A feasibility study for a randomised control trial on the effects of engagement with a dental anxiety online peer support group

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Abstract

The study presented in this thesis aimed to evaluate the feasibility of a Randomised Control Trial (RCT) on the effects of engagement with a Dental Anxiety (DA) Online Support Group (OSG) in an adult population. The purpose of a feasibility study is to ascertain whether an RCT should be conducted, can be conducted, and if so, how it should be conducted.

Background

DA is a common phenomenon, with an estimated 54% of the population in England reporting moderate to extreme anxiety. It is a condition that is more likely to affect women, younger adults and people from lower socio-economic backgrounds. DA can lead to avoidance of routine dental appointments, shame and stigma, and poorer oral health outcomes, and this cycle can be self-perpetuating. There is evidence that the impact of DA can be wide-ranging, negatively affecting self-esteem, health-related quality of life, eating habits and even relationships. DA often starts in childhood and a variety of exogenic and endogenic factors have been suggested as potential causes. Ways of managing DA currently include pharmacological (for example sedation or analgesia) and psychological therapies (for example hypnosis or cognitive behavioural therapy). However, pharmacological therapies only address the symptoms and access to psychological therapies is limited.

In the context of healthcare, OSGs are virtual communities, often focused on a specific condition or illness, where peers can share their lived experience, exchange information, provide and receive both emotional and practical support. OSGs can use a variety of platforms (for example chat rooms, discussion forums or social media sites) and can be either synchronous or asynchronous, moderated or unmoderated. People who live with conditions that are rare or that carry stigma are more likely to be motivated to join an OSG, and the anonymous nature of OSGs may encourage disclosure. Most OSG users are readers (commonly referred to as lurkers in the literature) rather than active posters. Some of the potential negatives of OSGs are misinformation, negative content and negative online behaviours. There is

some evidence that OSGs can support behaviour change and therefore promote health outcomes, however much of that evidence is qualitative, based on a self-selecting population of existing OSG users, or has methodological issues.

Systematic Review

Systematic reviews can help assess whether an RCT should be carried out on a specific topic. Therefore, a qualitative systematic review was conducted in accordance with JBI methodology to explore the experiences of users of OSGs for adults living with DA. Rigorous searches were conducted across seven databases but yielded only 2 papers. This limited number of papers shows that OSGs for DA are an under-researched area. Both studies were considered of sufficient quality to be included in the review but had some methodological limitations. Meta-aggregation led to five synthesised findings, most of which were rated as moderately dependable. These synthesised findings indicate that participation in an OSG can be a positive experience for adults with DA and help bring about positive cognitive and behavioural changes.

Methodology

Pragmatism is the chosen paradigm for this feasibility study, along with a concurrent mixed-methods design (where qualitative and quantitative data are collected in parallel) as this reflects the complexity of the topic and allows participants' perspectives to be considered. Both pragmatism and mixed methods are well-suited to a feasibility study.

The protocol was developed with input from a Patient and Public Involvement (PPI) focus group and panel, who provided input on their lived experience of DA and who gave feedback on a draft protocol as well as on the participant-facing materials (e.g. advert, questionnaire, participant information sheet). Their input was taken forward and shaped the final protocol that was granted approval by the University of Nottingham's Faculty of Medicine and Health Sciences' Research Ethics Committee in April 2023.

The study aimed to recruit 38 adults with moderate to high DA, as measured by the Modified Dental Anxiety Scale (MDAS), within 3 months. This sample size was based on a review of the literature on sample sizes for feasibility studies and allowed for an attrition rate up to 33%, based on evidence that online interventions can have high attrition. Recruitment took place through social media, predominantly through Facebook. Participants were randomly allocated to either a Wait-List Control (WLC) condition or to the OSG condition and asked to use it in a naturalistic manner (with no frequency or amount of time mandated) for a period of six weeks. Their usage of the OSG was measured by capturing logon data daily. At the end of the six weeks, semi-structured interviews were conducted with participants allocated to the OSG to explore the acceptability of the OSG intervention. Thematic analysis was conducted on the transcripts from the interviews. Participants completed pre- and post- measures of DA (MDAS) and intention to attend routine dental care (Dentist Contemplation Ladder). Descriptive statistics were produced to analyse the data.

Results:

40 participants were recruited within 3 months and attrition was lower than anticipated at 7.5%. Reductions in the mean MDAS score (indicative of a reduction in DA) were seen in both the OSG and the WLC conditions but were greater in the OSG condition. Increases in the mean Dentist Contemplation Ladder (indicative of a greater readiness to attend an appointment) were seen in both the WLC and the OSG conditions but again were greater in the OSG condition. The effect size based on the MDAS indicates that a sample size of 72 would be required for a fully powered RCT. Thematic analysis generated 4 themes: “Initiation” which examines the barriers and facilitators to accessing the OSG, “exploration” or how participants navigated the OSG, “engagement” and what fostered or hindered participants participation in the OSG, and finally “benefits and outcomes” that the OSG had fostered. Most participants were positive about the experience, with a small number rejecting the OSG, having decided early on that it did not meet their needs.

From a process perspective, there was variation in the level of usage of the OSG. Overall, the number of times participants logged on to the OSG was limited with a mean of 3.6 times over six weeks. Participants found the sign-up process and the measures simple and easy to complete. The phone or Teams call that formed part of the sign-up process was well received by participants and may have helped reduce the risk of imposter participants.

Conclusions:
The results of the study indicate that it is feasible to recruit sufficient eligible participants for an RCT after taking attrition into account. The usage of the OSG was acceptable to the participants in this study, although some participants engaged more than others. The MDAS would be an appropriate main outcome measure for an OSG, although both measures provided useful insight and were acceptable to participants. A full RCT is therefore both feasible and necessary to further understand the effect of OSGs on DA.

List of Conference Presentations and Publications under Review

UK Conference Presentations

British Psychological Society Division of Health Psychology Conference
June 2024 - Stirling
Oral Presentation
A feasibility study for a randomised control trial on the effects of engagement with a dental anxiety online peer support group

British Psychological Society Division of Health Psychology Conference
June 2023 - Sheffield
Work In Progress Poster Presentation
A feasibility study for a randomised control trial on the effects of engagement with a dental anxiety online peer support group

International Conferences

European Health Psychology Society Conference
September 2024 – Cascais, Portugal
Oral Presentation
A feasibility study for a RCT on the effects of engagement with a dental anxiety online peer support group

University of Connecticut “Health is Social” U-Conn Digital Conference
May 2023 - Virtual
Video Poster
The experiences of users of online peer support groups for dental anxiety: a systematic review

Publications under review:

Sorrell, C. Becoming a health psychologist and joining the conversation: a reflection on the DHP conference.
Health Psychology Update (Accepted August 2025, scheduled for publication June 2026)
Includes a summary of PhD results as presented at conference

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Chapter 1: Dental Anxiety

1.1 Chapter summary

In this chapter, I will consider the existing literature on Dental Anxiety (DA). Although estimates of the prevalence of DA vary, there is evidence to indicate that it is a prevalent condition which could affect up to approximately 54% of the population in England. More people are likely to experience mild or moderate DA than high anxiety or phobia, and it is more likely to affect women, younger adults and people from lower socio-economic backgrounds. A breadth of different DA self-report scales exists, with varying levels of brevity or complexity. There is strong evidence to indicate that DA has a significant physical, psychological and social impact on individuals who live with it and can lead to avoidance of treatment. It is also a cause of work-related stress amongst the dental profession. The aetiology of DA appears to be multi-factorial and may be a combination of exogenous and endogenous factors. Pharmacological and non-pharmacological treatments exist for DA, but they are not without limitations. Therefore, further research into DA and potential solutions is warranted.

1.2 Dental anxiety

As early as the 1940s, Coriat (1946) described Dental Anxiety (DA) as a dread of anything being done to the teeth, and an anticipatory anxiety that leads to the avoidance of treatment. More recent definitions have described DA as an impairing or negative state experienced in response to dental treatment or the anticipation of dental treatment (Duker et al., 2022). Anaesthesia and treatment methods may have improved since the 1940s, but DA seems to endure (Buchanan, 2012). Although it appears most likely to be triggered by invasive procedures such as injections or drilling (Holtzman et al., 1997; Humphris et al., 2000), a wider range of treatment aspects can also be fear provoking: the anticipation of treatment and the environment (e.g. waiting room, dentist’s chair), the sensory aspects of treatment (e.g. sounds, smells), as well as the risk of blood and injury

(Dempster et al., 2011; Kleinknecht et al., 1984). The existing literature on measurement sometimes uses the terms dental anxiety, dental fear and even dental phobia without always clarifying the distinction between these terms (Duker et al., 2022). The idea of clear boundaries between these terms or clear cut-off points on measurement scales to differentiate between them has also been acknowledged as challenging for a condition that exists on a continuum (King & Humphris, 2010). The evidence on prevalence (see Section 1.3.1 below) and on the impact of DA (see Section 1.5.1 below) would suggest that some level of DA is common, regardless of how it is measured, and that it can have a significant effect on those affected.

1.3 Prevalence and demographics

Reports on the prevalence of DA vary significantly in the literature, although most studies find that people are more likely to experience mild or moderate DA than high anxiety or phobia. In addition, there are many common findings in terms of who is more likely to be affected.

1.3.1 Variation in estimates of prevalence

At the lower end of estimates, Nicolas et al. (2007) found that in a French sample of over 2,700 participants (representative of the population in terms of age and urban distribution), 13.5% were identified as dentally anxious, with 7.3% classified as severely anxious and only 6.2% as moderately anxious. Nicolas et al.’s study used a French version of the Dental Anxiety Scale (DAS) (Corah, 1969) and differs from other studies in finding that more than half of dentally anxious participants were severely anxious (based on a score of 15 or higher out of a maximum of 20 on the DAS).

A slightly higher prevalence was found in a Dutch study by Oosterink et al. (2009). They asked a convenience sample of almost 2,000 participants to identify from a list of eleven potential stimuli (such as spiders, snakes, heights, or enclosed spaces) which ones they found fear-inducing. Dental treatment was identified as a source of fear by 24% of participants. The researchers then went on to use an additional checklist based on the

Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) to identify that 3.7% of participants experienced dental phobia. They provide validation for their additional checklist by comparing it with clinical interviews in a very small sub-sample. Nonetheless, a key issue with this study remains that it does not use an existing validated scale that measures varying levels of DA, making it difficult to compare their results with any other study.

Although at first glance a similar level of prevalence was found by Armfield (2011), this Australian study with over 1,000 participants found that the levels of DA varied across three different scales. This study estimated that the overall prevalence of DA ranged from 18.7% to 28.4% depending on the scale. However, estimates of high anxiety were more consistent across the scales, ranging between 7.3% and 9.5% of participants. Nonetheless, this highlights the importance of taking measurement into account when comparing prevalence data.

Amongst the higher estimates of prevalence, Enkling et al. (2006) found that 40% of their demographically representative German sample had medium (23%) or high (17%) DA. They used the Hierarchical Anxiety Questionnaire (Jöhren, 1999), an 11-question German language measure of DA, which considers a score of 31 to 38 indicative of moderate anxiety (out of a maximum of 50), and a score greater than 38 as high anxiety. An additional twelfth question measures avoidance in order to identify dental phobia, and Enkling et al. argue that 11% of their total sample could be classified as phobic.

Finally, the survey with the largest sample also has the highest estimate of prevalence. In the UK, an Adult Dental Health Survey (ADHS) was carried out every 10 years by the government until 2009 amongst a representative sample of more than 13,000 households in England, Wales and Northern Ireland (The Health and Social Care Information Centre, 2011). It included the five-question Modified Dental Anxiety Scale (Humphris et al., 1995). In total 48% of those surveyed had moderate to extreme anxiety, with 36% of the population scoring themselves as moderate (a score between 10 and 18 out of a maximum of 25), and 12% scoring themselves as extremely dentally anxious (a score of 19 or higher). More recently, in 2021 it was replaced by the Adult Oral Health Survey (AOHS) which used a representative sample of more than 6,300 individuals across approximately 4,400 households in England only (Office for Health Improvement and Disparities, 2024). Using the same scale, the findings showed an increase to 42% of those surveyed living with moderate anxiety and the same figure of 12% living with extreme DA.

This wide-ranging variance in estimates can, in part at least, be explained by the following contributing factors: each of these studies was carried out in a different geographical population, using a variety of different scales or measures, and these scales or measures may have different cut-off points at which they deem a person to be anxious or highly anxious. Whilst variation exists, even the lower estimates seem to indicate that DA affects a large enough number of people in western developed countries to warrant further investigation through research. Indeed, a systematic review and meta-analysis conducted by Silveira et al. (2021) drew similar conclusions: that although the studies included in their review had limitations and were heterogenous, the global prevalence of DA was certainly high enough to be a clinically significant issue.

1.3.2 Socio-demographic factors

According to the AOHS (Office for Health Improvement and Disparities, 2024), women are more likely to be dentally anxious, with 16% of women reporting extreme DA compared to only 8% of men. There appears to be agreement on the over-representation of women amongst the highly dentally anxious in most of the studies outlined above (Armfield, 2011; Enkling et al., 2006; Oosterink et al., 2009) but also in a study that compared the UK, Finland and Dubai (Humphris et al., 2000) and in a study based in the US (Holtzman et al., 1997). However, a higher prevalence of DA amongst women is perhaps not surprising, as there is a higher prevalence of almost all anxiety disorders (e.g., panic disorder, specific phobia, generalized anxiety disorder) amongst women (McLean et al., 2011). However, whether this higher reporting is related to gender differences in willingness to report or seek help for anxiety cannot be ruled out.

With regards to age, the AOHS highlights that a higher proportion of 16- to 24-year-olds reported extreme DA, and that DA was at its lowest in those aged 65 and over (Office for Health Improvement and Disparities, 2024). The finding that older age groups are less dentally anxious appears to be corroborated by studies from a variety of different countries (Enkling et al., 2006; Holtzman et al., 1997; Nicolas et al., 2007; Oosterink, De Jongh, et al., 2009). This confirms that advances in treatment and anaesthesia have not protected a younger generation from DA, although the reasons why young people are more affected remain unclear.

From a social perspective, the AOHS (Office for Health Improvement and Disparities, 2024) identified that extreme DA is more prevalent in neighbourhoods with higher deprivation (15% in the most deprived quintile vs 9% in the least deprived quintile) and slightly more prevalent in lower income households (14% in the 2 lowest income quintiles vs 10% in the highest two income quintiles). Bernabé et al. (2017) argued, based on data from the Adult Dental Health Survey (ADHS), that there is a link between socio-economic position (as defined by both education and household income) and DA, and that DA contributes to oral health inequalities for people with lower education levels, although not for the population as a whole. Disparities in DA based on social factors were also found in a study of French participants by Nicolas et al. (2007), who identified that that farmers and manual workers were more dentally anxious than executives, technicians, employees and shopkeepers, and that participants from rural areas were more likely to be anxious than those living in urban areas. Whilst there appears to be a lack of research on ethnicity and DA, there is some limited evidence from the UK that ethnic minorities may experience greater mistrust of dentists (Newton et al., 2001), and that experiences of racism may be linked to greater DA amongst black women in the US (Heaton et al., 2023).

1.4 Measurement

Whilst a definition is essential to help understand what is meant by DA, it could be argued that an understanding of measurement is equally important. As outlined in Section 1.3.1, prevalence data varies based on the scale or measurement used, possibly because scales differ in how they conceptualise DA, what elements they include, and therefore what exactly they are measuring (Armfield, 2011). Scales can be divided into two types: brief and complex scales, depending on the number of items that they contain. Regardless of length and complexity, all psychometric scales need to demonstrate both reliability (consistency of measurement) and validity (that they are measuring what they set out to measure) (Bannigan & Watson, 2009). An understanding of the most used scales and their limitations is therefore critical to provide context to the prevalence figures and to enable appropriate evaluation of research.

1.4.1 Brief self-report scales

The key benefit of brief self-report scales (that contain five items or fewer) is that they are quick and simple to administer and therefore could be easier to use in clinical practice. One such scale is the Dental Fear and Avoidance Scale or DFAS (Dempster et al., 2011) which aims to assess both cognitive and behavioural aspects of DA with two questions that ask participants to rate their degree of fear and avoidance on a scale of 1 to 10. However, whilst DA and avoidance are certainly linked, one challenge that could be levelled at the DFAS is that it is in fact measuring two distinct concepts. Furthermore, it has been argued that the simplicity of scales that are limited to one or two items undermines their validity (Kleinknecht et al., 1984) as they lack clarity about what exactly they are attempting to measure, and do not provide any insight into what precisely is causing the anxiety (e.g. needles, drilling…).
A commonly used measure across much of the literature is the four-item Dental Anxiety Scale (DAS), developed by Corah (1969). Corah et al. (1978) argue that it is simple enough to use in dental clinics, yet it still allows for a greater representation of the construct than the DFAS. However, Humphris

et al. (1995) criticised it for having an inconsistent answering scheme and not containing a question about injections or anaesthetic, a frequent source of concern for those with DA. In response, Humphris et al. developed the five-question Modified Dental Anxiety Scale (MDAS). The MDAS is available in more than 20 languages and has been found to be reliable both in the UK and in many other countries (Humphris et al., 2000; Newton & Edwards, 2005), making it an appropriate tool for cross-cultural research. Furthermore, UK population norms are available, allowing clinicians and researchers to establish how common a given score is (Humphris et al., 2013). The MDAS is widely used in research (Humphris et al., 2013) and is the most frequently used in dental practice in the UK (Dailey et al., 2001), as well as being the tool used in the AOHS (Office for Health Improvement and Disparities, 2024). However, both the DAS and the MDAS have been criticised for under-representing the construct, in other words not measuring all aspects of DA and fear (for example, avoidance), as well as for lacking a basis in theory and a clear definition of the construct they are trying to measure (Armfield, 2010).

1.4.2 Complex scales

Based on his criticism of the shorter scales, Armfield (2010) developed the more comprehensive Index of Dental Anxiety and Fear (IDAF), which contains 23 items. The IDAF is rooted in a clear theoretical construct covering the emotional, behavioural, physiological and cognitive aspects of fear and anxiety. It also aims to cover the elements of dental treatment that are likely to induce fear (e.g. pain, lack of control, gagging or choking). Armfield argues that optional additional questions allow differential diagnosis between fear and phobia. These additional questions explore the extent to which the fear impairs function, the distress caused by the fear and the belief that the fear is excessive, but they have been criticised for under-identifying phobic patients (Svensson et al., 2020). Armfield (2010) claims that the IDAF overall has greater predictive value for treatment attendance than either DAS or MDAS. It has shown good validity in terms of its correlation with other DA scales (Armfield, 2010; Svensson et al., 2020), and good reliability (Armfield, 2010).

Other scales that strive for a theoretically grounded, comprehensive measurement of DA include the Dental Fear Survey (DFS) (Kleinknecht et al., 1973) and the DAI or Dental Anxiety Inventory (Stouthard et al., 1993). The DFS was developed for research and its 20 items cover three components of dental fear (avoidance, physiological reactions and stimuli). It has been shown to have good reliability (Holtzman et al., 1997), and a strong correlation with missed or cancelled appointments (Kleinknecht et al., 1984). The DAI contains 36 items rooted in three "facets" of DA (the situation, the reaction and the duration of the reaction). It has strong correlation with the DAS and had demonstrated discriminant validity through low correlation with scales for general anxiety (Stouthard et al., 1995). In response to criticism of its length and complexity, a short form (S-DAI) was developed containing just 9 items, but this has been criticised for losing its theoretical grounding (Armfield, 2010).

In summary, whilst these questionnaires may allow a broader conceptual exploration of the components of DA, they lack the simplicity and brevity of DAS or MDAS and lack compelling evidence to demonstrate greater validity or reliability than the short scales against which their validity has often been measured.

1.4.3 Limitations common to all scales

Whilst all these scales have evidence to support their reliability, one issue is that they generally lack external or objective validation and therefore tend to establish concurrent validity by correlating one anxiety scale with another (Armfield, 2010; Dempster et al., 2011; Stouthard et al., 1995; Svensson et al., 2020). Some attempts have been made to validate DA scales against other external measures, such as treatment avoidance or appointment cancellation (Armfield, 2010; Kleinknecht et al., 1984), and Kleinknecht et al. (1984) unsuccessfully attempted to establish a correlation between dental fear (as measured by the DFS), palmar sweat levels and a patient's activity levels in the waiting room and in the dentist's chair. Dempster et al. (2011)

highlight the challenges associated with measuring physiological changes (e.g. heart rate, skin conductance), both in terms of feasibility of measurement in clinical practice, and because of the high levels of individual variation on such measures. A further criticism of the existing scales is that most agree on who is not dentally anxious rather than agreeing on who is (Armfield, 2011; Dempster et al., 2011), showing greater specificity than sensitivity. Most of the above scales differentiate between mild, moderate and high DA, but with sometimes limited evidence for these cut-offs, which Armfield (2011) goes as far as calling arbitrary. Armfield also highlights that the disagreement between scales is exacerbated at the high end of DA, where different scales will identify different people as highly dentally anxious. In summary therefore, in the absence of a perfect scale, it is important to understand the strengths and limitations of each and to note that DA is not a binary concept but rather exists on a continuum from mild distress to dental phobia.

1.4.4 Measurement in clinical practice

Beyond research, formal measurement is also important in clinical practice as dentists' clinical judgement in identifying highly anxious adult patients appears to be poor (Höglund et al., 2019). However, evidence suggests that less than 20% of dentists with a specialist interest in DA routinely use assessment tools in practice (Dailey et al., 2001). Although the data are more than 20 years old and usage may have increased in the intervening period, more recent data from Alshammasi et al. (2018) indicates that under-utilisation of assessment tools remains a problem at least in paediatric dentistry. According to Dailey et al. (2001), one barrier to the use of such tools in dental practice could be linked to concerns raised by clinicians that measurement could increase anxiety in patients. However, a randomised control trial conducted with a sample of over 1,000 participants by Humphris et al. (2006) demonstrated no increase in state anxiety in participants who also completed the MDAS compared to participants who only completed a measure of state anxiety, which would indicate that such concerns are unfounded.

1.5 Impact of dental anxiety

Whether an individual experiences moderate or high DA, dental fear or even dental phobia, there is a body of evidence to demonstrate that DA has a significant physical, psychological, and social impact on individuals living with the condition. It would also appear that the greater the anxiety, the greater the impact (Locker, 2003).

1.5.1 The self-perpetuating nature of dental anxiety

In 1984, Berggren developed a commonly cited model of dental fear and anxiety, suggesting that dentally anxious patients avoid or postpone treatment, leading to a deterioration of their oral health, which in turn leads to negative self-evaluations and negative social effects. These then lead to embarrassment and shame related to the dental state. Negative self-evaluations and social effects then reinforce the anxiety (Berggren, 2001). There is a wealth of evidence that supports different elements of Berggren’s model.

Firstly, the AOHS (Office for Health Improvement and Disparities, 2024) indicates that there is indeed a correlation between avoidance and anxiety, as a lower proportion of adults who attend regular check-ups reported extreme DA. In studies from Canada and Australia respectively, Locker (2003) and Armfield (2013a) found a similar correlation, and in a qualitative study Cohen et al. (2000) found that patients with high DA reported a pattern of avoiding, delaying and missing appointments, even in the presence of acute pain. However, Armfield's analysis also showed that less than a third of people with high dental fear were classed as avoiders on the basis that they had not attended a dentist in the previous 2 years. Therefore, it is important to take into account that while some individuals with high DA avoid dental treatment, that is not always the case for all highly anxious individuals.

Secondly, the correlation between DA and oral health is also evidenced by the AOHS (Office for Health Improvement and Disparities, 2024): adults who assess their own dental health as being good or very good are less likely to report being extremely dentally anxious. Similarly, Locker (2003) found lower self-ratings of dental health amongst participants who had previously been identified as being dentally anxious in a population-based survey in Canada. This could be explained through a lack of preventative treatments and a lack of early detection of problems, which in turn could lead to a dentally anxious patient requiring more intrusive treatment when they do attend the dental practice.

The third component of Berggren's model is the role that embarrassment and perceived negative social evaluations play in DA. Yuan et al. (2020) found that shame around ones' oral condition was associated with DA, and Berggren et al. (2000) highlighted that a very high proportion of their participants had feelings of anger, shame and low mood in relation to their dental fear. Indeed, the anxiety itself can be deemed embarrassing: Locker (2003) highlighted that concerns about negative social evaluation and fear of appearing foolish were likely to lead participants to hide their anxiety, and Cohen et al. (2000) highlighted that a lack of understanding around DA could lead to some people feeling stigmatised.

There appears therefore to be sufficient evidence to ascertain that DA can lead to embarrassment. Although there appears to be a paucity of evidence that the shame and stigma lead to greater fear, it could be that the shame and the stigma lead to greater avoidance, which in turn leads to greater fear: Abrahamsson et al. (2002) argue that avoidance does indeed lead to increased anxiety. Furthermore, both the ADHS (The Health and Social Care Information Centre, 2011) and Enkling et al.'s (2006) study found that DA increases the longer the participant has been without treatment. However, without evidence from a longitudinal study, these findings should be interpreted with caution, as no direction of causation can be established.

Finally, evidence to validate multiple aspects of Berggren's model can be found in de Jongh et al.'s (2011) study of patients attending a specialist clinic in the Netherlands. It shows that years of dental avoidance are associated with poorer dental health, not only in terms of self-assessment but also in terms of objective data on oral health. They also found that prolonged dental avoidance is a predictor of fear of negative evaluation, and that dental health is indeed a mediator between avoidance and fear of negative social evaluation. However, this study was conducted with patients with high DA (DAS ≥15), and therefore it cannot be assumed that it necessarily applies to those with moderate or mild anxiety.

1.5.2 Wider psychosocial impacts

Although Berggren’s model provides a partially validated model for how DA may create a vicious circle which exacerbates the problem, it could be argued that it does not capture all the wide-reaching impacts of DA. Further studies have demonstrated additional aspects of DA and the impact it may have. Locker (2003) found that high DA was associated with lower self-esteem and lower morale (defined as overall wellbeing and personal satisfaction), as well as an impact on relationships. Similarly, Vermaire et al. (2016), in a Dutch study comparing participants seeking treatment at a specialist dental fear clinic against a control group, found that people with high DA reported lower overall health-related quality of life and concluded that DA carries a high burden of disease. However, in these cross-sectional studies no causation can be determined, so caution is needed before stating that lower self-esteem or other psychosocial consequences are caused by DA. A further issue with both these studies is that the psychosocial impacts reported for those with high DA could be influenced by co-morbidities and more generalised fears and anxieties.

Further evidence for the psychosocial impact of DA is provided by Cohen et al. (2000). In a qualitative study of patients attending treatment at a dental sedation clinic, they identified that the impact of high DA went beyond avoidance as it also impacted on eating habits, on sleep and had a negative effect on interpersonal relationships both in a personal and a work context in the days leading up to treatment. Nonetheless, anxiety-induced avoidance may arguably have one positive side-effect: according to Cohen et al., it influences oral care behaviours as people engage more in preventative oral hygiene in order to reduce the need for treatment, although further evidence would be needed to confirm this.

1.5.3 Pain and dental anxiety

Pain is not included in Berggren's model, however, as pain is a biopsychosocial phenomenon that can be exacerbated by anxiety (Tang & Gibson, 2005), its role in DA merits consideration. There is recent evidence that DA is correlated with higher levels of pain during root canal surgery (Murillo-Benítez et al., 2020). More broadly, Lin et al. (2017) carried out a systematic review of 35 articles on the link between DA, state anxiety and pain linked to dental treatment. Their review found that DA had a consistent impact on the anticipation of pain, the experience of pain during treatment and pain post-treatment across different dental treatments. These findings can therefore contribute to our understanding of why dentally anxious people might avoid treatment. However, there appears to be limited literature on how the pain of untreated dental problems might act as a trigger to overcome one's fear and attend dental treatment despite DA. This additional pain, combined with poorer dental health could lead to the experience of treatment being more traumatic and reinforcing the underlying anxiety (Armfield et al., 2007; Beaton et al., 2014)

1.5.4 Impact of dental anxiety on dental health professionals

Finally, it has previously been argued that not only does DA have an impact on patients, it also appears to be a cause of occupational stress for the dental profession (Berggren, 2001). According to a descriptive study conducted amongst Danish dentists, this is due to the additional time required for dentally anxious patients, the impact on the dental team, and the associated costs (both of delay in treatment, cancelled appointments and of increase time for the consultation) (Moore & Brødsgaard, 2001). Furthermore, Goetz et al. (2019) in a study of German dentists found a correlation between the proportion of patients that dentists perceived as being anxious and the risk of burnout, and they argue that the challenge of caring for anxious patients requires special management skills.

1.5.5 Further contributing factors to dental avoidance

Whilst DA and dental avoidance are closely related, it is important to remember that they are two distinct concepts. As described in Section 1.5.1, there is a wealth of evidence that DA can lead to avoidance of dental appointments. However, it is important to consider what other factors may influence avoidance. According to Abrahamsson et al. (2002), whilst fear is a key reason for avoidance, socio-economic status also plays a part independently, with feelings of shame and inferiority towards dental professionals being cited as a reason for avoiding treatment. Furthermore, Yuan et al. (2020) used data from the ADHS (The Health and Social Care Information Centre, 2011) to demonstrate that communication with the dentist was significantly, although weakly, affected by a patient's socio-economic position. They argue that social rank theory suggests that that the social disparity between dentist and patients from lower socio-economic position can result in shame, and lead patients to withdraw from interactions. Abrahamsson et al. (2002) highlight that for their participants, financial considerations were also a deterrent, particularly when a history of non-attendance was likely to lead to a greater amount of treatment being needed, which could incur higher costs. The ADHS also highlights cost as an additional factor alongside DA in treatment avoidance but goes on to suggest that anxiety around cost of treatment could be an additional contributing factor to DA (The Health and Social Care Information Centre, 2011). Although no conclusions can yet be drawn about exactly how these factors interact and combine, socio-economic status certainly appears to be both a contributing factor to avoidance as well as increasing one's likelihood of living with DA.

1.5.6 Aetiology

DA is a complex phenomenon that combines the psychological, the somatic and the social. There is evidence to show DA frequently starts in childhood (Berggren et al., 2000; Edmunds & Buchanan, 2012; Grisolia et al., 2021), and both exogenic or external factors (such as distressing events) and endogenic factors (such as biological or genetic predispositions) have been suggested as potential causes.

1.5.6.1 Conditioning and modelling

Early research focused on exogenic explanations, and several studies have investigated Rachman's model (Humphris & King, 2011; Milgrom et al., 1995; Milsom et al., 2003) which proposes three possible origins for the acquisition of dental fear in childhood. The first is direct conditioning: exposure to distressing or traumatic dental experiences in early life. The second and third assume vicarious trauma, either through modelling (where a significant family member's DA becomes learned behaviour in the child) or through exposure to threatening information (such as media images). In a large-scale study on the causes of dental fear in primary school children in the US, Milgrom et al. (1995) identified conditioning as an important factor: children who had poor dental health and who had received previous treatment for toothache or extraction were more likely to report being dentally fearful. These findings echo Berggren et al. (2000) and Enkling et al. (2006) who found that most participants attributed the origin of their fear to painful dental treatment. Milgrom et al. (1995) identified that modelling was predictive of high DA in children, in other words that a child whose mother or guardian was dentally anxious was in turn twice as likely to be dentally anxious as a child with a non-anxious mother or guardian. Milsom et al. (2003), in a study of children in the North--East of England, found that direct conditioning was an important factor, as children with a history of tooth extraction were three and a half times more likely to experience DA (as reported by their parents).They also found that modelling played a part in the acquisition of dental fear, but second to direct conditioning. These findings have also been confirmed by more recent studies in adult populations (Humphris & King, 2011). Furthermore, Humphris & King (2011) found that distressing dental experiences (including extreme helplessness, embarrassment, nausea, and lack of understanding by the dentist) were all associated with higher levels of DA on the MDAS scale in a replication of a study by Oosterink et al. (2009) on a student population in the UK. Although the UK study showed some association between exposure to information in the media about dentists and high DA, the original Dutch study did not, and there appears to be less evidence to support the role of vicarious trauma that is not linked to modelling.

1.5.6.2 Limitations of conditioning

However, Rachman's model alone appears insufficient to explain DA, as previous painful or traumatic dental experience does not necessarily lead to DA. In their study of children in the Northeast of England, Milsom et al. (2003) found that a pattern of irregular attendance was a greater predictor of DA than negative dental experiences. They argue that regular attendance creates a history of positive experiences that provide latent inhibition. This in turn has a protective effect against subsequent negative experiences. In addition, De Jongh et al. (1995) hypothesise that the age at which the traumatic event occurred may play a role in the acquisition of DA, perhaps because younger children have fewer coping or cognitive resources than older ones, and fewer positive dental experiences to draw upon (Ten Berge et al., 2002).

In contrast, not everybody who experiences DA reports having experienced traumatic dental experiences. According to Topcu & Buchanan (2013), people from a Cypriot sample who reported a negative experience during a dental visit did indeed have higher anxiety scores. However, less than a third of people with MDAS scores of 19 or more (indicative of high DA) reported having had a bad experience during a dental visit.

Furthermore, dental trauma may not be the only form of trauma linked to DA. Humphris & King (2011) looked at the impact of other traumatic experiences (e.g. violent crime, natural disasters) on DA and found that past sexual assault significantly affected the presence of DA.

Finally, an issue with all studies on aetiology that rely on retrospective report is that biases in memory may influence how salient specific events are, meaning that it is difficult to determine whether people recall events as traumatic because of the anxiety, or whether the traumatic event triggered the anxiety (de Jongh et al., 1995).

