				
			NVQ3 or equivalent				
Chloe	23	Female	Bachelor's degree	Working full time	White	Chronic Migraines	17
Sarah	28	Female	Master's degree	Working full time	White	Chronic Migraine	17
Oona	30	Female	Master's degree	PhD student –	White	Slipped Disc - possibly Spinal	18
				Post Graduate		Arthritis	
				Teaching Assistant			

Participants were recruited via the researcher's own social media including Facebook and Twitter. Purposive sampling was used by the first author (PK) who contacted chronic pain charities and several, including Ouch UK, and Action Arthritis circulated the study information via their webpages. Individuals who were interested in taking part completed a consent form and demographics survey on Qualtrics whereby email addresses were collected for the purpose of scheduling interviews. Once completed, they were contacted via email in sequential order to arrange a suitable date and time for the online interview with PK.

#### Inclusion Criteria

Participants were eligible if they experienced chronic pain (diagnosed or undiagnosed), were aged between 18 and 30, and UK based. The age range reflected other research regarding young adults (Brown et al., 2021; Stinson et al., 2013). The eligibility criteria were assessed via the demographics survey.

#### Data Collection

A semi-structured interview schedule was developed which focused on coping strategies and barriers or facilitators to pain management. The interview schedule was guided by the NICE guidelines (2021) for primary and secondary chronic pain as questions explored participants experiences of the pain management techniques outlined in the guidelines. Questions were also influenced by the COM-B model (Michie et al., 2011) to identify barriers and facilitators for capability, opportunity, and motivation to engage with the pain management techniques. See Table 2 for example questions.

Topic Covered	Example Questions
Impacts of early symptoms and the	• Can you tell me about when you first started
diagnosis process	experiencing chronic pain?
Clarity of knowledge regarding	• Before you started experiencing chronic pain,
chronic pain	what did you know about chronic pain?
The impact of chronic pain on	• In what ways do you think chronic pain
different aspects of life	impacts your day-to-day life?
Barriers and facilitators to	• What has been your experience of obtaining
treatment for chronic pain	treatment for your chronic pain?
Coping strategies and support	• Can you tell me about any strategies or
	techniques that you use to help you to live with the chronic pain?
Advice for other young adults with	• What advice would you give to a young adult
chronic pain	<i>newly experiencing/diagnosed with chronic</i>
-	pain?

**Table 2.** Topics covered in the interviews and examples of questions asked.

Interviews took place via Microsoft Teams, allowing participation from across the UK. Interviews were recorded for transcription purposes. Recordings were transcribed verbatim, anonymised (using pseudonyms), and checked for accuracy. Interviews lasted 77 minutes on average (range 45 – 133 minutes) and took place between September 2022 and May 2023. Guided by the concept of 'information power' (Malterud et al., 2016), the sample size of 14 was influenced by the aim of the study, sample specificity, use of established theory, quality of dialogues and analysis strategy. Recruitment therefore ceased when it was felt that sufficient information relevant to the research aims had been provided. Following the interview participants were emailed a debrief sheet.

#### Data Analysis

Inductive Reflexive Thematic Analysis (RTA), as described by Braun and Clarke (2022) was used to analyse the data as it offers an accessible method for exploring and interpreting patterns across the data. It also provides a theoretically flexible approach, extends beyond topic description, and values the researcher's interpretative lens (Braun & Clarke, 2021). RTA aimed to identify patterns and meaning within the dataset regarding young adults experiences of living with chronic pain. This was conducted to from the standpoint of critical realism (Maxwell, 2012).

To guide the analysis process, the six phases outlined by Braun and Clarke (2022) were followed. Transcripts were read several times, with PK noting any initial observations. Codes were generated using NVivo software (NVivo, 2023) to add labels to specific sections of each data set. Semantic and latent codes were used to meet the aims of the project, which were inductive and deductive. Initial codes were semantic to capture explicitly expressed meaning but as the analysis developed latent codes were used to focus on implicit meaning. NVivo facilitated clear coding structures, as codes with shared meaning were inductively collated into provisional themes (Braun et al., 2014). Eight provisional themes were reviewed and deductively refined to correspond to the COM-B model as outlined by the research aims. Provisional themes such as 'coping' and 'sources of support' were merged due to their

overlap. Other provisional themes including 'advice for others' were discarded as they did not address the research questions. The final themes and sub themes were defined to ensure that they answered the research questions. As part of the review process, themes were discussed in depth with the second author. Lastly, the manuscript was produced whereby interview quotations using pseudonyms were presented to illustrate the themes.

Reflexive practice was applied throughout data collection and analysis. As part of the reflexivity, it was important to consider the positioning of the authors. At the time of analysis, PK was undertaking the professional doctorate in health psychology at Staffordshire University and working as a Trainee Health Psychologist within the NHS. PK has worked with young adults with chronic pain and has lived experience of a long-term condition (LTC) as a young adult. PK was aware of her lived experience and individually reflected on this in a reflective diary that was maintained throughout. To further enhance reflexive practice, PK discussed various stages of theme development with the second author who is a chartered health psychologist.

#### Results

Three themes were developed though RTA. These themes address the aim and research questions by exploring young adults' experiences of chronic pain, with reference to the barriers and facilitators to self-management and coping strategies used. Table 3 outlines the themes and subthemes and demonstrates how they reflect components of the COM-B model.

### Table 3. Themes and subthemes.

				COM-B Mapping	
Theme		Subtheme	Capability	Opportunity	Motivation
Pivotal role of self-advocacy and	-	Self-advocacy	Х		
diagnosis	-	Validation from diagnosis			Х
Understanding of chronic pain in young	-	A need for information to develop own	Х		
adults		understanding			
	-	A need to be understood by others		Х	
The resilience and adaptability of young	-	Resilience	Х		
adults	-	Adaptability and self-compassion	Х		Х
	-	Support networks		Х	

#### Theme 1: Pivotal role of self-advocacy and diagnosis

The first theme demonstrates the importance of self-advocacy, whereby participants voiced their needs to health care professionals (HCPs). Self-advocacy was important when trying to obtain a diagnosis or treatment from HCPs. It also highlights how diagnosis is key for young adults as it provides validation that their pain is real and creates opportunity for self-management.

#### 1.1 Self-advocacy

A shared experience among participants was having to self-advocate to obtain a diagnosis or treatment for their chronic pain.

"Be proactive with doctors and stuff like that and chase them for their being slow and that is really difficult when you have chronic pain and everything's exhausting, but it is really important because a lot of the time, otherwise you get left to the side or left on some waiting list..." (Julia, aged 25).

One of the reasons that young adults felt they needed to advocate for themselves was because of stereotypes held by HCPs that young adults are of optimum health.

"I think with younger people they tend to make out like it's not as big or they're kind of diminished their their pain and everything... there's notion that young people are healthy... and that's not necessarily the case" (Nadiya, aged 26).

Nadiya's quote highlights a disbelief, even scepticism, that individuals experienced due to their age, hence the need for them to self-advocate. The language (*"diminished"*) suggests

that her pain was not taken seriously which was disempowering and could be a barrier to obtaining support for self-management.

For some participants, their own background in healthcare increased their confidence to advocate for themselves in appointments.

"I think because I've got that medical background, I feel more confident in handling myself" (Amelia, aged 19).

Emma (aged 25) reflected that without having a master's degree in health psychology, she "would have just have accepted the medication and walked out". However, because of this education she felt that she could ask, "what other choices do I have". This suggests that knowing her right as a patient to ask about "choices" facilitated self-management.

When asked what advice they would give to a young adult newly diagnosed with chronic pain, Theo (aged 30) recommended that they should *"Keep a diary, write everything down, rate your pain... because when you go to the doctors, they're gonna want information"*. This implies that to advocate effectively, individuals need to be equipped for appointments by providing evidence of their pain.

#### 1.2 Validation from diagnosis

For many participants, receiving a diagnosis provided validation that their pain was real. This links to the subtheme above, as self-advocacy was often necessary to obtain a diagnosis. Subsequently, the validation from the diagnosis played a pivotal role in facilitating selfmanagement. "It was nice to know that there was a problem, and I wasn't just making up pain in my back..." (Theo, aged 30).

This validation meant that participants were able to shift their focus from obtaining a diagnosis and it empowered them to make behavioural changes to facilitate pain management.

"Now I know what it is, its giving me this sense of empowerment I guess... I know what I can do and I also know what I can't do." (Emma, aged 25).

Prior to diagnosis, participants were limited in what support they could obtain. The diagnosis also meant that some participants were able to better understand the cause of their pain, aiding them in management.

"I think that I understand kind of what's going on and 'cause I've got the diagnosis, I think I've got a bit more understanding of why, which I think helps deal more with it" (Amelia, aged 19).

#### Theme 2: Understanding of chronic pain in young adults

This theme highlights the importance of understanding chronic pain for effective selfmanagement. Individuals felt a need to obtain information to develop their own understanding of their chronic pain and the impact that it can have on day-to-day life. Secondly, there was a need for their experiences to be understood by others for selfmanagement to take place.
#### 2.1 A need for information to develop own understanding

Most participants reported that following diagnosis, they were not provided with information by HCPs "*personally I don't think I was given anything*" (Liam, aged 26). This meant that they were left to obtain their own information which impacted the way that they managed their pain.

"I would just be like well I'm not gonna let it [the pain] stop me, but which is a good mindset to have, but I should have let it stop me because I was doing things which were too much and I was hurting myself." (Amelia, aged 19).

Here Amelia draws attention to the risks of being ill-informed about chronic pain selfmanagement. Her lack of knowledge regarding pacing meant that she persevered with activities which resulted in her *"hurting"* herself. Had she been informed of appropriate selfmanagement techniques by HCPs then this may not have occurred. Most participants felt that it would have been helpful if HCPs had signposted them to appropriate information. This would have ensured that participants followed evidence-based guidance as opposed to potentially unverified information.

"I think having if they would have said actually there's this website, they're the, they're the specialist on this... I think that would have been really helpful..." (Emma, aged 25).

In this quote HCPs were viewed as the ideal source of expert (*"specialists"*) and therefore would provide trustworthy advice. When this was not forthcoming, individuals would explore

other options. Several participants explained that social media was a beneficial source of information for their chronic pain as it presented lived experiences, therefore raising awareness of self-management techniques for chronic pain.

"If I don't know about something first I'll google it and then I'll put on Tik Tok see what people say about it. Uh because even if they're not completely accurate, there's a sense of feeling that you know of of of what the condition feels like which you can't get on the NHS website." (Mia, aged 25).

Mia presents different sources of 'expertise' from lived experience and suggests that advice from someone with lived experience feels more personally relevant compared to information from a verified website such as the NHS that focuses mainly on providing factual information. However, there is a risk that individuals posting on social media could be misinformed about self-management techniques and may offer guidance that is not approved by medical professionals. For example, Liam (aged 26) left a Facebook support group as *"there was so much rubbish on there"*.

Charities were another source of information that participants relied on to develop their own understanding. Most participants praised charities and described them as *"beyond incredible"* (Sarah, aged 28) for the information that they provide. Charities were seen as providing approved information, whilst including a focus on the impact that chronic pain may have on daily life and coping strategies.

"There's been good support from places like the Migraine Trust... in terms of information for me to be able to then take, that felt like understand myself more and take that forward, that's been my main source of support I think." (Chloe, aged 23).

Charities also provided information in a variety of formats making it more accessible for young adults who may be more likely to use social media or read newsletters as a way of obtaining advice surrounding self-management.

"So like the Ehlers-Danlos charity is really good is like information and they've got like, they've got closed Facebook groups... and then like I get their newsletter and magazines..." (Amelia, aged 19).

This suggests that there is already a wealth of approved information and resources that HCPs could be signposting to, which would enable young adults to better understand their chronic pain.

# 2.2 A need to be understood by others.

Participants reported a need for their chronic pain to be understood by others for them to engage with self-management techniques. However, participants often experienced a lack of understanding from others surrounding the impact of chronic pain on their daily lives.

"I think more acknowledgement of how it affects someone. A lot of people hear chronic pain and just think "ohh they're in pain all the time" but they don't think of the mental and social and emotional effect for that..." (Ava, aged 20). In this quote, Ava is critical of those who think they have awareness of chronic pain but lack understanding of its potential impact. She draws attention to the social and emotional elements of pain that can be forgotten about.

There was a particular lack of understanding experienced from employers about the way that chronic pain can affect needing time off from work. When asked whether their chronic pain has impacted on employment, Liam (aged 26) explained that it *"has definitely impacted it because I left a job over it"*. Liam explained that he was made to feel uncomfortable around sick leave despite declaring his pain condition when he started the role, which led to him leaving. Liam shared another experience from a different role, whereby the manager asked him to *"get it [the pain] under control"*. This lack of understanding extended beyond managers as one participant recalled an occupational health review whereby the assessor responded:

"Well, there must be hundreds of people within the group that has migraines, so why do you need time off?" (Mark, aged 30).

In this quote, Mark highlights how the assessor tried to dimmish the severity of his chronic pain by stating that a large proportion of employees in the company are likely to share this same experience.

A lack of understanding from employers meant that individuals often felt pressured to prioritise work demands over self-management needs, which could have a negative impact on their health and wellbeing. Participants wanted and needed more flexibility in the workplace to accommodate for their chronic pain. Scarlet (aged 30) was unable to return to her role as a nurse and midwife in the NHS due to the severity of her chronic pain. She highlighted that there could be alternative roles in the department that she could fulfil from home which would facilitate self-management.

"I am skilled at what I do, I've not done 4 and a half years of the university for nothing. There must be something I can do from home. We need to get out of this 'oh well if you can't come back to your job then we're going to get rid of you" (Scarlet, aged 30).

# Theme 3: The resilience and adaptability of young adults.

The final theme underlines the importance of resilience and adaptability for young adults to cope with chronic pain. The theme also highlights that support networks could be important in facilitating resilience and adaptability.

# 3.1 Resilience

Participants demonstrated resilience regarding their experiences of living with chronic pain as they persevered with education and employment, despite facing various challenges. Moreover, they did not want their chronic pain to be a defining factor of their life as a young adult.

"I think it's having that sense of control over some elements of life... I'm a person with it, I it's not who I am, I just have this condition. It's not defining me kind of thing" (Emma, aged 25). This example acknowledges that while it is not possible to have control over everything, it is possible to not be defined by the pain. Although Emma recognises that she has chronic pain (*"I'm a person with it"*), it does not consume her whole identity (*"its not who I am"*). Hence, she is a person first and foremost and her pain experience is secondary to that.

Another participant reflected that it would have been easy to give up, especially because engaging with self-management requires strength and determination. Instead, she chose to find ways to cope by fighting for workplace adjustments and adapting social activities.

"It would have been very easy um for me to just sort of, I don't know dissolve into the into the universe really. That's like never get out bed, leave my job, leaves my home, potentially lose my husband..." (Scarlet, aged 30).

The powerful language used in the above quote (*"dissolve"*) emphasises that they want to be seen as the person they were prior to their pain and their pain is not allowed to make them disappear.

Similarly, having chronic pain as a young adult taught individuals that they can engage with the steps to manage and live with their pain, even when they previously thought that they would be unable to cope.

"I do feel like I'm braver than I have ever thought I would be able to be like if you told me a few years ago that all of this was going to happen... I would have said like I won't be able to cope with that... Erm but actually you can cope with it" (Julia, aged 25). This example demonstrates a positive shift in their identity associated with chronic pain, and it links back to the empowerment that was discussed in theme 1.

#### 3.2 Adaptability and self-compassion

It became clear that the ability to cope with chronic pain was often driven by the adaptable nature of young adults. All participants were able to recall adaptions that they made in at least one area of their life such as social life, education, or employment.

"I've just learnt to adapt things a lot better... umm so that I can still take part in things that I like doing ... because then I don't feel like I'm missing out which also helps with like the emotional part of it I think." (Chloe, aged 23).

This quote demonstrates that being willing to adapt enabled Chloe to engage with activities, which subsequently reduced the psychological burden of living with chronic pain. Chloe's reference to *"missing out"* suggests that being unable to engage in social activities due to the pain could have a detrimental impact on young adults' ability to cope.

A key piece of advice that participants wanted to share with other young adults experiencing chronic pain is to make day-to-day adjustments so that they could still have quality of life despite the pain.

"It's not where the world ends... basically, you have to adjust to lifestyle you know." (Kelvin, aged 28).

Kelvin's use of the phrase *"its not where the world ends"* underlines that life continues after experiencing chronic pain, but it is imperative that individuals have the flexibility to adapt for this to happen.

Lastly, a key component of being able to adapt was learning to have more self-compassion. When asked if living with chronic pain had taught her anything about herself, Oona (aged 30) explained that it had allowed her to "*appreciate herself in in a very different way*". She reflected that she has a "*much more loving relationship*... *I think I'm kinder to myself now*." This also shows a shift in identity whereby living with chronic pain provided a new perspective on who they are.

# 3.3 Support Networks

Resilience and the ability to adapt and be self-compassionate was influenced, for several participants, by their support networks. Participants reported their partners were their most significant support and would offer practical and emotional support to help them cope.

"Erm so yeah my partners to the biggest support I've got like definitely. Always there for me. Always trying to help me every time I've I say I've nearly got one [a migraine] then like first thing she says out of 10 how bad? Erm and then kinda she knows what she can do to maybe try and help lift it..." (Mark, aged 30).

One participant's husband even suggested different ways of communicating pain severity to reduce the burden.

"He even said in the pandemic, you know, why didn't you make a board and have like different faces on there like smiley and sad faces and you know update the board depending on your pain levels so that I know... so that I'm not constantly asking and you're not constantly telling." (Scarlet, aged 30).

This suggests that for Scarlet her partner was not only a source of support, but also creative and instrumental in helping her to develop coping strategies.

Parents and friends were also viewed as being another significant source of support which helped individuals to be more resilient and adaptable, reflecting the role that parents still play for young adults.

"Yeah so I speak to my mum quite a lot about it erm who's really good and then my two, I've got two close friends at uni and who are both like really good at just like listening to me like rant about it" (Amelia, aged 19).

The above quote suggests that friends and family provided an outlet for individuals to offload. Another participant described how her family were supportive of lifestyle changes that she made to manage her pain as *"they was all like you gotta do whats best for you"* (Emma, aged 25).

#### Discussion

This study aimed to explore the experiences of young adults living with chronic pain. Qualitative interviews took place with 14 participants aged 19-30 who experienced chronic pain. These interviews were analysed using RTA and three themes were developed: 1) Pivotal role of self-advocacy and diagnosis; 2) Understanding of chronic pain in young adults; 3) The resilience and adaptability of young adults.