1.5.6.3 Genetic factors

If exogenic factors alone cannot fully explain the aetiology of DA, perhaps endogenic factors can provide the missing pieces. An intriguing study by Ray et al. (2010) investigated whether there could be a genetic component to DA. By comparing monozygotic and dizygotic same-sex twins, they found that there was indeed some form of genetic predisposition, as monozygotic twins were more likely to experience fear at similar levels, particularly amongst female twins. However, the study also showed some conflicting results around the heritability in boys, as well as some changes in heritability over time. Whilst some of these results could be due to a lack of statistical power with the male sample, the study leads to the conclusion that although genetics may play a role in the origins of DA, that role is far from being fully understood. Without disregarding modelling theories, this study points to a more complex phenomenon that might be influencing the transmission of DA from one generation to the next.

1.5.6.4 Personality and cognitive vulnerability

If individuals differ in their responses to traumatic experiences, then individual differences such as personality traits could be another endogenic factor associated with DA. Halonen et al. (2012) identified a significant association between neuroticism and DA (measured with MDAS) in a Finnish student sample. Whilst there are limits to the conclusions that can be drawn from a cross-sectional study in a student sample about the origins of DA, Halonen et al. argue that neuroticism is a significant risk factor for the development of DA. However, as neuroticism is associated with higher anxiety in general, neuroticism alone is unlikely to be a cause of DA. Indeed, more recent explanations of the acquisition of DA have focused on the Cognitive Vulnerability Model (CVM) developed by Armfield (2006) in an attempt at a unifying theory. Armfield argues that the aetiology of fear can only be explained by a combination of individual differences in a person’s propensity to develop fear (personality traits, biological factors and past experience) and the characteristics that the individual perceives the object of fear to have. The characteristics that are associated with fear or anxiety are danger, disgust, uncontrollability and unpredictability. Armfield's proposal seems rooted in prior evidence (Lick et al., 1978; Lipsitz et al., 2002; Zvolensky et al., 2000), although limited evidence is presented to justify the inclusion of disgust. However, in later studies to test the CVM in the context of DA (Edmunds & Buchanan, 2012; Topcu & Buchanan, 2013), danger, disgust and uncontrollability were found to predict MDAS scores. Whilst these studies concluded that although there is support for the CVM in the maintenance of DA, there is an inherent issue with using retrospective perceptions when investigating aetiology, and therefore further research is needed to demonstrate its role in the acquisition of the condition (in which unpredictability may also play a part).

However, as with studies on conditioning, there is an inherent issue with using retrospective perceptions when investigating the aetiology of a condition many years after the acquisition of the fear. In addition, cross-sectional studies have limited value (compared to longitudinal studies) in terms of informing us on the origins of DA.

1.5.6.5 Factors in the maintenance of dental anxiety

Whilst it is important to understand the origins of DA, it is equally important to understand the factors that may perpetuate it, as addressing these could play a part in helping dentally anxious patients to overcome their fear. Some studies have pointed to the role that the relationship with the dentist can play in the acquisition of DA (Humphris & King, 2011), but there is also significant evidence that it continues to play a part once the anxiety is established. Berggren et al. (2000) highlight the importance of patience and supportive behaviours from the dentist for anxious patients, and according to the Adult Dental Health Survey (The Health and Social Care Information Centre, 2011), a greater proportion of adults who expressed a negative opinion about their relationship with their dentist had an MDAS score indicative of extreme DA. Furthermore, if a patient's perception of danger, uncontrollability, and possibly unpredictability (Armfield, 2006; Edmunds & Buchanan, 2012; Topcu & Buchanan, 2013) are important contributors to the maintenance of

DA, then it stands to reason that seeking to reduce these through communication between patient and dentist may help to alleviate anxiety.

As mentioned earlier, socio-economic status may also negatively affect communication and therefore the relationship with dentists (Yuan et al., 2020), and the AOHS also highlights cost as an additional factor alongside DA in treatment avoidance (Office for Health Improvement and Disparities, 2024). If DA creates a negative cycle of avoidance, poorer oral health and feelings of shame, it would perhaps be naïve to overlook concerns around affordability as a contributing factor to that cycle.

In summary, the most compelling conclusion seems to be that DA is complex and multifactorial, with underlying cognitive and genetic vulnerabilities apparently combining with different environmental risks and protective factors to determine the acquisition and maintenance of the condition.

1.5.7 Management of dental anxiety

According to Berggren et al. (2000) dentally anxious patients are highly motivated to overcome their anxiety, although the nature of their motivation may differ, and they may lack belief in the efficacy of treatment for their anxiety. However, as participants in their study were recruited from specialist clinics, there may be a wider population of dentally anxious individuals who are not only avoiding dental treatment, but also not actively seeking out solutions to reduce their anxiety.

1.5.7.1 Sedation and analgesia

Multiple studies have investigated potential solutions to help people who suffer from DA to overcome their fear and access treatment. For a long time, sedation and analgesia were seen as the main management strategies to help patients deal with both the pain and the anxiety of dental treatment. Analgesia often requires injection which in itself can be another trigger or component of fear (Armfield & Heaton, 2013; Humphris et al., 2000), and the effectiveness of analgesia is limited by the fact that pain is not the sole cause of DA. Therefore, pharmacological solutions may deal with some of the symptoms but do nothing to address the underlying anxiety and may even contribute towards it (Haworth et al., 2017).

1.5.7.2 Communication

One approach towards non-pharmacological management of DA could be measurement and communication. There is evidence (Dailey et al., 2002) to suggest that assessing DA and sharing that information with the dentist immediately prior to treatment can reduce a patient's anxiety. More generally, Armfield & Heaton (2013) and Freeman & Humphris (2019) argue that improved communication will help to reduce patient anxiety, as well as being beneficial to all patients, although it should be acknowledged that better communication requires participation from both patient and practitioner. Providing information on treatment (both in advance and during treatment) and giving a level of control back to the dentally anxious patient (for example through signalling and rest breaks) can be beneficial (Armfield & Heaton, 2013).

1.5.7.3 Non-pharmacological interventions

Evidence also exists for more complex interventions requiring specialist knowledge or training. In a 3-year longitudinal study of participants with high DA, Moore et al. (2002) compared the efficacy of hypnotherapy, group therapy and desensitisation (progressive exposure to the object of fear, often accompanied with relaxation techniques) against a control group of no treatment. They found that all three treatment groups saw a reduction in anxiety, improved trust and a change in dental beliefs, but more importantly they noted better dental treatment attendance after 3 years than the control group. The results did not show one treatment method to be more effective than the others. However, the authors note that many patients from the control group also successfully initiated and maintained regular dental treatment habits, and saw an improvement in dental beliefs and trust, but without a reduction in anxiety. This shows that avoidance is not an inevitability for the dentally anxious, and that anxiety can be managed, if not reduced, without an intervention. Furthermore, high levels of attrition in their treatment groups limit the conclusions that can be drawn from their study.

More recently, a pilot Randomised Control Trial (RCT) in the US (Arias & McNeil, 2020) has shown some promising results for desensitisation through smartphones for self-directed gradual exposure to a YouTube video of preventative dental visits. Participants in the intervention group reported lower anxiety and showed a reduction in cardiac reactivity vs the waitlist control. However, this was a small-sample pilot, and the results need to be confirmed through a fully powered RCT to see whether the reduction in anxiety can be sustained and whether it translates into patients attending treatment on a regular basis.

In a systematic review of studies comparing non-pharmacological interventions (used alongside local or general anaesthesia) against treatment as usual, Burghardt et al. (2018), found evidence that non-pharmacological interventions reduced mental distress, and that hypnosis in particular showed the largest effect, in spite of high levels of heterogeneity in the studies they included in their review. This is consistent with evidence from more general surgical procedures that hypnosis can reduce anxiety (Tefikow et al., 2013). However, it is unclear whether a reduction in anxiety can translate into long term behaviour change around attendance. In a systematic review and meta-analysis of studies on cognitive and behavioural treatments (including desensitisation, hypnosis, and relaxation), Kvale et al. (2004) found that the literature available at the time was fraught with issues: studies were not all randomised, did not always report attrition, some included pre-post comparisons rather than versus control. As with previous systematic reviews, they warn about the level of heterogeneity of the studies included. Nonetheless, they concluded that behavioural treatments were effective at reducing DA and identified large effect sizes. The studies analysed did not allow any conclusions to be drawn about the impact of treatment on long-term attendance. Subsequent reviews (Gordon et al., 2013; Wide Boman et al., 2013) have challenged the effect size identified by Kvale et al. (2004), but have found some evidence that cognitive-behavioural and behavioural interventions are effective at reducing DA and also increasing the acceptance of dental treatment. However, they also highlight the heterogeneity of studies, the low number of studies included, and methodological issues of the studies reviewed.

In addition to heterogeneity and methodological issues, a key issue with much of the research outlined above is that it is has been carried out in dental surgeries or clinics, therefore with participants who have already managed to overcome their fear enough to attend treatment. Reversely, many of the studies that investigate treatments for DA focus on those with high anxiety or even phobia (Wide Boman et al., 2013). Whilst it is understandable that those with the highest levels are targeted for treatment, there is less evidence that these solutions are either effective or appropriate for people with mild or moderate DA. Therefore, there is still a large proportion of dentally anxious people for whom the efficacy of these treatments has not been tested. Furthermore, most of these proposed solutions for DA rely on specialist skills that are beyond the expertise of most dentists in general practice and may therefore require referral to another health professional such as a psychologist (de Jongh et al., 2005). They should therefore be considered in the context of their accessibility. In the UK, the lack of awareness of self-referral and lengthy waiting lists are barriers to accessing free cognitive and behavioural interventions.

1.5.7.4 Social and peer support

One under-investigated way of addressing DA is the use of social support. Social support is a concept that describes an individual’s perceived or actual access to a social network that will provide different types of assistance such as emotional, instrumental (also described as tangible or material), or informational support, often in a reciprocal manner (Taylor, 2012). According to Taylor, this support can be provided by family members, friends, members of a community, or even by strangers, and there is evidence to indicate that social support can have a beneficial effect on both physical and mental health outcomes. Abrahamsson et al. (2002) argue that social support also plays a part in DA, by reducing the negative emotions that it can trigger. They argue that social support may increase a dentally anxious individual’s ability to use coping mechanisms, even without reducing the anxiety itself. Social support can take the form of peer support, which Reidy et al. (2024, p. 1) describe as “the connection of two or more people with shared lived experiences”, on a one-to-one basis or in group settings, either online or in person. In a study of online peer support, Buchanan & Coulson (2007) reported a statistically significant difference between the number of people who reported that their DA improved and those who reported that their DA remained the same after accessing Dental Fear Central, an Online Support Group (OSG) for people living with DA. However, this is based on self-reports of anxiety in a non-randomised retrospective pilot study, not on dental attendance. Therefore, more robust evidence is needed to confirm these results and ascertain whether that reduction in anxiety also translates into behavioural change.

1.6 Conclusion

In conclusion, DA is a prevalent condition with a significant psychosocial impact. Its aetiology is most likely multi-factorial, and although a variety of pharmacological and non-pharmacological ways of treating or managing the condition have been evaluated, all of them have their limitations. Given the prevalence and impact of DA, further research into ways of alleviating or managing the condition is warranted. The use of social support, and more specifically online peer support, as a way of managing DA is an under-investigated area. In the next chapter, I will therefore review the literature on OSGs, before considering the role that these may be able to play in health outcomes.

Chapter 2: Online Peer Support

2.1 Chapter summary

In this chapter, I aim to provide an overview of the literature on Online Support Groups (OSG), with a specific focus on health-related OSGs. As internet usage continues to increase, OSGs could provide an accessible and cost-effective way of providing support across a range of health conditions. These health-related virtual communities allow individuals to exchange first-hand experience, and like people living with Dental Anxiety (DA), OSG users are more likely to be female and under 65. People turn to OSGs to address unmet information needs, as well as for emotional and social support, particularly for stigmatised conditions. The way in which people engage with OSGs varies, with most users reading without actively posting, and there is conflicting evidence of how engagement affects outcomes. The reported benefits of OSGs include their availability and their anonymity which may encourage disclosure. There is also evidence that they can reduce social isolation. However, OSGs are also associated with negative aspects such as misinformation, exposure to pessimistic or distressing content, and rude or confrontational behaviours. There is some, albeit limited, evidence on how OSGs can help influence health outcomes, and some evidence for the psychological processes that might underpin health-related behaviour change. Therefore, further research is needed to understand the effect that OSGs might have on DA, and feasibility work is required to ensure any future Randomised Control Trial (RCT) is appropriately operationalised.

2.2 Internet access and usage

The last decade has seen a significant increase in the number of UK households that have access to the internet, from 73% in 2010 to 96% in 2020 (Office for National Statistics, 2020). Furthermore, there has been a rise in the number of people searching for health information online: according to the ONS, 60% of internet users over 16 in the UK report having searched for health-related information online (Office for National Statistics, 2020), compared to just 30% in 2010. The way in which people use the internet has also evolved over time, as people are increasingly looking for interactions and connections, rather than static information (Eysenbach, 2008). This is demonstrated for example by the rise in social media usage in adults in Great Britain - from 45% of adults in 2011 to 70% in 2020 (Office for National Statistics, 2020) - as well as in the US - from 50% in 2011 to 72% in 2019 (Fox, 2011). Although it is difficult to estimate the number of health-related Online Support Groups (OSGs), and how popular they are, in an online survey of a thousand internet users in the UK, O'Neill et al. (2014) found that more than a quarter of participants had participated in health-related OSGs. Furthermore, the recent COVID-19 pandemic prompted a significant number of peer support groups to move from face-to-face format to online, as these enabled physically safe connections during periods of lockdown or limited social contact (Judd-Glossy et al., 2022; McMullan et al., 2021; Rayland & Andrews, 2023).

2.3 Policy context of e-health

The World Health Organisation defines e-health as “the use of information and communication technologies for health” (World Health Organisation, 2025). Their broad definition encompasses areas such as health-care services as well as health education and research. Although less recent, Eysenbach (2001) offers a relevant definition of e-health as covering three domains: consumer interaction with health systems online, institution to institution transmission of health data, and peer-to-peer online communication around health. As the global population ages, healthcare systems face a growing challenge of increased demand for services (United Nations, 2019) and therefore associated costs. In the UK, this issue is compounded by staff shortages (NHS, 2019). The NHS has therefore set out ways of addressing these challenges in its Long-Term Plan (NHS, 2019). The plan outlines the NHS's ambition to encourage patients' activation and supported self-management, by improving patient knowledge and promoting healthy behaviours. The plan acknowledges the role that peer support can play in achieving this and emphasises the importance of digital resources in facilitating self-management. Furthermore, a report from the Good Things Foundation (2020) shows a six-fold return on investment for every pound invested in digital health literacy by the NHS, demonstrating the economic benefits of digitally enabled self-care. There is therefore value in reviewing whether online peer support could offer an easily accessible, cost-effective way of supporting people living with DA.

2.4 An introduction to online support groups

OSGs are interactive virtual communities where people get together based on a common interest. In the case of health-related OSGs, Eysenbach et al. (2004, p. 1166) describe them as “virtual communities where social networks are formed or facilitated through electronic media” and where peers “share experiences, ask questions, or provide emotional support and self-help”. These communities are generally focused on a specific condition or illness and allow individuals to exchange first-hand experiential knowledge about living with a specific condition (Kingod et al., 2017).

OSGs can be either synchronous or asynchronous. Synchronous groups imply that all participants converse with each other in real time (e.g. chat rooms), whereas asynchronous groups allow discussions to unfold over an extended period of time. Support groups can encompass a variety of different technical platforms, from message boards or discussion forums to social media groups (e.g. Facebook). OSGs can be moderated or unmoderated, and moderation can be provided by a health professional, by an employee or volunteer, or by a peer. Moderators have an administrative role, such as removing spam or comments that breach the site’s guidelines, and a facilitation role which can involve sharing information, responding to questions and encouraging discussion, for example by starting new discussion threads (Huh et al., 2016; Smedley & Coulson, 2017). Whilst some research reports evidence that participants feel safer on moderated sites (Huh et al., 2016), and that moderation had a positive impact on behaviour change (Lindsay et al., 2009), there is equally research to indicate that it can stifle discussion, mutual support and reduce self-moderation of community norms (Huh, 2015; Maloney-Krichmar & Preece, 2005).

2.4.1 Socio-demographic characteristics of online support group users

In terms of demographics, across both individual studies and systematic reviews, there is evidence to indicate that regardless of condition, women are more likely to use OSGs (Hu et al., 2012; Litchman et al., 2018; MacLachlan et al., 2020; Merolli et al., 2013). The over-representation of women amongst both the dentally anxious and OSG users is encouraging in terms of the acceptability of online peer support as a potential solution.

In terms of age, Owen et al. (2010) showed that those aged 65 and above were significantly less likely to have used an OSG. Although internet penetration in this age category has significantly increased in recent years (Office for National Statistics, 2020), it remains lowest in this age group. However, according to the AOHS (Office for Health Improvement and Disparities, 2024), this is also the age group least likely to be living with DA. Furthermore, internet usage in the UK is highest and most frequent amongst those aged 16-24, an age group which is most likely to participate in online social networking, and which is still as likely as the average population to look for health information online (Office for National Statistics, 2020) even though, arguably their health needs are lower than those of an older population. Therefore, there is strong overlap between the age group most likely to be living with DA and those most likely to potentially be receptive to an online solution.

Whilst DA seems to disproportionately affect people in lower socio-economic groups, there is evidence that OSG users are more likely to have higher levels of education, higher income, and are less likely to be from an ethnic minority background (Hong et al., 2012; Merolli et al., 2013; Moorhead et al., 2013). However, in a systematic review of research on users of social media for health communication (including but not limited to OSGs), Moorhead et al. (2013) found that some studies reported a higher proportion of low-income users and a lower proportion of non-Hispanic whites. These findings are echoed by Chou et al. (2009) who found that amongst internet users, social media and social networking sites in particular showed lower disparities in penetration based on education or race. This hints at an interesting possibility that social media may encourage access amongst a wider demographic than traditional forums. Furthermore, Hu et al. (2012) found that whilst a level of e-health literacy was required to search for and understand online health information, health-related OSGs made such information easier to access and understand. Allen et al. (2016) even argue that membership of an OSG may help improve health literacy. In any case, it is important to bear in mind that not everybody is digitally enabled, and that even in the UK, inequalities still exist in terms of access and digital and health literacy (Borg et al., 2019; Mee et al., 2024; Singleton et al., 2020). Those who are most disadvantaged are likely to face the greatest barriers to access, and whilst this does not invalidate online peer support as a potential solution for helping people overcome DA, careful thought would need to be given to ensure it is both accessible and suitable for all socio-economic profiles, in order to guard against exacerbating existing health inequalities.

2.4.2 Motives for seeking support through online support groups

A variety of factors may influence an individual’s motivation to turn to OSGs for support. Perhaps unsurprisingly, existing evidence would indicate that first and foremost there needs to be a perceived problem or an unmet need. According to Chou et al. (2009), individuals who experience higher levels of psychological distress and who have poorer subjective health are more likely to use OSGs. Furthermore, reviews by Ziebland & Wyke (2012) and Allen et al. (2016) identified how people turn to OSGs in order to address unmet information needs. Peers can provide expertise on the day-to-day management of a condition and practical support (Allen et al., 2016) . This appears to be equally applicable in the context of DA, as Buchanan & Coulson (2007) found that initial contact with an OSG was made when a problem manifested itself: participants were searching for help and solutions without the need to access a dentist. They also found that participants shared potential coping strategies and practical support on dealing with the oral health problems on a day-to-day basis. More broadly, Wright (2016) argues that people are more likely to access support online if they do not have access to adequate support within their existing offline networks, for example if their condition is rare or not well understood by either health professionals or their main social network. However, people would seem to turn to OSGs not only for unmet information needs, but also for emotional and social support (Moorhead et al., 2013). Members of OSGs also often report that offering help and advice to others is an important part of their online experience (Mo & Coulson, 2014; van Uden-Kraan et al., 2008a), contributing further to the creation of supportive, accessible communities. People living with conditions that they perceive to carry stigma or to be embarrassing appear to be particularly motivated to join OSGs. If the interpersonal consequences of living with a disease or condition are perceived as high, people are more likely to seek the support of others with similar conditions (Davison et al., 2000; Wright, 2016). This is particularly relevant as stigma has been identified as potentially leading to social isolation and to poorer health outcomes (Ettridge et al., 2018; Hatzenbuehler et al., 2013).

Whatever the motivation that leads participants to engage with an OSG, in order for their needs to be met, there is evidence that they need to connect with people whom they perceive to be similar or have similar experience, as this lends credibility to the information provided (Wright, 2016) and mitigates social isolation (Wright & Bell, 2003).

2.4.3 How do people engage with online support groups

People differ in the way that they use OSGs, both in terms of frequency of interaction and in terms of levels of engagement. The commonly used terminology distinguishes between “lurkers” who read other people’s posts but do not actively comment themselves, and “posters” who initiate threads or leave comments. According to O’Neill et al. (2014), the majority of users fall into the first group. Several studies (de Simoni et al., 2020; Joglekar et al., 2018; O’Neill et al., 2014) describe “superusers” who, although they represent a very small proportion of users, account for a high proportion of the posts. It is also worth noting, in the context of a study on DA which disproportionately affects women, that in a survey of 1,000 internet users on user-generated online health content, O'Neill et al. (2014) found that superusers were more likely to be male than female.

In terms of outcomes, previous research by van Uden-Kraan et al. (2008a) has shown negligeable impact on the psychosocial benefits reported by either lurkers or posters. However, Litchman et al.'s (2018) analysis of diabetes online communities indicated that high engagement with OSGs was a strong predictor of better glycaemic levels. Furthermore, O'Neill et al. (2014) argue that superusers were more likely to report that information accessed through an OSG affected their self-care behaviour. However, due to their methodology, none of these studies allow a definite causal link to be inferred, so those who experience the greatest psychosocial benefits could be encouraged towards greater participation and involvement, rather than the reverse.

Perhaps then, rather than the different roles that people can take on in OSGs, what really matters is their level of motivation to engage with the community. Eysenbach et al. (2004) highlight that for OSGs to effectively deliver psychosocial outcomes, participants may need to have a desire to engage. In relation to DA therefore, it is important to remember that few studies have been able to assess the efficacy of solutions amongst those people whose fear keeps them from engaging with either treatment or solutions to help them overcome their fear. OSGs may prove no more effective at reaching those whose motivation to overcome their fear is limited.

2.5 Benefits of online peer support

2.5.1 Availability

One of the key benefits reported by users of asynchronous text-based OSGs is the availability of these groups 24 hours a day, seven days a week (Malik & Coulson, 2008). This enables individuals to access information at a time that is convenient (Allen et al., 2016) but also means that support and information are available at a time of crisis when it is most needed (Tucker & Lavis, 2019). In terms of DA, this means that access to support is available on demand during the already anxiety-inducing anticipation phase, ahead of an appointment or scheduled treatment. This convenience of access is also important in terms of lower socio-economic groups, as they are more likely to be employed in less flexible jobs and require solutions that are not only available during the normal working day. Finally, access to OSGs is readily available and unlimited, unlike some of the cognitive and behavioural therapies previously described (see Section 1.5.7).

2.5.2 Anonymity

Asynchronous OSGs that are text-based provide a level of anonymity, allowing members to choose whether and how much to disclose about themselves (Allen et al., 2016; Barak et al., 2008; Broom, 2005). This anonymity may encourage disclosure, particularly on sensitive matters that members may not feel comfortable discussing face to face, and it may also encourage individuals to reach out for help and support (Allen et al., 2016; Mo & Coulson, 2014). Furthermore, by enabling access to individuals beyond ones' close social circle, OSGs foster "weak-tie" support: encouraging connection to a wide group of people from a broad range of backgrounds and a wide variety of opinions (Wright & Bell, 2003). This combination of weak-tie support and the anonymity that an OSG can provide, may reduce the fear of stigma, reduce the perceived inter-personal risk, and therefore also encourage greater disclosure (Wright & Bell, 2003; Wright & Rains, 2013). Indeed, research has found that people with conditions associated with greater social stigma or embarrassment (Davison et al., 2000) are more likely to use OSGs. This would indicate that OSGs could be highly relevant for people living with DA given the self-perceived social stigma and the fear of disclosure associated with the condition (Cohen et al., 2000; Locker, 2003). Indeed, in a qualitative study of participants who used an OSG for DA, Buchanan & Coulson (2007) report that shame stopped their participants from discussing their condition with friends and family, and that they turned to an OSG in order to interact with people who shared their fear. Furthermore, because of the anonymity provided by this format, people who are embarrassed about their dental condition may find it easier to engage in a text-based exchange (rather than face to face or video) that allows them not to be seen by the peers they are engaging with.

2.5.3 Emotional support and reduced isolation

Several studies have reported that online peer support, whether synchronous or asynchronous, can reduce the isolation felt by those affected by a chronic condition or illness by being able to interact with people with similar experiences (Merolli et al., 2014; Mo & Coulson, 2014). OSGs may provide validation (Allen et al., 2016) as well as a sense of community and even a shared identity (Merolli et al., 2014). Here again, these findings are supported with regards to DA by Buchanan & Coulson (2007) who found that participants were reassured to find that others also had similar anxiety and that they were not unique in having such "irrational" and sometimes extreme fears. Furthermore, they no longer felt that they had to face their anxiety alone but benefitted from communicating with others in a safe and supportive environment that allowed them to share their dental history and previously traumatic experiences.

2.5.4 Access to lived experience

Whilst health professionals can provide factual information, first-hand lived experience can provide information in a more accessible or engaging way (Mo & Coulson, 2014; Ziebland & Herxheimer, 2008) OSGs can provide access to peer narratives as well as information about outcomes (Sillence & Bussey, 2017). In particular, modelling has been highlighted as potentially playing a part both in self-management supported by OSGs (Allen et al., 2016) as well as in the acquisition of DA. Therefore, peer narratives could potentially serve a useful function in demonstrating that others have managed to overcome their DA and access treatment. Indeed, there is evidence to show that use of an OSG and seeing others sharing their success stories helped participants challenge their fears, leaving them encouraged and hopeful that they may also be able to attend treatment (Buchanan & Coulson, 2007). However, for OSGs to be considered efficacious in helping dentally anxious people to overcome their fears, more evidence is needed.

2.6 Negative aspects of online support groups

Although there is evidence for the benefits of OSGs, there are nonetheless still negative aspects, which may either deter some individuals from participating or impact the experience of participation.

2.6.1 Quality and quantity of information

One of the key criticisms levelled at OSGs underpinned by asynchronous text-based discussion platforms is the risk of misinformation. Several studies and reviews have identified concerns about the quality and reliability of the information provided (Mo & Coulson, 2014; Moorhead et al., 2013; Pfeil et al., 2009), to the extent that some consider it a reason not to engage with OSGs (Broom, 2005). However, on a selection of discussion threads across three health different conditions, Cole et al. (2016) found that whilst a small proportion of the information was assessed as being “poor” by health professionals and lay assessors, the assessors did not agree that the information would have necessarily been acted upon. As forums grow and gain in popularity, it is not just incorrect information that users may struggle to navigate, but also the sheer volume of information, which according to Mo & Coulson (2014) can make finding relevant material more difficult. Whether these negative aspects are salient for users of DA OSGs remains to be investigated.

2.6.2 Negative experiences

In a study of online infertility support group users, Malik & Coulson (2008) found that reading about other peoples’ negative experiences was a significant concern. Online users may be reminded of the severity of their condition (Sillence et al., 2013) or may be exposed to negative aspects of the disease or negative outcomes, causing concern that these could be relevant for them in the future (Holbrey & Coulson, 2013; Steadman & Pretorius, 2014; van Uden-Kraan et al., 2008a). Furthermore, some studies have highlighted that OSGs can be perceived as a platform where people revel in the negativity or catastrophise without seeking constructive solutions or outcomes (Broom, 2005; Holbrey & Coulson, 2013; Merolli et al., 2014). However, it is worth also noting that in some cases, positive experiences or success stories encountered online, rather than generating hope or optimism, can cause increased frustration through a negative comparison with one's own experience or situation (Malik & Coulson, 2008).

Whilst there may be evidence to show that completing a questionnaire about DA is unlikely to trigger anxiety, that evidence does not extend to demonstrating that being exposed to other people's lived experience of dental treatment or dental fear is not a trigger that could cause distress. In fact, one limitation of OSGs for some people with extreme dental fear could be that they may be unwilling to access sites that bring to life the very thing that they fear.

2.6.3 Misinterpretation and flaming

One potential drawback of an asynchronous online format which relies on the written word is the absence of visual cues or tone of voice. This can lead to incorrect assumptions or misunderstandings, which in turn can lead to feelings of awkwardness (Attard & Coulson, 2012). Furthermore, in the same way that online disinhibition can encourage disclosure, it can also encourage negative or inappropriate behaviour (Shoebotham & Coulson, 2016; Suler, 2005). The term "flaming" refers specifically to rude or confrontational behaviour online, which can lead to individuals feeling under personal attack for views they have expressed online, particularly if these are at odds with the prevailing opinion of the group (Allen et al., 2016; Mo & Coulson, 2014). Even without flaming, there is a risk that participants may find it difficult to integrate into an established network that they perceive as being a clique, particularly if their posts go unanswered (Holbrey & Coulson, 2013;

Shoebotham & Coulson, 2016; Steadman & Pretorius, 2014).

2.6.4 Over-reliance on online support groups

Whilst recognising that joining an OSG can provide access to social support that is not readily accessible in one’s existing social network, some studies report a risk of becoming excessively focused or over-reliant on OSGs, to the detriment of other daily activities (Holbrey & Coulson, 2013; Malik & Coulson, 2008; Shoebotham & Coulson, 2016) or even real-life relationships (Hinton et al., 2010; Mo & Coulson, 2014). Hinton et al. (2010) in a study on couples with fertility problems, go so far as to argue that it can increase isolation, as the shared experience from members of the support groups is contrasted with the lack of understanding from real life relationships. Other research highlights the risk that OSGs become forums for wallowing or even catastrophising (Broom, 2005; Merolli et al., 2014). In extreme cases, OSGs may also lead to reduced confidence in the way healthcare professionals are managing a condition (Holbrey & Coulson, 2013), which could potentially be compounded by doctors not engaging with or being dismissive of material that patients have found online (Broom, 2005; Malik & Coulson, 2008). However, it is important to note that across the literature, participants report more positive than negative aspects to their engagement with OSGs.

2.7 Theoretical perspectives

On balance, there appears to be much to recommend OSGs as a way of helping people with health conditions, including DA. However, to establish that online peer support can be a valuable tool, it is important to understand how OSGs might influence outcomes and what psychological processes might be involved.

2.7.1 Empowerment

Previous literature has shown that empowerment is an example of one such theoretical perspective that has helped elucidate how OSGs might help users achieve psychosocial outcomes. Barak et al., (2008, p. 1870) define empowerment as “both perceived capabilities in coping with various challenges and the perceived ability to overcome obstacles”. They argue that participation and the outcomes of participation in OSGs can lead to personal empowerment, as OSGs contribute to a sense of well-being, control and self-confidence, as well as more social interactions and a greater feeling of independence. Furthermore, in a survey of members of OSGs across 3 different conditions (arthritis, breast cancer and fibromyalgia), Van Uden-Kraan et al. (2008a) found that participants reported feeling empowered by their online activity. Specifically, participants not only experienced enhanced social wellbeing, and felt better informed, but also reported increased optimism and control (Van Uden-Kraan et al., 2008a). This aspect of empowerment could be relevant for DA as perceptions of unpredictability and uncontrollability and have found to contribute to the maintenance of the condition (Armfield, 2006; Edmunds & Buchanan, 2012). Perhaps more importantly, given the evidence around the influence of the relationship between dental practitioner and patient on DA (The Health and Social Care Information Centre, 2011; Yuan et al., 2020), another empowerment outcome identified by (Van Uden-Kraan et al., 2008a) was confidence in the relationship with the physician. These findings are supported by Mo & Coulson (2014) who found that users of an HIV OSG reported improved disease management and greater confidence in their relationship with a physician. Several studies have shown that knowledge and skills gathered by accessing peer experiences online can support a more active involvement in healthcare by helping to navigate health services, preparing for conversations with health professionals, supporting treatment decisions, and improving health literacy (Brady et al., 2017; Hu et al., 2012; MacLachlan et al., 2020; Sillence & Bussey, 2017; Ziebland & Wyke, 2012). Indeed, in the context of DA, these findings appear to be confirmed by Buchanan & Coulson (2007) who found that participants highlighted feeling empowered by the support they accessed online and specifically mentioned feeling more confident in discussing their anxiety with dentist because of their OSG participation.

2.7.2 Social comparison

According to Festinger's Social Comparison Theory (1954), individuals are driven to self-evaluate by comparison to other people. Social Comparison Theory also states that we are more likely to compare ourselves with other individuals who we consider similar enough to ourselves, either in terms of opinions and abilities (Festinger, 1954) or in terms of experience and identity (Barta et al., 2023), in other words people we are more likely to identify as peers.

Social comparison can enable individuals to either identify with others or provide contrast with others: Buunk & Dijkstra (2017) have proposed a model according to which upward identification (where an individual identifies with someone better off than themselves) can lead to optimism and hope and downward contrast (where an individual compares themselves positively to someone worse off) can support self-esteem or psychological well-being. Reversely, downward identification (where an individual identifies with someone worse off) and upward contrast (where an individual compares themselves negatively with someone better off) can have negative effects on self-esteem or psychological well-being.