The first research question wanted to understand the barriers and facilitators to selfmanagement for young adults with chronic pain. Receiving a diagnosis was imperative for participants as it provided validation that their pain was real and subsequently facilitated selfmanagement (Theme 1). This mirrors previous findings which highlight the importance of validation for young adults experiencing chronic pain, as often they have been dismissed or disbelieved due to their age which could prevent them from accessing support and developing self-management skills (Kapoor, 2015; Twiddy et al., 2017). Therefore, young adults with undiagnosed chronic pain could face additional barriers for self-management due to the lack of pain validation that can come from receiving a formal, clinical diagnosis (Nicola et al., 2022); subsequently this warrants further investigation.

Participants in the current study highlighted a need for information to understand their chronic pain (Theme 2). The lack of information provided by HCPs was a clear barrier to self-management. Similarly, Stinson et al., (2013) found that among young adults there was a need for more information about chronic pain. Although individuals in the current study were able to find information via social media, it is important that they verify information with their doctor to reduce the risk of being misinformed (Hurley-Wallace et al., 2022). Participants praised charities for providing a holistic view of chronic pain, as information also encompassed the psychological and social impact. This is important as psychological and social factors should be considered for self-management strategies (Meints & Edwards,

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2018). Therefore, HCPs could signpost young adults experiencing chronic pain to the wealth of verified information which is already provided by charities (Bull et al., 2014).

Another barrier to self-management was the lack of understanding from others, specifically employers as participants were apprehended for taking sick leave due to their chronic pain (Theme 2). Starting full-time employment is important developmentally for young adults (Arnett, 2011), yet this lack of understanding from employers meant that some individuals had to choose between their health or career. Consequently, this could have a negative impact on career aspirations and quality of life (Lewis & Rudolph, 2014). Therefore, employers need better awareness of how they can support young adults by giving them the opportunity to adapt their work for their pain, which may increase scope for self-management.

The second research question wanted to understand what techniques and coping strategies young adults use to manage their chronic pain. Firstly, there was a need for young adults to self-advocate for a diagnosis or treatment for their pain with HCPs (Theme 1). Previous findings in young adults (aged 19-23) with chronic pain contrast this, as they relied on parents to advocate on their behalf as they lacked confidence (Higginson et al., 2019). Our findings imply that some young adults are capable of advocating for themselves, especially when they felt that they were lacking answers due to their age. This difference in finding could be explained by the older age range in the current study (mean age = 26). Thus, ability to self-advocate may increase with age and experience of living with chronic pain.

Being resilient and adaptable was also an important coping strategy for chronic pain (Theme 3). Participants displayed resilience as they persevered with education and employment despite the challenges they faced regarding their pain. This is an important finding to

communicate as it suggests that resilience may be imperative for young adults to develop appropriate coping strategies. Resilience has been found to have an influential role in broader adults' ability to cope with chronic pain (Rolbiecki et al., 2017; Sturgeon & Zautra, 2010). However, limited research has explored resilience in young adults with chronic pain specifically. Further research may be beneficial to understand the barriers and facilitators to resilience in young adults experiencing chronic pain.

One possible facilitator for resilience was the support networks who enabled participants to adapt (Theme 3). This aligns with previous research into broader adult chronic pain populations which found that better social support was associated with individuals who were more resilient (Newton-John et al., 2014). Although participants in the current study reported that their families were a source of support, they did not feel dependent on them. This contrasts previous research which found that young adults aged 18-30 were often dependent on their parents. (Twiddy et al., 2017). However, the mean age reported by Twiddy et al., (2017) (24.33 years) was slightly younger than the current study (26 years). Moreover, participants in this study reported that the main source of support came from their partner or spouse, which could be reflective of the importance of romantic relationships for young adults (Arnett, 2011).

To our knowledge, this is the first study to apply the COM-B model (Michie et al., 2011) to explore self-management and coping strategies in young adults with chronic pain. By applying the COM-B model, the study explored whether participants had physical and psychological capability; physical and social opportunity; automatic and reflective motivation to engage with self-management and coping strategies. As outlined in Table 3, psychological capability increased through self-advocacy for a diagnosis, as it meant participants were able to better understand the cause of their pain. However, information was not always forthcoming from HCPs which left participants to obtain their own information and prior to accessing this, or when good quality information was difficult to source, they may have lacked psychological capability to engage with self-management. Psychological capability was further reflected through resilience and being adaptable, as participants were able to overcome challenges and implement adjustments to cope with their pain.

Individuals were provided with the social opportunity to self-manage through family and friends who offered support. Yet this social opportunity did not occur within the workplace where managers lacked understanding of chronic pain and only some participants were given the physical opportunity to self-manage, through the flexibility to work from home.

Reflective motivation increased through the validation that participants felt when they received their diagnosis, as they felt empowered to engage with self-management. Participants positive reflections on their self-identity, including self-compassion, demonstrate reflective motivation to self-manage and cope with the pain. However, these behaviours were not always automatic due to life context such as work not enabling them to self-manage. Findings from this study did not encompass physical capability or physical opportunity and they do not provide insights into how automatic motivation could be ensured. Therefore, further research should consider the barriers and facilitators for these components of the COM-B model in relation to self-management and coping among young adults with chronic pain.

#### Strengths and Limitations

This research provides important insights into young adults' experiences of living with chronic pain. It expands on previous research by exploring barriers and facilitators to self-management and exploring coping strategies used by young adults for their chronic pain, when most previous research has focused on older adults. A strength of this study was that the participant sample was representative of a variety of chronic pain conditions. Moreover, a range of ages between 19 - 30 were captured within our sample.

However, most participants were recruited from seeing the information on chronic pain charity websites. Consequently, the study may not represent young adults who do not use charity platforms. Most participants were educated at degree level or higher and their experiences may differ to those with a lower level of education. Literature shows that individuals in the UK with no education qualifications are more likely to have lower health literacy (Simpson et al., 2020). Therefore, having a lower level of education could influence self-management skills. Additionally, the sample in this study was predominantly female (n =10; 71.4%). Although chronic pain is typically more common in females (38%) than in males (30%) (NHS Digital, 2019), the sample could have included more young adult males. Similarly, a high percentage of participants were White (n = 11; 78.5%) and their experiences may not reflect those from other cultural backgrounds. For instance, a study which explored the experiences of chronic pain in Indian Asian women in the UK found that daily demands relating to cultural expectations was viewed as a barrier to self-management (Holt & Waterfield, 2018). Consequently, further research may be required to explore cultural differences in young adults with chronic pain that was beyond the scope of the present investigation.

# Conclusion

This study highlighted several barriers that young adults face in relation to self-management for their chronic pain. More information is required from HCPs to ensure that young adults have the capability to engage in appropriate self-management techniques. Better understanding of chronic pain in young adults is required by employers to create more opportunities for young adults to engage with self-management, such as home working. Nevertheless, participants in this study displayed resilience and adapted their lifestyle to cope with the pain. Further research may be required to explore the factors which may help or hinder resilience in young adults with chronic pain. Overall, this study has demonstrated some important findings in relation to self-management and coping strategies used by young adults with chronic pain that could be applied both in health care and employment settings.

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#### 3.2. Qualitative Study Commentary

#### Background

My interest in chronic pain was sparked during my placement at Bath Centre for Pain Research during my master's degree. Prior to this, I had little understanding of chronic pain and the impact it can have on an individual's life. This interest deepened whilst I was on placement for the professional doctorate in health psychology. My first placement was as a research assistant at the University of Warwick, where we investigated the impact of 'mental defeat' in adults with chronic pain. My second placement was as a trainee health psychologist at Bristol ME Service. This placement gave me a clinical understanding of the day-to-day impact that chronic pain can have, and the recommended self-management techniques. The specific interest in chronic pain in young adults stems from my own lived experience of having a long-term condition (LTC) as a young adult. From my personal experience, I felt that there was a gap between paediatric and adult care in which young adults do not fit into either framework. This interest grew through my placements when working with young adults who have chronic pain. Similarly, my voluntary role as Vice Chair on the Young Adults Advisory Panel for Crohn's & Colitis UK highlighted the need for more focus on chronic pain in young adults.

Young adulthood is viewed as a time where individuals are of peak health, yet approximately 20-30% of young adults experience persistent pain (Fayaz et al., 2016). Moreover, young adulthood is an important period which is often defined by developmental markers such as higher education, starting full-time employment, romantic relationships, starting a family and living independently (Arnett, 2011). Despite this, little research has focused on young adults experiencing chronic pain (Brown et al., 2021). Therefore, I decided to conduct a qualitative

study to explore experiences of living with chronic pain in young adults. I wanted to focus specifically on the barriers and facilitators for self-management techniques and identify coping strategies used by young adults with chronic pain, as this area has not yet been investigated. I also wanted to see how these mapped onto the COM-B model of behaviour change (Michie et al., 2011). I felt that a qualitative interview study would be the most suitable method for my research question due to the focus on their experiences and perspectives (Hammarberg et al., 2016). I have some previous experience of conducting a qualitative interview study for my undergraduate research project which was subsequently published in the journal 'Chronic Illness'. This experience of interviewing individuals with a LTC meant that I was familiar with the various stages of conducting a qualitative study.

#### **Ethical Approval**

Ethical approval was sought from the Staffordshire University Research Ethics Committee. I have experience of obtaining ethical approval from my previous qualitative study. I was also involved in the ethics process during my placement at the University of Warwick. Therefore, I felt confident in my ability to complete this process. I submitted the ethics form, consent form, demographic questions, letter of invitation, participant information sheet (PIS), distress protocol, interview schedule and debrief. I received support from my supervisor during this process and she recommended that I use Qualtrics for the consent from and demographics questionnaire for participants to complete before the interview. From my placement at the University of Warwick, I knew the importance of having a distress protocol in place, as risk of suicidality is 2-3 times higher in people with chronic pain (Campbell et al., 2015). Following my supervisor's recommendation, I signposted participants to appropriate organisations and charities in the PIS and debrief form. Ethics was approved subject to minor

amendments. Most changes were related to clarity in the consent form about risk and breaking confidentiality. I also needed to clarify why I required the amount of demographic data and how it would help meet the research aims. I met with my supervisor to discuss these amendments. I addressed the necessary points and provided a cover letter to outline the changes. Full approval was granted in May 2022. However, I submitted an ethics amendment to delay the start and end dates of the study, which was also approved in May 2022.

Overall, I found the ethics process to be a valuable learning experience as it made me think carefully about the methodology of the study such as the research aims and participants demographics. It also ensured from the offset that the justifications for the methodology were evidence based. For instance, it was difficult to determine the age range of 'young adults', but the ethics process motivated me to search existing literature to identify what other research defined it as. My feedback from the ethics committee taught me that I needed to be clear with my justification for why certain demographic details were required from participants. The ethics process was quite time consuming due to the number of documents that I needed to prepare, and I needed to allow an adequate amount of time for them to be reviewed. However, I think that I allowed myself enough time for this process and I would ensure to do so again in the future.

#### Methods

# Study Design

I selected semi-structured interviews to explore individuals' experiences of living with chronic pain in young adulthood as it would allow me to obtain in-depth information. I opted for reflexive thematic analysis (RTA) as it offers a robust method by developing, analysing, and interpreting patterns across the data (Braun & Clarke, 2022). Reflexivity involves the practice of critically interrogating what we do, how and why we do it and the influences of this on our research. I felt that this was important given my lived experience of having a LTC. Although I had previous experience of using Braun & Clarke's (2006) thematic analysis during my undergraduate degree, this was my first-time using RTA, so I was nervous to use this approach. RTA follows a similar framework that was outlined for thematic analysis by Braun and Clarke (2006) previously. However, it also adds reflexivity to the analysis process, which involves the practice of critical reflection on your role as a researcher and your research practice and process (Braun & Clarke, 2022). This suggests that researcher subjectivity is a key tool for RTA and subjectivity is viewed as a resource for engaging in analysis (Gough & Madill, 2012).

# Participant Recruitment & Data Collection

My previous experience of recruiting within a chronic pain population from my placement as research assistant gave me an understanding of what recruitment techniques were effective within chronic pain populations. Therefore, I contacted chronic pain charities and asked them to circulate the study information on their websites and social media accounts. I also shared the study on my own social media platforms and tagged chronic pain charities to widen my reach. It was challenging at times to arrange interviews once people had completed the consent form and demographic form. Although 25 people completed the consent form, only 14 of those completed an interview. There were instances where people did not respond to my invitation email, so I sent two polite reminder emails to see if they were still interested in participating. However, one individual became quite frustrated by my follow-up emails. Following this incident, I decided to only send one reminder email after the initial invitation to avoid causing further annoyance. There were also a few participants who needed to rearrange their interview with short notice due to ill health or other commitments. It is

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difficult to know whether there is anything that could be done differently next time; there needs to be flexibility regarding rescheduling due to ill-health when working with individuals with chronic pain or LTCs.

I felt that recruitment went well as I recruited the target number of participants (Braun & Clarke, 2019). However, interviews took place from September 2022 – May 2023, so it was quite a slow process. I felt slightly out of practice when conducting the interviews, especially as I had recently worked on a research study which was predominantly experimental and quantitative. However, I was able to transfer my experience from my placement at Bristol ME Service as I frequently conduct assessments with patients which has a similar format to an interview. I also carried out a pilot interview with a friend who has chronic pain to test the flow of the interview schedule. Due to the nature of our friendship, this interview was not recorded or included in the analysis as its purpose was to test the interview schedule and obtain feedback. Nevertheless, this pilot interview reassured me that I had covered the relevant areas of interest in my interview schedule. Additionally, the semi-structured nature provided flexibility so that I could ask further follow-up questions when participants raised important topics.

All interviews took place online via Microsoft Teams. I think that overall, this was a positive experience as it made the study more accessible to people with chronic pain from across the UK. Moreover, as I have mostly worked remotely for the past 3 years, I was familiar with having video calls on Microsoft teams. The only limitation was that there were some issues with internet connection or background noise at times, which meant the interview did not flow as well as it might have if it was conducted in person. Moreover, two participants opted to have their cameras switched off and interestingly these were two of the shorter interviews.

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I felt that it was more difficult to build rapport for these interviews as I was unable to detect any facial expressions or body language. Again, if all the interviews had been conducted in person, then this variation would not have occurred. Another positive of being able to reach a wider demographic was that I interviewed people with a range of chronic pain conditions. However, I noticed that with participants who had the same diagnosis as me, I had a deeper understanding of their experiences, and this probably influenced the depth of the interview. Nevertheless, I do think that I became more confident and consistent as the interviews progressed.

# **Data Handling and Analysis**

Data were transcribed verbatim. Although I have transcribed qualitative data previously, I underestimated how time consuming this would be. I used the transcription feature on Microsoft Teams, but when I listened back to check the accuracy of the transcription, the quality was highly variable. The quality of transcription was extremely poor for those with more pronounced accents and therefore they needed to be transcribed again. After the transcription process was complete, I read through the transcripts several times as part of the data familiarisation process. I decided to use NVivo software (NVivo, 2023) to facilitate the data analysis process as I had used it previously and found it to be helpful. However, after the first few interviews, I started to encounter issues with NVivo. The further I progressed with the coding, the slower NVivo became with the programme becoming unresponsive whenever a code was added. As I had already coded several interviews at this point, I felt that it was too late to start coding on Microsoft word. Instead, I used problem solving skills to try to resolve these issues. Firstly, I followed the guidance on NVivo's website, but this did not fix the problem. I then contacted NVivo support via direct message on Twitter. I was asked to

provide my contact details and a member of their support team emailed me to arrange a call. Even the process of arranging a call was time consuming and they were still unable to resolve the issue, as it appeared to stem from NVivo not being compatible with a Mac laptop. Luckily, I was able to borrow a Windows laptop to finishing my coding, but it had already cost me valuable time at this stage. Had I not been able to borrow a laptop, I would have probably had to start the coding from the beginning using Microsoft word. This whole process caused me a lot of frustration as I had wanted to use NVivo to facilitate the coding process, but instead it hindered me as it made it more time consuming. Therefore, I would not use NVivo again unless I have access to a Windows computer or laptop.

For the analysis process, I used Braun and Clarke's (2022) practical guide to ensure that I was following the necessary steps. Although I found this guide to be extremely helpful, I found the analysis quite overwhelming as I had over 2000 codes to organise, and I was unsure where to start. I had to take a systematic approach to try organising this many codes on NVivo. I decided to go through the codes in alphabetical order, taking the time to organise them into groups. However, I also had to be mindful to not just develop themes from the subheadings in the interview schedule. To aid the organisation of codes, I decided to make mind-maps to group the codes further. I still felt that these groups were topic summaries instead of themes and I found it difficult to arrange the codes in a different way.

Therefore, I scheduled a meeting with my supervisor for some support with the theme development. It was helpful to have a second person look at the mind maps and provide their perspective. My supervisor reminded me that I had decided to conduct a larger study with a range of aims, but not all the aims needed to fit within the one manuscript. Therefore, I

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decided to focus on one overarching aim but included three specific research questions, which provided the analysis with more direction and focus.

I think that I approached the analysis with the preconception that the focus would be the quality of care provided by health care professionals (HCPs) for young adults with chronic pain and the impact that this had on self-management. This was probably influenced by my own experiences with self-management and the positive and negative impact that HCPs can have. However, when my supervisor directed me back to my research questions, I remembered that HCPs were not the entire focus. Originally, I had eight provisional themes which were refined into four themes. However, it still did not feel as though they provided the 'story book' narrative. Therefore, with the support from my supervisor I refined the themes further and the following themes were developed: 1) Pivotal role of self-advocacy and diagnosis; 2) Understanding of chronic pain in young adults; 3) The resilience and adaptability of young adults.

#### Write Up and Dissemination

I familiarised myself with research in the area which helped me to decide which journal would be appropriate for me to aim to publish in. Originally, I felt that the British Journal of Pain would be suitable as they have published similar qualitative studies. However, the maximum word count for the British Journal of Pain was 5000 words. I knew that this would be a challenge to write so concisely but I thought that it would still be achievable. Despite writing succinctly, I was still considerably above the word count required for the British Journal of Pain. I felt that cutting my word count further would be too restrictive and could cause me to lose important quotes and findings. Therefore, I emailed the editor of the journal

to ask whether they would consider my article with a word count of 6500. Unfortunately, they advised that they could not increase the word limit and I would need put some of the content as supplementary material. Based on this, I felt it would be more appropriate to aim for a journal with a larger word limit. I decided that the British Journal of Health Psychology would be more suitable given that the word limit was 6000. Additionally, as the study incorporated the COM-B model (Michie et al., 2011) this meant that it was reflective of health psychology approaches and met the journal requirements. The manuscript submission guidelines for the target journal provided a structure for the write up. However, it was still difficult to limit the manuscript to a word limit of 6000 words and it took a lot of refinement. There were parts of the manuscript where I would have liked to provide more detail, such as providing examples of latent and semantic codes in the 'data analysis' section, but I did not have the word count to facilitate this. Nevertheless, I do think that the word limit encouraged me to produce a concise piece of work which was still able to communicate important findings. Furthermore, upon publication there might be scope to write a piece for 'The Conversation' to disseminate the findings further and reach a broader audience.

# Reflection

On starting this competency, I already had experience of conducting a piece of qualitative research from design to dissemination in a peer review journal. However, I was excited to develop my qualitative research skills further on the professional doctorate. Despite having previous experience, I was not equipped for the challenges that I faced relating to NVivo. This experience taught me the value in using a more manual approach for the coding that is not as reliant on technology. Additionally, for my qualitative study previously I only interviewed 7 participants whereas this time I interviewed 14, so I was working with double

the amount of data. Hence, my previous experience clouded my judgement of how much time would be required for the transcription and analysis. I have also learnt that theme development takes time, and it is not something that should be rushed if the themes are going to answer the research question and provide an 'analytic story' (Braun & Clarke, 2022). Despite facing some setbacks, I feel that I learnt a lot from conducting this qualitative study and I feel very privileged that the participants donated their time and shared their experiences with me. Overall, I think that it was a very important piece of research which allowed this population to have their voices heard.

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# **Chapter 4: Teaching and Training in Health Psychology**

#### 4.1. Teaching Case Study

This case study outlines the planning, design, and delivery of five live teaching sessions and one pre-recorded session in Health Psychology. The theme across sessions was 'Long Term Health Conditions'. An overview of the teaching series can be seen in Table 1. The live sessions included four in-person lectures and one delivered via Microsoft Teams. They were delivered at the University of Warwick, Staffordshire University, and the University of Liverpool. The group size varied from 2 to 64 students, and sessions varied in length from one to two hours. Session 5 was delivered to a group of practising nurses undertaking a postgraduate module in diabetes at Staffordshire University. I also had an additional teaching opportunity to deliver a 'pre-recorded' session at Warwick Medical School, as shown in Table 1. Stefani's (2009) systematic approach was adopted to develop the sessions and provided a framework to assess student needs, plan outcomes, design teaching sessions, implement strategies and assess outcomes.

# Table 1. Overview of Teaching Sessions

Session	Title	Audience	Number of	Duration	Location	Туре
			students			
1	An Introduction to	BSc Psychology students at the	2	1 hour	Microsoft	Live
23/11/21	Health Psychology	University of Warwick			Teams	
	and Chronic Pain					
2	Diabetes from the	MSc Health Psychology	6	1.5 hours	Staffordshire	Live
08/02/22	Point of Diagnosis	students – 'Long Term			University	
		Conditions' Module				
3	Pain	BSc Health and Medical	18 on the	1 hour	Warwick	Pre-recorded
24/02/22		Sciences Students - 'Health	module		Medical	
		Psychology' Module			School -	
					Moodle Page	
 4	Inflammatory Bowel	MSc Health Psychology	4	1.5 hours	Staffordshire	Live
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08/03/22	Disease	students – 'Long Term			University	
		Conditions' Module				
 5	Behaviour Change	Practicing Nurses –	6	2 hours	Staffordshire	Live
28/03/22	for Type Two	Postgraduate Diabetes Module			University	
	Diabetes					
 6	Role of a Health	BSc Psychology Students - 2 <sup>nd</sup>	64	1 hour	The University	Live
06/05/22	Psychologist-	year module 'Lifespan,			of Liverpool	
	Research Focused on	Development, Health and				
	Chronic pain	Wellbeing'				

### **Assessment of Training Needs**

According to Stefani's (2009) approach, the first stage of planning a teaching programme is assessing student characteristics and learning needs. As the level of students varied across sessions, a needs assessment was essential to ensure student requirements were met (Kember & McNaught, 2007). Assessments were informed using Biggs (2003) 3P Learning Process Model, which has received considerable support (Barattucci et al., 2017; Clinton, 2014). The needs assessments drew upon the presage factors, such as students' prior knowledge and ability. It also reviewed the teaching context, including institutional procedures.

To assess prior knowledge and ability, I spoke directly to the students that I cosupervise and asked them whether they had already undertaken a health psychology module or a chronic pain session. For sessions that were part of university modules, I met with module leads before the session to identify what had already been taught, allowing me to build upon students existing knowledge to promote deep learning (Clinton, 2014). I asked if specific content needed to be included within my session, to ensure I met the requirements of the module and wider course. I also asked for insights on group size and dynamics, as these are important aspects to consider when designing sessions (Kember & McNaught, 2007).

In line with the Disability Discrimination Act (2005) and the Equality Act (2010), I was informed of any students with additional needs. One student in session 6 was visually impaired. As visual impairments can range in severity, it was important to ask the individual how materials could be adjusted to improve their experience (Race, 2005). The module lead informed me that this student requested for there not to be an over-reliance on images and diagrams and to verbally explain any included. To ensure their needs were met, I only included diagrams when necessary and accompanied them with a verbal explanation. After

preparing the slides, I showed them to the module lead to ensure their expectations of the session were met.

#### Learner Styles and Characteristics

Learning styles and student characteristics are important to consider when planning sessions (Karagiannopoulou & Entwistle, 2019). Biggs (1987) examined how students construct learning whilst incorporating their motivations. Learning was found to be a self-directed, active, constructive process and students use one of three approaches within their learning experiences: surface, deep or strategic (Biggs, 1987). Surface motivations are characterised by passive learners who just need to pass whereas deep motivations, such as fear of failure. Based on this, I included a variety of activities to target different learner styles. For example, activities relating to module assessments were directed at surface and strategic motivations whereas group discussions targeted deep motivations. Additionally, I considered the specific needs of nurses, as teaching for healthcare professionals needs to be relevant to their role, consistent with their experiences and have practical applications (Bullock et al., 2008). Therefore, when providing examples of behaviour change techniques (BCTs) I applied them to the context of diabetes in primary care, as requested by the module lead.

#### **Development of Teaching Sessions**

Andragogy assumes that adults are self-directed learners with internal motivation and focuses on facilitating the acquisition of content to help adults learn (Knowles, 1980). The five principles of andragogy include self-concept, experience accumulated, readiness to learn,

orientation to learn and motivation to learn. Consequently, I applied teaching strategies to promote deep learning (Biggs & Moore, 1993) which consisted of a well-structured knowledge base, motivational context, learner activities and interactions with others.

#### Learning Outcomes

The second stage of Stefani's (2009) approach was to plan learning outcomes, which are statements that set out the desired result to be achieved and the process that should be undertaken for the outcome to be met. Additionally, learning outcomes are a critical component of the lecture (Thomas et al., 2016). Therefore, I used the information obtained in the needs assessments to consider my target audience, their baseline knowledge, and goals to tailor the learning outcomes (Harbell & O'Sullivan, 2022). The learning outcomes for my six sessions can be seen in Table 2. These outcomes identified important learning requirements, were achievable, assessable, and used language that students could understand (Walker, 1994). When developing the learning outcomes, I considered the six learning levels provided by a revised version of Bloom's Taxonomy (Krathwohl, 2002) to ensure they were suitably pitched. This two-dimensional framework allowed me to classify objectives and activities to provide a clear outline of the session. Prior to each session I checked the appropriateness of the learning outcomes with the module lead, unless they had specified that this would not be necessary.

Session	Learning Outcomes				
1	1. Define the terms 'health psychology' and 'chronic pain'				
	2. Understand the difference between key models of health and illness				
	3. Evaluate how psychology can be applied to chronic pain				
	4. Discuss the importance of health psychology				
2	1. To understand the symptoms and diagnosis process for diabetes				
	2. To consider the biopsychosocial impact of being diagnosed with diabetes				
	3. Discuss potential interventions we can offer as health psychologists to				
	improve the experience of, and adjustment to, diagnosis				
3	1. Describe and provide a definition of pain				
	2. Discuss differences between acute and chronic pain				
	3. Demonstrate how to measure pain and discriminate issues pertaining to				
	pain assessment				
	4. Consider biopsychosocial aspects of pain				
	5. Understand how pain can be managed				
4	1. To understand the challenges associated with having a 'hidden disability'				
	2. Discuss diagnosis and treatment approaches for IBD				
	3. To consider the information and support needs of individuals with IBD				
	4. Discuss psychological interventions health psychologists could offer				
	individuals with IBD				
5	1. To consider the biopsychosocial impact of diabetes				
	2. To discuss the challenges of changing behaviour				

	To implement potential behaviour change techniques for individuals with			
	type 2 diabetes			
6	1. To understand the biopsychosocial approach			
	2. To consider the role of a health psychologist in the community			
	3. To discuss the importance of health psychology research			

# Structure

The third step in Stefani's (2009) approach was to design the teaching sessions. Effective lectures should introduce a topic, outline the scope of a lecture, present the main points, and provide supporting materials (Copeland et al., 2000; Lenz et al., 2015). Therefore, I developed a logical narrative for each session so that students could understand the progression throughout the lecture. Each session began with clear learning outcomes (Table 2) and finished with a summary of how these outcomes had been achieved. For example, session 1 began with definitions of health before progressing onto theories of health, including the biomedical model and the biopsychosocial approach (Engel, 1977), which subsequently transitioned to the topic of health psychology. Harbell and O'Sulivan (2022) highlight the importance of summarising key take-home points and providing a call to action for the students. Therefore, I provided extra resources such as websites or journal articles for students to conduct further learning outside of the session.

# Knowledge Base and Literature

When developing sessions, I researched each topic thoroughly to provide a breadth of literature. I incorporated a variety of core health psychology models and theories, including

the biopsychosocial approach (Engel, 1977) and the Behaviour Change Wheel (BCW) (Michie, Stralen, & West, 2011). I included topical issues within the subject area, such as an article focusing on the challenges that different ethnicities face within type 2 diabetes. To support the key points of the lecture I provided a variety of information sources, including relevant journal articles, information from charities and news articles. Delivering information in multiple formats allowed me to target different students' preferences whilst meeting their academic needs (McKee & Scandrett, 2021). At the end of the sessions, I provided a reference list so that students could do further reading.

#### Learning Environment

The fourth stage of Stefani's (2009) approach is implementing learning and teaching strategies. I began sessions with activities to determine students' existing knowledge about a topic such as asking 'what do you already know about diabetes'. This strategy allowed me to assess student's baseline level of understanding to prevent repeating existing knowledge and allowing more time for learning new information. Literature suggests the learning environment should foster constructive alignment, whereby students construct their learning through relevant activities (Bligh, 1998; Scherman & Du Toit, 2008). Therefore, I incorporated activities to achieve the learning outcomes, whilst also creating the opportunity for collaborative learning. For example, in session 4 after providing information about treatments for Inflammatory Bowel Disease (IBD), I asked students to discuss with their peers how they think people with IBD feel when they require surgery. Similarly, in session 5 nurses were asked to draw on their experiences of behaviour change with patients, encouraging them to link theory to their daily practice. By presenting students with problems or questions it incited interest and engagement (Copeland et al., 2000).

It was important to consider that the average adult's attention span is thought to be 10-15 minutes and therefore, speaking to students continuously for greater than 15 minutes is not an effective way of learning (Bradbury, 2016). I strategically added pauses and tasks to provide opportunities for learners to consolidate, process and reflect on learning, which are essential steps for knowledge retention (Harbell & O'Sulivan, 2022). I utilised the small group size and seminar-style of sessions 1, 2, 4 and 5 and allocated time for group discussions surrounding topical issues (Lenz et al., 2015). This was particularly important for session 1, as research has highlighted that students disliked the decreased opportunity for interaction in online lectures (Wolf, 2018). This was more challenging to incorporate into session 3 which was pre-recorded. To overcome this barrier, I asked students to pause the recording to complete tasks such as answering multiple-choice questions.

Evidence also suggests that students value collaboration with peers as it enriches their learning (Melrose, 2004; Scherman & Du Toit, 2008). Therefore, in small-group sessions, activities included students working in pairs to discuss issues such as "What psychological interventions do you think we could offer individuals living with IBD?". Students shared their ideas back with the rest of the group, a technique known as 'think-pair-share' which can be useful within small group sessions (Dent, 2001; Harbell & O'Sulivan, 2022). Moreover, I incorporated group work to use theory, such as the BCW and COM-B model, to inform a behaviour change intervention and allow students the opportunity to apply theory to practice (sessions 2 and 5). Games within lectures have also proved to be a valuable method of increasing teamwork and responsibility in lectures (Eliasa, 2014), so I began session 4 with a 'quiz' to add a competitive element and engage students from the start.

Across all small group sessions, I opted for verbal group discussions and pair work for students to complete tasks, as outlined above. However, it was more challenging to incorporate activities within the large group session, as it was delivered in a large lecture theatre and there is often less participation in discussions within large groups (Pollock, Hamann & Wilson, 2011). Therefore, for the large group (session 6) I chose to take a different approach to what had been adopted for the small group, seminar style sessions. For session 6, instead of incorporating group discussions and paired work, the focus shifted to technology-based activities such as Poll Everywhere and Padlet to promote knowledgesharing, active learning and integrate problem-solving activities (Harbell & O'Sulivan, 2022; Lenz et al., 2015; Walker, 2020). For example, I provided students with a scenario on Padlet to use their role as a Health Psychologist to support an individual newly diagnosed with chronic pain. This provided students with the opportunity to apply theory to practice within a large group setting by using technology to share ideas anonymously.

# **Training Materials**

I developed lesson plans for each lecture to provide an outline of the session. All sessions used Microsoft PowerPoint, which has been found to be pedagogically effective in university lectures to stimulate the learning environment (Clark, 2008; Craig & Amernic, 2006). For sessions that were part of wider modules, PowerPoints were uploaded to the online teaching platform before the session, allowing students to engage in the session, rather than focusing on writing down information from the slides (Dent, 2001). For sessions 2 and 4, pre-session and post-session slides were provided to ensure that students did not read ahead for tasks and obtain answers before the session. I was unable to do this for sessions on other modules, however, I thought that this was an effective technique and is something I would incorporate for future sessions.

The most frequent recommendation for medical lectures is to keep slides simple (Blome, Sondermann & Augustin, 2017). As each of my sessions included medical elements,

I ensured that the PowerPoint slides were simple and accessible by limiting the amount of text, using a large font size and providing 'digestible chunks' of information (Mackiewicz, 2008). Across sessions, the number of slides varied from 30-46 and I cautiously used animations to allow information to appear on slides separately, to prevent content overload (Daffner, 2003; Dent, 2001). I also opted for readable fonts such as Arial for all sessions, as advised by the British Dyslexia Association (2018). To enhance students' interest, PowerPoint slides included bullet points, diagrams, tables and images, which were all verbally explained (Mackiewicz, 2008; Mayer, 2019; Mohan et al., 2010). I added teaching aids to encourage deep learning, including videos, handouts and sticky notes for tasks in small group sessions (Wongkietkachorn, Prakoonsuksapan, & Wangsaturaka, 2014). Alternatively, for the large group (session 6), online materials such as Poll Everywhere and Padlet were used for interactive tasks.

#### **Assessing Learning Outcomes**

The fifth stage of Stefani's (2009) approach is to assess outcomes. The Quality Assurance Agency (QAA, 2018) states that assessment is a fundamental aspect of the student experience, as students learn from assessment activities, interaction with staff and peers and gaining feedback on their progress and performance. According to the QAA, assessment methods are aligned to learning outcomes and teaching activities. Within my sessions, I used formative assessments to monitor student learning and provide feedback. The assessment results were also used to inform the final stage of Stefani's (2009) approach; the 'revision cycle', to make improvements to future sessions. As most sessions were with different groups, I assessed learning outcomes in a variety of ways. For small group sessions, group discussions were incorporated throughout to assess learning and engagement. For example, in session 1 formative assessments included asking students to identify ways that health psychology is applied to chronic pain.

I also incorporated formative assessment tasks at the end of sessions, providing students with the chance to use critical thinking skills and apply knowledge gained throughout the session. In session 2, I divided students into two groups and provided each group with a patient profile. I asked students to use the COM-B model (discussed in the session) to design an intervention to increase physical activity in someone diagnosed with type 2 diabetes. Students needed to consider the barriers to capability, opportunity and motivation and identify which functions of the BCW would be appropriate to address the barriers they had identified. This task linked with the end of module assessment to design an intervention, and it provided students with an opportunity to practice ideas and obtain feedback. This strategy was a successful way of assessing learning outcomes and as session 4 was with the same group, I applied a similar method of having a 'final task' to assess overall learning. This time I instructed students to work in pairs and specify components of a psychological intervention for someone with IBD. Upon reflection, these were successful ways of assessing group learning but not learning on an individualistic level.

As session 5 also focused on diabetes, I adapted the task that I had used for session 2. Health professionals went through the same initial steps as students in session 2, however, instead of using the functions of the BCW they were instructed to identify which BCTs (discussed within the session) would be appropriate, as this was more applicable to their roles as nurses. Some students were unable to complete the activity as they misunderstood the COM-B model, and despite having group discussions throughout the session, I was unaware of the misunderstanding until the final task. Going forward, alongside having a 'final task', I will assess learning earlier within the session using techniques such as multiple-choice questions, allowing me to address any misunderstandings at an earlier stage.

For the large group, I used Poll Everywhere to ascertain students' initial knowledge at the start of the session by asking what comes to mind when they think of 'health psychology'. As a final task, I provided students with the scenario on Padlet to use their role as a health psychologist to support someone diagnosed with chronic pain. This task provided an effective way of assessing learning outcomes within a large lecture, as it was evident that students had applied knowledge which was gained within the session. I also provided the module lead with an essay exam question and five multiple-choice questions reflecting my learning outcomes, as part of the summative assessment to evaluate student learning at the end of the module. As session 3 was pre-recorded, I was unable to identify whether students completed tasks and subsequently, I lacked the opportunity to assess learning.

# Conclusion

Completing sessions for the teaching competency has been a valuable experience. I have developed a deeper understanding of the teaching and learning process, including the importance of needs assessment and meeting with module lead to identify group dynamics before the session. Across sessions, I experienced some challenges, such as a lack of input from nurses in discussions, which resulted in the session being shorter than anticipated. Therefore, going forward I would have backup content available to introduce if needed, to ensure the session fills the allocated time. I would also include a variety of activities such as technology-based tasks or multiple-choice questions to account for students' preferences, as not all students contributed to discussions. Overall, I thoroughly enjoyed teaching and have since been offered additional teaching opportunities for the next academic year, which I have accepted.

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# **4.2. Teaching Evaluation**

This report provides a reflective evaluation of six teaching sessions focusing on 'Long-Term Health Conditions' (Table 1) which I conceptualised, designed, planned, delivered, and assessed. Evaluation is a method of understanding the effects of our teaching on students learning and is fundamental to successful teaching (Ramsden, 1992). Evaluation consists of collecting information about our work, interpreting the information, and making informed decisions about actions required to improve practice (Ramsden, 1992). To conduct my evaluation, I applied the following stages of Hounsell's (2009) evaluation cycle: choose sources of feedback; analyse and interpret feedback; decide on action and implement change.