In a health-related context, there is evidence that upward comparison (with individuals who are doing better or coping better) can support hope and motivation to engage in health behaviours, and that lateral comparison (with people who are doing neither better nor worse) simply helps individuals self-evaluate (Diel & Hofmann, 2019; Peng et al., 2019). According to Barta et al. (2023) online social comparison is no different and has been shown to either detract from or contribute to individual well-being, depending on the complex circumstances involved.

In the context of OSGs, Dibb & Yardley (2006) argue that for participants of an OSG for Ménière's disease, engagement in positive social comparison was associated with better adjustment to chronic illness, and negative social comparison was associated with worse adjustment. Furthermore, in a study on social comparison in an OSG for diet and weight loss, Malloch et al. (2023) argue that downward contrast can support self-esteem, and that self-esteem in turn can influence health efficacy which can in turn contribute to health behavioural intentions. Finally, Batenburg & Das (2015) provide support for the identification and contrast model in a study of users of breast cancer support OSGs. They found that users who engaged in downward identification and upward contrast reported lower psychological well-being than those who did not engage in negative comparisons. They also highlight the risk of very active users of OSGs becoming entrapped by negative social comparisons. In summary, social comparison in OSGs can contribute to either positive or negative psychological outcomes, and there is some evidence that it can contribute towards health behaviours.

2.8 Online support groups and health outcomes

There is some, albeit limited, evidence across different conditions to indicate that online peer support can help encourage behavioural change and therefore promote improved physical healthcare outcomes. Sillence et al. (2013) found that people with asthma were reminded of the severity of the condition by reading online about the experiences of others with the condition, which in some cases led them to re-engage with inhaler use. In a website survey of Canadian OSG users across multiple conditions, Audrain-Pontevia et al. (2019) argued that empowerment gained through OSGs positively influenced a patient’s adherence to prescribed treatment, both directly and indirectly through a patient’s commitment to a physician. In diabetes, both Nelakurthi et al. (2018) and Litchman et al. (2018) found that users of diabetes-specific OSGs or social media networks in the US monitored their glucose more frequently and reported better insulin compliance than non-users. However, in a Spanish study, Herrero et al. (2020) found lower levels of self-management and greater health complications amongst people with type II diabetes who engaged with OSGs. In a quantitative study with breast cancer survivors, Ruiz-Romeo et al. (2025) found evidence of increased empowerment after usage of an OSG. Importantly, all these studies are cross-sectional, meaning that the evidence should be treated with caution as a myriad of other factors could be affecting the observed outcomes.

In addition, many of the studies that have reported on the benefits of online peer support rely on participants who have chosen not only to participate in an OSG, but also to participate in research on the topic (Audrain-Pontevia et al., 2019; Coulson & Buchanan, 2008; Litchman et al., 2018), further compounding the risk that the participants amongst whom these results are identified are not fully representative of the wider population of people with the condition. Indeed, Eysenbach et al. (2004) highlight the risk that participants for whom OSGs do not bring benefits may be underrepresented in research, and that an inherent desire to participate in an OSG may be a pre-requisite for any benefits to manifest.

Several systematic reviews have been conducted to summarise the available evidence on the effect of OSGs on both psychosocial and physical outcomes, either with a focus on a single condition or across multiple conditions. Many of the qualitative reviews conclude that OSGs provide psychosocial benefits, such as increased knowledge or health literacy and empowerment (Johansson et al., 2021; MacLachlan et al., 2020; Merolli et al., 2013), as well as emotional or social support (Allen et al., 2016; Ihrig et al., 2020; Litchman et al., 2019; Merolli et al., 2013). In a review and meta-analysis of RCTs on cancer-related OSGs, Zhang et al. (2022) argue that they provide significant beneficial effects on quality of life, depression, anxiety and self-efficacy relative to controls. However, several other quantitative systematic reviews conclude that there is inconclusive or marginal evidence for psychosocial outcomes when operationalised as depression or quality of life scores (MacLachlan et al., 2020; Mccaughan et al., 2017; Van Eenbergen et al., 2017). Across both qualitative and quantitative reviews, many highlight the need for more randomised control trials to be carried out, with higher numbers of participants and greater methodological rigour (Eysenbach et al., 2004; Griffiths et al., 2009; Kiemen et al., 2023; MacLachlan et al., 2020; Mccaughan et al., 2017; Van Eenbergen et al., 2017; Zhang et al., 2022). There appears to be a lack of evidence for the effectiveness of OSGs on physical or behavioural outcomes (Kiemen et al., 2023; Litchman et al., 2019; MacLachlan et al., 2020; Merolli et al., 2013).

Therefore, whilst OSGs appear to have a positive effect on psychosocial outcomes, more research is needed in the form of RCTs, in particular to evaluate whether OSGs can impact physical outcomes or health behaviours. Eldridge et al. (2016) state that a systematic review is an essential initial step to address whether an RCT is necessary or desirable. Furthermore, according to Wright (2016), existing studies often suffer from confounding factors, and from poor implementation and operationalisation of the outcome measures. This highlights the need to also conduct rigorous feasibility work ahead of any RCT, as small-scale feasibility studies can be designed to help identify and resolve some of these issues and can provide evidence as to whether a larger RCT is possible and if so, how it should be conducted (Eldridge et al., 2016).

2.9 Statement of aims

Therefore, the aim of this PhD is to conduct a small-scale randomised feasibility study to establish whether a future RCT is possible and to inform its design.[1]

2.10 Conclusion

Online peer support could be an additional, useful tool to reduce stigma and help dentally anxious patients to sufficiently overcome their fears to help them access treatment. Although there is strong evidence to demonstrate positive psychosocial outcomes from OSG participation, much of it is qualitative and there is a paucity of methodologically robust and theoretically informed studies that demonstrate how OSGs can influence behaviour that leads to physical or clinical outcomes. Further research is required to provide robust evidence around the effects of online peer support on DA, and both a systematic review and rigorous feasibility work need to be conducted to ensure any future RCT is necessary, desirable and appropriately

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[1] An overview of the purpose of feasibility studies in general and more detailed aims of this study in particular can be found in Chapter 4, Section 4.2.2.

operationalised to deliver this evidence. Therefore, the next chapter is a systematic review to explore what is already known about the experiences of users of OSGs for DA.

Chapter 3: A Systematic Review of Experiences of Users of Online Support Groups for Dental Anxiety

3.1 Chapter summary

The aim of this systematic review is to evaluate the experiences of Online Support Groups (OSGs) for adults living with Dental Anxiety (DA).

This review included any qualitative studies without language restrictions that explore the experiences of OSGs for adults living with DA. This review excluded studies on paediatric DA, on face-to-face support groups, on online psychological therapies, and studies that investigate access to medical and dental professionals online.

The analysis included studies identified through searches carried out on the following databases: MEDLINE (Ovid), PsycInfo (Ovid), EMBASE (Ovid), ACM, CINAHL (Ebsco), DART and Web of Science from 1998 onwards. Searches were concluded in February 2022. Study selection, critical appraisal, data extraction and synthesis, were all conducted in accordance with the JBI methodology for the systematic review of qualitative evidence, and this chapter was written based on the JBI recommended template for systematic reviews.

Titles and abstracts were reviewed for 107 studies, from which only 2 qualitative studies met the inclusion criteria. These two studies represented a combined total of 249 individual participants. Both studies were UK-based and published more than 10 years ago. Both studies had ethical approval and were well illustrated with quotes from participants. However, both lacked explicit mention of their cultural, theoretical and philosophical premise, and both failed to acknowledge reflexivity and the influence that the authors had on the findings.

Across both studies, 29 individual findings were extracted which led to 5 synthesised findings through meta-aggregation: Sources of DA, negative cognitive and behavioural consequences of DA, initiating change, support provided by the OSG, and the OSG helps change thinking and behaviour. Synthesised findings from this review would indicate that participation in an

OSG can be a positive experience for adults with DA and can bring about positive changes. However, given the limited number of studies and the methodological limitations of the studies, conclusions need to be treated with caution and further research is required for validation. Finally, the strengths and weaknesses of the JBI methodology itself need to be considered.

3.2 Summary of findings

Table 3.1 lists the findings that were synthesised through the meta-aggregation process (see Section 3.4.6), their level of dependability and credibility based on the assessment of methodological quality, and their overall JBI ConQual score (Munn et al., 2014) (see Section 3.5.2).

Table 3.1: Summary of findings

Systematic review title: The experiences of users of online support groups for dental anxiety: a systematic review Population: Adults with Dental Anxiety (DA) Phenomena of interest: Online Peer Support Context: Studies in any language published from 1998 to present					
Synthesised Finding	Type of research	Dependability	Credibility	ConQual score	Comments
Sources of DA	Qualitative	Moderate (all findings from Buchanan et al., 2010)	Remains unchanged*	Moderate	*All findings were unequivocal
Negative cognitive and behavioural consequences of DA	Qualitative	Moderate (all findings from Buchanan et al., 2010)	Remains unchanged*	Moderate	*All findings were unequivocal
Initiating Change	Qualitative	Moderate (mostly findings from Buchanan et al., 2010)	Remains unchanged*	Moderate	*All findings were unequivocal
Support provided by the OSG	Qualitative	Low (mostly findings from Buchanan & Coulson, 2007 and some from Buchanan et al., 2010)	Downgrade one level*	Very Low	*Mostly unequivocal, but some credible findings
The OSG helps change thinking and behaviour	Qualitative	Moderate (mostly findings from Buchanan et al., 2010)	Downgrade one level*	Low	*Mostly unequivocal, but some credible findings

3.3 Rationale for the review

The NHS long-term plan (NHS, 2019) acknowledges both the role that peer support can play in supporting a patient’s knowledge, skills and confidence to manage their health, as well as the importance of digitally enabled self-management. Given the prevalence and impact of DA, the evidence for the psychosocial benefits of Online Support Groups (OSGs) from reviews on other conditions, and the potentially cost-effective nature of online peer support, there is value in reviewing what studies exist on OSGs for DA and what their findings are. Systematic reviews, because of the rigour and structured process involved, are considered a key pillar of evidence-based medicine (Aromataris & Munn, 2020). Furthermore, according to Eldridge et al. (2016) they are a pre-requisite for any feasibility study, to help assess whether an RCT is necessary or desirable. A qualitative review was chosen for two reasons: firstly, because there is a paucity of published quantitative studies on OSGs for DA, and secondly because an understanding of users’ experiences is an important first step in assessing the feasibility of an RCT. To date, it appears that no systematic reviews have attempted to collate, summarise, and evaluate the existing evidence on users’ experiences of OSGs for DA. Therefore, the objective of this qualitative review is to evaluate what is known about the experiences of online peer support groups for adults living with DA.

3.4 Methods

This systematic review was conducted in accordance with JBI methodology (Aromataris & Munn, 2020), which aims to provide a framework for the critical appraisal of healthcare evidence within complex settings and recognises the importance of both quantitative and qualitative evidence. The JBI methodology for systematic reviews of qualitative evidence aims to produce a critical synthesis of existing evidence through meta-aggregation. Reviewers therefore conduct a critical appraisal of included studies using the JBI Checklist for Qualitative Research (Aromataris & Munn, 2020), before identifying and extracting findings from included studies. Meta-aggregation then involves categorising the findings and aggregating them to develop synthesised findings.

A preliminary search of PROSPERO, Medline, the Cochrane Database of Systematic Reviews, EMBASE and Epistemonikos was conducted and no systematic reviews on the topic were identified, either completed or in progress. The protocol was registered in PROSPERO under registration number CRD42021278493 prior to full searches being conducted.

3.4.1 Inclusion criteria

The PICoS (Population, phenomena of Interest, Context, type of Study) framework was used for the inclusion criteria (see Table 3.2). The PICoS framework is an adaptation of the Cochrane endorsed PICO tool (Higgins et al., 2019), which was chosen because it is more suited to qualitative studies and has greater sensitivity than the alternative SPIDER framework (Methley et al., 2014).

Table 3.2: Inclusion criteria based on PICoS framework

Population	**Phenomenon of Interest**	**Context**	**Study Design**
Adults with Dental Anxiety	**Online Peer Support**	**Language & Date**	**Qualitative**
Includes parents, carers, family of people with dental anxiety. Includes studies where people living with DA are not the only population. Excludes studies where all participants are under 18. Excludes studies where the population includes both people living with dental anxiety and dental professionals.	Includes any type of online peer support. Excludes studies where online peer support groups are the recruitment method but not the phenomenon of interest. Excludes studies where the phenomenon of interest is online therapy (e.g. Cognitive Behavioural Therapy, desensitisation or distraction through Virtual Reality).	Includes studies in any language. Excludes any study published before 1998.	Includes any study which contains a qualitative element. Includes mixed methods. Excludes purely quantitative studies.

3.4.1.1 Population

This review included studies in which participants were adults with DA or dental phobia. Studies on paediatric DA and studies in which the only participants were children (under 18 years of age) were excluded. Studies which included participants who were using DA OSGs to access support for a partner, friend or family member were considered eligible.

3.4.1.2 Phenomena of interest

This review considered studies that explore the experiences of online peer support groups for people living with DA, both moderated and unmoderated. Studies using online peer support groups moderated by healthcare or dental professionals were considered eligible. This review considered online peer support delivered through any digital media, including online video meeting platforms and video messaging as well as text-based platforms. However, this review excluded any studies in which the phenomenon of interest is face to face peer support (with members physically in the same location), online psychological therapies (e.g., Cognitive Behavioural Therapy, exposure therapy) or access to medical professionals online for the purpose of communication between patients and health professionals.

3.4.1.3 Context

This review included studies published in or after 1998. This date has been chosen as the start of the interactive internet and user-generated content, often referred to as "web 2.0" (Eysenbach, 2008). This review did not exclude any studies based on geography or language.

3.4.1.4 Types of studies

This review considered eligible any peer-reviewed articles that include qualitative, text-based data (including for example transcripts of video messages). The search strategy aimed to locate peer-reviewed studies, both published and unpublished (e.g., doctoral theses).

3.4.2 Search strategy

An initial limited search of MEDLINE and PsycInfo was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy. For a list of key search terms used, see Table 3.3.

Table 3.3: Key Search Terms

Dental Anxiety Terms	AND	Online Support Group Terms
dental* phobi* OR dental* fear* OR dental* anxi* OR fear of dentist* OR odontophobia* OR		online chat* OR online discussion* OR online discussion group* OR online forum* OR online health communit* OR online patient communit* OR online peer support OR online support group* OR online social network* OR online fora OR virtual discussion group OR virtual patient communit* OR virtual peer support group* OR internet discussion group* OR internet forum* OR internet communit* OR internet peer support OR internet support group* OR digital communit* “digital peer support" "digital support group" "digital health communit*" "computer-mediated support group*" "computer-mediated discussion group*" "web-based support group*" "web-based discussion group*" "web-based communit*" "online fora*" "internet fora*" "chatroom*" "chat-room*" ISG OSG

Searches were conducted on MEDLINE (Ovid), PsycInfo (Ovid), EMBASE (Ovid), ACM, ASSIA (Proquest), and CINAHL (Ebsco). In addition, DART and Web of Science were included as sources of unpublished studies and grey literature.

The search strategy, including all identified keywords and index terms, was adapted for each database (for full details of search strategy by database see Appendix 1). The reference lists of all included studies were screened for additional studies. The searches were run in October 2021, and re-run prior to final analysis in February 2022 (yielding no new relevant studies).

3.4.3 Study selection

Following the search, citations were collated and uploaded into the Rayyan software collaboration tool (http://rayyan.qcri.org) and duplicates were removed. Titles and abstracts were then screened by me and both my supervisors against the inclusion criteria: Population, followed by phenomena of interest, followed by study design. Reviewers were blinded to each other's decisions until this initial stage of the review was completed and reasons for exclusion were recorded. Any studies on which the reviewers' decisions were not unanimous were taken through to full text review. The same three individuals reviewed the full text of the selected studies, still blinded to each other's decisions. The results of the search and the study inclusion process are reported in full Section 3.5.1.

3.4.4 Assessment of methodological quality

As my supervisors who were involved in the screening process were co-authors on studies eligible for inclusion, two new reviewers (KF and CB, two fellow PhD students at Nottingham University School of Medicine) were brought in to conduct the critical appraisal for methodological quality alongside me. Papers were provided to these two new reviewers in a blinded format (with any details of authors or institution redacted) to avoid any bias due to the identity of the authors. Critical appraisal was conducted using the standard JBI Checklist for Qualitative Research (Aromataris & Munn, 2020). Reviewers were blinded to each other's decisions until the discussion stage. The JBI checklist is composed of ten items, and all three reviewers discussed any disagreements at item-level to reach consensus.

3.4.5 Data extraction

Data were independently extracted and reviewed in a two-stage process by two reviewers (CS and CB), using the JBI SUMARI[2] (Munn et al., 2019) tool. In the first stage, data were extracted on the characteristics of the studies, including information on methods used, participant characteristics, setting and context of the study, geographical location, and any specifics about the phenomenon of interest. Authors of the papers were able to provide clarification or additional information where required. In the second stage, findings and illustrations to substantiate the findings were extracted by the same two reviewers. Any disagreements were resolved through discussion with a third reviewer (KF). Finally, two reviewers (CS and KF) assigned a level of credibility to each of the findings, and disagreements were resolved through discussion until consensus was reached.

3.4.6 Data synthesis

A qualitative synthesis was conducted on the findings extracted, according to the JBI meta-aggregation approach (Aromataris & Munn, 2020) which allows synthesis across different methodologies. Findings were extracted at the sub-theme level to reflect the richness of the original studies. Only findings that were rated as unequivocal or credible were included in the synthesis. These were then categorised based on similarity of meaning and aggregated to produce a single comprehensive set of synthesised findings. Findings from individual studies were synthesised without being reinterpreted, in keeping with the JBI meta-aggregation approach.

3.4.7 Assessing confidence in the findings

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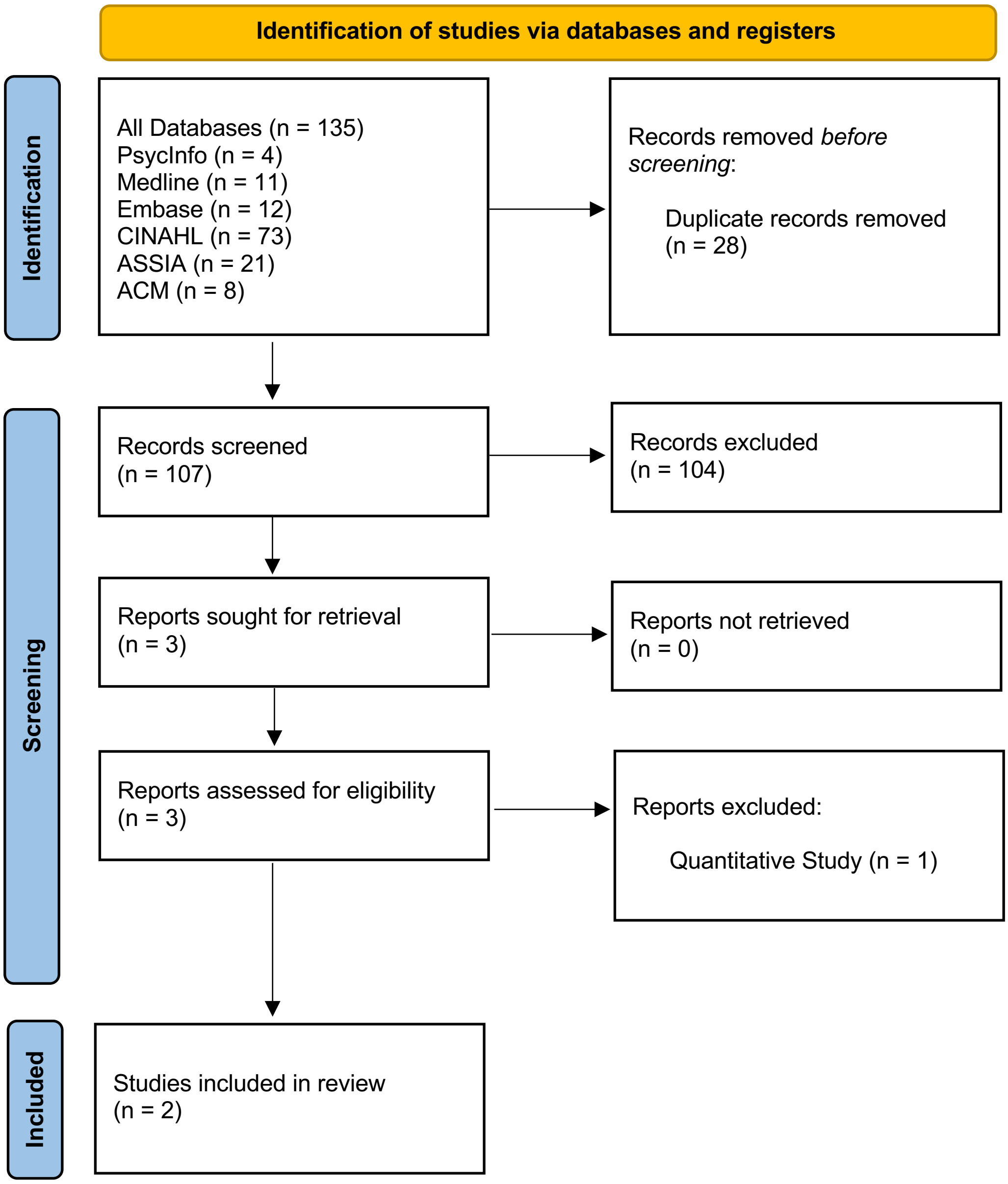
[2] The JBI SUMARI (System for the Unified Management, Assessment and Review of Information) tool is a software package designed to support the systematic review process and can be accessed at https://sumari.jbi.global/. The tool was made available to me following a JBI training course on systematic reviews.

Confidence in the synthesised findings was assessed and has been reported using the JBI ConQual approach (Munn et al., 2014) which considers the dependability and credibility of summarised findings based on both the methodological quality of the study and the credibility of individual findings. The summary of findings (see Table 3.1) outlines the major elements of the review and states on what basis the JBI ConQual score was assigned.

3.5 Results

3.5.1 Study inclusion

Figure 3.1: PRISMA flow diagram



The searches yielded 135 citations of which 28 were duplicates. Titles and abstracts were reviewed for the remaining 107 studies and 95 were excluded for featuring the wrong population (paediatric population). A further seven were excluded for featuring a different phenomenon of interest and two were conference abstracts, leaving three eligible studies for which full the text was retrieved. One study was subsequently excluded for being purely quantitative. Two studies were therefore taken forward for critical appraisal. No further relevant studies were identified from the citations of studies reviewed at full text stage. These results are presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram (Page et al., 2021) in Figure 3.1.

3.5.2 Methodological quality

After critical appraisal, all three reviewers were unanimous in their decision to include both studies for data extraction, although neither were without their methodological shortcomings. The results of the Critical Appraisal Checklist (Aromataris & Munn, 2020) are outlined in Tables 3.4 and 3.5.

Generally, both studies lacked information on the philosophical or theoretical premise on which they were based, and the reviewers were therefore unable to assess congruity between their philosophical perspective and their research methodology (Q1). The information provided to locate the researchers culturally or theoretically was either limited or absent (Q6). In addition, neither study demonstrated researcher reflexivity nor adequately addressed the influence of the researcher on the research findings (Q7). However, both studies showed strong representation of participant voices (Q8), had ethical approval from academic institutions (Q9), and were deemed to have conclusions that were supported by the analysis provided.

Buchanan & Coulson (2007) stated that their chosen methodology was phenomenological analysis, but the reviewers debated whether this was consistent with their data collection method which involved free text answers from a pre-determined questionnaire, rather than a more exploratory method such as a semi-structured interview. The reviewers also questioned whether the analysis of data from 143 participants would have only allowed the authors to present findings that were common to most participants and whether they would have been able to represent the lived experience of all participants in sufficient depth in a way that is consistent with the phenomenological approach.

Table 3.4: JBI Critical Appraisal Checklist - Buchanan & Coulson (2007)

Buchanan, H., & Coulson, N. S. (2007). Accessing dental anxiety online support groups: An exploratory qualitative study of motives and experiences. *Patient Education and Counseling*, *66*(3), 263–269.	
Q1 – Congruity between philosophical perspective & research methodology	Unclear
Q2- Congruity between methodology & research question or objectives	Yes
Q3- Congruity between methodology & data collection methods	Unclear
Q4- Congruity between methodology & data representation and analysis	Unclear
Q5- Congruity between methodology & interpretation of results	Yes
Q6- Statement locating the researcher culturally or theoretically	No
Q7- Influence of researcher on research addressed	No
Q8- Representation of participants and their voices	Yes
Q9- Ethical approval	Yes
Q10- Do conclusions flow from analysis	Yes
INCLUSION / EXCLUSION	Include

Table 3.5: JBI Critical Appraisal Checklist - Buchanan et al. (2010)

Buchanan, H., Coulson, N. S., & Malik, S. (2010). Health-related internet support groups and dental anxiety: The fearful patient's online journey. *International Journal of Web Based Communities*, *6*(4), 362–375.	
Q1 – Congruity between philosophical perspective & research methodology	Unclear
Q2- Congruity between methodology & research question or objectives	Unclear
Q3- Congruity between methodology & data collection methods	Yes
Q4- Congruity between methodology & data representation and analysis	Yes
Q5- Congruity between methodology & interpretation of results	Yes
Q6- Statement locating the researcher culturally or theoretically	Yes
Q7- Influence of researcher on research addressed	No
Q8- Representation of participants and their voices	Yes
Q9- Ethical approval	Yes
Q10- Do conclusions flow from analysis	Yes
INCLUSION / EXCLUSION	Include

Buchanan et al.'s (2010) study showed strong congruity between their stated methodology, their analysis, and their interpretation of results (Q3, Q4, Q5). Their research question was not clearly stated (Q2), however, their research aims appeared to be exploratory which was congruent with their stated choice of thematic analysis with an inductive approach.

Overall, the dependability of synthesised findings that mostly included individual findings from Buchanan et al. (2010) were downgraded from highly dependable to moderately dependable based as the answers to two of the questions were unclear and one was negative. The findings that were a combination of both studies were downgraded from high dependability to low dependability as only five questions about Buchanan & Coulson (2007) could be answered in the affirmative. For a reflection on the JBI evaluation process, see Section 2.8.

3.5.3 Characteristics of included studies

Details of the characteristics of included studies are provided in Table 3.6. Both studies included were conducted at research institutions in the UK, and both focused on an English language OSG for dentally anxious individuals. In both cases the participants were predominantly (but not exclusively) from the US and the UK. Across both studies, the total number of participants was 249. Both studies were published more than ten years ago.

Buchanan & Coulson (2007) recruited participants from the OSG and sent them an open-ended questionnaire about their experience. Phenomenological thematic analysis was conducted on data from 149 respondents, predominantly female (76.1%) aged between 16-64, and with a mean DA score of over 20 on the MDAS. On the other hand, Buchanan et al. (2010) conducted thematic analysis on messages posted on the forum over a 16-month period by 106 individual usernames who were otherwise anonymous.

3.6 Review findings

Across both studies, 28 individual findings were extracted. Eleven of these were extracted from Buchanan & Coulson (2007) and seventeen from Buchanan et al. (2010). Of these 28 findings, 23 were deemed unequivocal (U) and 5 were deemed credible (C) by the reviewers, on the strength of the illustrative quotes provided in the published articles. A full list of extracted findings by study, along with illustrations and credibility ratings, can be found in Tables 3.7 and 3.8.

Table 3.6: Characteristics of included studies

Study	Methods for data collection and analysis	Country	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results
1.Buchanan & Coulson (2007)	Approval obtained from discussion board administrator and message posted to board with invitation to participate. Data collected through an open-ended online survey (2 month data collection window). The survey included four questions about participants' experience of online support groups and background details (MDAS, age, gender, country of residence & marital status). Phenomenological thematic analysis was then carried by 2 researchers.	UK	Participants' lived experience of online support groups for dental anxiety	English language online support group (Dental Fear Central), with participants mainly from US (51.7%) & UK (35.6%) but also Canada, Australia, Germany and Slovenia (in decreasing order).	Sample size = 143 individuals who accessed the OSG and chose to participate. Participants were aged 16–64 years (mean = 36.57 years). Predominantly female (76.1%). Dentally anxious participants with an MDAS mean score of 20.03 & 70% scoring above 19 (indicative of a strong likelihood of dental phobia). 28% were single, 49.7% were married.	Three themes identified: 'Searching for help' (help-seeking behaviour online is what led the participants to the OSG), 'Sharing fears' (comfort of finding others with similar fear, sharing helps confront fears) and 'I feel empowered' (better information and confidence to face dental team).
2.Buchanan, Coulson & Malik (2010)	The group administrator of an internet suport group for dental anxiety granted permission to download messages posted over a 16-month period. In total, 67 threads containing 621 messages were downloaded in February 2007 (written text of the message, as well as the sender's username). Thematic analysis was conducted according to Braun & Clarke (2006) (it is unspecified how many researchers were involved in coding or theme generation).	UK	Online communication which takes place within support groups for the dentally anxious	English language online support group.	106 unique users of an Online Support Group for dental anxiety (all who posted during the study period). Data identifies users as both male and female, and from a variety of countries including US & UK. Due to anonymity, no further details are known about the sample.	Seven key themes identified. 'I can still remember…' / 'I was ashamed to smile or laugh' / 'This big dark secret I can't share with anyone' / 'I can't stand it anymore' / 'I cross the street rather than walk past the dental surgery' /'Talking to a computer is much easier' / 'Find a dentist that you are comfortable with'.

These individual findings were then aggregated into 11 categories based on similarity of meaning. These were in turn aggregated into 5 synthesised findings (see Table 3.9 for details). The findings provide an overview of the experience of users of an OSG for DA and start to frame their experience as a journey: from the source of their DA and the negative impact it has, to change being initiated and support being found online, through to their thinking and behaviour changing.