# Table 1. Overview of Teaching Sessions

Session	Title	Audience	Number of	Location & Delivery	Sources of Feedback
			Students		
1	An Introduction to	BSc Psychology students at the	2	Microsoft Teams	1) Verbal feedback from
	Health Psychology	University of Warwick		(Live)	students
	and Chronic Pain				2) Verbal feedback from
					colleague
2	Diabetes from the	MSc Health Psychology	6	Staffordshire	1) Student feedback form –
	Point of Diagnosis	students - 'Long Term		University	paper format (qualitative
		Conditions' Module		(Live)	questions)
					2) Observer report completed
					by module lead
3	Pain	BSc Health and Medical	18 on the	Warwick Medical	1) Written feedback via email
		Sciences Students - 'Health	module	School - Moodle	from module lead
		Psychology' Module		Page (pre-recorded)	

4	Inflammatory	MSc Health Psychology	4	Staffordshire	1) Student feedback form –
	Bowel Disease	students - 'Long Term		University	paper format (qualitative
		Conditions' Module		(Live)	questions)
					2) Twitter feedback
					3) Verbal feedback from
					module lead
5	Behaviour Change	Practicing Nurses –	6	Staffordshire	1) Student feedback form –
	for Type Two	Postgraduate Diabetes Module		University	paper format (qualitative &
	Diabetes	(6 students)		(Live)	quantitative questions)
					2) Written feedback via email
					from module lead
6	Role of a Health	BSc Psychology Students - 2 <sup>nd</sup>	64	The University of	1) Online student feedback
	Psychologist-	year module 'Lifespan,		Liverpool	form (qualitative & quantitative
	Research Focused	Development Health and		(Live)	questions)
	on Chronic pain.	Wellbeing'			2) Verbal feedback from
					module lead

### **Sources of Feedback**

Feedback is recommended from multiple sources (Hounsell, 2009; Theall, 2010), including students, colleagues, self-generated feedback, and incidental feedback (Fry, Ketteridge & Marshall, 2009).

Student feedback was obtained via evaluation forms, verbal feedback, and Twitter (Table 1). For session 1 I selected verbal feedback, as I already had a positive rapport with the two students (Kember & McNaught, 2007). However, as this feedback was not anonymous it might have been biased. This contrasts the Twitter feedback for session 4, which was unsolicited and likely to be unbiased. To ensure further feedback was unbiased, I used anonymous feedback forms. Kember & McNaught (2007) recommend devising your own feedback form if active learning has been encouraged within sessions. As the questions needed to reflect aspects of the students experience which they could make an informed comment on (Rowley, 2003), I included questions regarding delivery of content, breadth of information and engagement. I also asked students which aspects they found most useful and which aspects could be improved.

Initially, student feedback forms comprised of open-ended questions to provide rich, qualitative data (Keane & Labhrainn, 2005). However, I noticed that one-word responses were provided for some questions. Therefore, I revised the form for sessions 5 and 6 to include Likert scales alongside the open questions, to elicit both qualitative and quantitative feedback. Uptake of feedback was much more successful in the small group sessions where paper forms were used, compared to the large group session where just 2 out of 64 students completed the online feedback form. I obtained further feedback during live sessions by checking students understanding through assessment of learning outcomes and asking

students if they had any questions. As session 3 was pre-recorded, students did not have the opportunity to provide feedback specific to my session.

Peer observation and feedback is imperative to improve the quality of teaching in universities (Hendry & Oliver, 2012). Therefore, colleagues provided feedback at multiple stages of the teaching process. They previewed my PowerPoints ahead of sessions, commenting on suitability and making recommendations. Session 1 was observed by my colleague, and sessions 2-6 were observed by the module lead, providing feedback verbally or via email after the sessions. Feedback from session 2 was formatted as an observer report.

I also engaged in self-reflection to review my teaching experience. There are two types of self-generated feedback: reflection-in-action and reflection-on action (Schön, 1991). I reflected-in-action to adapt sessions accordingly and following each session I reflected-onaction using Gibbs Reflective Cycle (1988). As most sessions were delivered on different courses, I could not apply incidental feedback regarding attendance at subsequent sessions. Nevertheless, I reflected on incidental elements within sessions, including level of engagement and understanding in activities.

## Successes

# Teaching Style

Student, self, and peer evaluation reflected that my teaching style was a successful element of my sessions. This was particularly important for online sessions, as the quality of education in online learning is influenced by teaching style (Nycz & Cohen, 2007). Student feedback highlighted that sessions were delivered in a clear, organised way with the structure allowing students to identify which part of the session mapped onto each learning outcome.

Students reported that sessions included "lots of information, very relevant to the topic but not overloaded" (student feedback, session 2). The observer report supported this by expressing that content was "delivered clearly and confidently throughout illustrating expertise in the subject matter". I also implemented techniques such as introducing complex concepts as an overview before unpacking them in detail. I felt this method worked particularly well for students at both undergraduate and postgraduate level, as knowing the depth and breadth of a topic is a required quality for graduates (Curtis & McKenzie, 2001).

The teaching style differed for health professionals, as it was essential for them to be able to apply learning to practice within a healthcare setting (Miller, 1990). Therefore, to prepare nurses for the 'action' layer of Miller's pyramid (1990), I linked theories such as the COM-B model (Michie, Stralen, & West, 2011) to their everyday practice of working with diabetes in primary care. Subsequently, this mapped onto the 'competency' level of Miller's pyramid (1990), as it fulfilled the criteria of the nurses 'knowing how' to use the knowledge acquired. Feedback suggested that this technique was effective, as "the knowledge gained during this session (surrounding BCTs in particular) would be applied into practice" (student feedback, session 5). The module lead also reported that the session was pitched at the correct level for nurses who had been out of education for a while, as I ensured that it was not overly complicated and used minimal jargon.

I think that my enthusiasm was also a prominent factor in the success of sessions, as enthusiasm is required to motivate students (Kember & McNaught., 2007). One student in session 4 reported that it was one of their "favourite sessions on the course" (student feedback, session 4). They also tweeted positive feedback and informed me that the session had inspired them to explore the topic further. Moreover, the module lead mentioned that they had learnt "something new about IBD" (colleague feedback, session 4). I believe that my

passion for Inflammatory Bowel Disease (IBD), which derives from my own personal experiences, excelled within this session and contributed to its success.

# Tasks and Interactivity

For teaching to take place effectively online, a balance between practical tasks is necessary (Coman et al., 2020). As engagement in online sessions is often an issue (Kebritchi, Lipschuetz, & Santiague, 2017), I decided to encourage students' participation through discussions. This approach was successful and students in session 1 reported that they enjoyed the discussions. Moreover, the most important characteristic of small group teaching is the active involvement of learners in the entire learning cycle (Crosby, 2003). Therefore, for my small group sessions I opted for a seminar style and incorporated discussions to involve students throughout, which has been shown to be successful at fostering active learning and critical thinking (Schmidt et al., 2015). This technique worked well and in session 2, the module lead conveyed that discussions were managed well as I reflected the students point back to the group with added detail to expand upon their learning.

Based on previous experiences of being a student in large lectures, I thought that students would be unlikely to answer questions in front of a large audience. Therefore, for my large group session I incorporated tasks using online platforms such as Poll Everywhere and Padlet. This allowed students within a more 'conventional' lecture setting to engage in active learning, and complete tasks requiring critical thinking skills (Savery, 2015). Students found these tasks valuable and reported that they "liked the interaction using Padlet and Poll Everywhere, it perfectly split up the lecture and gave us an opportunity to have a short pause..." (student feedback, session 6). These tasks also allowed me to assess the learning outcomes, which is an important aspect of teaching evaluation (Theall, 2010). For instance, at

the start of the session students provided general responses on Poll Everywhere, suggesting that they lacked in-depth knowledge of health psychology. Contrastingly, responses to the Padlet task at the end showed that students had used the knowledge obtained within the session to formulate ideas, suggesting the learning outcomes had been met. If I was to deliver a large group session in the future, I would include technology-based tasks again.

Literature suggests that motivation in lectures can be sustained if sessions relate to overall course assessments (Hoskins & Newstead, 2009). Therefore, I designed a task in session 2 to directly relate to the module assessment. I asked students to apply the COM-B model to design an intervention to increase physical activity in someone diagnosed with type 2 diabetes. I felt that this successfully increased motivation, as all students engaged in the task and conveyed that they enjoyed it. Due to the success of the task in session 2, I adapted it for the subsequent session on diabetes with nurses, asking them to identify appropriate behaviour change techniques to increase physical activity for the patient profile I provided them with. As well as linking to their assessment, the task reflected real life practice and the module lead reported that it helped nurses apply theory to practice (Bullock et al., 2008; Miller, 1990). Using case-based learning such as this is important, as it enables healthcare professionals to engage in active learning (Graffam, 2007).

# Materials

I believe the materials I used throughout sessions were appropriate and effective. In line with technology enhanced learning, I used online systems such as YouTube videos, Poll everywhere and Padlet to directly support learning and teaching (Walker, 2020). Student feedback regarding materials was positive across sessions, reporting that the materials were engaging and the "PowerPoint was well organised and presented" (student feedback, session 2). In the observer report, the range of materials was identified as a strength, as videos were a useful way of providing information for different needs and preferred learning styles of students. Some students reported that the session would have been improved if it included more videos. However, videos were only added to encourage higher order thinking and including more could have encouraged passive learning (Bonwell & Eison, 1991).

The handouts that I provided for tasks also proved to be a success and were a key element in promoting and optimising student learning (Wongkietkachorn, Prakoonsuksapan, & Wangsaturaka, 2014). Students in sessions 2 and 5 found the Behaviour Change Wheel and COM-B system the most useful part of the session, both of which were provided as handouts. Similarly, one of the nurses reported that "the handouts given were useful" (student feedback, session 5). In addition to handouts, students from session 4 valued the use and explanation of my own research. This is supported by literature that underlines the value of staff research and its ability to motivate students in higher education (Jenkins et al., 2003). I felt that this strengthened the information I was providing, as I was able to provide first-hand research experience. Additionally, I used materials such as newspaper articles to encourage students to apply theory to real life scenarios. Providing a variety of materials targeted different learning needs and met students' preferences (McKee & Scandrett, 2021) and therefore is something I will continue to do in future teaching opportunities.

#### Less Successful Aspects & Areas for Development

# Tasks and Interactivity

My colleague suggested that there were too many interactive parts in session 1. Applying this feedback, I included fewer discussion points in session 2, however, this session was with a larger group and one student expressed that they would have preferred more discussions. This highlighted the importance of considering the context of the session and group characteristics (Kember & McNaught., 2007). Upon later reflection of session 1, I felt that the number of discussion points worked well for the small group size, as the delivery appeared more natural opposed to it being a didactic lecture. Therefore, for future small group sessions I will continue to incorporate multiple discussion points.

Another area for improvement was that in session 2, I did not always specify the timeframe for students to complete activities, which meant that students were unable to adequately plan their time. Communicating task time is necessary to motivate students to complete activities (Cheung & Cable, 2017), therefore, for subsequent sessions I specified the timeframe for activities. Both groups also misinterpreted the final task in session 2. Although I addressed this by checking with the groups, the peer feedback recommended that further explanation was needed. I rectified this within my next session with this group, as I added an 'instruction box' for the final task, including bullet points for 'things to consider'. This approach was successful as all students understood the task and completed it as instructed.

In my session with nurses, I felt that I did not engage all students as some looked disinterested. When I asked students to feedback on the final task it was evident that one group had misunderstood the COM-B model, which was a core component of their session and one of their learning outcomes. I tried to encourage students to think more about the components of the COM-B, however I was worried that I put the student on the spot. As the other group successfully completed the task, this reassured me that my explanation had been clear. During the task, I had also spoken with each group, and they assured me they understood. Initially I was disappointed with the lack of engagement, and I began to question my teaching ability. However, through the process of reflection I thought more about the learner's working context and other explanations for their lack of engagement, which restored

my confidence. The lack of engagement could have been due to tiredness from working as nurses alongside the module or individual differences in learning styles. To combat this, I could include a variety of smaller tasks to engage students with different learning styles, such as using the online platform Mentimeter for students to answer questions, rather than sharing answers verbally.

As session 3 was pre-recorded, it was challenging to embed interactive elements. I incorporated tasks where students were required to pause the recording to watch a video or answer questions. I tried to motivate students to complete tasks by using an encouraging tone of voice (Palis & Quiros, 2014), yet I was unable to monitor whether they participated. This contrasts the live sessions where I observed student progress and provided feedback.

## Pace

My pace was quite quick for session 5, which resulted in the session being shorter than intended "at times the pace at which slides were covered was a little quick... I needed time to make notes" (student feedback, session 5). It is important that I rectify this, as ineffective pacing can interfere with note taking (Dent, 2001). I also felt that initially my pace was quite fast when delivering the large group session, however when I noticed this I slowed down and students rated the pace as 9.5/10. These pacing issues could have been due to nerves of teaching healthcare professionals (session 5) and being in a large lecture theatre (session 6). Going forward I will speak slower and pause at the end of each slide, allowing students time to digest information (Harbell & O'Sulivan, 2022). I believe that through further teaching experiences, my confidence will increase, and perceived anxieties will be reduced; subsequently improving the pacing of lectures. Another action point regarding the

pace of future sessions is to allow students to have more time to answer questions within discussions, so that they can consider the question fully.

#### Unpredictable Situations

Within sessions I encountered some unpredictable situations, requiring me to adapt. I had anticipated using 'presenter view' on PowerPoint to view my notes. However, this was not possible in session 2 due to the layout of the technology within the room. I was able to adapt to this situation as I had rehearsed the lecture and knew the content. This experience taught me to have confidence in my knowledge and ability, as I did not need the notes to deliver the session effectively. I think it improved the session as it meant that I was able to talk directly with students, rather than focusing on reading the notes. Nevertheless, this experience emphasised the importance of checking a room ahead of the session. One action I took from this was to clarify the room layout and technology with the module lead before sessions.

In session 4 there were only 4 students in attendance instead of 6. I reflected in the moment (Schön, 1991), to adjust the group task and decided that it would be more effective for students to complete it in pairs rather than one large group. This allowed students to present different perspectives to the other group, enabling students to teach each other; subsequently meeting the highest level of Blooms Taxonomy (Bloom, 1956). Additionally, the whiteboard disconnected several times disrupting the session, resulting in there not being enough time to watch the video within the session. Therefore, I recommended that students watch the video after the session as homework. This was an appropriate solution, as the session time was utilised to provide key information and watching the video as homework provided students with an opportunity to recap learning. This also illustrates my ability to

remain calm in the face of challenges, reflect in the moment and adapt to the situation accordingly.

# Summary

Overall, sessions were received positively by students and colleagues. I have been asked to deliver two of my sessions again next year, which suggests that the module lead thought they were successful. I felt that there was a substantial amount of engagement and interactivity across sessions, therefore I will continue to incorporate a variety of tasks within future sessions. However, I need to be more comfortable with silence to allow students time to think when I ask questions. I also need to be conscious of the pace at which I am speaking and give clear instructions for tasks. One action I will take going forward, is to continue to include an 'instruction box' for tasks and to ask for student responses to ensure they understand before beginning the task.

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# **Chapter 5: Consultancy in Health Psychology**

# 5.1. Consultancy Case Study

# Background

Consultancy is a professional relationship whereby one party (the client) seeks assistance from another (the consultant). A consultant provides advice based on their expertise and they negotiate with the client to arrive at a mutually agreeable solution (Earll & Bath, 2004; Newton, 2019). They differ to a manager, as they have some influence over an individual, group, or an organisation but have no direct power to implement programmes or make changes (Block, 2011). A consultant is often independent of the client and involved on a temporary basis, but they add value to the client organisation by helping them to create change (Alvesson & Sveningsson, 2011; Newton, 2019).

For this consultancy work, I followed Earll and Bath's (2004) six stage approach:

- 1. Assessment of requests for consultancy
- 2. Plan consultancy
- 3. Establish, develop, and maintain working relationships with client
- 4. Conduct consultancy
- 5. Monitor the implementation of consultancy
- 6. Evaluate impact of consultancy

#### **Identifying the Consultancy Opportunity**

A consultancy opportunity may arise from the client approaching the consultant or vice versa (Newton, 2010). I approached a health psychologist based at a public health team within a city council and offered to do some voluntary consultancy work within their organisation. Initial online meetings discussed how my expertise as a trainee health psychologist could be used within a public health setting. In these meetings I demonstrated
what I could offer the client (Block, 2011; Nelson & Economy, 2008) by outlining my experience of working with people with long-term health conditions and knowledge of designing and delivering interventions. Once the proposal to have an honorary consultant was approved by the Director of Public Health and the board at the council, a meeting was held to discuss the plan for the consultancy work. The client identified a need for a piece of work on cervical cancer screening, which is discussed further in the negotiation and planning stage.

# Clients

The client is the person (or group) who the consultancy is aimed at (Newton, 2010). When undertaking a piece of consultancy, it is important to know who the clients are (Newton, 2010). Schein (1999) proposes 6 categories of clients which are identified in Table 1.

# Table 1. Client Categories

Client Category	Client		
Contact Client	Health psychologist & Behavioural Scientist at the council		
	• First line of contact regarding the consultancy project		
Intermediate Client	Members of the public health team also working on cervical		
	cancer screening		
	Involved in meetings		
	• Assist with aspects of the project		
Primary Client	Principle Public Health Specialists		
	Responsible for overall cervical screening project		
Ultimate Client	Residents of the city receiving the intervention		

	• Target audience for cervical screening who had missed		
	appointments previously		
Involved Client	A local NHS Integrated Care Board		
	• An external organisation working on a similar project to		
	increase cervical screening uptake		
	Local Health Centre		
	• A GP practice who would be helping to promote the		
	intervention programme		
Unwitting Clients	Members of the public who may benefit if the intervention work		
	is adopted and taken further by the council		

# **Negotiation and Planning**

# Scoping Meeting

A scoping meeting investigates whether the project is appropriate for both parties and outlines expectations (Block, 2011; Earll & Bath, 2004). The client sent an outline for the consultancy work, proposing that I conduct qualitative research regarding cancer screening, produce a report outlining behaviours and attitudes to cancer screening and develop a behaviour change intervention, designed to increase uptake for each of the three cancer screening programmes (cervical, breast and bowel). However, the client later decided that the work would just focus on cervical cancer screening, rather than focusing on all three. The client arrived at this decision as the cancer screening figures for all three programmes were low within Wolverhampton, but they had the capacity to support a piece of work on cervical cancer screening. I believed that the workload was too substantial for the timeframe, and I explained that as a trainee I would need to discuss the plan with my supervisor before agreeing to tasks. It was important that I reflected on the offer before negotiating the workload (Nelson & Economy, 2008), as my initial reaction might have been to agree to the tasks to please the client, yet this could have caused issues if I was unable to meet their expectations.

# Planning

As part of the planning stage (Earll & Bath, 2004), I had several online meetings with the contact client to agree the work and develop the consultancy contract. I used active listening skills, including verbal and nonverbal communication, to articulate and consider ideas that were proposed (Robertson, 2005). Important information was discussed, including when certain milestones would be achieved, the termination point and the overall timeframe, which was February 2022 – July 2022. As this consultancy was unpaid, I did not need to negotiate fees, but a hypothetical budget was created whereby I calculated the hourly pay based on the salary of a trainee health psychologist.

As the consultancy was conducted remotely, it was unlikely that there would be any expenses but if I did need to travel to the client's office, I was expected to cover the cost myself. Reflecting now, I should have negotiated that if the client needed me to go into the office, they should cover the travel expenses. Nevertheless, I negotiated boundaries of the work to ensure that I stayed within my level of competency, referring to the British Psychological Society (BPS) codes of ethics and conduct, (2018) and the Health and Care Professions Council standards of conduct (2018). The client initially stated that the intervention would belong to them, however I felt that it should be my intellectual property as I was designing it. I planned for the negotiation by familiarising myself with intellectual property rights and I used active and reflective listening skills to negotiate the intellectual

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property of the intervention (Roloff et al., 2003; Schultz, 1989). Subsequently, it was decided that the intervention design and materials would be my property, but the use of the intervention and materials by the client was not restricted.

The final part of the planning stage was to agree output and deliverables. The client originally outlined a significant amount of work, which was unrealistic for me to complete in six months. Therefore, I applied the problem-solving negotiation model (Goodpaster, 1992) to work with the client to identify a solution which we would be satisfied with. It was agreed that to reduce my workload the client's team would conduct the qualitative work and recruitment for the intervention. The agreed deliverables are outlined in Table 2.

Deliverable 1	To conduct a brief literature review (approx. 1500 words) of studies conducted in the UK that report on the barriers and facilitators to cervical
	cancer screening.
Deliverable 2	To take the lead on the design of a virtual, six-week group behaviour
	change intervention that aims to increase cervical cancer screening
	uptake.
Deliverable 3	To take the lead on the delivery of the six-week intervention to a group
	within Wolverhampton.
Deliverable 4	To conduct a brief evaluation of the intervention (approx. 1500 - 2000
	words).

 Table 2. Agreed Deliverables

Throughout the planning process, it became evident that I would be working within a combination of the Expertise Model and the Process Consultation Model (Schein, 1999). For

instance, I would conduct the literature review and design the intervention alone, but the client would still provide feedback and be involved.

# Establishing and maintaining the working relationship

# Establishing relationships

For the consultancy project to be successful, it was important to establish relationships (McGivern, 1983; Sharp et al., 2015). Given that the consultancy was taking place remotely, I aimed to create a good impression and build rapport with the clients by ensuring that I was prepared and passionate during online meetings. Effective communication was also paramount to establish relationships with the client (Weijermars, 2011) and I made sure that it was two-way communication in meetings and email (Hargie et al., 1999; Nelson & Economy, 2008).

#### Maintaining relationships

To maintain the working relationship, I completed the work to the best of my ability and applied feedback (Gregory & Levy, 2015; Nikolova et al., 2009). It was imperative to maintain open communication with the client (Weijermars, 2011), so regular Microsoft Teams meetings were scheduled to monitor progress and allowed collaborative feedback to occur. I also communicated with the client via email and showed a willingness to have impromptu calls when necessary (Hargie et al., 1999). However, this was quite demanding at times as I was completing the consultancy outside of my full-time job. To ensure that boundaries were maintained, I contacted the client directly (Nelson & Economy, 2008) to explain that it was not feasible for me to take unplanned calls in work hours. I used assertive communication skills, which have been found to strengthen the relationship with the client and reduce further conflict (Pipas & Jaradat, 2010). This was a difficult conversation as I did not want to damage the relationship, yet I was conscious that this was not contracted and if left unaddressed it could escalate. Nevertheless, having this conversation resolved the issue. Overall, the client was impressed with how I engaged with the team, particularly as we were working remotely.

# **Conducting and Monitoring the Consultancy**

The next stages in Earll and Bath's (2004) approach are conducting and monitoring the consultancy. The first deliverable was to provide a brief literature review on the barriers and facilitators to cervical cancer screening in the UK. In the feedback for the literature review, the client asked if I could include information about the homelessness cohort and Eastern European population. Including this information was not explicitly outlined in the contract, however, I felt that it was reasonable for me to add these sections as it would improve the quality of the review. This paid off, as feedback on the final review was positive and it is now used by the client as an exemplary literature review within their department.

The second deliverable was to design a 6-week intervention informed by findings of the literature review, focus groups and survey. The focus groups were unsuccessful as only 2 people attended. Upon reflection, focus groups were not the most efficient way to provide an assessment of the target group, particularly as they would have included different people to the intervention group. Although this was the client's decision, as the consultant and 'expert' I could have provided a stronger justification for not needing focus groups (Schein, 1999). For example, I could have conducted an assessment session with the intervention group prior to session one, which would have saved time. Through open communication (Weijermars, 2011), it was decided that as the focus groups were unsuccessful, the survey responses would be sufficient to inform the intervention design, and I would continually assess the group throughout the intervention sessions.

Using the literature review and survey findings, I devised an intervention plan which I proposed to the client in a Microsoft Teams meeting. In the meeting I used a PowerPoint presentation, as visual communication is an important component of communication in the workplace (Brumberger, 2007). As the aim of the project was to change the behaviour of the ultimate client by increasing their attendance at screening appointments, it was imperative that I was mindful of the management of this change throughout the consultancy process (Cope, 2003). The client and I discussed the length of the intervention and realised that the target demographic may be unlikely to attend a six-week intervention programme, as they currently were not attending screening appointments. It was mutually decided that to reduce participant burden, encourage participation and facilitate retention, the intervention should be delivered across four weeks, as this still had a sufficient evidence base (Fillion et al., 2008). However, the contract explicitly stated a six-week intervention, and this should have been revised to protect myself should the client changed their mind. The intervention sessions were originally planned to be 1 hour each, however, the client wanted to reduce these sessions to 30 minutes. I felt that 30 minutes would not be enough time to deliver the content effectively, so I negotiated this with the client, and we agreed that 30-45 minutes would be adequate. I created the intervention materials which included PowerPoint slides, a workbook, and a leaflet, which the client approved prior to the intervention delivery. This demonstrated further that I was working between the Expertise Model and Process Consultation Model, because although I lead the design, the Client had input on the deliverables (Schein, 1999).

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This was the first time that an intervention of this nature was being delivered via the client's organisation and it was important that I monitored and supported this change (Cope, 2003). For instance, there were several challenges regarding the intervention delivery that I had to overcome. Firstly, the client struggled to recruit individuals for the intervention which resulted in a delay. To account for this, I adjusted the timeline for the intervention delivery (Nelson & Economy, 2008). Although there was email correspondence to confirm these timeline changes, I should have also formally recorded these changes in the contract. Additionally, the contract stated that "A member of the Client's team will be present during the intervention sessions to oversee administrative tasks...". I was later informed that there was nobody available to assist with the sessions. At the time I did not mention this to the client as I was worried about creating conflict. Although I tried to adapt to this change of plan and deliver the session to the best of my ability, I became overwhelmed with having to deliver the session and oversee the administrative side of running an online intervention. Therefore, I reflected this back to the contact client and expressed that I needed support, and it was agreed that somebody from their team would perform these administrative tasks. This experience taught me that I should have stayed within my rights and referred to the contract (Lippitt & Lippitt, 1994), as it would have prevented the issues that occurred in the first session. Additionally, I could have used assertive communication (Pipas & Jaradat, 2010) to represent my rights and needs to explain why I needed their team to support the intervention delivery (Pipas & Jaradat, 2010).

Another challenge was that some individuals were unable to attend session one, but they wanted to attend subsequent sessions. To ensure that they did not miss important content, I displayed autonomous initiative and created a recorded version of session one for them to watch. Although this was not a task I had originally agreed to, I reviewed the alternative option of them missing content and decided to take on this additional workload to

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further facilitate the behaviour change of the ultimate client. As this piece of consultancy work was unpaid, taking on additional work did not have an impact on reimbursement. However, if this was paid consultancy work, I would have negotiated whether there was sufficient budget available for this additional task.

Part of the process for monitoring the consultancy (Earll & Bath, 2004) was applying feedback from the ultimate client, as Miller (2001) states that it is important to involve the client whose behaviour you are trying to change. Within the feedback, I was informed that the leaflet included too much information and not enough images. This leaflet had received approval from the primary client, however based on this feedback I revised the leaflet to suit the ultimate client's ability and needs. I discussed this with the contact client, who was happy for me to edit the leaflet. However, this decision meant I had to spend more time editing the leaflet, and if this was a paid consultancy, I would need to consider whether there is the budget for changes to materials. In this instance it seemed like the appropriate step, and feedback on the revised leaflet was extremely positive.

The last deliverable was an evaluative report. I sent the client a draft of the evaluative report which they provided feedback on. A primary client who had not previously been involved with the project asked me to include that the language used was a barrier to the intervention. However, this was not something that I found as part of the evaluation process, and it would have been unethical of me to include false findings (BPS codes of ethics and conduct, 2018). I communicated this with the client, and it was not included in the final report. The report was then signed off, which concluded the consultancy work.

#### **Evaluation of Consultancy Process**

Evaluation is key to the success of a consultancy project (Earll & Bath, 2004). I evaluated the effectiveness of the group intervention to identify if it successfully increased intentions to attend cervical cancer screening. To evaluate the intervention, a series of surveys were administered at baseline, after sessions: 1, 2, 4 and at 6 week follow up. The survey responses showed that the intervention successfully increased capability, opportunity, and motivation to attend cervical screening. The most apparent change was in knowledge and understanding of cervical screening, which substantially improved following attendance at all four sessions. I also incorporated feedback questions into a survey for the ultimate client midway through the intervention and after the last session. Overall, the qualitative feedback from individuals who attended the sessions was very positive: "excellent sessions, feedback taken on board". This suggests that the consultancy work had a positive impact on cervical screening uptake.

At the end of the consultancy, I received positive feedback from the contact client outlining that I had successfully met the aims of the consultancy and produced work that would be carried forward as part of the wider cancer screening workstreams. However, I was informed that at times my work was very academic which made it difficult for some individuals to understand. Particularly, I used academic language in the evaluative report regarding the COM-B model. This highlighted the importance of considering the audience and to think about ways that academic information can be conveyed for clients who are not from an academic or health psychology background.

#### **Reflection and Summary**

Consultancy was a new experience for me, and I was unsure what I could offer as the 'expert'. However, I thoroughly enjoyed taking the lead on an important piece of work that

allowed me to develop consultancy and intervention skills. One key learning point is that I should have amended the contract to reflect any agreed changes. For future consultancy work, I will ensure to make contract revisions when required so that I am protected as the consultant. Nevertheless, it provided me with an invaluable opportunity to work in a public health setting, and I think the experience will contribute to my development as a well-rounded health psychologist. It was an excellent learning experience for me to build new relationships and develop skills such as communication, project planning and budgeting. I also illustrated my expertise in several interactions with the client and challenged feedback when I did not agree, demonstrating my confidence and abilities to set boundaries and negotiate. Overall, the client's feedback was very positive, and I am excited to develop my skills further in future consultancy opportunities that arise.

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# 5.2. Contract and Working Conditions Agreement

# THIS CONSULTING AGREEMENT

# (the "Agreement") dated this 14<sup>th</sup> February, 2022

# **BETWEEN:**

on behalf of City Council Public

Health

(the "Client")

-AND -

Paige Karadag, Trainee Health Psychologist of Staffordshire University

(the "Consultant")

# 1. BACKGROUND

- 1.1 The Client is of the opinion that the Consultant has the necessary qualifications, experience, and abilities to provide services to the Client.
- 1.2 The Consultant is agreeable to providing such services to the Client on the terms and conditions set out in the Agreement.

# 2. THE SERVICES

2.1 The Client and Consultant hereby agrees to the following services that will be carried out between the months of February – July 2022.

- To conduct a brief literature review (approx. 1500 words) of studies conducted in the UK that report on the barriers and facilitators to cervical cancer screening.
  - The literature review will be presented in APA format and delivered to the Client in a Word document via email.
  - The review will include the barriers and facilitators to cervical cancer screening in different ethnic groups, deprived areas and the LGBTQ+ community.
- To take the lead on the design of a virtual, six-week group behaviour change intervention that aims to increase cervical cancer screening uptake.
  - The design must be appropriate for the intervention to be delivered via Microsoft Teams.
  - The development of the intervention will be informed by findings of the literature review and a focus group (conducted separately by the Client's team).
  - The intervention will be underpinned theoretically by the COM-B model of behaviour change.
  - Depending on the findings of the literature review and focus group, the intervention will target a subgroup within Wolverhampton such as individuals from a particular ethnic group, people from a deprived area or from LGBTQ+ community. This decision will be agreed through consultation with the Client.
  - The group intervention will consist of at least 10 individuals and will have a maximum capacity of 30. The exact size will be determined by

the focus group and how many residents of Wolverhampton agree to take part.

- To take the lead on the delivery of the six-week intervention to a group within Wolverhampton.
  - The Consultant will be responsible for the delivery of the intervention via Microsoft Teams.
  - A member of the Client's team will be present during the intervention sessions to oversee administrative tasks such as admitting individuals to the Microsoft Teams meeting and monitoring the 'chat' function.
- $\circ$  To conduct a brief evaluation of the intervention.
  - The evaluation will be presented as a formal report and will be approx.
     1500 2000 words.
  - The evaluative report will include findings from:
    - Self-report outcome measures used to evaluate the effectiveness of the intervention at baseline (one week before the intervention) and post-intervention (end of week six).
       These will consist of standardised measures that will be decided by the Consultant during the design phase of the intervention.
    - Qualitative feedback regarding the applicability of the intervention, including its ease of use and ease of communication. The Consultant will use evidence from the

literature review to determine the focus of these open text questions.

- The evaluation will also propose any areas of improvement.
- The intervention will be theory based and have the aim of increasing cervical screening uptake. However, the Client understands that increases in uptake following the intervention cannot be guaranteed by the Consultant.
- The Client and their team are responsible for conducting and analysing the focus group to be used to inform the development of the intervention. They are also responsible for the recruitment of individuals for the group intervention.
- The Consultant will provide the Client with weekly updates of progress of the Consultancy via emails and/or Microsoft Teams meetings. Meetings via Teams will be arranged as and when required, throughout the course of the consultancy.
- The Consultant will submit final versions of the agreed work to the Client via email. This includes the literature review, the intervention materials, and the evaluative report.

# 3. MILESTONES

3.1 The Consultant agrees to undertake activity to achieve the services within the following time frame agreed by the Client. These are intended dates which may change if required.

Month	February	March	April	May	June	July
Review						
Design						
Delivery						
Evaluation						

# 4. TERM OF AGREEMENT

- 4.1 The term of this Agreement (the "Term") will begin on the date of this Agreement and will remain in full force and effect until the completion of the Services or by the 31<sup>st</sup> July 2022, whichever arrives the soonest, subject to earlier termination as provided in this Agreement. The Term of this Agreement may be extended by mutual written agreement of the parties.
- 4.2 In the event that either Party wishes to terminate this Agreement prior to the completion of the Services, that Party will be required to provide 1 month's written notice to the other party.

# 5. PERFORMANCE

5.1 The Parties agree to take the necessary actions to ensure that the terms of the Agreement take effect.

- 5.2 The Consultant shall deliver all of the services remotely from their home. This includes the group intervention, which will be delivered via Microsoft Teams. If the Consultant is required to attend the Client's offices, this will be agreed by both parties in advance.
- 5.3 The Client and Consultant agree to give reasonable notice to the other party for any period of holiday, sickness or other absence during which they are unable to perform their duties relating to the Services outlined in this Agreement or if this is to impact the Agreement in any way.
- 5.4 The Client will be responsible for ensuring that any members of their team, that are required for successful delivery of the Services, are in attendance at meetings or events organised in order to achieve the Services.

# 6. COMPENSATION AND REIMBURSEMENT OF EXPENSES

- 6.1 There will be no payment associated with this work. It is envisaged that this work will be mutually beneficial to both parties as the Client will gain value from the consulting intervention and the Consultant will gain experience in support of their Professional Doctorate in Health Psychology.
- 6.2 The Client has agreed that instead of payment, there will be the opportunity to publish the intervention following the completion of the services listed above, whereby the Consultant will be the first author.

6.3 There will be no expenses associated with this work. However, if the Consultant is required to travel to the Client's office, then travel expenses will apply.

# 7. CONFIDENTIALITY

- 7.1 Confidential information (the "Confidential Information") refers to any data or information relating to the business of the Client which would reasonably be considered to be propriety to the Client including, but not limited to, accounting records, business processes, and client records and that is not generally known in the industry of the Client and where the release of that Confidential Information could reasonably be expected to cause harm to the Client.
- 7.2 The Consultant agrees that they will not disclose, divulge, reveal, report or use, for any purpose, any Confidential Information which the Consultant has obtained, except as authorised by the Client or as required by law. The obligations of confidentiality will apply during the term of this Agreement and will survive indefinitely upon termination of this Agreement.
- 7.3 All written and oral information and material disclosed or provided by the Client to the Consultant under this Agreement is Confidential Information regardless of whether it was provided before or after the date of this Agreement or how it was provided to the Consultant.

# 8. INSURANCE AND LIABILITY

- 8.1 The Client and this project are covered by City Council's Indemnity Insurance and the Client will be taking overall responsibility for the project.Therefore, the Consultant is not required to have their own indemnity insurance.
- 8.2 The Consultant does not accept liability for any action taken by those in receipt of the Services outlined in this Agreement.

# 9. ETHICAL AND LEGAL FRAMEWORK

- 9.1 The Consultant is a doctoral student of Staffordshire University. As such, their professional practice is bound by ethical and legal codes of Staffordshire University and Health and Care Professions Council's guidelines.
- 9.2 The Consultant will conduct the Services in line with the Health and Care Professions Council's 'Standards of conduct, performance and ethics' (2016) and the British Psychological Society's 'Code of Ethics and Conduct' (2009).

# **10. INTELLECTUAL PROPERTY**

10.1 For the literature review, only material available to the public will be used, such as academic papers and information in the public domain. The Intellectual Property rights will remain with these original sources.

10.2 The design of the intervention and any materials for the intervention, that are developed under this Agreement, will be the Intellectual Property of the Consultant. The use of this Intellectual Property by the Client will not be restricted in any manner.