Table 3.7: Findings extracted from Buchanan & Coulson (2007)

Study 1: Buchanan, H., & Coulson, N. S. (2007). Accessing dental anxiety online support groups: An exploratory qualitative study of motives and experiences. *Patient Education and Counseling*, *66*(3), 263–269.	
Finding	Dentally anxious individuals used the internet to information, advice and support and found OSG **(U)**
Illustration	I began reading online support groups when I started considering returning to the dentist. My wisdom teeth were decaying and clearly needed to come out—one of them was falling out in chunks. I was completely terrified and did not know what to do, so I started doing a bit of research on wisdom teeth on the internet. At that point I did not really know that such a thing as ‘dental phobia’ as a proper condition existed, but I learned that as I was researching. It was through googling ‘dental phobia’ that I found some online support groups (28-year- old female)
Finding	Participants realised that their experience of DA is not unique or uncommon **(U)**
Illustration	‘‘It is nice to know that I am quite normal in my anxieties and phobias’’ ‘Well I can say I clearly do not feel alone, and actually did find the name of a dentist who is 2 h from me, so I might get the courage to call him up and see what he can do’’ (32-year-old female) ‘‘I am a new member and have yet to post in the group . . . however, just reading what others have posted has already given me some peace of mind. I know I am not alone in this’’ (24-year-old female).
Finding	OSG as rich and varied source of information **(C)**
Illustration	‘‘They helped me to talk about things and also gave some useful advice about finding a dentist and eventually communicating my fears to them’’
Finding	OSG helped them understand their anxiety **(U)**
Illustration	‘‘It has helped me define and face what about the dental clinic setting that causes my fears. I have also learned to have enough courage to speak for myself and to be my own advocate’’
Finding	Increased confidence with the dental team **(U)**
Illustration	‘‘Knowing that I am not the only one who is fearful has made me feel more confident. (If I had to find another dentist, I would feel more confident about saying that I am fearful and also saying what is helpful.) Also, I am now much better informed about dental treatments, which again has made me feel more confident" (46-year-old female).
Finding	Empowered by OSG to confront and challenge their fear **(U)**
Illustration	‘‘It has helped me define and face what about the dental clinic setting that causes my fears. I have also learned to have enough courage to speak for myself and to be my own advocate’’

	‘‘Well I can say I clearly do not feel alone, and actually did find the name of a dentist who is 2 h from me, so I might get the courage to call him up and see what he can do’’ ‘‘It gave me the courage to finally make my appointment. And the words of encouragement helped me to stay at the office and not run for my life’’ (40-year-old female).
Finding	Participants gain benefits from reading other members' positive experiences **(U)**
Illustration	‘‘There are some incredible success stories in the forum that have already been encouraging for me. When someone posts about what they are going to have done and how scared they are, they sound exactly like me. Then when they get through that appointment they were so dreading and fearing, they post again and say how well it went and that it was not as bad as they thought. I figure if they can do it, maybe I can too’’
Finding	Reactions of members contrast with reactions of non-members **(U)**
Illustration	‘‘... it was a place where I could post questions without being told that I am stupid and make a fuss over nothing (like my childhood dentists and others since would say)’’
Finding	OSG as a source of understanding and empathy **(U)**
Illustration	‘‘Being able to find other caring and sympathetic people who know how you feel. Most people I talk to all say the same thing ‘oh nobody likes going to the dentist’. They do not understand that this is not just a little nervousness, it is full blown fear. This support group has been a good place to come anytime I need reassurance’’ (26-year-old female). ‘‘. . . it was a place where I could post questions without being told that I am stupid and make a fuss over nothing (like my childhood dentists and others since would say)’’ (46- year-old female).
Finding	OSG as a safe, anonymous and non-judgmental environment **(U)**
Illustration	It is anonymous and feels like a safe environment which is non-judgmental as everyone has experienced [or is still experiencing] fear or anxiety at some level (26-year-old female)
Finding	OSG as a source of social support **(C)**
Illustration	‘‘They helped me to talk about things and also gave some useful advice about finding a dentist and eventually communicating my fears to them’’ (32-year-old female)

Table 3.8: Findings extracted from Buchanan et al. (2007)

Study 2: Buchanan, H., Coulson, N. S., & Malik, S. (2010). Health-related internet support groups and dental anxiety: The fearful patient’s online journey. *International Journal of Web Based Communities*, *6*(4), 362–375.	
Finding	DA related to previous experiences at the dentist **(U)**
Illustration	"I have had dental phobia most of my life. It started when I was almost five years old (I am almost 42 now), after a particularly horrendous visit to the dentist I went in for two extractions and was having “gas” there was a doctor present to administer the anesthetic, I CAN STILL SEE HIS FACE TO THIS DAY!!!"“I can still remember...being in a nitrous oxide fog, feeling pain but being unable to react to it or make it stop.” (Member 11) “I went to the dentist as a kid and had a horrible experience. Had to have oral surgery that went very badly. I could feel everything they were doing to me.. and when I protested they told me to be quiet!” (Member 34)
Finding	Feelings of powerlessness & lack of control **(C)**
Illustration	“I didn’t ask him for an alternative once he’d already started because I didn’t know you could request some of these methods of sedation…I thought only the dentist could decide on that and allow you to have it if he felt like it.” (Member 12) “Its just the dam unknown that freaks me out, ya know. Will it be bad news, will it be good news, will I have to go through extractions again.” (Member 3)
Finding	Realising they are not alone in their anxiety **(U)**
Illustration	“Ok I’m sitting bawling my eyes out! Do you know I really and truly thought I was alone in my dentist phobia! I had never heard of another person who was scared or who had the same emotional and physical reactions as I did” (Member 34)
Finding	Embarrassment related to appearance and state of dentition **(U)**
Illustration	“I’m terrified of going to the dentist mainly because I’m mortified of how my teeth look. I am so ashamed and afraid the dentist is going to look at me in disgust.” (Member 19)
Finding	Embarrassment leads to further avoidance **(U)**
Illustration	“I am a 29 year old who has a fear of dentist…I am afraid of the fact that my teeth have gotton so bad over the years that I feel most dentists will think bad of me. I have pain about three or four times in a year and suffer abscesses. I usually go to the doctors to get antibiotic. I’m not scared of pain its just total embarrassment.” (Member 21)
Finding	Lack of understanding leads to feelings of shame and to secrecy **(U)**
Illustration	“My dilemma now is that this huge ‘dirty secret’ I have hidden from him and my family will soon be out.” (Member 1) “In general I don’t tell people of my dental phobia. However I work with a woman who is like a mentor to me we talk about everything and I felt very close to her. I told her about my dental phobia last week and she said “Duh. No one likes going to the dentist, but we just do it. How simple can it be?” I tried to explain the extent of my phobia, but her response was basically ‘grow up’ I felt incredibly pathetic after talking to her. She has shared some personal things with me, including her depression, but I try to be sympathetic and would never make light of something that was serious to her. Has this happened to anyone else?” (Member 2) “It’s so strange to be a competent mom, wife, have friends...a decent life...and have this big deep dark secret I can’t share with anyone!” (Member 34)
Finding	Fear and anxiety as barrier to accessing treatment **(C)**

Illustration	“Would love to move on and conquer this phobia, have the dammed teeth out and be able to smile again so how do I go about doing that?? I cross the street rather than walk past the dental surgery, I have even left the local pub while in the middle of a lunch because the dentist came in for his lunch!! I feel a hopeless case, anyone got any good suggestions??” (Member 17) “I remembers cancelling my first appointment. I thought of a feasible excuse and just did it but I knew the time would only come round again ad I would feel this tremendous amount of anxiety all over again, I didn’t sleep, eat and my every thought was consumed with this dental appointment. I finally did go though and the dentist was fantastic with me. The thought of what could happened is far worse than the actual visit itself, trust me!” (Member 24)
Finding	Physical symptoms of anxiety **(U)**
Illustration	“Anyway, I have avoided seeking a dentist all of these years but have no choice, the idea of actually going there and having work done is making me feel sick. My first appointment is this Thursday afternoon. Will you think of me? Thank you friends.” (Member 20) “I no what you mean about shaking, heck I was shaking so hard my legs were trembling, and my dh asked me if I was cold I told him no just very nervous :’(. Its awful when you are so scared you shake…” (Member 8)
Finding	Anonymity facilitates disclosure **(U)**
Illustration	“I have never felt so frightened in my life I just don’t know what to do…Sorry bout this but talking to a computer is much easier than talking to anyone else.” (Member 5)
Finding	OSG provides empathy and understanding **(U)**
Illustration	“It is just amazing to find out how not alone I really am! It is actually a wonderful feeling! Earlier when I placed my first post, I felt so horribly scared and alone. Now, Im still scared to death of my dilemma but not so alone. Thank you guys so much for caring! All of you! This is way more than I expected" (Member 1)
Finding	Advice around importance of finding a sympathetic dentist **(U)**
Illustration	“I don’t know what past experiences have brought you here, but many if not most people find that the most important aspect is the relationship you have with your dentist – whether you like them and trust them For some reason I cant fathom, I’ve used the term ‘surrender’ myself in the past, but the odd thing is that what really helps is a dentist who makes you feel in control and empowered about your treatment options.” “My dentist was very kind and explained almost every step to me, so another bit of advice (as takingflight said) find a dentist that you are comfortable with, one that will listen to your every word and not push you into anything. Do that first, find a dentist…doesn’t matter if it takes a month or more make sure you are comfortable, after all it is you that is getting the work!.”
Finding	OSG helps combat sense of isolation and abnormality by encouraging disclosure **(U)**
Illustration	“Definitely keep posting – talking about your anxiety and sharing it with others who feel the same way is very helpful. You don’t feel so alone that way. I even told myself yesterday sitting in the chair waiting for my x-rays to come back that there are people on this board and through my blog that care about how I’m doing in dealing with this and are supportive that alone made me feel much stronger and more confident in what the dentist came back to me with. So keep posting – there’s always someone here to listen and be supportive/☺.” (Member 18) “I would also suggest talking with your partner about this, there is another poster… who felt the same way about telling their partner that you do but she did and is so happy that she did as he has given her so much support, so much so that

	she has made her first appointment and I due to go this week. You may be surprised how your partner takes this and it will be like a huge weight has been lifted from your shoulders." (Member 24)
Finding	Encouragement to rationalise and put things in perspective **(C)**
Illustration	"Have you ever thought of all the different phobias that affect the majority of us human beings? I bet the same dentist that you go see might faint at the sight of a spider, or at the idea at a trip on the sea, or who knows what…..☺. Embarrassment and shame are the two major issues that keeps us away from the chair. But I'm sure you wouldn't feel the same embarrassment going to a doctor because you have neglected an infection in…lets say one of your toes. Teeth have such a psychological weight but I wont go into any boring philosophical or psychological talk. I just ask you to think of how you would deal with the same problem in any other part of your body. Would you die of embarrassment going to the doctor's telling him you haven't had your ears checked in a long time? Or your eyes?" (Member 22)
Finding	Empowered to take action by OSG **(U)**
Illustration	'You guys are so sweet your advice helps more than you know. Thank you so much. I found a new dentist I am going to try in the new area that specializes in fear of dentists. It's a miracle! I have yet to find out if they will take my insurance...I pray they do. I will keep you guys posted.' (Member 29) "Thank you for the advice and support! I also have decided (just writing stuff down sometimes helps), that I am going to write down everything I want to talk to my dentist about so that I do not get intimidated and nervous and forget to tell him what my concerns are." (Member 35) "I'm starting to warm up to towards the access center…I feel that if I take the first step and go anywhere at all, it would be easier to go and register and go regularly. Whether it works like that in reality, don't know. But it would be a step somewhere forward ☺." (Member 28)
Finding	Pain as a trigger to overcome fear **(U)**
Illustration	"The pain of the tooth and knowing it'd be over, was inducement enough to stuff my fears as best I could and just get it done." (Member 18) "Also, its true once ur in pain, like I was back in the day with the molars, to me, no treatment could be worse than the pain I was in. And that's true. Sometimes its worse pain if you don't get the treatment." (Member 3)
Finding	Desire to overcome fear - not wanting to be trapped **(U)**
Illustration	"I feel trapped by this phobia and I just wish so much that I could beat it. The one thing that makes me feel most trapped is that no one I know understand exactly how this feels." (Member 15)
Finding	Dissatisfaction with lifestyle changes brought on by DA **(U)**
Illustration	"I'd like to eat steak again and re-train myself to smile the way I used to before I was conscious of covering the; 'spackled' side of my mouth (that dentek stuff is great but if you put it on before you go to sleep it spreads). Yeah Im petrified. But I don't want to look like a homeless person and I don't want to live on nutritional shakes through a straw." (Member 11)

3.6.1 Synthesised finding 1: sources of dental anxiety

Participants in Buchanan et al.'s (2010) study reported experiencing previous negative or traumatic experiences at the dentist, often in childhood. Participants attribute their DA to these experiences. No findings of similar meaning were found in Buchanan & Coulson (2007), although this could be because this topic did not feature in their online questionnaire.

3.6.2 Synthesised finding 2: Negative cognitive and behavioural consequences of DA

According to Buchanan et al. (2010), the negative impact of DA is wide-ranging. Participants experience physical symptoms of anxiety, but also feelings of embarrassment and shame, both about the state of their dentition and about the anxiety itself. Fear and embarrassment both lead to avoidance of treatment.

3.6.3 Synthesised finding 3: initiating change

Different motivations and triggers prompted participants to seek help. Dentally anxious individuals turned to the internet in search of information, advice and came across the OSG (Buchanan & Coulson, 2007). Triggers included pain or need for treatment (Buchanan et al., 2010; Buchanan & Coulson, 2007), dissatisfaction with the lifestyle adjustments that their dentition & anxiety required, and a desire to overcome their fear rather than be trapped by it (Buchanan et al., 2010).

3.6.4 Synthesised finding 4: support provided by the online support group

Both studies highlight anonymity, which creates a safe, non-judgmental space, thus facilitating disclosure. Participants view the OSG as a source of both information and social support (Buchanan & Coulson, 2007). Both studies highlight how participants realised that they were not alone in living with DA and that their experience was not uncommon when they started using the OSG, and how they find empathy and compassion that is lacking elsewhere. Finally, by reading about the positive experiences of other users, the OSGs enables participants to hope (Buchanan & Coulson, 2007).

Table 3.9: JBI Meta-Aggregation Schematic

Finding	Category	Synthesised Finding	Description of Synthesised finding	Dependability	Credibility
DA related to previous experiences at the dentist	Previous negative experience	Sources of DA	Participants often attribute their DA to a traumatic dental experience	Moderate (all study 2)	Moderate (all unequivocal)
Fear and anxiety as barrier to accessing treatment	Negative Consequences of DA	Dental Anxiety carries negative cognitive and behavioural consequences	The negative impact of dental anxiety is wide ranging: from embarrassment and shame to avoidance and physical fear.	Moderate (all study 2)	Moderate (all unequivocal)
Physical symptoms of anxiety					
Embarrassment related to appearance and state of dentition	Embarrassment				
Embarrassment leads to further avoidance					
Lack of understanding leads to feelings of shame and to secrecy					
Pain as a trigger to overcome fear	Trigger for change	Initiating change	Different motivations and triggers prompted participants to seek help online and to try and overcome their fear	Moderate (mostly study 2)	Moderate (all unequivocal)
Desire to overcome fear - not wanting to be trapped					
Dissatisfaction with lifestyle changes brought on by DA					
Dentally anxious individuals used the internet to seek information, advice and support and found OSG	Using internet to find support				
Anonymity facilitates disclosure	Anonymity & safety	The online support group provides support in a variety of ways	In a safe and anonymous environment, participants find empathy and compassion which is lacking elsewhere. By providing emotional, social and practical support, and through positive stories, the OSG allows hope.	Low (study 1 and some study 2)	Downgrade one to Very Low (mostly unequivocal, but some credible)
OSG as a safe, anonymous and non-judgmental environment					
OSG as rich and varied source of information	Benefits of OSG				
Participants gain benefits from reading other members' positive experiences					
OSG as a source of social support					
Participants realise that their experience of DA is not unique or uncommon	Not alone				
Participants realise they are not alone in their anxiety					
Reactions of members contrast with reactions of non-group members	Empathy & compassion				
OSG provides empathy and understanding					
OSG as a source of understanding and empathy					

Participants were empowered by OSG to confront and challenge their fear	Empowerment	The OSG helps change thinking and behaviour	The OSG reduces isolation, helps participants to understand their anxiety and find ways of coping. Participants also feel empowered by the OSG, allowing them to challenge their fears and take action	Moderate (mostly study 2 and some study 1)	Downgrade one to Low (mostly unequivocal, but some credible)
Feelings of powerlessness & lack of control					
Participants gain benefits from reading other members' positive experiences					
Participants reported increased confidence with the dental team					
Empowered to take action by OSG					
OSG helped participants understand their anxiety	Advice for coping				
OSG helps combat sense of isolation and abnormality by encouraging disclosure					
Encouragement to rationalise and put things in perspective					
Advice around importance of finding a sympathetic dentist					

3.6.5 Synthesised finding 5: the online support group helps change thinking and behaviour

Across both studies, participants described how the OSG had provided them with advice for coping, either by helping them understand their anxiety and by offering practical solutions such as finding a sympathetic dentist (Buchanan & Coulson, 2007) or by helping reduce their sense of isolation and helping them rationalise and gain perspective (Buchanan et al., 2010) . In both studies, participants felt empowered by the OSG. In particular, they described how their DA was associated with feelings of powerlessness and loss of control (Buchanan et al., 2010) and contrasted this with how the OSG had helped them confront and challenge their fear (Buchanan & Coulson, 2007) and had empowered them to take action (Buchanan et al., 2010), even leading to increased confidence when talking to their dental team (Buchanan & Coulson, 2007).

3.7 Discussion

This systematic review is the first to examine the qualitative literature to evaluate what is known about the experiences of OSGs for DA. Whilst there is a paucity of research on this specific topic, there is a wealth of literature which addresses either DA or OSGs. This review will now consider the findings in light of previous literature on these two topics.

The first two synthesised findings provide insight on the sources of DA and its negative and behavioural consequences. These findings are consistent with the existing literature on the aetiology and psychosocial impact of DA. Previous research has also found that people living with DA attributed their anxiety to a traumatic dental experience, often in childhood (Berggren, 2001; Enkling et al., 2006). However, the literature would also indicate that whilst a traumatic experience is often a contributing factor to DA, the aetiology of the condition in reality is often more complex and multifactorial, with environmental risks and protective factors (Oosterink, de Jongh, et al., 2009; Ten Berge et al., 2002) combining with underlying cognitive and genetic vulnerabilities (Armfield, 2006; Ray et al., 2010).

In terms of the negative behavioural and cognitive consequences of DA, the direct link between fear and avoidance is well documented (Armfield, 2013b; Berggren et al., 2000; Locker, 2003), and the physical symptoms of fear mentioned in this review are consistent with previous qualitative research (Cohen et al., 2000). The findings from this review also illustrate how participants' embarrassment at their state of dentition acts as a further barrier to attendance, which is consistent with Berggren's model (2001). Furthermore, DA itself is identified as leading to shame and prompting secrecy, specifically due to a lack of understanding from offline networks. This has previously been highlighted by Locker (2003) who found that a fear of being judged may lead dentally anxious individuals to hide their anxiety, and Cohen et al. (2000) who reported that a lack of understanding around DA could lead individuals living with the condition to feel stigmatised.

There appears to be less literature which has specifically focused on what triggers or prompts individuals to overcome their anxiety, which makes the synthesised finding "Initiating Change" particularly interesting. Pain or need for urgent treatment has previously been identified as a trigger to attend treatment but often delayed and sometimes only as a last resort (Armfield, 2013a; Cohen et al., 2000). Dissatisfaction with lifestyle changes (in particular in relation to food and eating) brought on by anxiety and poor dentition are consistent with exploration of the negative behavioural changes brought on by DA (Cohen et al., 2000). According to qualitative research by van der Zande et al. (2021), the barriers to accessing dental treatment are complex and layered (e.g., socio-economic conditions, availability of resources, DA, embarrassment), and overcoming those barriers also requires a complex combination of factors. Overall, further exploration of which factors can act as a trigger to take action is merited.

Whatever the trigger may be, turning to an OSGs for unmet information needs and social or emotional support is consistent with previous literature on what motivates people to seek out online peer support (Allen et al., 2016; Moorhead et al., 2013; Ziebland & Wyke, 2012). The findings highlight how participants felt unsupported by their offline social networks and this is consistent with Wright (2016) and Davison et al. (2000) who argue that people are more likely to turn to online support if they feel they do not have access to adequate support in their existing offline networks, or if their condition carries a level of shame or stigma.

Indeed, the findings from this review demonstrate the contrast between the lack of understanding participants experienced offline with the support, empathy and compassion found in the OSG, and emphasise participants' realisation that they are not alone. Previous literature has shown the importance of empathy (Wright & Bell, 2003) and more recent studies across a variety of other conditions such as Parkinson's disease (Attard & Coulson, 2012) or chronic pain (Merolli et al., 2013) have shown the importance of OSGs in reducing isolation and loneliness.

Furthermore, previous literature on DA (Abrahamsson et al., 2002; Bernson et al., 2011) has proposed that social support plays an important part in overcoming DA, possibly because it helps develop coping mechanisms and encourages readiness to act. The findings from this review corroborate this by suggesting that the advice for coping from the OSG was instrumental in helping participants change their thinking and behaviour. This is consistent with Mo & Coulson's (2010) findings that users of an OSG for HIV scored higher on measures of coping than non-users. However, as all of the studies above are retrospective, the risk of participation bias cannot be excluded: those who are more inclined to take action and are ready to develop coping mechanisms may be more likely to seek out support from OSGs.

The findings of this review contrast the lack of control that participants felt in relation to their DA with the empowerment they gained from the OSG, and participants reported having increased confidence with the dental team. Previous research has highlighted the role that empowerment can play: in a study across 3 different conditions (arthritis, breast cancer and fibromyalgia), Van Uden-Kraan et al. (2008a) found that participants felt empowered by their involvement in the OSG. A further study by the same authors found that empowerment outcomes included increased optimism and control and greater confidence in the relationship with their physician (van Uden-Kraan et al., 2009). Similar findings were presented by Mo & Coulson (2014), who found that users of an HIV OSG reported greater confidence in their relationship with their physician as an empowerment outcome of OSG participation.

However, it is interesting that none of the findings highlighted any of the negative aspects of participation in an OSG. This may of course be due to the nature of the questions asked in Buchanan & Coulson (2007) that did not elicit any discussion of this topic. With regards to Buchanan et al. (2010), because it is an analysis of threads and messages posted, some of the negative aspects such as over-reliance on the OSG or concerns about the reliability of the information posted may not have been explicitly discussed. In addition, any rude and challenging behaviour or distressing content may have been removed by the OSG's moderators, and those users that did have bad experiences may have left the forum. Whilst an element of bias in the researchers' analysis, leading them to focus on more positive themes, cannot be excluded, the absence of some of the potential downsides of an OSG is consistent with other studies. For example, van Uden-Kraan et al. (2008c) found that only a minor proportion of postings across the three OSGs included in their evaluation contained negative content, and they found no evidence of confrontational or deliberately rude behaviour.

Overall, there are significant limitations to the insights that can be drawn from this review. Firstly, only two relevant studies were identified, despite extensive searches. This demonstrates the under-researched nature of the topic but also limits the conclusions that can be drawn from the synthesised findings. Furthermore, although attempts were made to ensure that bias was reduced when critically appraising the studies included in the review (through involvement of additional reviewers who were blinded to the authors of the studies being appraised), the reality is that the authors of the included studies are my PhD supervisors which could have led to unconscious bias. In terms of the studies themselves, both failed to provide sufficient information to situate the research and the researchers in terms of their cultural, theoretical and philosophical premise, and both studies lacked information to demonstrate researcher reflexivity and acknowledge the potential influence that the authors had on the findings. Whilst the majority of the findings extracted from the studies were deemed unequivocal and well-illustrated by quotes from participants, both studies had some methodological limitations. One study involved predominantly female participants, and the other study did not have access to demographic data due to the way the data were collected (from threads posted, often under pseudonyms). Whilst there is evidence that both people with DA and OSG users are also more likely to be female, there is nonetheless insufficient information to assess whether the participants across both studies were representative of the general population, of the dentally anxious population or the average OSG user. Furthermore, with 249 participants but only 55 illustrative quotes, it is impossible to tell whether the voices of all participants have been adequately represented. Whilst the word count limits imposed by publication mean this is an issue across all qualitative research, here it is exacerbated by the high number of participants. Therefore, no matter how unequivocal the findings are, there will always be limits to the generalisation of the results of both studies. In summary, limited conclusions can be drawn from two studies with methodological limitations.

3.8 Reflections on the JBI methodology

The JBI methodology is rooted in evidence-based healthcare, and focused on clinical implementation, yet one of its strengths is that it recognises and embraces the qualitative paradigm and strives to develop appropriate tools for that paradigm, whilst maintaining the normative rigour of a systematic review (Aromataris & Munn, 2020). The JBI qualitative methodology includes a strong recognition that qualitative research is situated, and the researcher cannot distance themselves from the research itself and its findings (Aromataris & Munn, 2020). Another strength of the JBI methodology is that it includes a clearly defined appraisal tool in the form of a checklist. In a comparison of different qualitative appraisal instruments, Hannes et al. (2010) found that the JBI tool facilitated the evaluation of interpretative and theoretical validity, due to its focus on congruity between philosophical perspective, methodology, research question and data collection methods. They found it to be more sensitive to qualitative aspects of validity than the critical appraisal skills program (CASP) tool. Although they found other tools more useful for appraising the generalisability of findings, overall, they found the JBI tool the most congruent.

However, it could be argued that the JBI methodology sets a high standard for the amount of information it expects on philosophical perspective and on researcher positionality and reflexivity. This standard is laudable, and this information would indeed contribute to research integrity, particularly in qualitative research where researcher positionality and subjectivity is integral to the process (Braun & Clarke, 2021). However, most journals have word count limitations that do not lend themselves to that information being provided, as authors are more likely to prioritise describing the methods or findings of their research to demonstrate the rigour or novelty of their study. The reviewers involved in this systematic review therefore found themselves wondering how many published articles would achieve a positive score, particularly on the questions of philosophical perspective and statements locating the researcher culturally or theoretically. Similarly, the extent to which the JBI appraisal tool expects qualitative research to be illustrated by participant quotes may be at odds with most journals' word count limitations. Finally, from a user perspective, all three of the reviewers (CS, CB and KF) found the tool easy to use, even though only one of the reviewers (CS) had received formal training on its use.

3.9 Conclusions

The aim of the review was to evaluate the experiences of OSGs for adults living with DA. The synthesised findings from this review are consistent with the existing literature on DA, in terms of the sources of DA and negative consequences of living with DA. The synthesised findings from this review also describe how change is initiated, how participants are supported by the OSG and how this helps empower them to change their thinking and behaviour. Once again, these findings are consistent with previous literature on OSGs for other conditions. Overall, the findings from this review would indicate that participation in an OSG can be a positive experience for an adult with DA and can bring about positive changes. Where these findings differed from the literature about other OSGs is that no negative aspects of participation were highlighted. However, this should not be interpreted as meaning that no negatives exist. Given the small number of studies and given the methodological limitations of the studies included, limited conclusions can be drawn based on these findings.

Further research is needed to provide robust evidence around the effects of online peer support on DA, in order to evaluate the role that OSGs can play in either reducing anxiety or influencing behaviour that enables regular access to dental care. The findings from this systematic review are nonetheless encouraging in the context of a feasibility study, as there is nothing to challenge the advisability of either a feasibility study or an RCT on this topic, and much to indicate their necessity. In the next chapter, I will therefore consider the methodology and methods for a feasibility study on this topic.

Chapter 4: Feasibility Study Methods

4.1 Chapter summary

In this chapter, I will outline the theoretical perspective and methods adopted for this feasibility study. The aim of the feasibility study is to establish whether a Randomised Control Trial (RCT) could and should be carried out. The choice of a pragmatic perspective is congruent with the decision to use mixed methods, which are particularly suited to a feasibility study. A Patient and Public Involvement (PPI) focus group was conducted to ensure the protocol for the study was developed with input from people with lived experience of Dental Anxiety (DA). The study protocol was granted ethical approval from the University of Nottingham and was registered and made public on Open Science Framework.

This study was a two-arm randomised online feasibility trial. It compared six weeks' use of an Online Support Group (OSG) to a wait-list control. Adult participants with DA were recruited through social media, with a target of recruiting 38 participants in 13 weeks. Participants randomised to the OSG condition were asked to use an existing OSG (Dental Fear Central) in a naturalistic manner for a period of six weeks.

Two questionnaires were used as pre- and post-measures of DA and intention to attend a dental appointment and descriptive statistics were produced, as well as a calculation of effect size to determine the required sample size for a full RCT. In addition, interviews were conducted with participants allocated to the OSG condition and thematic analysis was conducted on the transcripts.

4.2 Methodology

I have chosen pragmatism as my theoretical perspective. Pragmatism is rooted in the scientific method of enquiry (Allemang et al., 2022), yet acknowledges the complexity of real-world environments, in which individual health behaviours and outcomes cannot be dissociated from the social context in which they arise (Cornish & Gillespie, 2009). A pragmatist perspective lends itself to the adoption of the most appropriate method of enquiry to address a specific research question (Moon & Blackman, 2014). Furthermore, pragmatism is rooted in democratic values, which makes it particularly suited to research that focuses on patient-identified priorities and the involvement of people with lived experience as partners in the research process (Allemang et al., 2022).

4.2.1 Mixed methods

Mixed methods research, which according to Tashakkori et al. (2020) presents an alternative to the dichotomy between qualitative and quantitative methods, seeks to use whatever methodological tool is most appropriate to answer the research question. Thus, mixed methods studies that combine both qualitative and quantitative are becoming increasingly popular in healthcare research as they reflect the complexity of the topics being investigated and allow a broader understanding of a phenomenon that would not have been achievable using a single approach (Shorten & Smith, 2017). According to O'Cathain et al. (2007) and Donald (2018), mixed methods research is particularly suited to feasibility or pilot studies ahead of an RCT and is entirely congruent with a pragmatic perspective. Mixed methods also allow a variety of perspectives to be brought into research (O'Cathain et al., 2007; Shorten & Smith, 2017) and are therefore particularly useful in the context of a feasibility study that seeks to include the patient's perspective on an intervention.

Fetters et al. (2013) argue that there are three types of mixed methods designs: exploratory sequential (where collection of the qualitative data precedes and informs the quantitative), explanatory sequential (where collection of the quantitative data precedes the qualitative which is used to further exploration and elucidation), and convergent or concurrent designs (where the qualitative and the quantitative data are collected in parallel). This feasibility study was conducted using a convergent design, where the quantitative and qualitative data were analysed and reported separately in Chapters 5 and 6 of this thesis, before being integrated through narrative discussion in Chapter 8. This approach was selected to address the different aims of the study, which each require different tools, whilst still allowing a full and comprehensive understanding of the research question. This convergent design allows triangulation between the different types of data, providing a greater understanding through elaboration (a deeper understanding of a specific point), complementarity (by providing a wider understanding), or contradiction (where the differences in results between methods provide insight) (Brannen, 2005) and these different ways of achieving triangulation are not mutually exclusive (Fielding & Fielding, 2012). For this study, both qualitative and quantitative methods were given equal priority with each method addressing a different aspect of the study's aims.

4.2.2 Feasibility studies

According to Eldrige et al. (2016), feasibility studies are conducted in advance of a randomised control trial to address the question of "whether something can be done, should we proceed with it, and if so, how." (Eldrige et al., 2016, p.1). However, across the literature, the conceptual distinction between the terms pilot and feasibility study is often unclear (Eldridge et al., 2016). Donald (2018) also acknowledges that definitions and conceptualisations of feasibility studies vary, whilst also highlighting that the distinction between pilot and feasibility is greater in more recent publications, indicating a move towards conceptual distinction. Bond et al. (2023) argue that pilot studies are a sub-set of feasibility studies and they distinguish between three types of feasibility studies: firstly randomised pilot studies, which Eldridge et al. (2016) state could also legitimately be called randomised feasibility studies, and which reflect as much as possible the future trial, secondly non-randomised pilot studies, and thirdly feasibility studies that are not pilot studies (for instance because they are only looking at the feasibility of one aspect of a trial). These definitions are consistent with National Institute for Health and Care Research (NIHR) guidance on feasibility studies (NIHR, 2023).

According to Eldridge et al. (2016), feasibility studies are appropriate wherever there is uncertainty about the feasibility of a future RCT. This is consistent with the UK Medical Research Council guidance that recommends a feasibility and evaluation stage as part of the design and implementation of any complex intervention (Skivington et al., 2021). Furthermore, the NIHR argue that a feasibility study can reduce the risk of wasting resources on a large RCT that fails to produce valuable evidence (NIHR, 2023).

Bowen et al. (2009) argue that the purpose of a feasibility study is to enable comparison of an intervention to an unbiased control from the same population to test whether an intervention could work. More specifically, Lancaster et al. (2004), argue that one of the main aims of any feasibility study should be to gather sufficient data around the primary outcome measure to enable the calculation of a sample size for a suitably powered RCT that would aim to assess the effect of an intervention. Further aims should include testing the trial procedure, protocol and data collection methods, testing the randomisation method, assessing recruitment and consent rates and the acceptability of the intervention, and determining the primary outcome for the subsequent RCT (suggesting that two or more outcomes may initially be proposed). Morris & Rosenbloom (2017) add that their purpose is also to determine how well different components of the study work together. More importantly, there appears to be consensus across the field that the role of the feasibility study is not to evaluate the effect or effectiveness of an intervention (Donald, 2018; Eldridge et al., 2016; Lancaster & Thabane, 2019), that statistical analysis of feasibility studies should be descriptive, and that if any evaluation of the efficacy of an intervention is conducted, it should be reported with great caution (Arain et al., 2010).

Therefore, this PhD will aim to conduct a small-scale randomised feasibility study which reflects as closely as possible an intended future trial and addresses the uncertainties associated with a complex study protocol and intervention. Specifically, this study will seek to understand:

- If it is feasible to recruit sufficient eligible participants for an RCT (by understanding both the response rates to the recruitment for the feasibility study and the sample size that would be needed for an RCT)
- Whether participants are willing to be randomised
- The attrition rate amongst participants

- Whether the usage of the Online Support Group (OSG) is acceptable to adults with Dental Anxiety (DA)
- Whether the chosen measures are appropriate, and which might serve as primary measure for a full RCT
- What amends (if any) to the protocol would need to be made
- What the effect size of OSG usage is on the outcome measures and what size of sample may be needed for a full RCT.

4.3 Patient and Public Involvement (PPI)

According to Bowen et al. (2009), meaningful involvement of community members in conceptualising and designing feasibility research is essential. More broadly, Greenhalgh et al. (2019) argue that patients have a right to input into research on their condition and that PPI reduces the power imbalance between researchers and their participants. They also argue that it improves the value of research by ensuring its increased relevance and can improve its efficiency (e.g. by improving recruitment). Finally, they highlight that it can increase the accountability and transparency of research.

NIHR Applied Research Collaboration East Midlands (2019) guidelines outline three ways of involving and engaging the public in research. The first is in an advisory or consultative capacity, where involvement might take place in the form of a survey or a focus group, at one or several points in a project where input on a specific topic or issue is required. The second is through collaboration where the public is involved at every stage of the research and decisions are shared. The third is through coproduction, which builds on collaboration but also involves the public in selecting research priorities and shaping the direction of future research. Whilst coproduction is the gold standard of involvement, NIHR ARC East Midlands also recognize that this is not an achievable goal for all research projects. Although there was no public involvement in setting the topic for this PhD, it is worth noting that the James Lind Alliance (2024), a non-profit organisation dedicated to bringing together patients, carers and clinicians to identify research priorities, has identified addressing DA as one of its priorities for oral and dental health, albeit just outside of its top ten list.

In response to the COVID pandemic, much PPI research moved to using virtual tools (NIHR School for Primary Care Research, 2025), and according to the National Coordinating Centre for Public Engagement (2020), online PPI should not be seen as a poor relation to face-to-face meetings, providing careful planning is carried out and the session is designed with the virtual format in mind.

For this study, I have used PPI in an advisory and consultative capacity. This seemed particularly important as I have no lived experience of DA and wanted to gain an insight into living with DA beyond the understanding provided by my literature review. The first step was therefore to set up a focus group of people living with DA. The aim of this focus group was to gain feedback on my proposed research, specifically on my draft protocol and my proposed measures, and to gain insight into the barriers and facilitators to participation in my research. According to Bloor et al. (2001b), focus groups can be of particular value at the exploratory stage of research, and thus lend themselves well to PPI work. Furthermore, focus groups can bring together people with shared experience in a context that is non-hierarchical, ensuring that participants' views and ideas can be explored without the researcher's pre-conceptions having undue influence. Mutual support between participants living with the same stigmatised condition may also facilitate disclosure, allowing participants to explore their own feelings on the topic (Kitzinger, 2013). This in turn may help reduce the distress that the discussion of DA could otherwise trigger.