10.3 The data collected during the evaluation of the intervention will be the property of the Client. This is to adhere to General Data Protection Regulation (GDPR), as it will be data collected from the residents of Wolverhampton. If the Consultant would like to use this data for any reason that is not outlined in this Agreement, they will inform the Client of this via email first.

10.4 The Consultant will be able to use any new intellectual property for the requirements of the Professional Doctorate.

# **11. RETURN OF PROPERTY**

11.1 Upon the expiry or termination of this Agreement, the Consultant will return to the Client any property, documentation, records, or Confidential Information which is the property of the Client.

#### **12. CAPACITY/ INDEPENDENT CONSULTANT**

12.1 In providing the Services within this Agreement it is agreed that the Consultant is acting as an independent Consultant and not as an employee. The Consultant and the Client acknowledge that this Agreement does not create a partnership between them, and is exclusively a contract of service.

# **13. REQUESTS**

13.1 All requests, notices, or demands or other communications required by the terms of this Agreement will be given in writing and delivered to the Parties of this Agreement as follows:

- i) on behalf of City Council Public Health Team
- ii) Paige Karadag of Staffordshire University, Stoke-on-Trent, England, ST4 2DE

# 14. ADDITIONAL CLAUSE FOR INFORMATION – PROFESSIONAL DOCTORATE IN HEALTH PSYCHOLOGY

- 14.1 The Consultant is undertaking a Professional Doctorate in Health Psychology at Staffordshire University. In order to receive the Qualification in Health Psychology (QHP), the trainee must complete five competencies:
  - Professional Skills
  - Psychological Interventions
  - o Research
  - o Teaching
  - o Consultancy

14.2 This Agreement will allow the Consultant to demonstrate the consultancy skills required to fulfil the consultancy competency and it will be an opportunity for the Client to benefit from the expertise of the Consultant.

14.3 The Client agrees to allowing the Consultant to use anonymised copies of correspondence and documents generated during the consultancy as evidence of completion of the consultancy competency as part of the Professional Doctorate in Health Psychology.

14.4 The Client agrees to allowing the Consultant to write up the consultancy work as a case study in order to fulfil the requirements of the Professional Doctorate in Health Psychology.

# **15. MODIFICATION OF AGREEMENT**

15.1 Any modification of this Agreement by either Party will only be binding if evidenced in writing signed by each Party.

#### **16. TIME OF THE ESSENCE**

16.1 Time is of the essence in this Agreement. No extension or variation of this Agreement will operate as a waiver of this provision.

# **17. ASSIGNMENT**

17.1 The Consultant will not voluntarily, or by operation of law, assign or otherwise transfer its obligations under this Agreement without prior written consent of the Client.

#### **18. ENTIRE AGREEMENT**

18.1 It is agreed that there is no representation, warranty, collateral agreement or condition affecting this Agreement except as expressly provided in this Agreement.

#### **19. GOVERNING LAW**

19.1 It is the intention of the Parties to this Agreement that this Agreement and the performance under this Agreement, and all suits and special proceedings under this Agreement, be constructed in accordance with and governed, to the exclusion of the law of any other forum, by the laws of the Country of England, without regard to the jurisdiction in which any action or special proceeding may be instituted.

#### **20. SEVERABILITY**

20.1 In the event of any of the provisions of this Agreement are held to be invalid or unenforceable in whole or in part, all other provisions will nevertheless continue to be valid and unenforceable parts severed from the remainder of this Agreement.

#### **21. WAIVER**

21.1 The waiver by either Party of a breach, default, delay or omission of any of the provisions of this Agreement by the other Party will not be constructed as a waiver of any subsequent breach of the same or other provisions.

**IN WITNESS WHEREOF** the Parties have duly affixed their signatures under hand and seal on 14<sup>th</sup> February, 2022



Paige Karadag (Consultant)

# **Chapter 6: Health Psychology Interventions**

#### 6.1. Individual Face-to-Face Intervention Case Study

## Background

Covid-19 has had a profound impact on the health of millions of people globally (World Health Organization, 2021). In some cases, a range of symptoms persist beyond the acute infection. If symptoms persist beyond 12 weeks, it is classified as Post-Covid 19 Syndrome (PCS) (NICE, 2021). One of the most common symptoms of PCS is severe and persistent fatigue (Crook et al., 2021; Van Herck et al., 2021). There is no universal definition of fatigue, as its experience is subjective (Chalder et al., 1993; Nicholson, 2015). However, it can be described as an unpleasant physical, cognitive, and emotional symptom which is not relieved by common strategies that restore energy. It varies in intensity and duration, reduces the ability to perform activities (Galland-Decker et al., 2019) and can significantly impact quality of life (Vyas et al., 2022).

Being diagnosed with a Long Term Condition (LTC) such as PCS can be challenging as individuals often need to adjust to new levels of function (Holman & Lorig, 2000). Therefore, equipping individuals to self-manage and cope with their illness is imperative to their physical and psychological wellbeing. This case study provides an overview of a faceto-face health-psychology intervention that I designed, delivered, and evaluated within my placement at Bristol M.E. Service with a client experiencing PCS.

#### The Client and Intervention Aim:

The client was a 55-year-old female who contracted covid in August 2021 and was diagnosed with PCS in December 2021 by a post-covid clinic. Following input from the post-

covid clinic, the client was referred to Bristol M.E. Service in January 2023 as fatigue continued to impact daily activities.

The primary aim of this intervention was to improve the client's self-efficacy to manage their fatigue and increase their coping skills. Secondary outcomes included improving quality of life and reducing the impact of fatigue. These aims were decided in collaboration with the client. It is important to note that this intervention was not aiming to reduce fatigue. This is because recent NICE guidelines for Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) (2021) underlined that although psychological interventions such as Cognitive Behavioural Therapy (CBT) can help with symptom management and improve quality of life, they are not curative. As there is a large overlap of symptoms between of ME/CFS and PCS, the guidance for management is similar (Twomey et al., 2022; Wong & Weitzer, 2021). Reflecting service protocols, the ME/CFS NICE guidelines were applied in the context of this client experiencing fatigue as part of PCS, alongside the NICE guidelines for long-covid (2021). The intervention consisted of six sessions which occurred fortnightly between February and April 2023.

# Inclusion Criteria

Bristol M.E. Service support individuals with ME/CFS or post viral fatigue syndrome, including PCS. To meet the criteria for Bristol M.E. Service, individuals with PCS must first be assessed in an NHS long-covid clinic and be referred for support. They must also undergo a series of blood tests and investigations to rule out other causes of the fatigue.

#### Assessment

The first stage of designing an intervention is to determine the problem (Kennerley et al., 2016). An assessment is required to analyse cognitions, emotions, and behaviours to arrive at a formulation which is agreed by the client and clinician (Kennerley et al., 2016).

#### Initial Service Assessment

I conducted the initial service assessment via video consultation when the client entered the service in February 2023. Video consultation was used as Bristol M.E. Service mostly operates remotely to prevent further fatigue from travelling to appointments. During this assessment, I reviewed the client's symptom onset and patterns of fatigue. I accounted for other variables such as underlying health conditions, potential trauma, and mental health difficulties to ensure that the fatigue was associated with PCS. The client informed me that prior to contracting covid, they lived an active and healthy lifestyle. Based on the timeline provided by the client, I was confident that the fatigue was associated with PCS. I assessed the impact of fatigue on their daily life and psychological wellbeing (including risk) via open questions during the video consultation. Although they were frustrated and upset about their symptoms of PCS, they felt that their psychological wellbeing was relatively stable, therefore I categorised risk as 'low'. Lastly, the client expressed a preference for 1-to-1 sessions to focus on fatigue management and they opted for these sessions to be in-person.

# Intervention Assessment

In sessions 1 and 2 I conducted a further assessment to formulate an intervention plan. This was informed by a CBT model which assessed predisposing, precipitating and perpetuating factors in relation to the 'problem'. CBT assessment also includes cognitions, emotions, behaviour, and physiological changes (Kennerley et al., 2016). To reduce assessment burden on the client, I used measures that are routinely completed upon referral to Bristol M.E. Service (Table 1). I added an additional measure at the start of session 1 to measure symptom self-efficacy to capture whether they felt able to engage in activities despite their symptoms; further reflecting ability to self-manage and cope.

# Table 1. Assessment Measures

Measures	Rationale	Date Completed	Baseline Assessment Score
Symptom Self Efficacy	Measures self-efficacy to engage in	At the start of session 1.	Total Score
Scale.	various activities despite	Repeated at the end of session	(<20 suggests low self-efficacy
	symptoms. This is a variation of the	6.	>40 = high self-efficacy)
	Pain Self Efficacy Questionnaire		21/60
	(Nicholas, 2007) which has been		
	adapted to include 'symptoms'		
	instead of 'pain', allowing it to be		
	applied in the context of fatigue.		
Subsection of Bristol	Includes numerical rating scales	Upon referral to Bristol M.E.	Effect of fatigue in last 7 days
Rheumatoid Arthritis	asking about impact of fatigue and	Service (prior to initial	(0 = no effect, 10 = a great deal
Fatigue - Numerical Rating	coping with fatigue. The BRAF-	service assessment).	of effect)
Scales Version 2 (BRAF-	NRS V2 has been validated in six	Repeated at the end of session	9/10
NRS V2).	countries (Hewlett et al., 2018).	6.	

			Coping with fatigue
			(0 = very well, 10 = not at all)
			4/10
EQ-5D-5L	Quality of life measure including	Upon referral to Bristol M.E.	Total Score:
	mobility, self-care, usual activities,	Service (prior to initial	(0 = no impact/ problem, 10 =
	pain/discomfort, anxiety/	service assessment).	extreme impact/ problem)
	depression. It demonstrates	Repeated at the end of session	12/25
	excellent psychometric properties	6.	
	across a variety of populations and		NRS health rating
	settings (Feng et al., 2021).		(0 = worst health imaginable,
			100 = best health imaginable)
			30/100
Activity Diary	I gave the client an activity diary to	After session 1.	Patterns identified in diary:
	complete before session 2. It asked		- Some days there were 4-5
	the client to rate the intensity of		hours of consistent medium
	different activities to help us to		or high intensity activity

identify any patterns regarding	without a break, indicating
activities, rest, and fatigue.	a lack of pacing.
	- Boom-bust pattern of
	'pushing' herself to do
	more on days where she
	had more energy and to
	spend time with family.

The scores reported in Table 1 demonstrate that client had relatively low symptom self-efficacy. Although the 'coping with fatigue' score was within the higher half, the EQ-5D-5L and 'effect of fatigue' ratings suggest that fatigue had a significant effect on quality of life. These scores further justified the need for an intervention to focus on improving self-efficacy to manage fatigue and increase coping skills.

## Formulation

Formulation is central to any psychological intervention (Johnstone & Dallos, 2013). It should draw on psychological theory to provide a framework for describing a client's problems, detailing how they developed and how they are maintained (Division of Clinical Psychology, 2010). Formulation should provide a shared rationale and guide for the intervention (Kennerley et al., 2016). A 'five areas model' of formulation was used for the client (Figure 1). This model is derived from CBT, and it highlights important links between cognitive processes, emotional responses, and behaviour (Wright et al., 2002). I opted for this model as it is applicable for health care practitioners and clients in clinical settings (Williams & Whitfield, 2001) and it allows a range of problems to be summarised within a single model; helping to provide a clear intervention focus.


The formulation highlighted that the 'problem' of fatigue and the lack of coping and self-management are perpetuated by a series of unhelpful thoughts such as *"If I do not stay active, I will decondition"* which result in the client overdoing physical and cognitive activity. These thoughts and behaviours trigger a 'boom-bust pattern' which leads to physical reactions including severe fatigue, brain fog and headaches, resulting in frustration, sadness, disappointment, and fear. This maintains the cycle and feeds into thinking and behaviour. From this formulation, it was evident that there needed to be a combination of practical techniques to facilitate self-management, alongside constructs to overcome the psychological factors that were perpetuating the cycle.

#### **Intervention Design:**

To ensure that the intervention was evidence based, the design was informed by the British Association of Clinicians in ME/CFS (BACME) therapy guide (BACME, 2022). Although the guide is designed for ME/CFS, no such guide has been developed for PCS. As several symptoms of PCS overlap with ME/CFS (The ME Association, 2022), the guide seemed appropriate for this intervention. The guide consists of 4 phases for therapy, as shown in Table 2. The guide is not intended to be a fixed process and there is no timescale outlined for each phase, as all clients differ (BACME, 2022). This reflects the principles of Evidence Based Practice (Sackett et al., 1996), whereby patient values are integrated with clinical expertise and evidence from research. Therefore, the guide provided a flexible structure for the work that we would be undertaking around self-management of fatigue.

The formulation demonstrated that there were a series of unhelpful thoughts which influence and are influenced by behaviour. CBT is a 'first wave' psychological therapy, which aims to change thinking and behavioural patterns to improve psychological or physical

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wellbeing (Beck, 2011). It is frequently used in the field of health psychology in treatment of people with a LTC, to help manage distress or improve function in relation to their LTC (Bradley et al., 2003). Evidence from a recent case-study suggests that CBT can be effectively applied for the self-management of long-covid (Skilbeck, 2022). Subsequently, CBT seemed appropriate for this intervention to improve the client's self-efficacy to manage their fatigue and increase their coping skills.

An outline of how the components of the BACME therapy guide and CBT techniques would be applied throughout the sessions can be seen in Table 2.

# Table 2. Outline of Sessions

Session	BACME Phase	Session Focus	CBT Techniques & Intervention
			Tools
1 & 2	Engagement Phase	Assessment and formulation	• Building a therapeutic relationship
	To engage the person in a relationship with the		• Active and reflective listening
	therapist that facilitates collaborative working		• Activity diary
	towards the clients' goals. The client is supported		• Psychoeducation
	through the therapist's expertise to develop self-		• Goal setting
	management skills and make changes that align		
	with their goals.		
3 & 4	Regulating Phase	Fatigue self-management	• Socratic questioning
	To reduce the boom-and-bust pattern through	Activity management	• Client as a co-investigator
	stabilising daily routines and identifying their	Pacing	• Self-monitoring
	'baseline' for activity. This creates a sense of	Coping with fatigue	• Behavioural experiments

control and provides the client with a foundation for		0	SMART goals
improvement.			
Increasing Phase	Fatigue self-management	0	Psychoeducation
To gradually build the level of activity in line with	Increasing activity	0	SMART goals
the client's goals. This could include increasing the		0	Self-monitoring
intensity, frequency, duration, or quality of an			
activity. It is always guided by the client's goals and			
is a gentle incremental approach that supports			
sustainable change.			
Sustaining Phase	Managing setbacks	0	Psychoeducation
To continue improvement regarding the client's	Evaluation and review of	0	Problem solving
goals and working towards an improved quality of	sessions	0	Action plan
life, whilst acknowledging the demands of daily life			
over time.			
	control and provides the client with a foundation for improvement. Increasing Phase To gradually build the level of activity in line with the client's goals. This could include increasing the intensity, frequency, duration, or quality of an activity. It is always guided by the client's goals and is a gentle incremental approach that supports sustainable change. Sustaining Phase To continue improvement regarding the client's goals and working towards an improved quality of life, whilst acknowledging the demands of daily life over time.	control and provides the client with a foundation for improvement.Fatigue self-managementIncreasing PhaseFatigue self-managementTo gradually build the level of activity in line with the client's goals. This could include increasing the intensity, frequency, duration, or quality of an activity. It is always guided by the client's goals and is a gentle incremental approach that supports sustainable change.Managing setbacks Evaluation and review of sessionsSustaining PhaseManaging setbacks evaluation and review of sessions	control and provides the client with a foundation for improvement.oIncreasing PhaseFatigue self-managementoTo gradually build the level of activity in line with the client's goals. This could include increasing the intensity, frequency, duration, or quality of an activity. It is always guided by the client's goals and is a gentle incremental approach that supports sustainable change.oSustaining PhaseManaging setbacksoTo continue improvement regarding the client's goals and working towards an improved quality of life, whilst acknowledging the demands of daily life over time.o

#### **Delivery and Implementation**

The intervention sessions were delivered face-to-face in a clinic room at North Bristol NHS Trust on a Friday morning. The sessions occurred fortnightly and lasted between 45 minutes – 1 hour. By scheduling the sessions fortnightly, it provided sufficient recovery time from attending in-person and allowed the client to engage in homework tasks. The techniques implemented within the intervention are discussed below.

#### Building a Therapeutic Relationship

A therapeutic relationship is imperative for an intervention to be successful (Norcross, 2010; Weck et al., 2015). I ensured that sessions were patient centred by using active and reflective listening skills to explore the client's problems (Fuentes et al., 2014). It was important that I validated their feelings and responded appropriately with empathy via verbal and non-verbal cues to convey understanding of their experiences (Kornhaber et al., 2016). I also shared thinking with the client to encourage their involvement (Kazantzis & Dobson, 2022). For example, I confirmed the five area's formulation (Figure 1) with the client and checked their understanding.

#### Activity Diary

Activity diaries are an important tool for patients living with fatigue as they help identify patterns and triggers for fatigue (Harenwall et al., 2021). The activity diary used within Bristol

M.E. Service asks clients to record all activities (including sleep) for approximately one week and to rate the intensity of activities. I introduced the diary to the client in session one and asked them to complete it for session two. The activity diary was a key component of the 'engagement phase' as it facilitated collaborative working and provided an opportunity for honest reflection. In line with a CBT approach, this homework facilitated self-management by encouraging the client to think about changing their own unhelpful behaviours, such as overdoing activity (Beck et al., 1979; Kazantzis et al., 2010).

#### **Psychoeducation**

Psychoeducation is frequently used within CBT to provide the client with knowledge about their LTC, to empower them and encourage effective coping strategies (Hedman-Lagerlof & Axelsson, 2019). Psychoeducation was first used within the 'engagement phase' to improve the client's understanding of fatigue and to increase their self-efficacy regarding fatigue management. Following completion of the activity diary, education was needed to clarify the meaning of pacing and rest. For instance, the client thought that she was pacing, but upon analysis she was still engaging in low-level activity such as checking her mobile phone during rest breaks. Psychoeducation was used in the 'increasing phase' to provide information about cautiously and incrementally increasing activity. Lastly, it was applied in the 'sustaining phase' to share information about managing setbacks.

#### Socratic Questioning

Socratic questioning was another CBT technique which was used within the 'regulating phase' to better understand the client's beliefs, experiences, priorities, and choices in relation to her fatigue (Kennerley et al., 2016). I asked the client "*what do you think would happen if you stopped trying to protect the people around you and stopped 'pushing through' with activities*". By asking this question, I encouraged her to think about what would happen if she changed her behaviour to have more rests and pace activities. These questions can start to shape behavioural testing and motivate the client to engage in experiments (Kennerley et al., 2016).

#### Behavioural Experiments

Behavioural experiments are thought to be one of the most effective methods for facilitating change in CBT (Bennett-Levy et al., 2004). They allow the client and facilitator to work in collaboration to gather evidence which assesses the validity of the clients' beliefs (Bennett-Levy et al., 2004). The experiment was used within the 'regulating phase' to target unhelpful cognitions that were preventing the client from pacing. The unhelpful cognition identified was "I need to protect my family from seeing the impact of my fatigue". Prior to conducting the experiment, I shared the five areas formulation (Figure 1) with the client to demonstrate the impact that such thoughts have on her behaviour. For instance, the client had noticed that because she wanted to protect her family, she would push herself to get out of bed earlier on the weekend, which had a negative impact on her fatigue throughout the day. By doing this, I communicated my ideas and conclusions to the client and provided a rational behind the decision to do a behavioural experiment, thus creating further motivation for the client to engage. As homework following session 4, the client was tasked with staying in bed later on the weekend to allow time to rest. The client completed the experiment and reflected that her family did not question that she stayed in bed later. This prompted further behaviour changes such as not pushing herself to complete household chores for others.

#### Goal Setting

Goal setting is another valuable technique that is frequently used in health psychology interventions and is recommended as part of self-management for long-covid (NICE, 2021). It is important that goals are SMART: specific, measurable, achievable, realistic, and timely (Kennerley et al., 2016). Goal setting was used at the start of the intervention to engage the client and assure them that the sessions were centred around their goals. It was then used in the 'increasing phase' to facilitate the client to think about how they could gradually increase activity levels. Therefore, I created a SMART goals worksheet for the client to complete as homework. The client completed this in detail and through discussion within the session, the agreed goal was to engage in yoga and/or meditation for 10 minutes, 3 times per week.

#### Action Plans and Problem Solving

Action plans are considered highly valuable in changing health related behaviours (Handley et al., 2006; Wiedemann et al., 2011). An action plan is an agreement between patient and clinician that the patient will make a specific behaviour change (Handley at al., 2006). Action plans were verbally agreed each session and mostly centred around incorporating pacing techniques. They then focused on engaging in physical activity during the 'increasing phase'. Problem solving was another technique that was encouraged within sessions, and it was often applied if the action plan had been unsuccessful. It was particularly important within the 'sustaining phase', to find out how the client would problem solve around any potential setbacks that they might encounter in the future. The client reflected on a setback that she had encountered between sessions 5 and 6 whereby she had caught an infection. She problem-solved around how she could still meet her goals whilst recovering from the infection and decided that instead of pushing herself to practice yoga, she could focus on the meditations instead.

### Evaluation

To evaluate the effectiveness of the intervention, the client repeated the assessment measures at the end of session 6 (Figure 2).

Figure 2. Comparison of Results



The measures show that the symptom self-efficacy score increased by 11 points at the end of session 6, suggesting that there was a moderate increase in self-efficacy. The scores also demonstrate that quality of life slightly improved, with a particular increase in the health rating. However, there were few changes in the fatigue related constructs and the 'coping with fatigue score' did not improve.

Qualitative feedback was gathered from the client in session 6 to evaluate the intervention sessions. The client felt that all sessions were helpful and created a space for honest reflection about her experiences with PCS. The client found the activity diary useful to identify how much rest and activity she was engaging in and trying to change that. Additionally, she felt that the sessions allowed her to focus on re-learning and applying skills like pacing, resting and meditation and the sessions acted as a reminder that these tools should be used consistently. This suggests that the psychoeducation was a particularly valuable component of the sessions.

It was evident that self-management of fatigue improved throughout the sessions as the client informed me that she incorporated daily guided meditations to ensure she was having real rests. Additionally, the client reported that instead of 'pushing through' and perpetuating the boom-bust pattern, they had used alarms to take regular rest breaks throughout the day. This suggests that the CBT components such as the Socratic methods and behavioural experiment successfully led to behaviour change regarding pacing activities.

Psychological change was also demonstrated as the client reported that she felt more positive about her situation. Additionally, within the final session the client demonstrated ability to cope with setbacks and there was a psychological shift in recognising that setbacks will not last forever, whereas previously a setback would have potentially triggered catastrophic thinking patterns. The client demonstrated more acceptance of fatigue towards the end of the intervention by letting go of the idea that she needed to return to work to feel valuable. Lastly, the client highlighted that the sessions empowered her and gave her the confidence to try new things. I asked the client if there were any aspects of the intervention that she did not find helpful, but she felt that it was all useful.

#### Summary:

This proved to be a valuable intervention to improve self-management and coping in someone experiencing fatigue as part of PCS. The outcome measures showed moderate improvements in symptom self-efficacy and marginal improvements in quality of life. Although there was no change in the 'coping with fatigue' measure, qualitative feedback suggested that the client's ability to self-manage and cope with the fatigue did improve across the course of the intervention and both psychological and behavioural changes were demonstrated.

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#### 6.2. Individual Face-to-Face Intervention Commentary

#### Description

This report includes a reflective commentary on the face-to-face intervention that I designed and delivered with a client experiencing fatigue as part of Post Covid-19 Syndrome (PCS) within my placement at Bristol M.E. Service. In this report I use Gibbs (1988) reflective cycle to guide the reflections. As detailed in the case study, the intervention aimed to improve the client's self-efficacy to self-manage their fatigue and increase their coping skills. It also aimed to improve quality of life and reduce the impact of fatigue. The intervention included six sessions which occurred fortnightly.

#### Feelings

Initially I felt nervous to deliver an in-person intervention, as most of my experience has involved remote working. Additionally, prior to my role at Bristol M.E. Service I have had limited clinical experience; therefore, it was difficult to avoid feelings of imposter syndrome whilst delivering the intervention (Jones & Thompson, 2017). Although I recently gained level two accreditation in Cognitive Behavioural Therapy (CBT), I was still relatively new to using it. Similarly, the training I completed was not tailored to health psychology, so I was apprehensive about applying CBT to a patient experiencing PCS. Upon reflection, I became more relaxed as sessions progressed and rapport had been established. I could also feel my confidence grow regarding CBT and delivering the sessions in person. I think that these skills and techniques are something that will continue to grow with experience.

#### **Evaluation and Analysis**

#### Successes

As outlined in the case study, the assessment surveys indicated that the intervention moderately improved self-efficacy to manage fatigue. Quality of life also improved following the intervention sessions, and this was further supported by qualitative feedback provided by the client as they reported that the intervention empowered them to try new things. Although the 'coping with fatigue' score did not change, qualitative feedback suggested that the client felt more able to cope with their fatigue.

The client and I developed a positive rapport from the first session, which helped to build the therapeutic alliance that was needed for us to work in collaboration. As the sessions progressed, the client became more honest about how she was feeling, which implied that she felt it was a safe environment to disclose her thoughts. Although the client reported that she felt fatigued following our sessions, she continued to attend in-person, suggesting that she found them valuable. The client was receptive to activities throughout sessions, and she consistently completed homework, which further demonstrates a willingness to change.

Another successful part of the intervention was the assessment and formulation. The five areas formulation was clearly presented and easy to interpret, which meant I was able to share it with the client within sessions. This demonstrates that I was confident in my ability to formulate, and it was also an effective tool to encourage participation in the behavioural experiment. By involving the client in the formulation, it further facilitated collaborative problem solving. For example, when the client identified barriers that prevented her from effectively pacing, I drew on her experience as a nurse and asked what she would suggest if this was her patient.

Throughout this intervention, behaviour change was successfully demonstrated by the client as they incorporated rest breaks into their routine and effectively paced activities. I think that this change was prompted by the Socratic questioning and the behavioural experiment, as they encouraged the client to test new behaviours. The SMART goals also encouraged behaviour change, as the client successfully engaged in gentle yoga or meditation 3 times per week. Moreover, the psychoeducation helped facilitate this change as the client approached activity in a flexible manner and understood that 'pushing through' or wanting to increase the amount of the yoga could have negative consequences if it was not approached with caution. I feel that these successes were a huge achievement, and I am proud of the progress that was made. It has increased my confidence regarding designing and delivering face-to-face health psychology interventions and I am looking forward to having the opportunity to deliver more in the future.

#### Challenges and Areas for Improvement

One of the main challenges with the face-to-face case study was identifying a suitable client for an in-person intervention. For individuals experiencing PCS or Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), exerting energy to travel to an inperson appointment could exacerbate their symptoms. Additionally, the hospital environment may provoke anxiety surrounding catching infections as they could potentially trigger setbacks. Therefore, it is important that they are given the option of a remote appointment (NICE, 2021). Many clients who enter Bristol M.E. Service prefer telephone or video appointments for this reason. This also reflects services post pandemic, as many now offer remote appointments to provide more flexibility (D'Anza & Pronovost, 2022). Based on this, it was difficult to identify an appropriate client who could commit to attending a block of sessions in-person.

One area that I need to develop further within my face-to-face interventions is allowing the client to have time to answer the question, as I often filled the silence or provided potential answers. Silence can be important within interventions, particularly when problem solving, as it can encourage reflection, responsibility, and expression of feelings from the client (Hill et al., 2003). This was highlighted to me by my supervisor when I was being observed with another client and we reflected in supervision about why this was occurring. I think one reason that this happened was due to my limited experience in delivering face-to-face interventions and my lack of judgement about how much thinking time the client required. Furthermore, my own nerves would often lead me to want to fill the silence or provide example answers. Once I became aware of this, I made a conscious effort to give the client time to think. Alternatively, if the client struggled to answer I would reflect this back to them or I would ask the question in another way.

I think that the intervention would have been more effective if it had more sessions. I opted for six-sessions as it has a sufficient evidence base (NHS, 2022) and as the sessions took place fortnightly, it meant that the total intervention length was 12 weeks. However, the first two sessions were used for the assessment and formulation, which only left 4 sessions to focus on the remaining three phases of the British Association of Clinicians in ME/CFS therapy guide (BACME, 2022). Upon reflection, it seemed ambitious for me to try and fit all four phases of this guide into six-sessions, particularly as the guide is meant to be used flexibly. This meant that most of the intervention was spent focusing on the regulating phase and I was only able to briefly touch on the increasing phase in the final two sessions. We were able to address this in session 6

as I conducted a review with the client. We agreed to continue our face-to-face work, with the focus shifting to increasing activity.

#### Conclusions

There are several learning points that I have been able to take away from this face-to-face intervention. This intervention further demonstrated the importance of the therapeutic relationship and had this not been developed, the client might not have engaged the way that she did. I also learnt that the client's own readiness to change their cognitions and behaviour can play a huge role in the success of the intervention. In this instance, the client showed a willingness to change as they were extremely receptive to activities, homework and were open and honest throughout. However, not all client's may be ready for change to take place and that could influence the outcome of the intervention. Although my confidence has grown, I feel that I could develop my clinical skills further, particularly surrounding the application of CBT methodology and being more comfortable with silence in sessions. However, this is something that will improve as my experience grows. Another thing I have learnt is to not overestimate how much I can fit into six sessions, particularly if the first two are used for the assessment and formulation.

#### **Action Plan**

For future face-to-face interventions, I would use a similar approach as detailed in the case study to build a therapeutic relationship as it worked well. I would also use a CBT assessment and the five areas formulation again, as I think they contributed to the success of this

intervention. Nevertheless, there are still some clinical skills that need to be developed through delivering more face-to-face interventions. To ensure that I develop these clinical skills, I will engage in regular reflective practice and hold myself accountable if things do not go to plan. Lastly, I would plan for future interventions to have more sessions to allow enough time to focus on the client's goals, especially as Bristol M.E. Service is able to offer clients as many sessions as required.

Overall, I think that this was a great learning experience for me to apply health psychology theory into practice within an NHS setting.

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#### 6.3. Group or Remotely Delivered Intervention Case Study

This case study outlines my experience of designing, delivering, and evaluating an online group intervention to increase uptake of cervical cancer screening. The intervention was a piece of consultancy work for a public health team within a city council.

#### Introduction

In the UK, cervical cancer is the 14<sup>th</sup> most common cancer in females, with approximately 3200 new cases every year (Cancer Research UK, 2018). Cervical screening is routinely offered to women aged between 25 and 64 years in England and can significantly reduce the incidence of cervical cancer (Baker & Middleton, 2003). Individuals who do not attend cervical screening appointments are at higher risk of developing cervical cancer (Szarewski et al., 2011). In Wolverhampton, cervical cancer screening was at 65.1% in 2020-2021, which is lower than cervical screening in England (69.1%) (Office for Health Improvement and Disparities, 2022). Therefore, I conducted a group intervention to increase uptake of cervical screening within a group of women in Wolverhampton.

#### Recruitment

Recruitment for the intervention was undertaken by the public health team at the council. Following requests from a local GP practice, the intervention originally planned to target Eastern European females, as cervical screening was particularly low within this group. I aimed for a group size of 10 individuals, as 6-9 is generally recommended and it would also account for any attrition (Whitaker, 2003). The public health team promoted the intervention across multiple communication channels, including text messages from a local GP practice, but nobody signed up. Therefore, the criteria were broadened to include any females in Wolverhampton who had not attending cervical screening. A member of the outreach team promoted the intervention through community contacts, which resulted in nine individuals signing up to the intervention (Table 1).

#### Table 1. Uptake of Sessions

Session	Attendance
Session 1	9 (8 live and 1 recorded)
Session 2	7
Session 3	6
Session 4	6

#### Assessment

Assessment is an essential component of psychological interventions. To design an intervention, there needs to be an analysis of the behaviour and the mechanism's that need to be altered to create the behaviour change (Michie et al., 2011). Health needs assessments can involve adapting and transferring knowledge that is already available (Wright et al., 1998). Therefore, a literature review was conducted to detect barriers and facilitators to cervical screening among different groups within the UK. The COM-B model (Michie et al., 2011) can be used to identify specific barriers to cervical screening uptake (O'Donovan et al., 2021), as it

proposes that there are three essential conditions required for behaviour change: capability, opportunity, and motivation. I utilised the COM-B model of behaviour change as an assessment framework, as it also reflects the cognitive, emotional, and behavioural process that may need addressing in an intervention.

To conduct a health assessment, qualitative and quantitative methods should be used to collect original data and should be tailored to the target population (Wright, et al., 1998). Whilst recruitment for the intervention was ongoing, the assessment was going to be conducted via focus groups led by the public health team, using questions informed by the COM-B framework. However, focus groups were unsuccessful as only two individuals participated. Nevertheless, a survey including similar questions to the focus groups was administered across Wolverhampton. Survey respondents were recruited via the council's social media platforms and newsletters. Additionally, the survey was circulated to local GP practices to be promoted. In total, 57 females completed this survey. The demographic information for the survey sample is displayed in Table 2.

Characteristic		Ν	%	
Attend	Attended cervical screening			
(Last 3	(Last 3-5 yrs.)			
	Yes	52	91.23%	
	No	5	8.77%	
Age				
	16-24	3	5.26%	
	25-34	14	24.56%	
	35-44	18	31.58%	
	45-54	11	19.30%	
	55-64	9	15.79%	
	65 or over	1	1.75%	
	Prefer not to say	1	1.75%	
Ethnicity				
	White British	41	71.93%	
	Asian/ Asian British	5	8.77%	
	Mixed Ethnicity	4	7.02%	
	White Other	3	5.26%	
	Black/Black British	2	3.51%	
	Preferred not to say	2	3.51%	
Sexual Orientation				
	Heterosexual	35	61.40%	

# Table 2. Survey Demographic Information

Lesbian	5	8.77%
ıal	12	21.05%
	2	3.51%
not to say	3	5.26%
	esbian Ial not to say	Lesbian5Ial1222not to say3

As the intervention group had not been recruited at this stage, the survey provided an initial assessment of the wider female population and the demographic information highlight that the sample was representative of Wolverhampton's population (Office for National Statistics (ONS), 2021). Once the intervention group had been recruited, it appeared that at surface level the survey sample was reflective of the intervention group, which included women aged 18-65 and was ethnically diverse. However, demographic data was not formally collected for the intervention group regarding age, ethnicity, or sexual orientation. Upon reflection, this information would have provided valuable insights regarding the effectiveness of the intervention for specific demographic groups. Therefore, I will ensure to collect such data for future interventions.

I also designed a baseline survey for the intervention group, which was sent out before session 1. This survey assessed capability, opportunity, and motivation to attend cervical screening and included a validated self-efficacy questionnaire (Fernandez et al., 2009) to help ascertain physical capability, by asking questions regarding scheduling and attending screening appointments. Only five individuals completed this survey and all stated that they had previously attended cervical screening. Due to the low uptake, I assessed individuals via interactive activities in session 1, including Menti-Meter questions such as "what is the purpose of cervical cancer screening?", allowing individuals to provide anonymous responses.

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A second survey was sent out at the end of session 1 which 8 out of 9 women completed: providing a more comprehensive overview of the group. It showed that although some individuals had previously attended screening, several had not attended their most recent appointment. Therefore, the intervention would be beneficial to maintain or increase attendance. There were clear similarities between these findings and the wider survey in Wolverhampton, as both samples showed a clear lack of understanding of cervical screening. However, there were noticeable differences too, as the wider survey highlighted that embarrassment was a clear barrier to attending screening, yet this was not the case for the intervention group. This highlights that although the wider survey initially guided the intervention, the content required further tailoring to the specific needs of the intervention group.

#### Formulation

Formulation provides an in depth understanding of a client or group, which is used to develop a treatment plan (Selzer & Ellen, 2014). Formulation combines the client's difficulties and impacting factors in a systematic way, incorporating theory, models, and evidence for the individual (Dale & Bull, 2021). While recruitment for the group intervention was ongoing, I formulated an intervention plan based on the literature review and wider survey, which are discussed in turn below.

#### Literature Review Findings

The literature review illustrated that over half of Wolverhampton's population (54%) were living in the most deprived areas of England (ONS, 2011). Wolverhampton is also an

ethnically diverse city, as 18% are Asian, 6.9% are Black and 5.1% are Mixed ethnicity (ONS, 2011) and these demographics are likely to have an influential role on the uptake of cervical screening (Abdullahi et al., 2009; Karbani et al., 2011; Marlow et al., 2019; Thomas et al., 2005). The literature highlighted that woman across different groups experienced emotional, practical, and cognitive barriers to cervical cancer screening. For instance, emotional barriers included fear and embarrassment surrounding cervical screening (Healthwatch Wolverhampton, 2020; Logan & Mcilfatrick, 2011). Practical barriers comprised of appointment times and inconvenient locations (Logan & Mcilfatrick, 2011; Marlow et al., 2019), whereas cognitive barriers refer to a lack of knowledge regarding cervical screening (Lovell et al., 2021; Thomas et al., 2005).

#### Survey Findings (Wolverhampton Residents)

An overview of the barriers, facilitators and recommendations identified in the survey can be seen in Table 3. The recommendation section consists of quotes provided in response to open questions on the survey.