4.3.1 Recruitment for PPI focus group

Adverts were placed on the NIHR's website, peopleinresearch.org (PiR), on social media and in community venues (e.g., libraries, cafés and community centres) in socio-demographically diverse areas around Nottingham (see Appendix 2 for PPI communication materials). Participants needed to meet the eligibility criteria of being over 18 and identifying as dentally anxious. Ocloo et al. (2021) stress the importance of addressing equality and diversity in PPI, and therefore from the 23 people who responded to the advert (mostly from PiR), eight participants were selected using purposive sampling, where participants are actively selected in order to match the sample to the research aims (Campbell et al., 2020).

This number was based on existing guidance around group size and the standard practice of over-recruiting, allowing for last minute cancellations (Bloor et al., 2001a; Kitzinger, 2013). The aim was to have between 4 and 8 participants, enabling group discussion to take place whilst still allowing all participants to contribute within the time constraints. Participants were each offered a £20 Amazon voucher in recognition of their contribution. The focus group was conducted online for two reasons: to ensure accessibility to participants regardless of their geographical location and to learn from the experience of using an online format (and specifically Microsoft Teams software) with external participants at an early stage of the PhD.

Participants were aged between 24 and 53 (mean age 39.1), with an even gender split (4 female and 4 male). Three of the participants described themselves as White British, two as being from the Asian community, one as Bajan, one as mixed race and the eighth did not disclose any information about their ethnicity. Two of the participants described themselves as housewives, one as not working and one as a student. The other four participants were employed in a range of administrative or managerial roles.

Guidance from both the National Coordinating Centre for Public Engagement (2020) and the NIHR School for Primary Care Research (2025) were used in planning the focus group. A guide was sent to all participants on how to use Microsoft Teams ahead of the focus group that was scheduled for an hour and a half and was facilitated by me with the support of a fellow PhD student who monitored the chat function. All eight participants attended the focus group, although one joined late, declined to turn their camera on, responded only to direct questions through the chat function, mostly to state their agreement with what had already been said. All participants agreed to be contacted again via email for further PPI work.

4.3.2 Focus group discussion

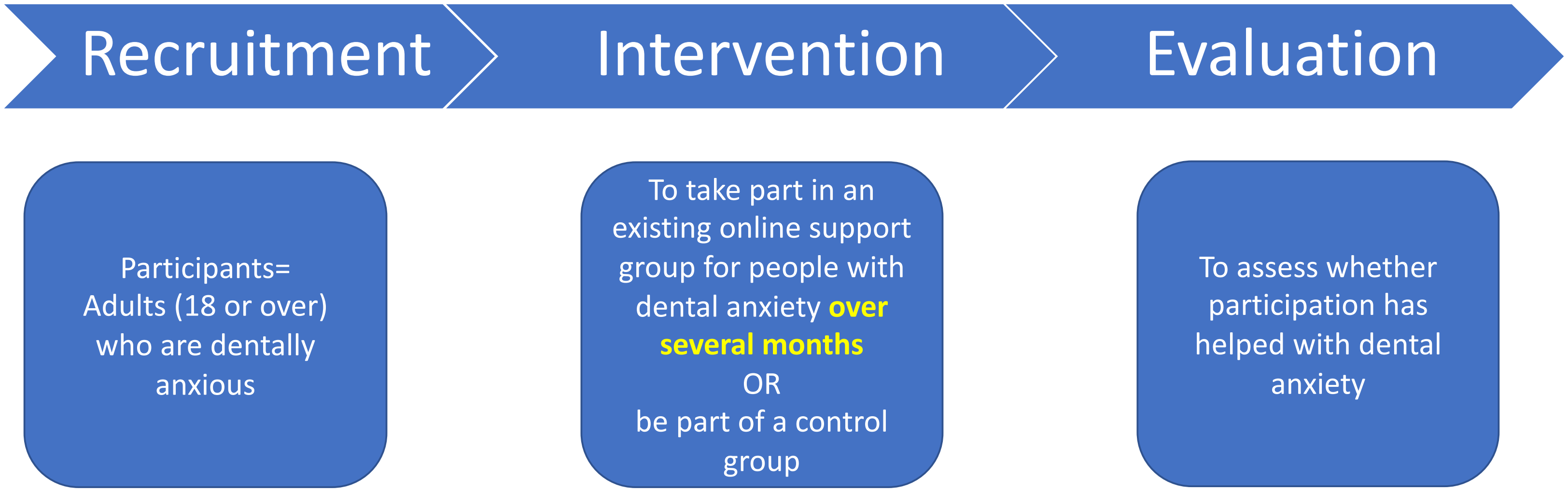
4.3.2.1 Modified Dental Anxiety Scale (MDAS)

Participants were asked to anonymously complete the MDAS (Humphris et al., 1995) using Microsoft Forms via a link provided in the chat function, in order to be able to share their views on their experience of completion in the group discussion. None of the participants had seen or completed the MDAS before. They highlighted that they found it brief and quick to fill in, easy to understand and to complete, and felt that it accurately captured the different stages of anxiety, in particular anticipatory anxiety. However, they also commented that it brought back bad memories of visiting the dentist, and that the questions did not differentiate between the type of visit (e.g., routine check-up or major treatment). They also highlighted that their answers would also depend on which dentist they were due to see, as their experience of anxiety varied between “good” and “bad” dentists. Finally, they expressed the view that more questions could be asked, given the brief and simple format of the MDAS.

4.3.2.2 Feedback on study protocol

Participants were then shown a diagram outlining the main elements of the study protocol and asked for comment (see Figure 4.1). This led to a challenging discussion about the locus of control of DA, with one participant rejecting the notion that it resided with the dentally anxious individual, attributing the issue instead to some dentists. This idea that “*it’s them, not me*” resonated with most participants, leading to several participants suggesting that solutions, and therefore my outcome measures, needed to focus not on the anxious individual but on the health professional team, the environment and even the treatments themselves.

Figure 4.1: Feasibility Study Outline used in PPI Discussion



Recruitment

Intervention

Evaluation

Participants=
Adults (18 or over)
who are dentally
anxious

To take part in an existing online support group for people with dental anxiety **over several months**
OR
be part of a control group

To assess whether participation has helped with dental anxiety

Participants will be asked to complete the questionnaire you completed today

Participants might be asked to logon several times per week, or might be asked to record how often they log on

Participants will be asked to complete questionnaires and/or take part in interviews about their experience

However, when prompted, the group listed several desirable positive outcomes, including the ability to build up trust with their dentist, a less stressful experience when visiting the dentist, which in turn would enable more regular attendance. They also recognised that some of these outcomes might be achievable by reducing their anxiety (even only slightly) rather than by eliminating it completely. Generally, their belief was that their anxiety could be reduced, but not removed by an OSG, as their DA would endure until the cause of the anxiety had been addressed (bad dentists, painful treatment and distressing environments).

4.3.2.3 Barriers & facilitators to taking part in the study

After a fifteen-minute comfort break, participants were asked about what the potential barriers and facilitators would be for them to sign up for the study. Overall, the most vocal participants were adamant that they would be unlikely to join an OSG for DA, and none of the less vocal participants voiced any disagreement. One participant stated that she was unlikely to sit around on a computer discussing her DA with others. Part of the rejection of OSGs was that it was an individual-focused solution, rather than a solution that changed the experience of a visit to the dentist and the treatment itself. Several participants felt that an OSG for DA was “not for them”. The reasons given included that DA was not an “everyday thing” (in other words it was not on their mind daily and was easy to ignore most of the time), not severe enough to warrant an OSG, or that their DA was too extreme for an OSG to be able to help. In all cases there was a concern that taking part in an OSG would involve discussing topics that they could easily avoid thinking about or that would be triggering. Another barrier outlined by participants was the time commitment. They felt that logging on multiple times per week would be a significant commitment, although further discussion clarified that the convenience of being able to manage when and how to log on could potentially mitigate against this barrier. Finally, a few participants mentioned the issue of digital exclusion, as some people either lack access to the digital world or lack confidence and skill with technology. However, they felt some of this could be mitigated by good technical guides and support that would need to be factored into the project.

Whilst there was little enthusiasm from participants for joining a DA-specific OSG, they recognised that OSGs in general provide peer support and understanding which reduces isolation, as well as advice, guidance and coping strategies. They also highlighted greater knowledge and increased confidence to advocate as positive outcomes. The benefits of being able to talk about ones' issues was also recognised, and a few participants also stated experiencing benefits from taking part in the focus group itself.

Participants also identified that small financial incentives (such as an Amazon voucher) would encourage them to sign up to a study and stay engaged. However, an equally important motivator to participate in research was altruism and the desire to contribute to valuable research that could help others. Linked to this, participants felt that they would be more motivated if the research was likely to lead to a service improvement, either because the findings would be shared with dental surgeries or used to provide best practice guidelines.

4.3.2.4 Feedback and reflections from the PPI focus group

Additional feedback from participants included how the communication ahead of the focus group (advert, emails and participant information sheet) had been clear throughout, and how the choice of image for the advert (a cartoon image of a tooth) was sufficiently eye-catching, yet non-threatening (see Appendix 2 for PPI communication materials). This feedback was taken forward to the adverts and communication in the recruitment of participants for the feasibility study. However, the questions that the focus group participants asked both ahead of the meeting via email and during the meeting made me realise that I had been naïve in thinking that participants would all read and retain the information I had sent them ahead of the focus group, even if they found it easy to understand and clear. This led me to reflect on how to ensure participants were giving informed consent, having fully understood what is involved.

I was ambitious in the amount of material I had hoped to cover during an hour and a half, and it was an important learning experience about balancing my agenda with participants' desire to share their thoughts and experiences of DA. This is something that I was conscious of when creating a discussion guide for qualitative interviews for the study.

As mentioned in Section 4.3.1, one participant joined the focus group late and did not engage in the group discussion, responding only via the chat when prompted and repeating what previous participants had said. This participant sent an email immediately after the focus group requesting payment in cash rather than a voucher, a request that was declined based on university guidelines for PPI compensation. However, this incident alerted me to the risk of imposter participants in qualitative research (Roehl & Harland, 2022) and prompted me to read more broadly on the subject which in turn informed my approach to participant recruitment for the feasibility study.

In addition, the focus group highlighted that there can be a potential difference between what participants might say in a group setting and their actual behaviour. This became apparent when participants stated that they would not be willing to discuss their DA with strangers online, even whilst participating in an online focus group on the topic. From this, I became aware of the need to explore beyond the surface of what people say when conducting qualitative interviews for the study to really understand what the underlying issues might be.

Finally, the PPI focus group helped me understand that any future communication to, and discussion with dentally anxious individuals needs to be careful not to position DA solely as an issue with the individual but instead acknowledge the shared responsibility of dentists who can play a role in either exacerbating or reducing a patient's anxiety.

4.3.3 Key actions arising from the PPI focus group

The feedback from the PPI group and the reflections on the focus group were then incorporated into the final protocol. Following feedback about the brevity of the questionnaire, consideration was given to what other measure could usefully be added to the study. In addition, considering issues around participants reading information that is sent to them, I decided to conduct a phone call with participants to ensure fully informed consent. Furthermore, two members of the PPI group who had agreed to be contacted again were asked to provide feedback on the recruitment advert and the participant information sheet for the feasibility study. They provided further advice on the wording to ensure it was sufficiently clear and appropriate for a lay person.

4.4 Feasibility study protocol

4.4.1 Ethical approval and registration

The University of Nottingham’s Faculty of Medicine and Health Sciences’ Research Ethics Committee granted approval for the study in April 2023 under reference number FMHS 225-0323 (see Appendix 3).

In the interest of academic integrity, the protocol was registered on the Open Science Framework platform after ethical approval had been received, but before any participant recruitment or data collection was initiated. The registration can be found on https://doi.org/10.17605/OSF.IO/9MBFY.

4.4.2 Protocol summary

This study was a mixed methods individually randomised feasibility trial. It was a two-arm trial comparing six weeks’ use of an OSG to a wait-list control. The study was conducted entirely online. Participants allocated to the OSG were asked to participate in an OSG for DA in a naturalistic manner for a period of six weeks. Participants in the wait-list control were signposted to the OSG at the end of the study, after a period of approximately six weeks.

All participants were asked to complete pre- and post-measures of DA using a validated scale: Modified Dental Anxiety Scale (MDAS) (Humphris et al., 1995). Participants' intention to attend dental appointments was assessed using the Dentist Contemplation Ladder (Coolidge et al., 2011). Qualitative interviews were conducted with participants who were assigned to the OSG to understand how they engaged with the OSG (or if they did not engage, why they did not), the barriers and facilitators to usage of the OSG, and what positive or negative aspects they experienced whilst using the OSG. Process evaluation data collected comprised rate of recruitment, retention and OSG usage (as measured by logon data).

Compensation in the form of Amazon vouchers with a value of £10 was offered to participants for completion of all questionnaires (pre-and post) and of £15 for participation in interviews. No allocation was made if the participant withdrew from the study before data from either the questionnaires or the interviews were complete.

4.4.3 Sample size

The study aimed to recruit 38 participants over a period of 3 months (13 weeks), with a planned contingency of one month. This sample size was derived using existing literature on sample sizes for feasibility studies: an audit by Billingham et al. (2013) showed a median sample size of 36 per arm, but with a range from 10 to 300, depending on whether the study had public or industry funding and whether the outcome was continuous or dichotomous. Taking a more theoretical approach, Julious (2005) argues that for a feasibility study where little is known, statistical considerations indicate that 12 per group is sufficient, based on feasibility and precision about the mean and variance.

An additional consideration for online studies is that attrition rates could be high: a systematic review by Meyerowitz-Katz et al. (2020) of app-based studies for health-related interventions (both RCTs and observational studies) indicated a median attrition rate of 40% for RCTs. However, the rates were highly heterogeneous ranging from 9% to 84%. In addition, a systematic review by Linardon & Fuller-Tyszkiewicz (2020) found that RCTs for mental health interventions delivered via smartphones had mean attrition rates between 24.1% (short follow-up of less than 8 weeks) and 35.5% (long follow-up). It is worth noting that the definition of attrition for this type of intervention varied between studies (with overlap between attrition and adherence) but was often defined by the level of usage of the app-based intervention, based on a threshold that was designed to deliver clinical benefits.

Considering this evidence, a target attrition rate of 33% was set. This was considered achievable based on the rationale that the intervention had a short follow-up and that participants were asked to engage with the OSG in a naturalistic manner. Therefore, a recruitment target of 38 allowed for the desired sample size of 12 per group to be achieved post-attrition.

4.4.4 Participants

Participants were recruited from the general population. The inclusion criteria were as follows:

- Aged 18 or over
- Dentally anxious (as defined by a score of 10 or over on the MDAS)
- Digitally enabled (with access to an internet-enabled device)
- Able to read and write English (based on self-report)

Once recruitment was completed, the sample consisted of 40 participants, of which 35 were female and 5 were male. The mean age was 42.4, the median was 40, and participants' age ranged from 21 to 73.

Participants were also asked what ethnicity they identified as (in a free-text answer box) when completing the post-MDAS questionnaire on MS Forms. The response to this question was made optional, but no participants opted out of responding. Three participants described themselves as mixed race, four as Asian or British Asian, one as Black and 29 as White British or White European.

Finally, participants who took part in the interviews were asked what their highest level of education was. Five participants had post-graduate level education, 4 degree-level, 2 had A-Levels and 2 participants had GCSE-level.

4.4.5 Recruitment for the feasibility study

Recruitment predominantly took place online through social media.

Participants were not recruited through existing OGS for DA, or through dental practices, as this could have introduced a bias towards individuals who have sufficiently overcome their anxiety to enable dental attendance. The study was advertised through social media, specifically on X (formerly known as Twitter), on Facebook, Instagram and LinkedIn (See Appendix 4 for examples of adverts). In addition, paper posters or flyers were placed in community venues in the Nottingham area (libraries, community centres, local parkruns, and cafés). However, this recruitment method was not effective and to my knowledge did not yield any participants.

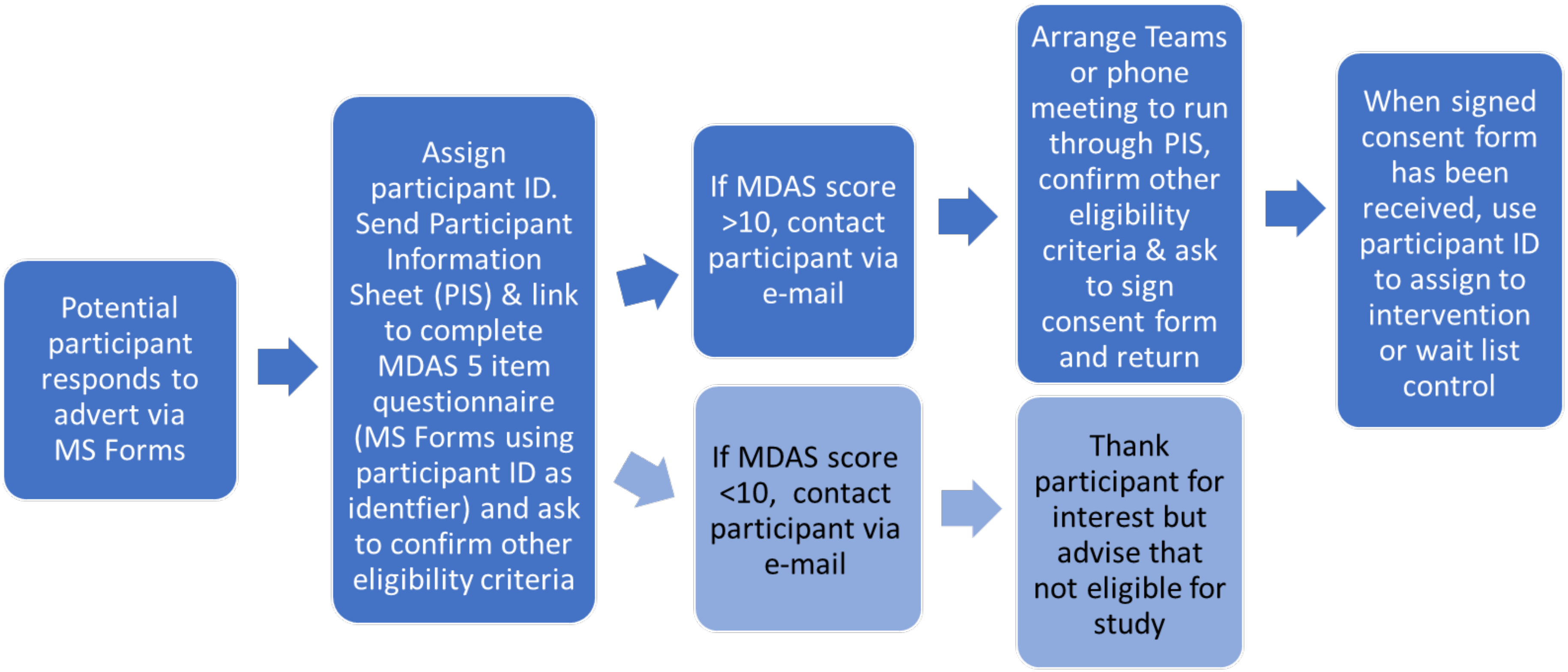
A Facebook business page called “Fearful of the dentist” was created for the study, using images similar to the image of cartoon teeth endorsed by the PPI group (See Appendix 5 for a screenshot of the Facebook page). The page contained an outline of the study as well as a link to the enquiry form. This Facebook page was used to create five paid adverts over a period of approximately 2 months with a total spend of £31.24. The adverts were set up to be shown on both Instagram and Facebook to target a broader demographic. The first advert was set to be shown to a large target audience (aged 18 to 65+ in the United Kingdom), but in an attempt to increase diversity of the sample, subsequent adverts were set to target specific large urban areas (Birmingham, Bradford, Leeds, Leicester, London, and Nottingham) and the final advert was set to target men (as respondents to previous adverts had been predominantly female). “Fearful of the dentist” was also used to post on a local community Facebook page, to generate posts that could be shared organically, and was shared on my personal Facebook page, asking people to like and follow the page.

In addition, the advert was shared on my personal X profile and my Linked-In profile and subsequently retweeted by people in my network. Finally, the advert was sent to individuals who had responded to the advert for the PPI group but not been selected and had agreed to be contacted again by the study for potential future involvement.

4.4.6 Sign-up process for participants

An overview of the sign-up and consent process is outlined in Figure 4.2. The adverts contained a link (or in the case of paper adverts, a QR code) with the prompt “find out more” which took participants to an enquiry form on MS Forms (see Appendix 6).

Figure 4.2: Participant Informed Consent Flow Chart



The enquiry form asked for their name, age, gender and email address, and asked them to confirm that they were over 18 and felt anxious or nervous about visiting the dentist. By completing this form, participants were assigned an ID number. Participants who completed the enquiry form were then contacted via e-mail (see Appendix 9 for emails to participants) and sent a link to complete the MDAS (via MS Forms) to verify their eligibility. They were informed of their participant ID and asked to use it as an identifier when completing the MDAS to ensure their responses were anonymous.

The e-mail also included a copy of the Participant Information Sheet (PIS) (see Appendix 7) and the Consent Form (see Appendix 8), and participants were asked to read these. One exception to this process was a participant with both dyslexia and a visual impairment who asked for the PIS and consent form to be sent to them in a specific paper format. Although this led to some delays in them being able to start the study, it felt important to make those reasonable adjustments to be inclusive and enable participation. None of the participants who completed the MDAS achieved a score below 10 or were aged below 18, therefore all participants who responded were deemed eligible.

Participants were then contacted and offered dates and times for a possible phone call or video call on MS Teams (as they preferred) to brief them on the study and check eligibility before asking them to complete the consent form if willing to participate. During the call, participants were taken through the key elements of the study, advised what their involvement and compensation would be, reminded of their right to withdraw at any point, and given the opportunity to ask any questions they may have or raise any concerns. They were also reminded that if they were allocated to the OSG, there was no expectation that they should engage with any subject matter they may potentially find distressing (e.g., description of dental treatment, discussion of dental appointments). They were also provided with guidance about staying safe online (e.g., not using their real name as a logon and being mindful about posting personal information). In addition, they were advised that if they were allocated to the control group, they would be asked not to take part in any OSG for DA but would be signposted to the OSG once they had completed their final questionnaires. At the end of the call, participants were asked if they had a copy of the consent form or if they needed it to be resent and were advised that if they still wanted to participate, they should complete the consent form and return it via e-mail. Two imposter participants were identified during these calls (see Chapter 7 on Process Evaluation, Section 7.2.5), and their enrolment was taken no further.

An email reminder (see Appendix 9.5) was sent to participants who had completed the enquiry form but not the MDAS, to participants who had completed the MDAS but not responded to the email to set up a phone call (Appendix 9.6), and to participants who had completed the phone call but not returned the consent form (Appendix 9.7), unless they had explicitly stated during the call that they did not want to participate in the study.

After 39 participants had returned the consent form, the study was marked as being closed on the Facebook page and on the MS Form. However, one subsequent enrolment was accepted from the participant who had requested reasonable adjustments due to the delay in sending out paper copies by post.

When consent forms were received, participants were sent an acknowledgement email and a link to complete the Dentist Contemplation Ladder on MS Forms and advised to use their participant ID as an identifier. Participants were then randomly allocated to either the OSG or the wait list control (WLC) (see Section 4.4.7 for detail on randomisation).

4.4.7 Randomisation

Each participant was automatically assigned a number in the order they responded to the advert, and participants were informed of this number as their participant ID and advised to use it when completing questionnaires. Participants were individually randomised as they signed up. A random number generator (random.org) was used to select from the recently signed-up participants which numbers to assign to the wait-list control. The numbers that were not selected were allocated to the OSG condition. If a number was drawn that was assigned to a participant who did not consent to the study, or if a number was drawn twice, the draw was disregarded.

4.4.8 Dental Fear Central: the intervention

Participants who were not assigned to the control group were asked to join Dental Fear Central (DFC). The reason this publicly available OSG was selected is that it is a public forum of sufficient size (over 30,000 members) to generate a sustainable level of interaction between participants. In addition, it is a moderated site, and there is evidence that some participants feel safer on moderated sites (Huh et al., 2016), as the risk of some of the negatives associated with OSGs (e.g. misinformation or negative behaviours) can be reduced by effective moderation (Smedley & Coulson, 2017). Written permission was sought and granted from the administrators of DFC to use their OSG for the study (see Appendix 10). They consented to participants and the lead researcher signing up to the DFC website and joining the OSG like any other user. The administrators did not request a list of users who were part of the study, although participants were advised that during the sign-up process, when asked what had prompted them to sign-up, they could either state “Dental Anxiety Research Study” or list their own reasons for wanting to join.

DFC is a website that features tips and stories from people living with DA, factual information from dental professionals, resources to download, as well as a section for dental professionals. It also contains an OSG referred to as a “support forum” (see Appendix 11 for visuals of the forum). Although the forum is public and can be browsed without signing-up, users need to register and logon to post or react to other peoples’ posts. In terms of structure, the forum has headings (e.g., “Success stories”, “Your dental phobia questions answered”), which in turn feature different topics (e.g., “ask a dentist”, “wisdom teeth”). Each topic has several discussion threads: written communications where one user initiates a new discussion or asks a question and other users comment or reply, creating a back and forth between users. It is this asynchronous forum part of the website that participants were signposted to, although nothing prevented them from accessing other parts of the site.

How participants engaged with the OSG was not prescribed, and no minimum frequency or amount of time spent on the OSG was set, allowing participants to interact with the OSG in a naturalistic way. There were several reasons behind the choice of naturalistic engagement. Firstly, it was felt that this would have more ecological validity as it was more likely to replicate the way a person with DA would engage with an OSG outside of a study. Secondly, this level of flexibility was deemed important by the PPI group who felt that a prescriptive format would inhibit sign-up to the study as potential participants might worry about the time commitment required. Finally, after discussion in a supervision meeting, I felt it was important to allow participants freedom to engage in a way that they felt comfortable with to reduce the risk of distress from participants feeling they had to engage with specific content or for a specific duration. However, notifications were sent to participants approximately three weeks after their sign up to the OSG, reminding and encouraging them to use DFC. In addition, participants who did not opt-out during the sign-up process will have received emails from DFC advising them of “a few of the new threads you’ve missed since your last visit”. These emails are sent twice a month by DFC.

Participants were provided with a visual guide (using screen shots) outlining how to log on to DFC, and how to navigate the forum (see Appendix 12). The guide reminded them not to use their real name as a logon and that there we no set guidelines about usage. As part of the sign-up process, participants were asked to agree to DFC’s terms and privacy policy. Once they had completed that process, DFC sent them an email verification and allowed them to log on to the site. Participants were deemed to have started using the forum once they were logged on and had confirmed their logon to me via e-mail. Participants in the wait-list control were signposted to the OSG after a period of approximately six weeks, and after completion of the post-measures. They were provided with similar guidance on how to sign-up and navigate the site.

4.4.9 Data management

A spreadsheet containing participant records (name, email address, age, gender, username for the OSG) was held securely in electronic format only and password protected. Access to the information was limited to myself (but would have been made available to my supervisors or any relevant regulatory authorities if requested or needed). My University of Nottingham One Drive was used for the storage of all files relating to the PhD. Microsoft Teams was used for the recording of the interviews before the corrected and redacted transcripts were transferred to One Drive and the recordings deleted. Microsoft Teams was chosen as it encrypts data both in transit and at rest and is approved against the University's Handling Restricted Data Policy. Both One Drive and Teams provide several layers of automatic back up and, in a disaster scenario, files can be recovered. Access to data stored on One Drive and on Teams is via secure log-in with multi-factor authentication. Although screen captures of publicly available data from the "last member online" section of the OSG were captured on a personal device, these were transferred onto the One Drive at the earliest possible opportunity and subsequently deleted from the personal device.

4.5 Quantitative data

4.5.1 Outcome measures

Two outcome measures were chosen, as a future RCT would either need to demonstrate that usage of an OSG can reduce DA, or can reduce avoidance of dental appointments, or possibly even both.

Therefore, the first outcome was a measure of DA, for which I chose the Modified Dental Anxiety Scales (MDAS) (Humphris et al., 1995), as it has been validated in multiple languages and across several populations (Humphris et al., 1995, 2000) and population norms are available for the UK (Humphris et al., 2013). It is a commonly used measure in both practice and in research (Dailey et al., 2001; Humphris et al., 2013). Perhaps most importantly, it is short and simple (composed of just five questions), whilst still addressing multiple aspects of the dental experience (see Appendix 13 for a full version of the MDAS). Furthermore, it was well-received by the PPI group who found it simple and brief to complete.

The second outcome measure was the Dentist Contemplation Ladder (Coolidge et al., 2011), which was chosen after a review of the existing literature, as a measure of a participant's readiness to attend dental appointments. Unlike DA, where a variety of different measures exist, the literature indicated a paucity of validated measures. The Dentist Contemplation Ladder is based on the Transtheoretical Model of stages of change (Prochaska & Diclemente, 1983) and was adapted from a similar ladder used for smoking cessation. It is a brief measure to complete with a single question that can be scored 0-10, and Coolidge et al. (2011) argue that there is good evidence to support its construct validity, and some preliminary evidence for criterion validity, although they recognise a larger sample is needed to confirm this. Finally, the Contemplation Ladder has been shown to have no significant relationship to DA, which makes it a valuable additional measure for this feasibility study.

All participants were asked to complete pre- and post-measures at the start of the study and after completion of their six-week usage of the OSG or after six weeks on the waiting list. As outlined in the sign-up process, participants were asked to complete the MDAS on MS Forms as a screen for eligibility before signing up to the study. Very shortly after signing up (no more than 2 days), participants were emailed a link to MS Forms and were asked to complete the Dentist Contemplation Ladder. The visual element of the ladder was retained on MS Forms (see Appendix 14 to view how both questionnaires appeared on MS Forms). Participants allocated to the OSG were then asked to complete both questionnaires again (on MS forms) after six weeks' usage of the OSG, and those allocated to the WLC were sent links to the questionnaires at the same time as their OSG counterparts from the same random allocation batch. Participant data were only included in the data analysis if all pre- and post-questionnaires had been completed, and therefore the total sample size was 37, with 19 participants in the wait list control condition and 18 participants in the OSG condition.

4.5.2 Process measures

Two main process measures were captured: response rates to the advert over time and usage of the OSG. MS Forms recorded the date and time at which participants responded to an advert by completing the enquiry form, as well as when they completed the screening questionnaire. This enabled me to track response rates compared to when Facebook adverts went live and when posts were made on Twitter and Linked-In.

Participants were also asked to share their usernames for the OSG by emailing them to me after signing up to DFC. These usernames were logged against the participant's name on the password protected spreadsheet containing personal data. Participants were made aware that this was a requirement in the participant information sheet and during the phone call before completing the consent form. They were also advised and reminded to ensure that these usernames did not allow easy identification (e.g., not using real names). The purpose of capturing usernames was to enable daily tracking of which participants had logged on to the support forum. DFC were consulted about the best way of monitoring usage of the OSG, and they advised that they were not able to provide any data on this. Their recommendation, which was followed, was to keep a daily photographic log (by means of a screen capture) of the publicly available "last member online" section of the forum which shows which users have signed into the OSG in the last 24 hours. A picture was taken at approximately the same time every day, starting on the day the first participant shared their username. Once all participants had completed their usage of the OSG, no more photos were taken. The information from the pictures was transferred into a password-protected Excel spreadsheet: if the participant's username appeared on a daily photo, this was logged against the relevant participant's ID number. Due to way the data were captured, usage data represents the number of days a participant had logged on, rather than the number of individual logons. If a participant logged on twice in the same day, they would only register as having logged on that day. The photos were checked twice (in increasing date order and in reverse date order) to reduce the risk of missing any relevant usernames, and data were entered for a period of 145 days in total. Despite best endeavours, when logging the data, it became apparent that no photo was available for one of the 145 days (whether the picture was not taken or was not transferred onto the One Drive before being deleted from the personal device was unclear). Usernames were not used for any other purposes (e.g., analysing the content or nature of any information they may have posted on the site).

4.5.3 Statistical analysis

The data from the MDAS and Dentist Contemplation Ladder were exported from MS Forms into MS Excel and formatted to allow further analysis (e.g. labelling individuals based on their allocation to the OSG or the WLC). An initial analysis was performed to observe means and ranges, to identify any missing data or anomalies that may have needed resolution (none were found), and to identify any outliers. Graphs were produced to visualise the data by individual and by condition for each measure.

The data were then exported into SPSS (version 29.0 for Mac) for further statistical analysis. Means and standard deviations were calculated at baseline for both the MDAS and the Contemplation Ladder. As participants were randomly allocated to the different conditions, any variation between the two conditions was assumed to be equally random and an artefact of sampling.

Data visualisations were used to examine the data, specifically histograms for the distribution of the samples, and box plots for the means, standard deviations and confidence intervals. Histograms for the residuals from the model were produced, and for the MDAS, the assumption of normal distribution could not be made. To overcome this issue, the bootstrapping function was used on SPSS software, which allows multiple random sampling from the same data. As the assumption of normal distribution did not appear to be violated for the residuals from the model for the Ladder, bootstrapping was not used. After this, the effect sizes were calculated using a paired samples t-test for each of the measures and a power calculation was carried out to estimate the sample sizes required for a full RCT based on each measure, still using SPSS.

Finally, descriptive statistics were produced from the logon information (e.g., average frequency of access), and the sign-up data was graphed and marked for key advert dates.

4.6 Qualitative data

4.6.1 Semi-structured interviews

A total of 18 participants took part in semi-structured qualitative interviews. These were conducted on MS Teams and lasted between 30 minutes and one hour. The first two interviews were conducted before participants had completed their post-questionnaires, and the remaining 16 were conducted after completion. Interviews were scheduled at a time convenient to the participant and the researcher, no less than six weeks and no more than eight weeks after they had first logged on to the OSG.

The semi-structured interviews were conducted using a discussion guide (see Appendix 15) that was developed to address the specific elements of the research question that are best answered through qualitative research (O'Cathain et al., 2015) such as the perceived value, benefits or harms of the intervention, the overall acceptability of the intervention, potential mechanisms of action of the intervention, and the acceptability of the study processes. The discussion guide was also informed by the literature on both DA and on OSGs and was developed with input from my supervisors. It was also piloted with an individual with lived experience of DA who had no background in or involvement with research, and who was taken through the sign-up process and asked to briefly engage with the OSG as part of the pilot. The discussion guide was structured in three parts: it started by asking about the recruitment and allocation process, then about participants' experience of using the OSG, before asking them to reflect on the experience as a whole. After the first few interviews, a change was made to one of the questions to better elicit the desired information from participants. The discussion guide remained otherwise unchanged throughout the interviews.

At the start of each interview, participants were asked to confirm their name and age and asked what their highest level of education was, where in the UK they were from and whether they had access to an NHS dentist or not. They were also reminded of their right to withdraw, and that their data would remain anonymous. They were advised that the interview could be stopped at their request at any point and given guidance on what to do should technical issues occur during the interview. At the end of each interview, a debrief was conducted to ensure participants were not distressed and to ensure any concerns or questions were addressed. Although the research protocol stated that participants would be signposted to the Samaritans, to their GP, or would be advised to self-refer to NHS talking therapies, none of the participants expressed an increase in distress or a need to be signposted to further support. Most questions in the debrief revolved around the research itself, or about the origins of DA: participants were keen to understand whether other adults attributed their DA to the same causes.

The interviews were recorded with the participants’ knowledge and consent, and MS Team was used to generate transcripts from the interviews. The transcripts were then checked against the recordings and corrected for errors. They were also anonymised, any personal details or identifying features (locations, names) were redacted, and the recordings were then deleted, based on the UK Data Service guidelines for qualitative research (https://ukdataservice.ac.uk/learning-hub/research-data-management/).

4.6.2 Analysis

4.6.2.1 Choice of reflexive thematic analysis

As stated at the start of this chapter, I highlighted that my PhD has been conducted from a pragmatic perspective. As such, my starting point for this analysis is an experiential orientation, meaning that language is assumed to reflect the reality and the lived experience of participants (Terry et al., 2017). I chose reflexive thematic analysis based on Braun & Clarke’s (2021) methodology as it enabled me to critically engage with the data whilst providing a participant-driven, descriptive account. The question I am seeking to address through these qualitative interviews is the acceptability of the recruitment and sign-up process and of the OSG itself. Finding a balance between exploring the experiences of participants, allowing them to share their narratives, and getting an almost binary answer to a research question has at times been a challenge. With that specific research question in mind, I conducted an inductive and semantic analysis: themes were driven by the data itself rather than a pre-existing theoretical concept, and the analysis explored meaning at an explicit and manifest level.

This form of thematic analysis recognises and values researcher subjectivity, acknowledging that themes are produced by the researcher through their immersion and engagement with, and their interpretation of the data. Essential to the process is the researcher's understanding of their own perspectives and positionality. As such, I recognise that I come to this research as someone who has conducted previous research on OSGs and found them to have value. In addition, I recognise that as a white, middle class, well-educated female researcher who has neither dental issues nor DA, I need to be mindful that my privilege could create a power imbalance or act as a barrier to creating rapport with my participants (Suyemoto et al., 2022).

In order to reflect on my subjectivity and how it affected both data collection and analysis, I kept a reflexive diary throughout the process. I found this of greatest value during data collection: immediately after each interview, I wrote down my thoughts on how I felt the interview had gone (for example whether I felt a rapport had been built with the participant, or whether I had successfully encouraged the participant to expand on their answers), how I felt I could improve for the next interview, any particular emotions I experienced in relation to the interview (and why that might be), and any reflections on what the participant had said. I then revisited these reflections before conducting the next interview, to ensure that I was both consciously learning about my interview technique and reflecting on my own reactions to participants and their narratives.

4.6.2.2 Familiarisation, coding and theme generation

Although Braun & Clarke (2021) advocate a sequential process of familiarisation with the whole data set, followed by coding, after which themes are generated, I found myself unable to refrain from starting to make connections and find similarities between interviews, as early as those first reflexive journal entries. Whilst some of those early connections were later discarded as immature interpretations or less relevant sub-themes, several of those early connections found their way into the final analysis as robustly evidenced themes. However, I did follow this step-by-step approach, starting with familiarisation during which I made notes on a physical copy of each transcript, highlighting what seemed relevant or important and reflecting on my reaction to that particular piece of data. Working on individual transcripts, I found working from paper copies offered convenience, as it enabled me to carry a transcript around and work on it whenever the opportunity arose. Once I had worked my way through each transcript, I wrote up a summary for each participant in my reflexive journal, before looking back and comparing it to my original interview reflection. Once the familiarisation stage was almost complete (16 out of 18), the transcripts were imported into Nvivo 14 software for Mac, and I started coding. Familiarisation with the final two transcripts was conducted in parallel with coding. Although it could be argued that these steps should be kept sequential to avoid reaching premature conclusions, I felt that I had enough of a sense of my data set after sixteen transcripts to be able to move to the next phase. I was already familiar with using Nvivo software from my MSc Health Psychology, and although I did not use the full functionality that the tool allows, I did find it valuable for quickly moving between transcripts, and for revising codes as I worked through the data, allowing me to reflexively lead the analysis.

Braun and Clarke (2021) argue that coding is a preliminary stage that should be completed before themes are generated. In reality, I found myself keeping a piece of paper and my reflexive journal alongside the on which I started to “test” themes as I worked through the coding. As with my journal entries made during data collection, some of those themes were refined and elaborated on until the end of the analysis, whilst others were removed along the way. Although I have outlined three stages (familiarisation, coding and theme generation), the reality is that the process was far more fluid and iterative, with both codes and themes evolving until the write-up of the results.

4.7 Triangulation

The final element of analysis was an attempt to triangulate between the qualitative and the quantitative data. As outlined in Section 4.2.1, elaboration, complementarity and contradiction were all considered when attempting triangulation, which included comparing frequency of access between what participants reported during their interviews and their individual data on OSG usage (contradiction), using the interview data to gain further insight into the potential mechanisms of action of the OSG (elaboration) and comparing the recruitment data with participants reports of where they saw the adverts (complementarity).

4.8 Summary

The mixed-methods approach and design of this study have been conceived with the aim of answering questions around the feasibility of an RCT. PPI input and pre-registration of the protocol have added rigour to the process. Participants were recruited through social media and randomly assigned to the OSG or a WLC condition. Participants in the OSG condition were asked to use an existing OSG in a naturalistic manner for a six-week period. Semi-structured interviews were carried out and thematic analysis was carried out on the transcripts. Participants were asked about their usage of the OSG and its acceptability as well as any perceived outcomes or benefits. Two questionnaires were used as pre- and post-measures of DA and intention to attend a dental appointment. Descriptive statistics and a calculation of effect size were produced. Participants were asked about their experience of the questionnaires in the semi-structured interviews. Finally, data on the number of times participants logged on to the OSG was captured and analysed. Therefore, in the next chapter, I will focus on the analysis of the quantitative measures, in line with the approach outlined in Section 4.5.3 and in the pre-registered protocol, with the aim of assessing the feasibility of using the two outcome measures, and estimating the required sample size for a full RCT.

Chapter 5: Analysis of Quantitative Outcome Measures

5.1 Chapter summary

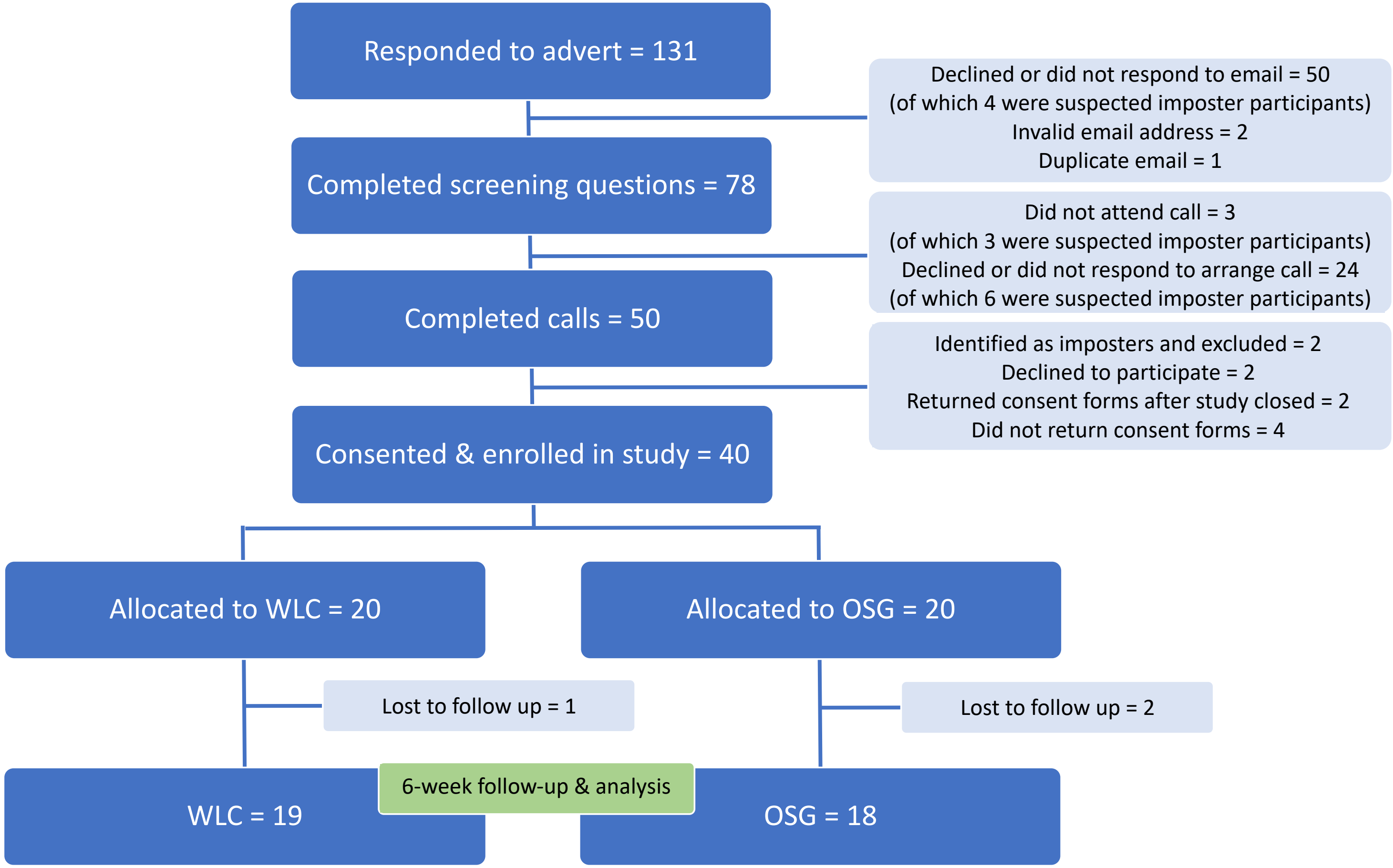
The aim of this chapter is to understand and analyse the quantitative data from the outcome measures to review how they can inform the feasibility of an RCT. In terms of recruitment and participant flow through the study, the adverts yielded 131 enquiries from which 40 participants were enrolled in the study. Over the course of the study, 3 participants were lost to follow-up which equates to an attrition rate of 7.5%. Participants were predominantly female, with an average age of 42.2 years. The Online Support Group (OSG) condition and the Wait List Control (WLC) condition were well matched in terms of age and gender. Both conditions were also well matched in terms of the Modified Dental Anxiety Scale (MDAS) and the Dentist Contemplation Ladder scores at baseline. On average, participants in the OSG condition logged on 3.6 times (with a range of 0-13) during the six-week study period. In terms of outcome data, the MDAS mean score was reduced (representing a reduction in Dental Anxiety or DA) in both the OSG and in the WLC conditions at six weeks, with a greater reduction in the OSG condition. The Dentist Contemplation Ladder mean scores increased (indicating an increased readiness to attend a dental appointment) in both conditions. Effect sizes for both outcome measures were calculated using t-tests and whilst no effect size was detected for the Dentist Contemplation ladder, a Cohen’s d effect size of 0.68 was detected for the MDAS. A power calculation was then performed based on the MDAS which indicated that a sample size of 36 participants in each condition would be required for a full RCT. Analysis of the outcome data seems to indicate that the MDAS could be a feasible measure for an RCT. The Dentist Contemplation Ladder may have a ceiling effect, although its use in an RCT should not be ruled out at this stage.

5.2 Participants

The flow of participants from recruitment through to analysis can be seen in the Consort Flow Diagram (see Figure 5.1): of the 131 participants who responded to the advert (see Appendix 4) by completing the Enquiry MS Form (see Appendix 6), 78 completed the screening questionnaire (the Modified Dental Anxiety Scale; MDAS). None of the participants who completed the MDAS achieved a score below 10 or were aged below 18 years, therefore all participants who responded were eligible.

Of the 78 who completed the MDAS, 50 agreed to a phone call or MS Teams call to explain the details of the study and ensure informed consent (see Chapter 4, Section 4.4.6). The reasons for non-response to the invitation to set up a call are unknown. Of the 50 who took part in a call, 40 returned the consent form. Twenty were allocated to the Online Support Group (OSG) condition and 20 were allocated to the Wait List Control (WLC) condition. One participant was lost to follow-up from the WLC: they had only completed the initial MDAS questionnaire that was used both for data collection and for eligibility screening and they failed to complete the Dentist Contemplation Ladder questionnaire. One participant completed the questionnaires but did not provide their logon details for the OSG. In both cases the reasons are unknown as the participants did not respond to two follow-up emails. The third participant lost to follow-up had provided her logon ID and engaged with the OSG. She had scheduled her interview for one week before her expected pregnancy due date but did not respond to the follow-up questionnaires and did not attend the interview. I felt it would not be appropriate to follow her up. From the WLC condition, all participants who completed the baseline questionnaires went on to complete the 6-week follow-up questionnaires. From the OSG condition, 18 of the 19 participants who provided their logon details for Dental Fear Central went on to complete the 6-week follow-up questionnaires. In total, of the 40 participants enrolled in the study, 37 completed all measures, equating to an attrition rate of 7.5%.

Figure 5.1: Consort Flow Diagram



5.3 Baseline characteristics of the two conditions

As described in Chapter 4 (Section 4.4.7), participants were randomly allocated to either the WLC condition or the OSG condition. The aim of randomisation is to ensure that any difference between the two conditions is due to chance (Berger et al., 2021). However, key differences between the conditions could still arise, and due to the small sample size involved in a feasibility study, these differences need to be noted and understood. Baseline characteristics for the participants allocated to each condition are reported in Table 5.1. The mean baseline MDAS score was slightly higher in participants allocated to the WLC condition (M=21.6) than for participants allocated to the OSG condition (M=20.8) indicating a slightly higher level of anxiety, and the mean baseline score on the Dentist Contemplation Ladder (referred to as 'ladder' for brevity) was slightly lower (M=5.8) for those allocated to the OSG than for those allocated to the WLC (M=6.1), indicating a slightly lower willingness to attend a dental appointment in the OSG condition (for full anonymised data by participant, see Appendix 16). However, the WLC score falls within the standard variation for the OSG condition score and vice-versa, meaning that the differences are likely to reflect normal variation within the data rather than be indicative of bias. The mean age of participants allocated to the OSG condition was 43.6 and the age of participants ranged from 21 to 71 compared to 40.9 in the WLC condition, with a range from 24 to 73. Both conditions were made up of predominantly female participants. Based on the information outlined in Table 5.1, the two conditions were well matched for age, gender and both measures at baseline.

Table 5.1: Baseline characteristics of participants

Characteristic	OSG	n	WLC	n	Total	Total N
Age (years)	43.6 (13.2)	18	40.9 (13.1)	19	42.2 (13.0)	37
Gender						
Female %	88.9	16	84.2	16	86.5	32
Male %	11.1	2	15.8	3	13.5	5
Baseline MDAS	20.8 (2.8)	18	21.6 (2.6)	19	21.2 (2.7)	37
Baseline Ladder	5.8 (2.9)	18	6.1 (3.7)	19	5.9 (3.3)	37

MDAS = Modified Dental Anxiety Scale
Ladder = Dentist Contemplation Ladder
Values are mean (SD) unless otherwise stated.

A review of the histograms of the frequency of scores for the baseline measures in the control and the OSG conditions shows that the for the MDAS (see Figure 5.2), distribution was skewed towards the higher scores in both the WLC condition and the OSG condition. The inclusion criterion for the study was an MDAS score greater than 10, and participant scores ranged from 14 to 25, indicating that in both conditions (OSG and WLC), participants had a high level of Dental Anxiety (DA).

However, for the ladder (see Figure 5.3), some differences between the conditions should be noted: the distribution of the answers shows that in the WLC condition, the modal score was 10, with 7 participants (36.8%) scoring themselves on the highest level of readiness, compared to only 3 participants (16.7%) in the OSG condition. Furthermore, the OSG condition had two modes of 4 and 8, with four participants each (22.2% of participants). These differences will be taken into consideration before any conclusions are drawn from the results outlined in this chapter.

Figure 5.2: Histogram of MDAS scores at baseline.

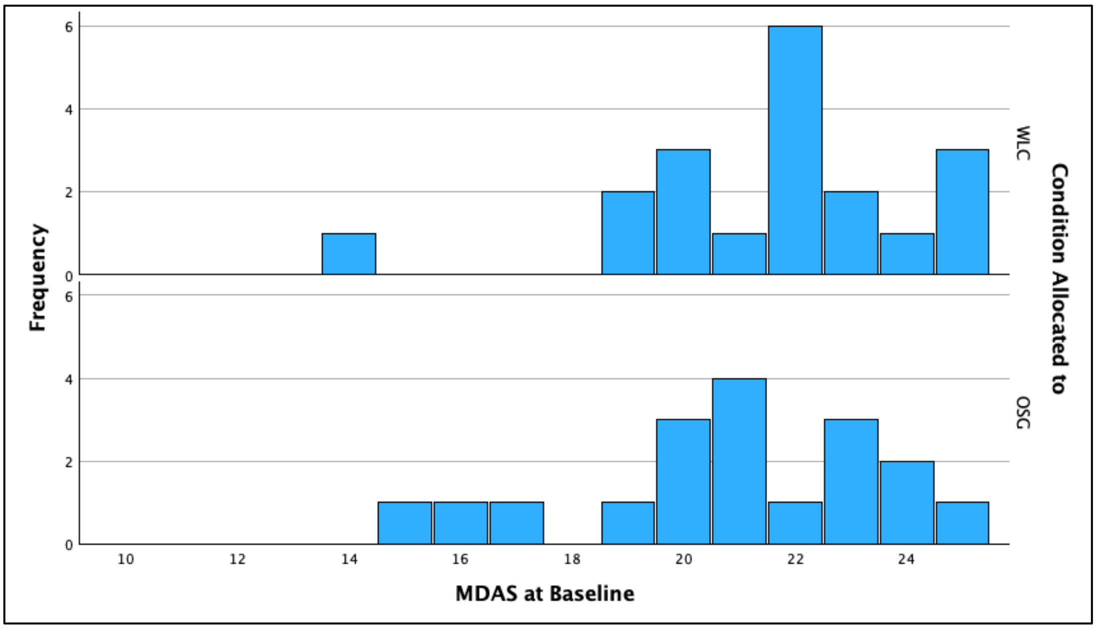
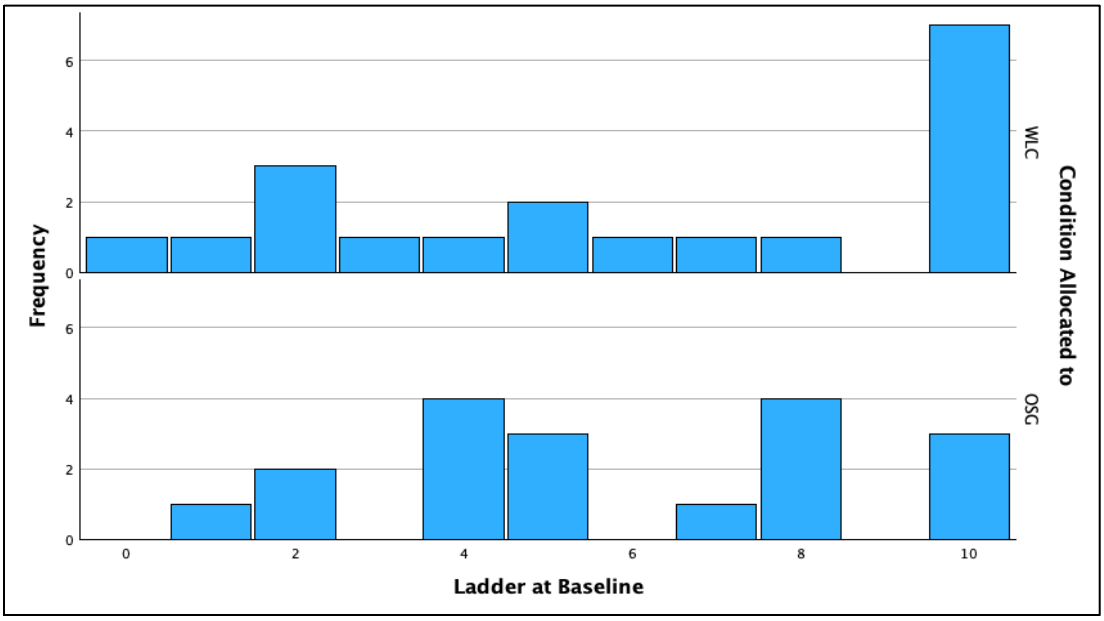


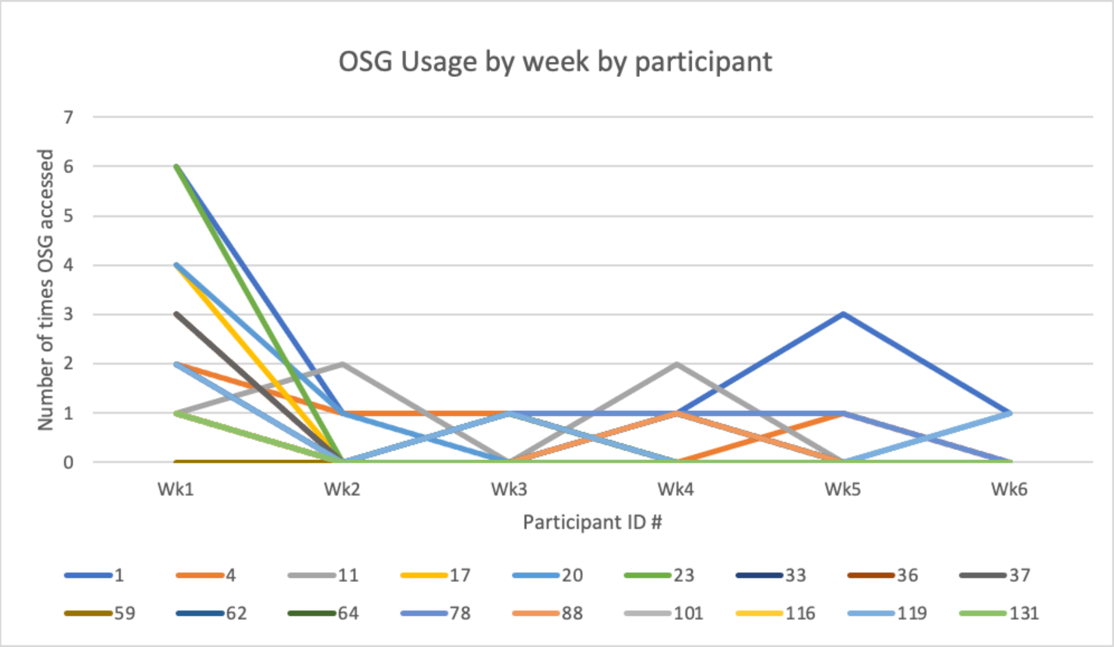
Figure 5.3: Histogram of Dentist Contemplation Ladder scores at baseline.



5.4 Frequency of usage of the online support group

As outlined in Chapter 4 (Section 4.4.8), no minimum frequency or amount of time spent on the OSG was mandated, allowing participants to interact with the OSG in a naturalistic way. Data on usage of the OSG included the number of days a participant logged on, and the specific dates that they logged on. The mean number of days logged on by participants during the eligible period (six weeks from the day their logon was first used on the OSG) was calculated in Microsoft Excel and found to be 3.6 times (ranging from 0 to 13). For most participants, usage of the OSG was more frequent at the start of the study period (see Figure 5.4), with 60.6% of logons occurring in the first week of participation. Three participants logged onto the OSG more than once a week (13-7 times), 7 participants logged on 3-5 times during the six-week period, and 8 participants logged on just once or twice. One participant did not logon to the OSG at all from the time they shared their logon ID via email to the date their interview took place (see Chapter 7, Section 7.5.3 for more detail). In addition, as outlined in Chapter 4 (Section 4.5.2), one day's worth of data is missing: a daily screenshot was taken of the list of usernames that had logged onto the OSG in the previous 24 hours. During analysis, it became apparent that for one of the days in the study, no screenshot exists (this was either not taken or accidentally deleted). This could potentially have affected 10 of the participants (as other participants had either already completed or not yet started their six-week usage period). It is unlikely that this missing data would have made a material difference to these results.

Figure 5.4: OSG usage by week by participant



5.5 Outcome measures

All participants completed the two measures at both baseline and at six weeks. The changes in means and standard deviations on these outcome measures with 95% confidence intervals were calculated using SPSS and are reported in Table 5.2.

Table 5.2: Outcome measures at baseline and at 6-weeks

Outcome	OSG (n=18)			WLC (n=19)		
	Baseline (SD)	6 weeks (SD)	Change (95%CI)	Baseline (SD)	6 weeks (SD)	Change (95%CI)
MDAS	20.8 (2.8)	17.8 (3.1)	-3.1 (-4.3, -1.8)	21.6 (2.6)	20.0 (3.0)	-1.6 (-2.5, -0.7)
Ladder	5.8 (2.9)	6.9 (3.3)	1.1 (-1.0, 3.1)	6.1 (3.7)	6.7 (2.7)	0.7 (-0.4, 1.8)

MDAS = Modified Dental Anxiety Scale

Ladder = Dentist Contemplation Ladder

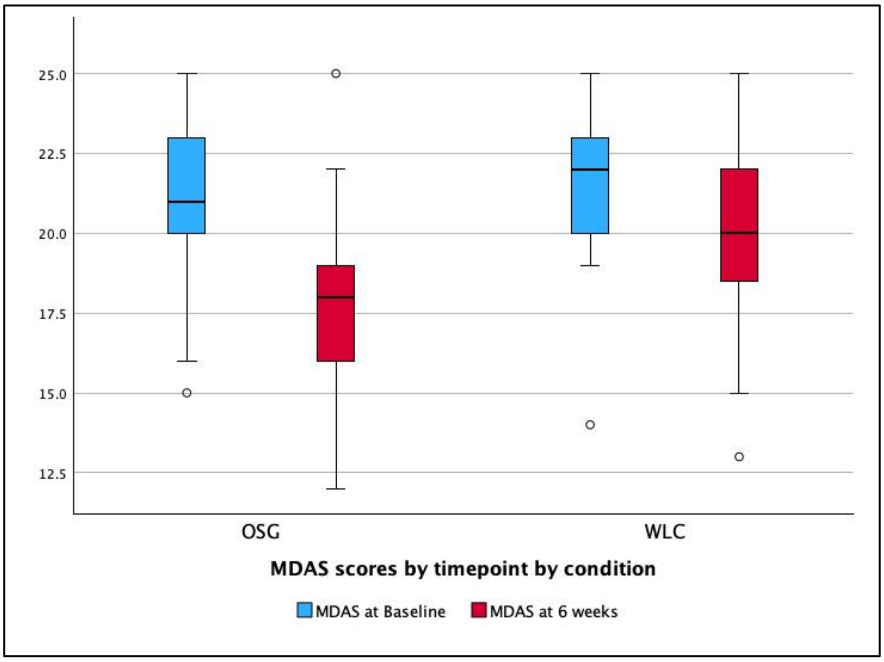
Values are mean (SD) unless otherwise stated

5.5.1 Dental anxiety scores

5.5.1.1 Distribution of MDAS scores

Changes in the range of MDAS scores can be found in Figure 5.5. These box plots show that the MDAS median score was reduced (representing a reduction in DA) in both the OSG and in the WLC conditions at the six-week follow-up point. However, in the OSG condition, there is no overlap in the interquartile range between the baseline scores and the scores at six weeks, and apart from one outlier, both the maximum and the minimum scores have been reduced. In the WLC condition on the other hand, there is still overlap in the interquartile range between baseline and 6-week scores, and the median at six weeks is level with the baseline lower quartile value. In addition, although the minimum has reduced between the two time points, the maximum scores have not changed.

Figure 5.5: Box plots for change in MDAS scores



5.5.1.2 Means and standard deviations for MDAS

As outlined in Table 5.2, reductions in the mean MDAS score were seen in both the OSG and the WLC conditions. The greatest mean difference was seen in the OSG condition which saw a reduction in mean score of -3.1

(standard deviation = 2.4), compared to a reduction of -1.6 in the WLC condition (standard deviation = 1.9). The overlap in confidence intervals for the mean change in MDAS is slightly more than moderate (Cumming, 2012). Although the mean baseline MDAS score was slightly higher in the WLC condition (M=21.6) than in the OSG condition (M=20.8), the reduction in the mean score on the MDAS from baseline to 6 weeks was 14.7% in the OSG condition, compared to a reduction of 7.3% in the WLC condition. Of note are the number of participants who reported a reduction from an MDAS score of 19 or above, which is the threshold for extreme DA or dental phobia (King & Humphris, 2010) to below 19 (see Table 5.3). The OSG condition saw a reduction of 60% in the number of participants whose score went from above to below 19, whereas the WLC condition saw a reduction of 22.2%.

Table 5.3: Number of participants with an MDAS score of 19 or above.

	MDAS Score ≥19 at baseline	MDAS Score ≥19 at 6 weeks	% difference
Total	33	20	-39.4%
OSG	15	6	-60.0%
WLC	18	14	-22.2%

5.5.2 Dentist Contemplation Ladder

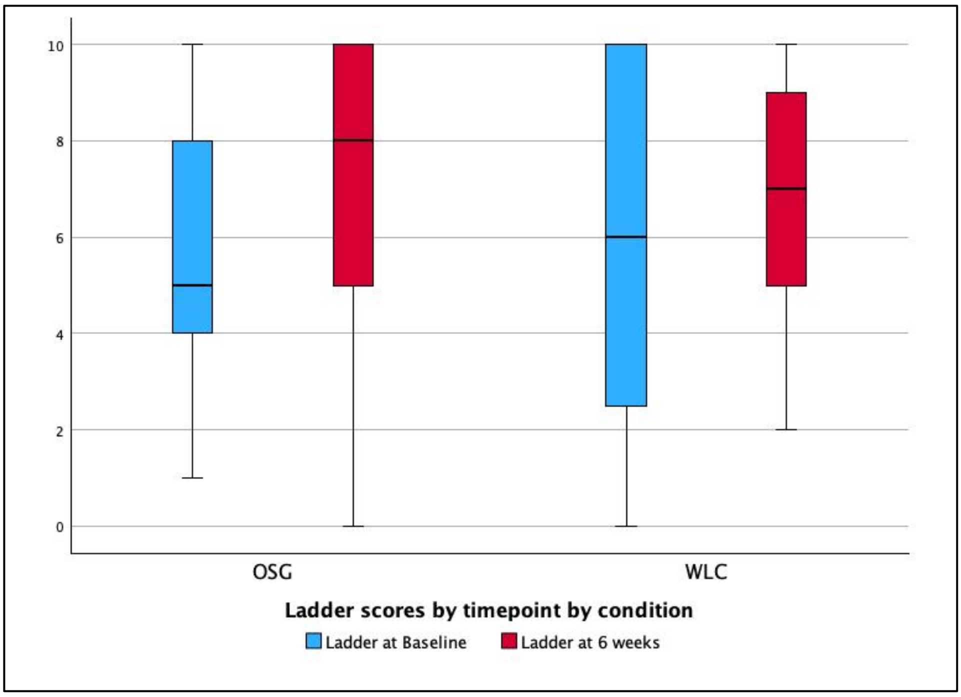
Changes in the range of scores on the Dentist Contemplation Ladder for the OSG and the WLC conditions can be found in Figure 5.6. These box plots show that the ladder median score increased in both the OSG condition and in the WLC condition at the six-week measurement point, indicating an increased readiness in both conditions to attend a dental appointment.

5.5.2.1 Distribution of scores

In the OSG condition, the scores at the six-week follow-up indicate a more positive skew than the scores at baseline. However, the median for the baseline score is level with the lower quartile value at six weeks, and the median for the six-week score is level with the upper quartile value of scores at baseline, leaving a large area of overlap. Whilst the maximum data value for both time points is the maximum score of 10, the maximum value and the upper quartile value at six weeks are the same (the maximum score available on the scale). However, it should also be noted that the minimum score is lower at six weeks than at baseline, and that at six weeks, the spread of scores covers the entire scale (0-10).