#### Table 3. Survey Findings

Barriers
Lack of understanding - 52% believed the purpose of cervical screening was to detect cancer
or cancerous cells
21% reported negative experiences including it being pointless, undignified, embarrassing or
extremely painful
Unable to book appointments and inconvenient appointment times

Lack of information in different languages including sign language

## **Facilitators**

50% reported positive experiences of cervical screening – it was 'quick and easy'

Peace of mind

Early detection and intervention

Maintaining health

Fear of cancer

Family history

Celebrity stories in the media

## **Recommendations**

"Making sure that language is inclusive of everyone who has a cervix"

"Sending reminder letters to patients in their own language would be helpful"

"More advertising and more information"

"More appointments available at the doctors, more receptionists to answer the phone"

From the literature review and survey findings, a six-week intervention was formulated, which was based on previous literature evidencing that six-weeks is an appropriate length for a behaviour change intervention (Alageel et al., 2017). Wearn (2020) emphasised that the Behaviour Change Wheel can be used to develop intervention strategies that are likely to be effective in addressing socioeconomic inequalities in cervical cancer screening. Therefore, a plan for the sessions was devised, which highlighted the behaviour change techniques (BCTs) that would be used to increase capability, opportunity, and motivation to attend cervical screening (Table 4).

 Table 4. Preliminary Intervention Plan

# WEEK SESSION PLAN TARGET BEHAVIOUR CHANGE TECHNIQUES

1	Assessment and		
	introduction		
2	Psychoeducation –	Improve knowledge and	Health consequences
	what is cervical	understanding to increase	
	cancer & cervical	psychological capability	
	screening	and motivation	
3	Psychoeducation	Reduce stigma to increase	Modelling
	using relatable stories	psychological capability	
		and motivation	
4	Goal setting session	Reduce practical barriers	Goal setting
	and problem-solving	and increase opportunity	Problem solving
	homework		
5	Action planning	Increase opportunity and	Action Planning
	session	motivation	
6	Summary and debrief		

After further consideration of the target group, it seemed unlikely that they would attend sessions for six weeks, as they were unable to attend a one-off screening appointment. Instead, four sessions seemed more appropriate as it would provide enough time to cover the content yet having fewer sessions would make attendance more achievable. Additionally, there is still a sufficient evidence base for a four-week intervention (Fillion et al., 2008). Subsequently the sixweek plan was condensed into four weeks whereby some of the activities would be given to the group as homework instead. I created an intervention booklet that mirrored this plan.

Once the group was recruited and the baseline survey responses had been received, I calculated the mean scores for the capability, opportunity, and motivation. It appeared that the group had high levels of self-efficacy (physical capability), opportunity and motivation to attend cervical screening. However, they had poor knowledge regarding the purpose of cervical screening and risk factors for cervical cancer, indicating that they had low psychological capability. This suggests that the group had low health literacy, which reflects their ability to obtain, process and understand information that are needed to make health decisions. Previous literature has highlighted that low health literacy is associated with poorer use of health care services and poorer health outcomes (Berkman et al., 2011).

These findings differed to the literature review and the subsequent formulation. The literature review suggested that there are emotional, practical, and cognitive barriers to cervical screening. The baseline survey on the other hand, highlighted that the most common barriers were cognitive but there were very few practical or emotional barriers. This shows that it is important to tailor the intervention to the target group so that it is meaningful to them. Therefore, I continually assessed individuals throughout session 1 and again at the end of the session via a

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second survey. The results from this second survey, showed that even after attending one educational session, there was still poor understanding of cervical screening. Consequently, I reformulated the intervention to primarily have an educational focus. Throughout the reformulation process I had continuous communication with the behaviour change specialist at the council, who had better insights regarding public health interventions and was able to provide support and feedback.

#### **The Intervention**

#### Intervention Design

As part of the design process, I identified appropriate intervention functions from the behaviour change wheel (Michie et al., 2014) and BCTs from the behaviour change taxonomy (Michie et al., 2013). A prominent BCT that was used throughout sessions to increase psychological capability was 'behavioural practice and rehearsal', which was encouraged through homework tasks and group activities. For group activities, I initially opted for platforms such as Menti-Meter and Padlet so that individuals could provide anonymous responses, allowing the group to be open without feeling embarrassed. However, I also wanted to utilise the group format to encourage knowledge transfer, so I incorporated group discussions in later sessions once the group had settled in (Lenz et al., 2015). The target and contents of each session can be seen in Table 5.

WEEK	TARGET FROM	TOPICS	TOOLS & TASKS	INTERVENTION	<b>BEHAVIOUR CHANGE</b>
	NEEDS	COVERED		FUNCTION	TECHNIQUE
	ASSESSMENT				
ONE	Continue	• Purpose of	• Menti-Meter activities	• Education	Information about
	assessment with	cervical	• Video from Jo's Cervical	• Persuasion	health consequences
	group	screening	Cancer Trust	• Modelling	• Demonstration of the
	• Increase knowledge	• What is cervical	• Talk to a friend or family		behaviour (modelling
	and understanding	screening & who	about something new		via video)
	(psychological	is invited	you learnt about cervical		Behavioural practice/
	capability)	• Risk factors for	screening		rehearsal
	• Highlight	cervical cancer	• Supplementary leaflet		
	opportunities	• What is HPV	(homework)		
	Increase motivation		• End of session survey		

TWO	• Assess change in	• Recap of what	Padlet Tasks     Education	Behavioural practice/
	psychological	cervical	Group discussion     Modelling	rehearsal
	capability	screening is	• Repeat homework task to	• Identification of self as
	• Reduce barriers	• Recap of HPV	talk to someone else	a role model –
	• Increase motivation	• Barriers and	about cervical screening	encouraging others to
		facilitators to	Feedback survey	attend screening
		attend cervical		
		screening		
THREE	• Continue to	• Reduce stigma	• Revised leaflet shown in • Education	Behavioural practice/
	increase	and spread	session • Modelling	rehearsal
	psychological	awareness	• True or false activity	• Credible source –
	capability	• Symptoms of	• Video	public health England
	• Increase motivation	HPV and	• Public health England	• Demonstration of the
		cervical cancer	resource	behaviour (modelling
			Motivational messaging	via video)

# FOUR

Increase capability
 Recap of

- Motivational messaging Education
- Increase everything opportunity covered
- Group discussion
- End of intervention

survey

- Increase motivation Q & A
  - Focus on risk

    - factors for
    - cervical
    - screening

- Behavioural practice/
  - rehearsal

#### *Implementation & Delivery*

The intervention sessions were delivered via Zoom once a week for four weeks. PowerPoint slides were developed to aid each session and a supplementary leaflet was provided, so that the key information was provided in a written format that individuals could refer to and share with others. The online format and using Zoom were decided by the public health team, and it reflects the public demand for increasing online health resources (Griffiths et al., 2006). There are unique benefits to delivering intervention sessions within a group, such as learning from one another and providing social support (Turk & Gatchel, 2018). However, it was imperative that I remained mindful of the group dynamics, as there can be disadvantages of group settings such confrontation or interruptions (MacNair-Semands, 2002), which could occur more frequently in online sessions (Griffiths et al., 2006). Therefore, I started the first session with some ground rules using the acronym 'ABC', which represented 'Active participation, Be respectful, Confidentiality'.

As the sessions were delivered online, it was important that I built a therapeutic relationship with the group from the offset (Hilton & Johnston, 2017). To facilitate this, I planned to start with an ice breaker activity, but due to some technical difficulties and late arrivals I decided to skip it and proceed with the session. To ensure I was still able to develop a therapeutic relationship, I focused on building group cohesion, showing empathy, and listening to client feedback (Norcross & Wampold, 2011). Within the feedback, I was informed that the leaflet included too much information, which resulted in the group not reading it. Therefore, I updated it to only include essential information and have more images. The revised leaflet was positively received by the group and demonstrated the importance of listening to feedback.

The group were quiet to start, but as the sessions progressed the group engaged well and created a friendly atmosphere. I was flexible in the delivery of the session content as things did not always go to plan. For example, nobody completed the homework for session 1, which was to speak with friends or family about cervical screening. Instead of giving up, in session 2 I tasked them with trying to complete the homework again. This time, I applied the BCT of modelling to explain that I had set this homework so that they could be role models by demonstrating the importance of cervical screening to others. This was in line with a collaborative intervention approach, as I shared the formulation with the group which then prompted action. I was pleasantly surprised in session 3, to hear that everyone had completed the homework and were all willing to share their experiences. This highlighted that patience and perseverance were required when delivering the intervention.

#### Evaluation

The intervention was evaluated through a series of surveys that were administered throughout the intervention. It was not possible to evaluate whether the intervention directly increased uptake in cervical screening, therefore, I measured their intentions to attend future screening appointments. The results from the assessment surveys can be seen in Table 6. Unfortunately, only one individual completed the survey at six-week follow up, so their results were not included as they were not reflective of the wider group.

# **Table 6.** Assessment Survey Results

	Number of survey responses	Knowledge rating (Mean)	Knowledge test (Mean percentage correct)	Self-efficacy (Mean)	Motivation rating (Mean)	Likelihood to throw away invitation (Mean)	Barriers (Mean)
Survey 1 (Baseline)	5	5/10	74%	31.25/35	8.3/10	1/10	11/30
Survey 2 (End of session 1)	8	6/10	83%	30.57/35	8.7/10	1.4/10	13/30
Survey 3 (End of session 4)	6	9/10	100%	32.9/35	10/10	0.8/10	9.4/30

The survey results show that knowledge surrounding cervical screening increased across the four sessions, implying that psychological capability successfully improved. Additionally, open responses in survey 1 and 2 highlighted that the group misunderstood the purpose of cervical screening. However, by survey 3 all responses regarding the purpose of cervical screening and risk factors were correct, suggesting that attitudes and beliefs about cervical screening also changed. It is interesting to note that self-efficacy decreased following session 1, however this could be because there were more completers for survey 2 compared to survey 1.

Motivation to attend cervical screening was already high at baseline, as the mean score for these questions was 8.3/10. However, motivation continued to increase throughout the sessions, as demonstrated in Table 6. At baseline individuals reported regular opportunities to attend cervical screening, yet multiple barriers were specified including lack of information and difficulty obtaining an appointment. Open responses in survey 3 suggested that barriers were reduced across the sessions, for instance "I can't see any [barriers] now that I am well informed". However, some barriers were reported in survey 3, including "not getting an appointment". Practical barriers such as this were difficult to address within this intervention, and it highlights that it is not possible to resolve all barriers by changing individual behaviours.

Survey 1 highlighted that few individuals within the group would throw away their invitation letter, and this decreased further by the end of session 4; suggesting actions also improved. Lastly, individuals who attended all sessions reported that they intended to go to their next screening appointment, which implied that the intervention increased intentions for cervical screening. Overall, these findings show that the intervention successfully increased capability, opportunity, and motivation to attend cervical screening. The largest increase was in knowledge and understanding of cervical screening following attendance at all four

sessions. Nonetheless, as only one person completed the 6-week follow up survey, it is unclear whether these increases were maintained.

The group also completed open questions after sessions 2 and 4 to provide qualitative feedback. Individual's responses varied, with some expressing that the most useful part of the sessions was sharing their own experiences and listening to others, learning about HPV and being aware of the purpose of cervical screening. This emphasised that although it was a group intervention, individuals valued different aspects that were important to their own needs. Regarding improvements, the most common response was to have longer sessions and more time for questions. Other feedback included delivering the sessions in person to help motivate individuals to travel to their screening appointments. There was also the option to provide any other feedback, and this was extremely positive with individuals expressing thanks and stating that the sessions were useful and well needed.

I communicated the outcomes of this group intervention to the public health team through an evaluative report which included findings from the intervention, a section on lessons learnt and future recommendations. This intervention is now being used by the council and has been shared with a local NHS Integrated Care Board to inform future cancer screening initiatives.

### **Summary**

Despite the initial barriers recruiting and assessing the target group, this was the first online, group intervention of this kind in the UK that aimed to increase uptake of cervical cancer screening. The survey findings showed that there were modest improvements following one session, yet there were substantial improvements following attendance at all four sessions. However, some practical barriers regarding appointments times were not

overcome. Similarly, women who attended the intervention sessions recommended having regular reminders from the GP regarding cervical screening to increase motivation; however, this was beyond the scope of this intervention. Overall, this experience highlighted the importance of assessment, formulation and acting on feedback throughout the intervention process to ensure that it successfully meeting the needs of the group.

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#### 6.4. Group or Remotely Delivered Intervention Commentary

#### Overview

Reflection is an important component of training, particularly when designing and delivering psychological interventions (Lilienfeld & Basterfield, 2020). In this report I reflect on the group intervention that I designed and delivered to increase uptake of cervical screening in Wolverhampton. Initially I was apprehensive about conducting a group intervention for a city council, as working in public health was a new experience for me. Nevertheless, this experience was extremely valuable as it allowed me to develop new skills and apply health psychology in a different setting. A reflective commentary for the delivery of the intervention is detailed below which is informed by Gibbs reflective cycle (Gibbs, 1988).

#### **Successes**

As outlined in the case study, the assessment surveys suggested that the groups needs were met throughout the sessions, as their capability, opportunity, and motivation to attend cervical screening increased. Although there was some attrition throughout the sessions, 6 out of 9 individuals attended all four sessions, which implies that the group found the sessions interesting and beneficial as they continued to attend. The qualitative evaluation forms also highlighted that the group sessions were well received by attendees, and they left positive feedback including that "it was very useful" and was "well needed".

One strength of the intervention delivery was that I used a flexible approach and listened to feedback. I reflected on action (Schon, 1991) within sessions, adapting them as required. For example, in session two I had planned to do 'true or false' questions based on

the leaflet that I sent out. However, when I asked the group about the leaflet, they informed me that they had not read it as it was overloaded with information. Therefore, I decided to postpone 'true or false' until the following week, meaning that we could focus on more valuable content. Based on the group's comments, I edited the leaflet, and the revised version was well received. This underlined the importance of piloting materials with the target audience to ensure that they are accessible. Feedback for the overall intervention included: "excellent sessions; feedback taken on board" suggesting that the group appreciated that I listened to them and applied their feedback throughout.

As the weeks progressed, the attendees and I became more comfortable with one another and engagement within the sessions increased. I felt as though my confidence grew with each session and I was guided by the group regarding the type of tasks to include. For instance, I included tasks on Menti-Meter and Padlet as I thought the group would prefer the anonymity they provided. However, by session 2 I realised that these tasks required a lot of explanation and were taking up time. I recognised that these tasks were challenging for individuals who were using their phone for the sessions as it meant they were unable to view the two screens simultaneously. Going forward, I included group discussions or tasks where individuals could type their answers in the chat box on zoom. This worked well and taught me that sometimes keeping it simple can be more effective.

#### Challenges

I found the assessment and formulation stage particularly challenging and consequently this had an impact on the intervention delivery. The council expressed that focus groups would be used to design the intervention; however, this was unsuccessful due to lack of participants. Upon reflection, focus groups were not the most appropriate assessment method, as they did not directly assess the intervention group and subsequently the assessment needed repeating. To assess the intervention group, I sent a survey out via email to be completed prior to session one. Despite sending reminder emails, only five out of nine individuals completed the assessment survey. This highlighted the challenges of delivering online sessions with members of the public, as they may not check emails regularly and could lack time or motivation to complete such surveys. As detailed in the case study, although I used the literature review and broader survey to assess and formulate on a population level, when I assessed the intervention group, different needs were identified to what had been found previously and the intervention needed reformulating. Specifically, there were differences in the barriers that the intervention group faced compared to the wider survey sample. It is difficult to know why there were differences, particularly because demographic data was not formally collected for the intervention group. Subsequently, it would have been useful to have these insights to see if any differences in demographics reflected the different barriers and next time, I will ensure such data is collected. Nevertheless, it highlights that when working with a subsection of a community or population, their needs could differ or be more specific than at a population level. It was also challenging to formulate and design the intervention without having met the group first, as I did not know what their group characteristics would be like. Therefore, in the future I would instead have an 'assessment session' with the target intervention group prior to the first session.

There were also some technical challenges that I had to overcome when delivering the intervention sessions. In session one, some people arrived 10 minutes late, meaning that the session was disrupted and started later than planned. Additionally, the council required the sessions to be delivered via Zoom, but as they did not have a licence the zoom session would only last for 40 minutes. As I began the session late it expired mid-way through, and everyone had to re-join. I finished the session feeling like it had been unsuccessful, and I was

worried that the group would not return the next week. I relayed the issues regarding Zoom back to the council, but it was not possible to obtain a licence. I had to be meticulous in my time keeping going forward and it meant that I would have to start on time regardless of late arrivals. After further reflection, I realised that I had tried to include too much content into the first session. Therefore, I reduced the amount of content in subsequent sessions to prevent me from running out of time. This approach was successful, and I received feedback from one attendee who explained that they preferred the session as it was not as overloaded with information. Therefore, in the future I will ensure that sessions do not contain too much information.

I also found it difficult to deliver the session whilst trying to oversee the logistical side. I raised this with the council and a member of their team was able to help with the administrative tasks going forward. Having this additional support was very beneficial, particularly as they already had good rapport with the group from working with them in the community previously. They were also able to send WhatsApp reminders for the group to complete any surveys or homework. This was particularly successful, as uptake in survey responses improved following the first session. This taught me that at least two members of staff are required for group interventions to run smoothly, particularly for online sessions where there are technological factors to consider.

## Areas for Improvement

There were some elements of the intervention that could be improved further. Group feedback stated that the sessions would be improved if they were longer, particularly so there could be more time for discussions and questions. I had originally planned for the sessions to be for one-hour, but the council thought that people would not attend the sessions for that long, so I changed them to 30-45 minutes. Additionally, as zoom was limited to 40-minutes, it was not possible to have longer sessions. However, for future group interventions I would increase the length to one hour to allow more time for group interactions, as they are an important component of group interventions (Lenz et al., 2015).

Additionally, in feedback from the group one attendee asked whether it would be possible for the intervention slides to be shared, so that they could pass on information to their communities. Reflecting now, one way I could have improved the sessions would have been by creating a session summary that could have been circulated to the group after the session. This way the group would have had written information that they could take away from the sessions to share with their communities. The reminder of the session may have also prompted future behaviour by utilising the behaviour change technique of prompts and cues.

# **Summary**

Considering that this was the first time that a group intervention of this nature had been conducted for cervical cancer screening, I think that it was both successful and insightful. After the initial technical difficulties experienced in the first session, my confidence increased, and I gained a lot of valuable skills. The intervention is now being used to inform bowel cancer screening initiatives within the council and the intervention pack that I created has also been passed on to a local NHS Integrated Care Board that are also working on increasing cervical cancer screening.

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