In the WLC condition, the range of scores at baseline covers the entire scale (0-10), the interquartile range at baseline is larger than at six weeks, indicating a narrower spread of scores at six weeks. The median at six weeks falls within the baseline interquartile range. Furthermore, the maximum value and the upper quartile value at baseline are the same. The interquartile range at six weeks falls completely within interquartile range of baseline, and although the minimum has reduced between from the baseline to the six-week scores, the maximum scores have not changed.

Figure 5.6: Box plots for change in Dentist Contemplation Ladder scores



5.5.2.2 Means and standard deviations for the Dentist Contemplation Ladder

An increase in the mean score on the Dentist Contemplation Ladder (representing an increased readiness to attend a dental appointment) was seen in both conditions and was greater in the OSG condition. As shown in

Table 5.2, the greatest mean difference was seen in the OSG condition which saw an increase in mean score of 1.1 (4.1 standard deviation), compared to an increase of 0.7 (2.3 standard deviation) in the WLC condition. The confidence intervals for the mean change in the ladder scores fully overlap.

Although the mean baseline ladder score was slightly lower in the OSG condition than in the WLC condition, indicating a lower readiness to attend a dental appointment, the increase in the mean score on the ladder from baseline to 6 weeks was 18.1%, compared to an increase of 11.3% in the WLC condition. In detail, the individual scores show that the number of participants who scored themselves the maximum score of 10 in the OSG condition was 3 at baseline (16.7% of participants within the condition) and 5 (27.8 % of participants) at six weeks. In contrast, the number participants who scored themselves 10 in the WLC condition was 7 (36.8%) at baseline but was reduced to 4 (21.1%) at six weeks.

5.6 Effect size and power calculation

Using SPSS, an independent t-test was performed to calculate the effect size for both measures. For the MDAS, the effect size using Cohen’s d was 0.68, which represents a medium to large effect size (Field, 2018). For the Dentist Contemplation Ladder, no effect size was detected as Cohen’s d was 0.11 (see Appendix 17 for effect size calculations). A power calculation was therefore performed in SPSS to evaluate the sample size required for a full RCT based on the MDAS (see Table 5.4). The assumptions used were an α of 0.05, 1-β of 0.8, and the values used to input into the model were means and standard deviations to the second decimal point: 3.06 (SD 2.44) for the change in the OSG condition and 1.58 (SD 1.89) for the change in the WLC condition. The required sample size would be 36 participants in each of the conditions, so a total sample of 72.

Table 5.4: Power Analysis Table in SPSS

	N1	N2	Power (1-β)	SD	SD	Mean Diff.	α
Two-sided Test for Mean Difference	36	36	0.8	1.89	2.44	1.480	0.5

5.7 Discussion

In the context of this feasibility study, the aim of the outcome analysis was to examine the feasibility of the outcome measures, and if appropriate decide which might serve as a primary outcome measure for a full RCT. In addition, the aim of was also to understand what the effect size of OSG usage might be on the outcome measures, and therefore what size of sample size might be needed for a full RCT.

5.7.1 Reflections on the MDAS

The results from the analysis of baseline scores indicated that the sample recruited for the feasibility study had a high level of DA. The criteria for inclusion in the study was a score of 10 or above on the MDAS, as scores between 10 and 18 are considered indicative of moderate DA and scores above 19 are considered indicative of high DA (Office for Health Improvement and Disparities, 2024). The lowest score reported by a participant at baseline was 14 and the highest was 25. However, the mean MDAS score at baseline across both conditions was 21.2, which is indicative of high DA, as only 11.6% of the UK population have a score of 19 or above, and a score of 21 would place a woman aged 35-54 in the 89th percentile based on population norms for the MDAS (Humphris et al., 2013) .This could be because some participants with higher DA are more motivated to find a solution to alleviate their anxiety, and therefore more likely to respond to an advert for a study on this topic. However, this does not seem to be a sufficient reason to change the inclusion criteria for a future RCT.

5.7.2 Reflections on the Dentist Contemplation Ladder

For the Dentist Contemplation Ladder, the baseline scores indicated that 27% of participants reported their score as the maximum of 10 at baseline, demonstrating that they are already attending or taking action to attend a dental appointment. In the WLC condition, 10 was the most frequently given score at baseline with more than a third of participants scoring themselves at this level of readiness. This seems to indicate a ceiling effect, and whilst it was more evident in the WLC than the OSG condition, careful consideration needs to be given to this before proceeding to an RCT, as a ceiling effect could make it difficult to detect any improvement in scores linked to the OSG. This highlights that although there is a recognised association between DA and dental avoidance, the two concepts are clearly distinct. According to Armfield (2013b) 38% of people with moderate to high DA avoid visiting the dentist (as opposed to less than 1% of people without fear). Although these figures clearly establish the link between fear and avoidance, they also show that most people with DA do attend appointments. Solutions to resolve the issue of a ceiling effect could include only using a measure of DA as outcome, or screening people with the ladder for their readiness to attend as part of the eligibility criteria, and to exclude people who score very highly. However, it should also be noted that the number of participants in the WLC who scored themselves a 10 reduced from 7 at baseline to 4 at six weeks, indicating some variation independent of any intervention, which at this stage cannot be explained, and for which the qualitative data on participants' experience of completing the measures may provide some insight. Dismissing the Dentist Contemplation Ladder as a measure at this stage would be premature.

5.7.3 Frequency of usage

The data on the frequency of usage indicates that with one exception, participants did indeed take up the opportunity to log on to the OSG, and although usage of the OSG was limited with a mean of 3.6 times during the six-week period, this is consistent with the guidance given to participants on using the OSG in a naturalistic manner. However, it should be noted that although participants were asked to logon to the OSG, access was possible without logging on and participants did not remain logged on if they left the site. This means that the data on frequency of usage may in fact be an underestimate of the actual engagement with the OSG.

5.7.4 Implications for a randomised control trial

The power calculation indicates that 72 participants (36 in the control condition and 36 in the intervention condition) are required for a fully powered RCT. The feasibility of achieving this number of participants will be considered in Chapter 7 on Process Evaluation (see Section 7.7.3). Whilst the purpose of a feasibility study is not to explore the effectiveness of an intervention, it is interesting to note that the greatest mean difference in MDAS score was seen in the OSG condition, and the independent t-test showed a medium to large effect size. This appears to support the MDAS being used as a primary outcome, which is perhaps unsurprising given the high number of studies that have confirmed its reliability and its validity (Humphris et al., 2013; Humphris et al., 1995, 2000). The small sample size of this feasibility study means that all results should of course be treated with caution, but the number of participants in the OSG condition whose score went from above the clinical threshold for extreme DA to below the threshold could provide an interesting avenue for investigation at RCT stage. A larger sample may establish whether the OSG intervention can lead to clinically significant changes as well as statistically significant ones. However, it should also be noted that the MDAS scores showed an improvement in both the OSG and the WLC condition. Therefore, whilst on balance the MDAS would appear to be the more appropriate primary measure, the feedback from participants themselves about the measures should be taken into account (see Chapter 7, Section 7.6.1) before any recommendations are made for a future RCT.

5.8 Conclusion

Whilst the outcome measures raise some interesting questions that would benefit from further exploration as part of an RCT, the analysis seems to indicate that the MDAS could be a feasible measure, and although the Dentist Contemplation Ladder may have a ceiling effect, it is too early to conclude that it should not be included in a future RCT.

The next chapter will examine the participants' experience of using the OSG, the barriers and facilitators to accessing the OSG and its overall acceptability in the context of an RCT

Chapter 6: Thematic Analysis of Qualitative Interviews

6.1 Chapter summary

The aim of this chapter is to present the thematic analysis from the qualitative interviews that were carried out with 18 participants who were allocated to the Online Support Group (OSG). Transcripts from the interviews were analysed following Braun & Clarke's (2021) reflexive thematic analysis methodology. The aim of the analysis was to understand the acceptability of the OSG for the participants[3]. Four main themes were developed from the data, with nine sub-themes in total. The first theme is "initiation" which explores what the barriers and facilitators are to accessing the OSG. The second theme is "exploration" which outlines how participants approached their initial interactions with the OSG, with sub-themes around how previous social media usage shapes their behaviour, how exploratory browsing helps them gain familiarity with the OSG, and how they decide what to attend to on the OSG. The third theme is "engagement" which includes two sub-themes to differentiate between participants who decided that the OSG was not for them, and those who were willing to engage. The fourth and final theme explores what "benefits and outcomes" participants felt they experienced by using the OSG. Overall, participants differed in their response to the OSG, but only a minority of participants decided that the OSG was not something they wanted to engage with. Participants found the OSG to be neither wholly positive nor wholly negative, and whilst recognising that they encountered distressing content, participants highlighted how the forum was a friendly and supportive environment. Most perceived that there were wide-ranging and clear benefits to engagement with the OSG. The data from the interviews

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[3] The qualitative interviews also provided information on participants' experience of the study itself, however these will be reviewed as part of the next chapter on process evaluation.

therefore seems to indicate that the OSG would be an acceptable intervention as part of an RCT.

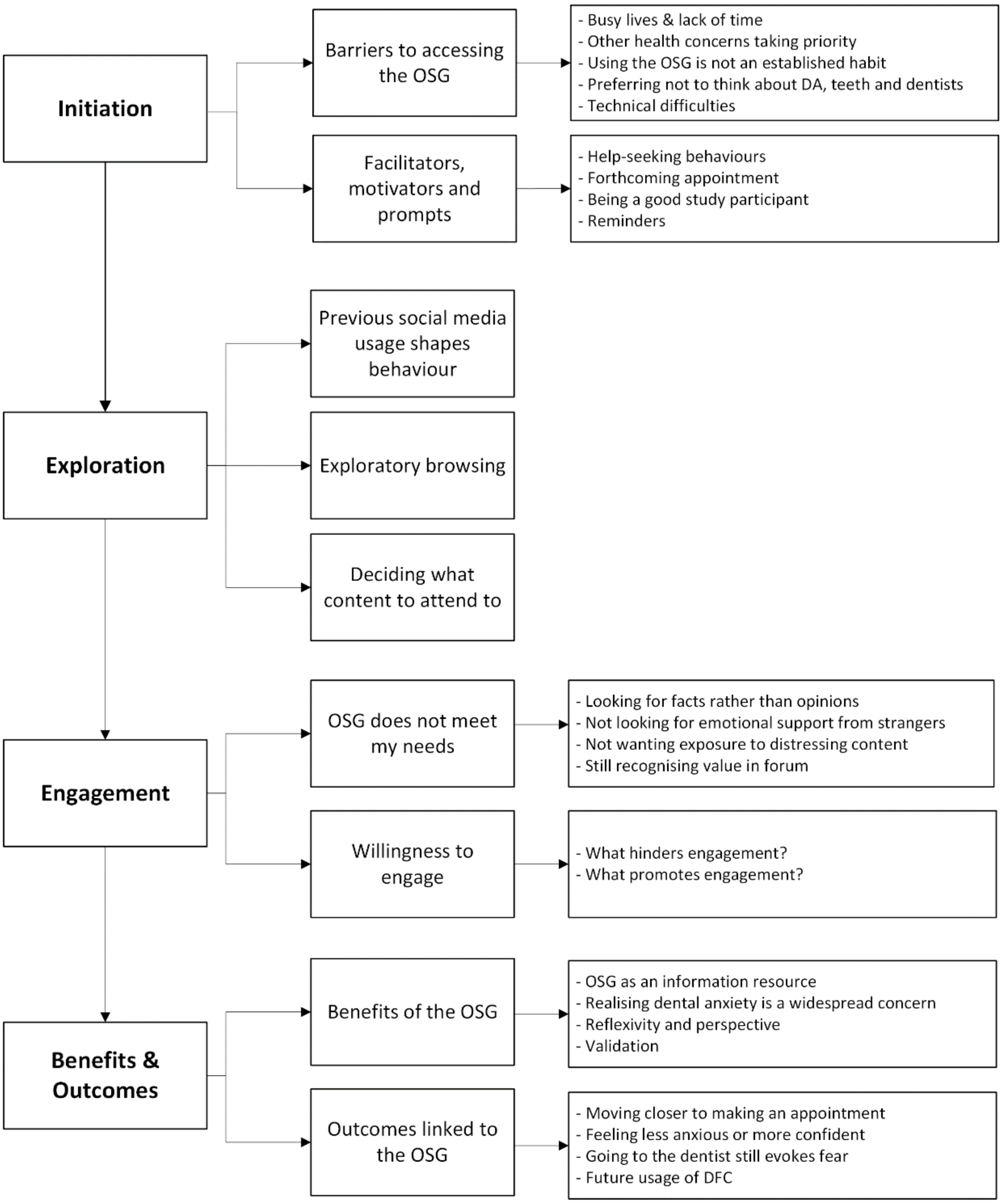
6.2 Summary of thematic analysis

As described in detail in Chapter 4 (Section 4.6), 18 semi-structured interviews were conducted with participants allocated to the Online Support Group (OSG) with the aim of exploring the acceptability of the OSG as an intervention. The interviews took place on MS Teams, the transcripts were automatically generated before being verified and corrected against the recordings and analysed using reflexive thematic analysis using Braun & Clarke's (2021) methodology. The analysis was inductive and semantic, meaning that themes were driven by the data itself rather than a pre-existing theoretical concept, and the analysis explored meaning at an explicit and manifest level. Four main themes were developed from the data, with nine sub-themes in total (see Figure 6.1).

6.3 Initiation of OSG access

Firstly, the theme of "initiation" examines what the barriers and facilitators were to accessing the OSG for this group of participants. This includes what may reduce motivation to access the OSG, as well as what may get in the way regardless of motivation. It also includes what might help overcome some of the barriers and prompt participants to visit the website and use the OSG.

Figure 6.1: Diagram of themes and sub-themes from qualitative interviews



6.3.1 Barriers to accessing the online support group

6.3.1.1 Busy lives and lack of time

Perhaps unsurprisingly, the most common reason given for not accessing the OSG more frequently was lack of time. More specifically, participants highlighted work commitments and caring responsibilities as being barriers to accessing the OSG more frequently.

> *“Um, I only, I mean because I've been so very, very busy with work. I only went on it when I got an e-mail prompt and then for not very long and I think that was mainly through the pressures of work. It wasn't that the site wasn't relevant or interesting. But I have just been so overwhelmingly busy.” (participant 119, Female age 52)*
>
> *“I just wasn't able to-, like with my auntie passing and my dad being elderly, I, I, kind of have other, uhm, priorities with him.” (participant 20, female age 37)*

A few female participants highlighted that the timing of the study coincided with summer holidays, a time when routines are disrupted, leaving limited time for additional discretionary activities such as taking part in a study.

> *“But yeah, this times weird, isn't it? When, in the summer, especially when the summer holidays, and you haven’t really got routine so…” (participant 78, female aged 32)*
>
> *“And it was the summer holidays, which is always slightly chaotic here! And so yes, distraction as well, which didn't help.” (participant 101, female age 47)*

Even when talking about how they did access the OSG, participants often raised the issue of finding time to do so.

> *“So, I just had it set up on my phone and it was just times. I don't know. I think when I sat watching my son play cricket. Yeah, just… I suppose just times when I had time.” (participant 11, male age 43).*

6.3.1.2 Other health concerns taking priority

A few of the participants specifically identified other health issues as taking precedence over their Dental Anxiety (DA) and acting as a barrier to accessing the OSG.

> *“...because of coming out of hospital, I wasn't doing well. Erm… I've got physical and mental health conditions going on so…” (participant 1, female age 45)*

> *“I probably didn't go on as much as I might have liked, wanted, expected, but some of that was to do with my own health and which has been erratic this year uhm, and then, sort of, a couple of weeks ago, I lost my voice again and… argh!” (participant 23, female age 56)*

6.3.1.3 Using the OSG is not an established habit

Participants described how in many cases, they were not making an explicit choice to avoid accessing the OSG. Using Dental Fear Central (DFC) simply was not a regular habit or part of their routine activities, and the idea of using an OSG for DA was low on their priority list. Therefore, in the absence of an external prompt it lost out to other competing demands on their time.

> *“I think it's just, along with sort of work and things, it's sort of, forgetting to sort of go on to it, and then sort of, trying to remind myself thinking right, you know, have a look just… click onto it. Have a look and… even if it's just a sort of a 5-minute glance and then… to see what's around.” (participant 36, male age 41).*
>
> *“But no, there was no reason I didn't go. I wasn't not going, in a sort of conscious sense.” (participant 101, female age 47)*

6.3.1.4 Preferring not to think about DA, teeth and dentists

In contrast to the previous sub-theme, some participants spoke of actively trying to ignore their DA and trying not to think about their teeth or the dentist. Therefore, without additional motivation to prompt them to use the OSG, they preferred not to confront something that was a potentially distressing subject.

> *“Erm… especially with this subject, I suppose it is-, it's something that I like to avoid for sure… Um, so…” (participant 37, female age 32)*
>
> *“I'd-, like if I had to go to the dentist weekly, I think I would have been like, oh it's always in the front of my head. But because it's like a once-a-year thing, it's like-, until it's like the few weeks before you kind of don't really think about it.” (participant 62, female age 21)*
>
> *Um, and that's probably my… whole, you know, if I don't talk-, my normal health response to things is it-, if I pretend it, it'll go away-, it might. (participant 101, female age 47)*

6.3.1.5 Technical difficulties

Two participants brought up technical difficulties as a barrier to accessing the OSG. One participant felt that these technical issues were linked to her device rather than the site, but she would have wanted notifications of interactions on her posts or her replies to prompt her to go back and visit the site again. The other participant had difficulties getting past the initial registration process and used the site without logging on.

> *“I've also been having tech-, tech issues that my phone-, I just can't seem to get the settings right so that I get notifications come up without kind of getting notifications coming up every three seconds, so it's kind of like… how to strike the balance.” (participant 23, female age 56)*
>
> *“Well, I did try and I-, well, I did register, and I sent you my username and then when I try to get on to it... It just kept coming back with your name is ro-, not recognised?” (participant 59, female age 71).*

6.3.2 Facilitators, motivators and prompts

6.3.2.1 Help-seeking behaviours

Most participants listed DA as their main reason for signing up, and in many cases that included either seeking help for themselves or wanting to help others who faced similar issues to themselves.

> *“Um, and yeah, long standing issues with dental treatment. I just thought it might be a useful thing to do. Um, yeah, to tackle the issue, yeah.” (participant 11, male age 43)*
>
> *“I thought oh, maybe this can help me as well.” (participant 33, female age 31)*
>
> *“I thought it's worth having a look and seeing, and seeing kind of what my experiences are compared to everyone else and is there anything I can kind of chip in that might help somebody else?” (participant 20, female age 37)*

As well as being a motivator to sign up to the study, help-seeking behaviour could also act as a prompt to use the OSG, particularly if it was triggered by a specific dental issue.

> *“...if my teeth were, you know sore or different and I might go, well actually I could go and have a little look at that forum and see if there's anything that's*

> *going on there that you know might be relevant to me." (participant 4, female age 55)*

6.3.2.2 Forthcoming appointment

Most participants made it clear that they would prefer not to think about their DA, but several participants described how either a problem with their teeth that might require attention from a dentist, or an upcoming scheduled visit to the dentist forced them to confront their anxiety and could act as a prompt to actively reconsider the help that the OSG could provide, and therefore encourage them to access the OSG.

> *"...it's the difference between kind of a support group for something that has an immediate active ongoing kind of issue being presented, as opposed to something that you know is… activated, but not necessarily active." (participant 23, female 56)*
>
> *"I think definitely on the run up to actually going to the dentist for sure." (participant 37, female age 32)*

Once this heightened state of alert triggered by a problem or an upcoming appointment had passed, the OSG became something that slipped once more to the back of participants' minds.

> *"You know, once the appointment was cancelled, I don't know. I don't, I didn't have any big issues, I guess, that made me think about it either." (participant 101, female age 47)*

6.3.2.3 Being a good study participant

Several participants mentioned helping research on a topic that is relevant to them as a motivation for signing-up to the study.

> *"I have a strong, um, sense that taking part in research is a really important thing to do when you can, so it's something that I do try to do actively" (participant 101, female age 47)*

This same motivation carried through to people's OSG usage behaviour. Participants stated that a sense of responsibility or duty towards the study, and possibly towards the researcher, was one of the things that made them either overcome their reluctance to think about their DA or find time in their busy lives to use the OSG. They described both wanting to make sure that they were being helpful and feeling that they had to honour the commitment they had made.

> *"There were several other times when I thought, no, you know, to be a good test subject. I should go back." (participant 116, female age 47)*
>
> *"I guess if I'm completely honest, I was also conscious that I was part of the study, so I would have to make some effort to actually engage too. And I think that helped." (participant 37, female age 32).*
>
> *"Didn't want your, didn't want your efforts to be in vain!" (participant 17, female age 64)*
>
> *"Cause I thought, oh, yeah. I was supposed to do that! I'll go back in and have another little browse around. If I'm being honest." (participant 4, female age 55)*

6.3.2.4 Reminders and prompts

Most participants were prompted to use the OSG by the emails that were sent, either by the researcher or by DFC (for those who had signed up to receive notifications from the website). For some the email simply reminded them of the existence of the forum, others may have been reminded of their sense of duty to the study.

> *"Um, when you sent me the reminder, I went on it straight away actually, cause I was on a dog walk." (participant 59, female age 71)*
>
> *"But then when I-, and then I forgot about it. And then you reminded me." (participant 101, female age 47)*
>
> *"Err, but the, the reminder was good to kind of just remind me that it was there and was in the back of my mind." (participant 20, female age 37)*

However, others described either how the emails brought their DA (a subject they would rather not think about) to the forefront of their mind, or how they perceived them more positively as a reminder of help that was available to them, prompting them to logon once more.

> *"Erm, I would say that really it was the emails that was prompting me to go in. I wasn't going there of my own volition, I wouldn't say. It was more the emails that were kinda triggering, and I suppose making me think about having to go to the dentist and having to confront that". (participant 37, female age 32)*
>
> *"So, then the reminder was good in in terms of going, don't forget you've got this thing you can do." (participant 116, female age 47)*

In many cases, these conflicting barriers and facilitators co-existed simultaneously, creating tension that encouraged or discouraged accessing the forum. However, logging on and accessing the forum is just the first step in the process of engaging with the forum, and the next section will consider the behaviours that participants engage in once they have logged on.

6.4 Exploration of the OSG

The theme of “exploration” includes how participants approached their initial interactions with the OSG and its content. This includes sub-themes of how existing usage of social media shapes their behaviour on the OSG, how they first approach the OSG to gain familiarity, and how they decide which content to attend to.

6.4.1 Previous social media usage shapes behaviour

This sub-theme explores how previous social media usage, and any previous experience of other support groups or forums shapes participants’ interaction with DFC. Although none of the participants had used an OSG for DA before, a few had used OSGs for other conditions. Participants were not against the idea of an OSG for DA but simply had not realised that one existed or had not felt the need to seek one out.

> *“I might Google some stuff to try and get some more, you know, information. But actually finding a forum where people are talking about similar things to what I'm going through no, I had-, you know, I hadn't really considered that. If I'm being honest.” (participant 37, female age 32)*
>
> *“Um, certainly not for, for dentistry stuff, at all. Wouldn't have even crossed my mind, to be honest. Um, I have used on to-, online support groups for other things.” (participant 4, female age 55)*

Whether they have previously used an OSG or not, before they even engaged with DFC, participants had already decided whether they were readers or posters[4]. That meant that how they engage with other forums, and

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[4] Whereas some of the literature refers to people who read content without posting on OSGs as “lurkers”, for the purpose of this PhD, I had decided to adopt the term “readers”, as the word “lurker” could carry negative connotations that I do not want to ascribe to this behaviour.

with social media in general, shaped their behaviour. Furthermore, how they behave in online group settings is described in terms that make it part of their online identity or online persona, rather than a behaviour that is specific to DFC, or a role that they had chosen in response to the environment they had encountered within that forum.

> *"No, I'm not a responder on anything. I don't respond on anything. I don't respond on respond on group chats, you know, family group chats! (participant 78, female age 32).*
>
> *"[on reluctance to post] I, err, that wasn't because I had any reason to, to feel that that wouldn't be kindly dealt with. That was more, I just, I just don't generally." (participant 101, female age 47)*

Very few of the participants described themselves as active posters who initiated conversations (i.e. threads) of their own, rather than simply reading other people's posts and occasionally responding. Many participants used their pre-existing online persona (e.g. as a poster or a reader) from other social media or other forums to explain their reluctance to generate new posts:

> *"... even on social media I'm, I'm bit more of a viewer than a, you know, an actual, you know, creator of posts or, or, you know, I make comments sometimes but they're pretty inane really." (participant 4, female age 55)*
>
> *"But just, no-, just being there for people is how I am anyway. And that's how I tend to use the other forums that I use. It's not very often that I'll start my own thread. It's generally I give advice and support to other people." (participant 1, female age 45)*

Occasionally, a wider justification for this online identity was given, such as a desire for privacy or a concern about how a post might be perceived.

> *"I must say, when I'm on any social media, I, I don't post a lot anyway. Um, I am a, a reader more than anything, but I think because of the job that I do as well, I'm really careful about… um, you know online activity and… you know, posting the, you know, the wrong thing and, and getting into trouble." (participant 11, male age 43)*

6.4.2 Exploratory browsing

Perhaps unsurprisingly, most participants started by exploring the OSG in a tentative manner, trying to gain an overview of the forum and trying to orientate themselves. This is not only in terms of navigation but also trying to "*see what it was all about*" (participant 20, female age 37), as if participants were trying to understand the kind of topics and gauge the tone and the norms of the forum.

> *"So that was the first step and then I'm just having a bit of a, a poke around really and just looking. [...] I was a little bit aimless, just exploring, really." (participant 11, male age 43)*
>
> *"I read a few to get a sense of what was kind of going on." (participant 23, female age 56)*
>
> *"Uhm, so in the beginning I kinda just browsed and had a look at what kind of the most recent posts were about and then kind of had a bit of a-, a browse kind of through each topic and just saw, you know, like the most recent things and what people were saying." (participant 20, female age 37)*
>
> *"I think I just sort of had a little look around to sort of… see what information was available on it and what was… Who was-, almost who was put it-? What sort of things people were putting on first, just sort of… get a, you know, get a little gist of it." (participant 36, male age 41)*

At this stage, participants' behaviour often seemed more passive, and they described how reading and learning about the site felt more comfortable than reacting or posting. This did not negate or reduce the value that many participants experienced, as it appears that this learning phase provided them with rich content and information and allowed them to explore without risking exposure.

> *"...but at that point I was still very new. I still thought I was probably going to go in multiple times, so I was still just a lurker." (participant 116, female age 47)*
>
> *"I wasn't, it wasn't that I had to interact and so that I could kind of just be in the background if I didn't feel comfortable to kind of, talk about my, my thoughts and feelings." (participant 20, female age 37)*
>
> *"I think I just found it easier reading other people's stories and then knowing myself that I related to that rather than… writing down like I relate to that and*

> *why. Like it was just easier to read it rather than trying to describe why I felt like that." (participant 62, female age 21)*

For some, this behaviour appeared to be linked to their online personas, and seemed not to change over time, but for others it was more a reflection of still getting to know the forum before building up towards more interaction.

6.4.3 Deciding what content to attend to

This exploratory behaviour then generally gave way to a more focused approach, often as participants realised the breadth of content available and became aware that they could not hope to have an exhaustive overview of the site. Participants then started to select specific threads to focus on topics that are relevant and helpful to them, for example because it was a topic that resonated with their lived experience or because it was a treatment that they may have been considering or in need of.

> *"Err, there were a lot of them and like I say on, on that initial page, there were a lot of different places to go, um, and I don't feel like I've kind of covered all of the site to be completely honest, but I kinda just went for the kinda top hits at, at the top of the page and then just looked for content that was actually, sort of speaking to me in terms of, you know, stuff that I had perhaps gone through or you know, have experience with or are concerned about having to do in the future." (participant 37, female age 32)*
>
> *"I kind of just read the first sentence and if it kind of was personal to me, like, I could like relate to it, then I was more engaged to read the whole story." (participant 62, female age 21)*

At the same time, they were trying to avoid topics that may have been less relevant or even distressing.

> *"...they usually had a like a headline about what that discussion thread was and quite a few of them I could just sort of scroll by because they didn't feel that, I didn't feel that they would help me, or I couldn't help because I wasn't in that situation." (participant 101, female age 47)*
>
> *"So yeah, I was just going through really looking at the titles and the headings and looking for things that I thought might be helpful to-, selfishly, helpful to me or you know, not cause me any additional angst about the whole dentist thing." (participant 4, female age 55)*

This exploration and navigation between finding topics that participants wanted to engage with and avoiding topics that were not helpful enabled participants to gain an overview of the forum and contributed towards deciding whether they were interested in engaging further or not.

6.5 Engagement

6.5.1 Online support group not meeting needs

One third of participants, having accessed and explored the forum declared that the OSG was quite simply not something that they felt met their needs or helped them with their DA. In most cases, the decision that the OSG was not for them was reached quite rapidly after an initial browse of the forum.

> *"Um, so yeah, I just didn't think there was anything else there for me that, that would be of, of use..." (participant 17, female age 64)*
>
> *"I think I was on there for probably-, not long enough, but I think my immediate impression was I'm not going to get much out of this." (participant 64, female age 30)*

Their reasons for rejecting the forum included prioritising fact over opinion, not wanting emotional support from strangers, and finding the forum too distressing. However, even those who rejected the forum as being "*not for me*" (participant 116, female age 47) still expressed an understanding that it may benefit others or that it may meet their needs at some point in the future.

6.5.1.1 Looking for facts rather than opinions

The main reason which led people to decide that the forum was not something for them is that they prioritised fact and expertise over opinion. They often stated that they found value in the "ask the dentist" section of the forum, preferred the information pages and articles on the DFC website to the forum, and one participant liked that dentists had a tag that identified them as professionals when they were responding to posts on the forum.

> *"I like facts more than anything. I mean, it was slightly interesting to read some people's stories, but that's, that's, um, yeah." (participant 17, female age 64)*

> *"... the only thing that I've used, I think, was, um, Ask the dentist. That was something that I really liked." (participant 33, female age 31)*
>
> *"Again, because the only things that I was really giving any credence to, like I was really listening to, were the professional's opinions" (participant 88, female age 31)*

It is worth noting that factual articles and the input from dentists were also valued by other participants who were more willing to engage with the OSG, and who appreciated having access to both lived experience and professional expertise. The big difference between these participants and those who decided the forum was not for them is that the latter positioned professional opinions as being better informed and more reliable than lived experience, with people's lived experience at times even being considered unreliable or untrustworthy.

> *"Again, the fact that it's written by an expert, it doesn't mean that it's going to work for, for you. It's going, yeah, but it just feels like there's some sort of research done about it. And, um, you know that, you know, it has been studied and that theory will work better, let's say, than what other people will tell you. So I just feel that it's a bit safer sort of, to read that and to trust that." (participant 33, female age 31)*
>
> *"I think that for me, I am quite wary of what people say online, like it could literally be anyone posting anything like I could have posted under there a completely fabricated story and no one would know. But I think having that clear view of the professionals was really helpful." (participant 88, female age 31)*

Some participants even suggested more involvement from dentists in the forum, in the form of question-and-answer sessions or moderated video chats, as they considered this expert input more valuable than peer to peer support.

> *"I'm just kind of making this up now, but it-, we have 5 dentists here who are users on like a little like banner at the top. Like 5 dentists, here are their expertise. Pop them a chat, pop them a question and they might respond. And… instead, it felt very like… Here you all are. You're all like, scared of the dentist. Just chat among yourselves." (participant 64, female age 30)*

6.5.1.2 Not looking for emotional support from strangers

Whilst some participants recognised that people go to the forum to find *"support and kindness and contact [...] that they may not be getting it in other ways"* (participant 101, female age 47), others were quite explicit that they were not looking for emotional support for their DA, but rather practical advice which they found lacking. In addition, the anonymity of the forum can be a disincentive to participation, as some participants found the idea of sharing their fears with strangers unappealing.

> *"Like, I don't wanna hear other people sympathising with me. I don't wanna hear people's sob stories. I want a professional to be like you are not dying. You are gonna survive. You have a cold." (participant 88, female age 31)*
>
> *"I just felt that I would only get um, messages of encouragement and that's it. But maybe not really tips and tricks on how to solve my fear of dentists, so…" (participant 33, female age 31)*
>
> *"I don't think chatting to strangers online is, is for me really. I just don't think it is." (participant 17, female age 64)*
>
> *"I'm the kind of person who really likes to… to have this close up, and to actually see who am I talking to and also show myself or something…" (participant 33, female age 31)*

6.5.1.3 Not wanting exposure to distressing content

Another reason for deciding not to engage with the OSG is that these participants had no desire to expose themselves to distressing content. This could be a concern before they even accessed the forum.

> *"I just thought if it's going to be, if there are going to be lots of horror stories in there, I might not get very far through that forum! Might put me off! So that that was one of my thoughts that went whizzing through my head." (participant 4, female age 55)*

When these fears of distressing content became a reality, participants were concerned that other people's fears could almost be contagious or that or reading about bad experiences could generate new fears for them and exacerbate their existing anxiety.

> *"So, I started looking at root canals and then immediately just went 'Oh my God. Oh, no. No, no, no, no.' This is very much a, a world in which I need to just put my trust in a professional because the, the fear and the stories and*

> *the worst-case scenarios and the… panic around it is just gonna feed mine." (participant 116, female age 47)*
>
> *"I went on the post about the person who had this fear of brushing their teeth and I felt it was too much because… it just made me imagine this situation and maybe I guess I'm, I'm just a little bit weak in this sense, when I have this anxiety and I'm just afraid that it's going to, to become even bigger." (participant 33, female age 31)*

6.5.1.4 Still recognising some value in the forum

However, with just one exception, even those who declared that the forum was not a space for them were able to recognise that it could be of value to others, or that it could even be of value to themselves at some point in the future, either ahead of dental treatment, or if they needed to research a specific topic.

> *"Although it's not for me, I would still recommend it to others. Because we're all very different, Caitlin. And what works for one, doesn't always work for another. And, er, just because my experience as well, yeah, I got a bit of use out of it, for other people it might be a life saver, you know?" (participant 17, female age 64)*
>
> *"I could see myself going, like where you're actually having to confront something pretty primal. And you don't have that experience and that trust to fall back on." (participant 116, female age 47)*
>
> *"So I would recommend it, er, to all the people who have this, because I think that everyone can find something. If you want to talk to people that have the same problem, or if you are looking for an advice, you can post on the forum, but if not, you can also just have a read. I don't know. Look at the interview, um…or any other things. There are many of, let's say, opportunities for you to discover. So yes, I would recommend it." (participant 33, female age 31)*

6.5.2 Willingness to engage

With the exception of those who decided early in their exploration that the OSG was not for them, most participants were willing to engage in the forum, some more tentatively than others. They found both aspects that fostered and aspects that hindered further participation. The barriers to engagement included distressing content and navigation difficulties, whereas success stories from OSG users and the friendly environment of the forum facilitated engagement.

6.5.2.1 What hinders engagement?

6.5.2.1.1 Distressing content

Distressing content was not an issue only for those who rejected the OSG, it was also an issue for those who were willing to engage with the forum and caused participants to pause and consider whether the forum was appropriate for them. It was an anticipatory concern before they started to use the OSG, and concerns around exposure to upsetting content did indeed materialise when they use the forum.

> *"I suppose when I signed up, the worry was that, um, you know, it would be… coming into contact with people that had all sorts of horrendous experiences and um, I know that's not what I need to be-, um hearing, and I don't, I don't necessarily think that's gonna help me. So, I think that was my preconception." (participant 11, male age 43)*
>
> *"That it's… gonna probably kind of… bring up some stuff that you go 'oohh', that, that bit no, no, I can't read that cause that's actually making me feel ill." (participant 23, female age 56)*
>
> *"... but actually again I found myself reading some quite distressing things and, and... wondered if it was helping me or not." (participant 101, female age 47)*

However, generally the presence of distressing material was expected and considered a normal and unavoidable part of the OSG. It was also understood that such content was not posted with an intention to cause distress.

> *"And that's the thing with, with dentistry, you're gonna get people who have, you know, fallen broken teeth, broken faces. Do you know what I mean? And there's gonna be blood, guts and gore and things like that. And, and the odd unfortunate situation. So, yeah. Fine." (participant 20, female age 37)*
>
> *"...you kind of almost have to sort of…go a bit with the territory." (participant 23, female age 56)*

> *“I don't think there was any kind of intentional, um… you know, fear incited from anybody, but I just think people's experiences are things that you know, to use a dental pun, touch a nerve.” (participant 11, male age 43)*

Most participants had coping mechanisms to deal with such content, such as selectively avoiding threads that could be triggering, moving away from a particular thread, or stepping away from the OSG altogether.

> *“Um, I think I, I avoided anything with words that… I, I just felt I wasn't… comfortable looking at.” (participant 11, male age 43)*
>
> *“I didn't spend a lot of time on those sorts of… um, threads. If I felt that they were gonna be a bit traumatic, but for my own preservation, really.” (participant 101, female age 47)*
>
> *“I remember just kind of like thinking about it and, and then just having to kind of have a cut-off point and just having to go and do something else cause I was kind of dwelling on it, um, and I was kind of getting in my own head, I think in terms of you know what it, it kind of brought up. So I think yeah, it was just a case of kind of putting down my phone and going doing something else.” (participant 37, female age 32)*

One participant acknowledged that those coping mechanisms were not always effective, as she accidentally exposed herself to content she would have preferred to avoid, and she recognised that tolerance levels can vary from one day to the next, making it difficult to predict what may cause distress.

> *“Yeah, yeah, yeah, it was. It was really what I was kind of… not necessarily… thinking before clicking. But we all do that, don’t we?!” (participant 23, female age 56)*
>
> *“Uhm, it, it's like the difference between being able to read something or watch something one day, and you know, two days later kind of just going ‘no, no, no. It’s just, today is a no.” (participant 23, female aged 56)*

6.5.2.1.2 Fear of disappearing down “rabbit holes”

Some participants made a conscious choice to limit their engagement with the OSG, particularly after their initial exploration. For some, they found themselves trying to read exhaustively and going deep into threads on topics that potentially were not even that relevant. They were either concerned that they could become overwhelmed by the volume of content or concerned by the amount of time that they could potentially spend on the forum without it being productive.

> *"So, I kind of sort of got a little bit rabbit holey with a couple of them, where like I'd read one and then I'd read all the experiences as replies. Um or, you know, I would get down to like a certain number of the replies to them, be like, OK, everyone's saying the same thing now." (participant 78, female aged 32)*
>
> *"...because I think it's for me a bit of a rabbit hole. Um, and, and I would, um, yeah, I could spend hours probably on there. Um, reading and, and hearing things that actually aren't relevant to me. And that's time… and this is my other concern about forums, you know I-, I'm self-employed and I'm paid by the hour. So every half hour scrolling is, is time wasted." (participant 101, female age 47)*

Others were concerned that they were displaying morbid curiosity towards distressing content, with the risk that this could ultimately increase their anxiety.

> *"I'd like-, the morbid curiosity. It was really very much a-, cause I do have a morbid streak sometimes, but I didn't find that kind of thing here. I didn't really want to go down the 'I've had a complete catastrophe, please help!' rabbit holes" (participant 116, female age 47)*
>
> *"And then things that have gone wrong and whatever else, or they felt that's been wrong. And I think if you went down that rabbit hole, you could, you know, you could make your own phobia much worse." (participant 4, female age 55)*

6.5.2.1.3 Anticipated negatives

A small number of participants described negatives that they associated with OSGs in general and that they expected to encounter, although their comments were all hypothetical and not necessarily an accurate reflection of their subsequent experience on DFC.

> *"I didn't know whether it was gonna be one of those forums where people… you know, just be really negative about everything." (participant 11, male age 43).*

A barrier to posting their story for some participants was a concern around distress as a *"competitive sport*" (participant 23, female aged 56), as encountered on other forums, in other words a concern that their story might lead to other users either dismissing it as not as serious as their own experience or reversely being judged for not coping as well as others when facing up to their anxiety.

> *"'But I've got it worse. Ohh, I've got it much worse!' Uhm, but, actually… Oh, and also at the other end of kind of 'I'm dealing with it better'. You know, kind of 'why can't you deal it with it better', you know, and… Illness and disability are not competitive sports!" (participant 23, female aged 56)*
>
> *"I'm just more interested in being a fly on the wall than kind of people, they need to one up, you know, like, um, what would my granny say? My granny always says my black cat's blacker than your black cat, you know." (participant 78, female aged 32)*

One participant was concerned about other users involving her in conflicts or disagreements, and this made her reluctant to engage with the community beyond reading other people's posts.

> *"I have found in the past when I have sought, sort of, a shared experience, maybe, or a community in a very specific subject, that I sort of get dragged into other people's situations and that isn't always healthy for me." (participant 101, female age 47)*

A final concern that participants expressed was not knowing and not trusting other people's motivations for being on the forum. Therefore, they approached DFC not knowing whether the information could be fully trusted.

> *"... you don't know about the quality of, of such online fora. Um… So it's a-, I was a bit dubious." (participant 119, female age 52)*
>
> *"But yeah, but having-, cause you never know who's on the forum groups." (participant 36, male age 41)*
>
> *"...even just things like kind of trying to unpick out…people who…maybe shouldn't be there." (participant 23, female age 56)*

Whereas for most participants these negatives did not materialise, and when asked most participants stated that they had not encountered any distressing or negative behaviours, one participant did find behaviours that she found unhelpful in the comments section of the website, which discouraged her from engaging further with the forum.

> *"It was, it was an article rather than anything else and I think, yeah, the ones where I went on and I was a bit like [pulls a face] were ones that had*

> *comment functions on where people weren't being particularly helpful. I don't know, maybe it's just my perception of it, but I feel like, if you're going to comment back, comment something helpful you know..." (participant 88, female age 31)*

6.5.2.1.4 Users from other countries

A handful of participants found the presence of people from other countries (particularly North America) jarring and confusing, and in some cases, this led to them discarding the content as not being relevant to them.

> *"I just sometimes found it confusing when people were talking about non-NHS and I think they were in America or something. Sometimes it can be difficult when, when it's, it's… a forum that's used by people in other countries. Sometimes you can get a bit confused because of the terms they use and when they're talking about particular medications and things." (participant 1, female age 45)*
>
> *"You know a story from someone who was in another country, that sort of had a psychological sort of like immediate effects of, OK, well, they're in another country. Their system is completely different. Like, you know, it isn't that relevant. And I was kind of looking for excuses, I think, in, in, in terms of the success stories [...] So yeah, it it's sort of just gave me an excuse I suppose to try and find faults with the success stories." (participant 37, female age 32)*

6.5.2.1.5 Navigation difficulties

For some of the participants, their first impression of the forum was that it was busy or cluttered. They struggled to understand the logic behind the layout, and some found that the different headings were not differentiated enough to help navigation.

> *"Because it is quite busy… It's a quite, quite a busy forum. There's quite a lot going on on there" (participant 1, female age 45)*
>
> *"... in terms of the actual content, there was lots of it, erm, and, well, I also did feel like I was kind of just, not cherry picking, but just it was almost luck as to what I was seeing sometimes, erm, so there wasn't, there wasn't a whole lot of structure there, I don't think with the content in terms of it being 100% obvious to me anyway of all of the different types and the way that it was structured I thought yeah, it, it did feel sometimes like I was just finding things by accident almost." (participant 37, female age 32)*

A few participants reported that this issue may have been exacerbated as they were trying to use it on a phone rather than a laptop.

> *“It probably would have been better to use a, a computer. It might have been slightly more manageable visually, um, but I think... I suppose the other-, there was just quite a lot-, there was quite a lot going on on the actual forum” (participant 11, male age 43)*

Some participants found it confusing that pinned content at the top of the page is not necessarily the most recent, and they found it frustrating to start reading content only to realise that it had been posted several years earlier.

> *“...if I remember this correctly, I think some of the posts were quite old, like from a few years ago. So I'm thinking, even if I post now, that's from ages ago. Who's gonna-? Just felt like a weirdo posting. Posting now like, looking at these posts that are so old!” (participant 64, female age 30)*
>
> *“And the first thing-, I did notice that there was quite a few old threads on there, but then when you obviously narrow it down, there was quite a lot of recent threads, so you can see kind of how much of a struggle people are going through.” (participant 20, female age 37)*

However, for others having guidance from the study on what the main sections of the forum were helped alleviate the issue, and as participants gained familiarity with the OSG and its functionality, this issue receded.

> *“...now I know what this forum is… um… I know what to expect, so I know for instance to go on to like the search function and look for something specific, and that's what I did. (participant 64, female age 30)*

6.5.2.2 What promotes engagement?

6.5.2.2.1 Ease of navigation

Whilst some found the forum difficult to navigate, others reported its ease of navigation as a positive, but the majority described it in more neutral terms, as something that could have been a barrier, but was not. By not encountering any difficulties in navigating or using the forum, it became easier to engage with the content available. The words “*fine*”, *“standard”* and *“straightforward”* were commonly used by participants to describe their experience. The simplicity of the layout minimised distractions, and the structure of the forum as whole was deemed satisfactory and fit for purpose.

> *“I, um, actually thought-, this is gonna be a bit like maybe a bit silly, but I thought the actual forum itself in terms of like layout and how to navigate it, was really easy to use. I really liked it for that.” (participant 64, female age 30)*
>
> *“… the font was easy to read and the-, it was white and, you know, clear. It-, there wasn't any stupid graphics kept popping up or, um, you know, it wasn't written in green or any of these are the things people do to make things look cool. No. Think it was pretty good.” (participant 101, female age 47)*

6.5.2.2.2 Success stories

One feature of the OSG that participants often highlighted as being a positive aspect that encouraged further engagement in the forum was the “Share your Success Story” section where people share positive experiences, particularly around attending dental treatment after a long period of avoidance. More generally, reading about other people’s positive experiences across the forum was perceived as a valuable aspect of the forum.

> *“Because, you know, there's quite a big emphasis, it looked like, on kind of positive stories and you know, that kind of thing, success stories.” (participant 37, female age 32)*
>
> *“I think I was, um… most drawn to, to people's posts of, of uh, regarding you know what happens, or the benefits of actually engaging in, in, in dental check-up.” (participant 119, female age 52)*
>
> *“... you can pose a question if it's about a certain aspect of the treatment that you're about to have, or something like that, and then get feedback from other people or you know, maybe it's a treatment that you've, you've got booked that you've never had done before and then you know, like I've never had a crown, for example. And then someone can then tell you, oh, you know, it was fine when I went, I had mine done, blah blah blah… And that can be really like I say, just reassuring…” (participant 1, female age 45)*

One participant who had almost disengaged because of distressing content explains how finding the success stories section had changed her view of the OSG:

> *“Um… And then, I don't know whether there was a prompt e-mail, and I went back in and had another look around and, and that's when I found the success stories thread and, and I felt completely the opposite that time.” (participant 11, male age 43)*

6.5.2.2.3 A friendly environment

Participants described the OSG as being a friendly and supportive environment, at times to their surprise. They were aware of the distress being shared on the forum and were appreciative of the kindness with which it was often met.

> *"But like I say, what people had posted seemed to be coming from a really supportive place." (participant 11, male age 43)*
>
> *"Everyone was friendly and kind. And yeah, like there was no-, the threads that I saw, like there was no real hostility. I think it's such a sensitive subject sometimes, uhm, that, yeah, I think people were pretty... Yeah, that people were pretty kind to each other actually." (participant 20, female age 37)*

Even amongst those who decided that the forum was not for them, there was a recognition of this positive aspect of the OSG.

> *"It felt a bit like Reddit, where people were just like shouting and other people were like, can I help in some way or just responding, but like a friendlier version when no one was being mean!" (participant 88, female age 31)*

6.5.2.2.4 Seeing the OSG as a community

A minority of participants who actively engaged by responding to others or sharing posts perceived the OSG as a community which they are a part of rather than just a resource that can assist them with their DA. They described how they might provide practical support and tips by sharing their own experiences.

> *"I put on about my experience of going to a dentist and… I think the one, I'm sure, I put on… certainly about the um, the Calms and Rescue Remedy… Not sure whether I mentioned music. (participant 36, male age 41)*
>
> *"Uhm yeah, I did say that I'd taken diazepam before going. And that it helped, and it might be worth asking the GP for some to see if they'd maybe prescribe that to just help take the edge off." (participant 1, female age 45)*

They may also have shared empathy and emotional support that was rooted in a shared experience and an understanding of what the other individual is going through.

> *"But um, but it's also sort of being able to tell people that… lots of people have fears of the dentist." (participant 36, male age 41)*

> *"...when I kind of looked at it myself, how many dentists I've been through and the reasons why I've left the dentist, and uhm… yeah, just, it's saying, you know, you're not you're not alone sort of thing." (participant 20, female age 37)*
>
> *"Yeah, even if just as a-, like, you know, well done on... facing your fears and… sending you a hug and you know that kind of thing just, just being reassuring. And, and like being a friend, I suppose." (participant 1, female age 45)*

One participant described the progression from simply browsing and reading other people's posts to posting as slowly gaining confidence, before feeling ready to post.

> *"I, I wasn't, it wasn't that I had to interact and so that I could kind of just be in the background if I didn't feel comfortable to kind of, talk about my, my thoughts and feelings. I could just see you know how other people were. And then if I felt comfortable, like, just, just joining in, really." (participant 20, female age 37)*

These participants were more likely to engage in a dialogue rather than simply broadcasting their stories. This dialogue encouraged more regular participation but could at times generate a sense of responsibility towards others.

> *"A couple of people did reply back and say thank you for the comments and that kind of thing so… I think that they liked what I'd written." (participant 1)*
>
> *"... just to see like what new threads or if anyone had kind of responded to any threads that I'd commented on" (participant 20, female age 37)*
>
> *"I wasn't kind of thinking 'Oh my God, I've let people down by not like doing this now' and more just kind of like 'Oh, I, yeah, I, I could probably have done with following that up, or kind of going back to see what was happening with that particular person more." (participant 23, female age 56)*

One participant reported finding sharing her story particularly helpful as it allowed her to explore her own feelings and process her own traumatic experience.

> *"I think it was beneficial for… giving me a space to… articulate history and current feelings. I think it was beneficial in terms of… giving access to other people's experiences…and being able to respond to those." (participant 23, female age 56)*

Even some of the participants who felt the OSG was not right for them recognised that engagement could be self-sustaining: the more someone posted and shared, the more involved they would feel in the community, and that they did not feel part of the community because they made a choice to stay on the outside:

> *“I think I felt a little bit like an outsider, but still think if I'd kept going in, I probably would have felt a little bit more engaged.” (participant 116, female age 47)*
>
> *“But if you wanna be part of the community itself, um, I guess you have to really be ready to get involved? “(participant 33, female age 31)*

6.6 Benefits and outcomes of using the online support group

Regardless of how they engaged, the majority of participants felt that overall, they had benefited from using the OSG, and some were able to articulate what had changed for them after using the OSG. In terms of benefits, participants reported gaining new information, realising they are not alone, gaining perspective and feeling validated. In terms of outcomes, some reported feeling closer to making an appointment or less anxious at the prospect of attending an appointment. However, whatever benefits or improvements they have experienced, participants are clear that their DA endures.

6.6.1 Benefits of the online support group

6.6.1.1 The online support group as an information resource

Whereas some of the participants prioritised factual, expert information over what they considered to be opinion, other participants reported the value of gaining information from people’s lived experiences. They valued this information not just in the form of success stories (as outlined above), but as an opportunity to learn from somebody they could relate to, particularly when information was presented as a more personal narrative and was articulated in lay terms, thus reducing barriers to understanding.

> *“I think I was, um… most drawn to, to people's posts of, of uh, regarding you know what happens, or the benefits of actually engaging in, in, in dental check-up. And, and seeking that dental intervention and what happens if you don't or leave it for any period of time, for whatever reason?” (participant 119, female age 52)*
>
> *"But again, it's kinda just seeing how… other people are kind of handling the situation.” (participant 20, female age 37)*
>
> *“Um, then it might be that other people have… have been through that, ‘cause I think when you read about things online, even when you look in on a dental website, it's, you know, the information is very scientific. Um, and I think that the bonus of the forum is that you hear it in people's own words. Um, and you know, and that's a… a huge factor really for me personally.” (participant 11, male age 43)*

A few participants found value in having the articles and expert information on the same site as the forum and used both.

> *“So it’s sort of handy to sort of see those top topics sort of appearing… and then having a bit of information to the side so you can sort of relate almost to the both, to the both of them.” (participant 36, male age 41)*

In some cases, participants were able to pick up helpful tools and learn about new things (for example about sedation or anaesthesia), again by using resources from across the website, including the forum.

> *“Or, um, just something that I was like, oh God, I didn't know that existed. That they've got numbing cream for when you put injections in it, and I didn't know that! Why did they not use that with me? Um, one of my biggest fears is the injections part.” (participant 78, female age 32)*
>
> *“And I also felt that when I'd read a few bits that I thought were interesting, you know, that, the fact that… you can have sedation and these things called dams because one of the things I really struggle with is this sense of I might choke or might be sick and they might not stop.” (participant 17, female age 64)*
>
> *“But you know, there's, there's ways you can-, there's coping ways, there's, there's mechanisms that you never even thought or heard of are out there.” (participant 131, female age 49 on sedation and gel wands)*
>
> *“I found the downloadable forms that you could complete and take to the dentist, which I thought were genius. So I downloaded all of those.” (particpant 101, female age 47)*

6.6.1.2 Realising dental anxiety is a widespread concern

A significant positive effect from using the OSG that was brought up by many participants, was realising that they are not alone, and that DA is more common than they had previously thought. Participants therefore felt less isolated and felt reassured as realising how common it is helps them normalise their anxiety.

> *“it's a perfectly, um, normal thing that lots of people worry about and it's okay to be worried about it.” (participant 101, female age 47)*
>
> *“People always think, am I just the only one that has this phobia of going to my dentist? But then obviously with the forum realising that no, you can probably guarantee that when you're sat in your dentist’s waiting room, the person sat next to you is… probably more scared than you are. (participant 36, male age 41)*
>
> *“I would tell them that it's really helpful to speak to other people who have gone, gone through similar experiences. It’s because it can just give you reassurance in itself, knowing that other people feel the same things that you feel.” (participant 1, female age 45)*

A couple of participants explained how the OSG had not only normalised their anxiety but had also prompted them to reflect more kindly on themselves and be less self-critical of themselves for having DA.

> *“And so, you know, I've sort of told myself off, I suppose about, you know, being so ridiculous. And I think perhaps I'm a bit kinder to myself now that it's a perfectly, um, normal thing that lots of people worry about.” (participant 101, female age 47)*
>
> *“I'm a sensitive over-thinky person at the best of times, so it, it kind of bolstered me that like… Appreciate that the anxiety is coming from that sensitive, over-thinky side as opposed to actually anything… clinical?” (participant 116, female age 47)*

Even those who decided that the OSG was not a place for them often acknowledged the same sentiment, and in some cases using the forum helped them realise that that it is OK to need support, even if the OSG is not the place that they would turn to in order to find that support.

> *“You don't feel so alone, do you? Like, oh, there are other people who are nervous about this and um, I think, I think maybe it just normalises your*

> *experience. You don't feel so alone and like I've just got to get on with it and deal with it." (participant 64, female age 30)*

6.6.1.3 Reflexivity and perspective

By taking part in the study, participants were made to engage with a topic that is not at the forefront of their thoughts, and that is preferably avoided. Both completing the questionnaires and browsing the forum made participants confront and reflect on their DA, both through introspection and by comparison to others.

> *"I guess the only thing that the questionnaires made me confront was having to think about going to the dentist and having to confront that anxiety. And I suppose that's the only thing, you know. Uhm, and I suppose the actual forum too kinda did that." (participant 37, female age 32)*
>
> *"Yeah, definitely beneficial, I mean. It's like I said, like, you can put your head in the sand, and not deal with the stress and the anxiety of it all, but like, you're not helping yourself, you're not… um, nothing's getting better though, the stress is always out there, but if you are dealing with the stress and you're looking it head on, like it can only be beneficial, can't it?" (participant 78, female age 32)*

In some cases, their inward-focused reflection helped them realise that their DA had improved over time or allowed them to appreciate the coping skills that they had developed, and their ability to manage their anxiety.

> *"...it made me realise that my dental anxiety, though it's a real and, and uncomfortable… part of my life and it stems from my childhood history, but that over-, it made me realise that over the years I've sort of got better mys-, I've got better with it" (participant 17, female age 64)*
>
> *"Which then makes you feel like, okay, for me at least, I felt like, okay, it's not that big of a deal, like I can do this. It's fine." (participant 64, female age 30)*
>
> *"Um, I think… it made me quite proud that I do push through and I do go, and that the kids have gone and that's… I felt like, yes, I'm doing the right things." (participant 101, female age 47)*

For a small number of participants, the OSG helped them reflect on how avoidance wasn't a helpful strategy, and reading about others who had benefited from treatment helped them realise that they might benefit too.

> *"Uhm, yes, it cause when I was filling in the questionnaire yesterday, I think I was probably a bit more positive than the first time. Uhm, so as I say, it made me think, you know, there are other people out there in worse situations, uhm, but also, by putting it off and avoiding it, I'm not helping myself." (participant 20, female age 37)*

Participants reported realising through using the forum that other people's anxiety is much worse than theirs, or that other people's dental problems are much worse than theirs. Gaining perspective in this manner was found to be helpful.

> *"I think certainly, probably about my anxiety of thinking that, yeah, it's, it's not as bad as others… It's, it's still there." (participant 36, male age 41)*
>
> *"There are people living like that in the world, and it's kind of almost nice to see that you're the lower end of the scale of that community, you know?" (participant 78, female age 32)*

This benefit was reported both by those willing to engage in the forum and by those who decided it was not for them, sometimes even as an additional reason why they felt the forum did not meet their needs.

> *"I also think that, um, although I have dental anxiety, um, I realise that some people have it a heck of a lot worse than me. Much worse than me! Um, so yeah, I just didn't think there was anything else there for me that, that would be of, of use..." (participant 116, female age 47)*

6.6.1.4 Validation

Whereas some participants had experienced their DA being dismissed, either as something that is not serious, as something irrational, or as an overreaction, the OSG provided validation by acknowledging the very real fear and distress that DA provokes. It offered a space where people shared concerns that could not be voiced elsewhere.

> *"I do think that fear of going to the dentist is not really talked about and-, or to the extent where it's almost made a joke of, like, you know, and it's not a proper serious thing. But for people that actually have it-, it's, it's a very different story." (participant 37, female age 32)*
>
> *"I guess it makes me realise that, um, there are many, many other people in my situation or in in the same… suffering with the same problem, let's say,*

> *because I always had the feeling that I'm alone, everyone around me was always telling me oh, stop being so afraid." (participant 33, female age 31)*
>
> *"I think I'm definitely actually more at peace with what I have gone through and the legitimacy of what I have felt and still feel about having to kind of deal with dental treatment." (participant 23, female age 56)*

6.6.2 Outcomes linked to the online support group

Whereas participants were comfortable talking about the benefits of using the OSG, asking them about any changes to their cognitions, emotions or behaviours seemed to be more of a challenge, as they often struggled to identify what exactly would change going forward. However, an important outcome for some of the participants was that they had actively moved closer to making an appointment with a dentist. For others, they felt more confident or less distressed by the idea of a visit to the dentist. A few were very clear that their anxiety remained unchanged. Looking to the future, most participants report that they would continue to use and recommend the OSG to others.

6.6.2.1 Moving closer to making an appointment

A small number of participants reported that the OSG had helped them move closer to making an appointment. For some, just contemplating the possibility of an appointment was a step forward, some were actively looking for a dentist, and others were now actively thinking about making an appointment, whereas one had set herself a goal to have more treatment done.

> *"I feel like I'm slowly building up to it, but it's better to do that rather what I was doing before, which was just not thinking about it and not interacting whatsoever, just giving it no thought, not doing anything." (participant 37, female age 32)*
>
> *"I'll probably need to challenge myself to sit there longer, you know, to let them do what they need to do and, and go back and have some work done. That's the challenge for me to go back and actually have the work done." (participant 4, female age 55)*

The reasons for this were varied. Some reported that reading about the consequences of non-attendance had spurred them into action. Some found that reading about positive outcomes and potential solutions had reassured them enough to change their behaviour. For others, it was putting their anxiety and their dental issues into perspective that had helped them move closer to attending the dentist.

> *“Uhm, so as I say, it made me think, you know, there are other people out there in worse situations, uhm, but also, by putting it off and avoiding it, I'm not helping myself.” (participant 20, female age 37)*
>
> *“So, I suppose in it-, in one respect it's got me thinking about it again, but it's also… got me thinking about it in a more positive way. Like I say, hearing solutions, hearing that there are solutions out there that I could potentially seek, it was a, you know, it's a bit of a game changer really.” (participant 11, male age 43)*
>
> *Which then makes you feel like, okay, for me at least, I felt like, okay, it's not that big of a deal, like I can do this. It's fine. So actually, from the, the study, that's why I've been thinking, OK, I do need to book the dentist. I do need to book the dentist appointment. (participant 64 female age 60)*

However, it is important to understand that half the participants interviewed already attended the dentist regularly, therefore for them the issue of being more likely to consider making an appointment was not relevant.

> *“I think we'll stick, you know, the visit-, the visits we have are kind of pre-programmed. You know, they tell us in six months come back and I can't see that changing.” (participant 101, female age 47)*

6.6.2.2 Feeling less anxious or more confident

Some participants reported feeling that their anxiety had been alleviated slightly by using the OSG, making the prospect of a dental visit less distressing. For some, the OSG provided hope that their anxiety could be resolved.

> *“...when I was filling in the questionnaire yesterday, I think I was probably a bit more positive than the first time.” (participant 20, female age 37)*
>
> *“Yes, definitely. It made me feel-, um, I think it might put my mind at ease.” (participant 131, female age 49)*
>
> *“I'm not gonna lie and say it's, you know, it's opened Pandora's box and everything's… you know, I can see how… it's all going to be sorted, but just I*

> *do think that it's brought me a little bit closer to feeling positive about that." (participant 11, male age 43)*

Others went further and felt that it would change their interactions with the dentist, because they felt more confident. Some of the differences were that they would feel more comfortable disclosing their anxiety to the dentist, asking more questions, for example about solutions they had read about on the OSG, or even challenge the dentist if they felt that the care they were receiving did not meet their needs.

> *"I think it's helped knowing…that, like, if I go to the dentist like, I think I'd be a bit more confident going in." (participant 62, female age 21)*
>
> *"I might behave differently in the sense of, if I had to have some major work done, I might talk about whether sedation would be appropriate, um… whereas perhaps before I wouldn't perhaps have done that because it wasn't something that I knew was available." (participant 17, female age 64)*
>
> *"So, I think I'm feeling more emboldened to, err, make more demands!" (participant 101, female age 47)*
>
> *"I think it's probably given me a bit more confidence to challenge…where, if, when, uhm, I have a less than lovely experience. Because I think I'm probably a bit more… kind of I guess, like able to say, you know what, no!" (participant 23, female age 56)*

6.6.2.3 Going to the dentist still evokes fear

Notwithstanding some of the positives outlined above, several participants who identified that the OSG was not a helpful space for them were at pains to point out that going to the dentist was still an aversive experience and that the OSG had not really had an effect on their fear.

> *"And I don't think my answers changed because the fact of the matter is when I'm sitting in the waiting room, I do still have that, you know, sweats and palpitations and that sort of thing." (participant 116, female age 47)*
>
> *"I can't imagine that I would go to the dentist without having to prepare myself the way that I do anymore. So I think that's still there." (participant 17, female age 64)*

Some of them also reported that they still felt no closer to attending the dentist.

> *"I think there is an element of a negative effect and like I said earlier, I don't think it's something I would want to continue doing because there was as much, you know, negative on there as positive really and you kind of have to fish through and stuff and even the positive things are you know are good and positive. But actually positive enough to make me want to go and sit in the dentist chair? I'm not sure! (participant 4, female age 55)*
>
> *"So I'm still anxious about going to the dentist. Like I still wouldn't wanna go. It would still make me feel, like horrible, anxious." (participant 88, female age 31)*

6.6.2.4 Future usage of Dental Fear Central

Many participants reported that they would continue to use the forum, and many reported that they would recommend it to others.

> *"I would tell them that it's really helpful to speak to other people who have gone, gone through similar experiences. It's because it can just give you reassurance in itself, knowing that other people feel the same things that you feel." (participant 1, female age 45)*

Some felt that they might post in the future, as they built up their confidence and became more comfortable with the forum.

> *"I didn't think, oh, I'll go and see what the forum says about that. Well, which is interesting cause I think actually I could have asked that question. It might have been a really helpful place to do that. [later in the interview] And I might pluck up the courage to ask if anyone's had, uh, had a tooth removed, um, willingly. And kind of what happened." (participant 101, female age 47)*

Others felt that they would use it sporadically and in a more targeted way, for example as a resource ahead of an upcoming appointment, to find information about a relevant topic.

> *"If I was able to, you know, find a dentist right now, then I may well go back to the forum… Um, you know, look at other things, questions that arise from the process of going to the dentist..." (participant 11, male age 43).*
>
> *"I guess it depends if it's, you know, just a simple like check-up or you know like a scale and polish or whatever, then maybe not so much. But if it was like an actual procedure like getting your wisdom teeth out. Erm, I think particularly in that case yes, erm, because I would want to be reading, I think*

> *more positive, um sort of stories about, you know, erm, to kind of convince me that I'm, I'm doing the right thing, I suppose." (participant 37, female age 32)*
>
> *"I think I will when I have an appointment coming up, just to like, go on there and remind myself, like the tips and, um… Like… just stuff like that of what I can do and just all that. But I think as like a regular thing, I wouldn't." (participant 62, female age 21)*

However, for some, they felt that the OSG had delivered its benefits during the course of the study.

> *"Um, I don't know. I think being able to access it in the future would be good. Um, but I feel like it's served its purpose." (participant 11, male age 43)*

6.7 Discussion

The aim of the thematic analysis on the data from the qualitative interviews was to understand the acceptability of the OSG to the participants as a potential RCT intervention. The analysis therefore aimed to explore what the barriers and facilitators were to accessing and engaging with the OSG, the perceived value, benefits or harms of the intervention, and any potential mechanisms of action. The analysis revealed many individual differences, showing that not everyone responded to the OSG in the same way. At this stage, it is important to acknowledge that people who are determined not to engage with their DA probably ignored the Facebook or Twitter adverts and did not sign up to the study. Therefore, despite best endeavours to attract a wide range of participants, an element of self-selection remains in the sample.

Nonetheless, it is interesting to understand the differences between those who were willing to engage and those who rapidly decided that the OSG would not benefit them. It could perhaps best be summarised by the difference between people only looking for fact and information who were less likely to engage and those looking for support, validation and connection who were more likely to engage. However, it would be wrong to assume that the OSG was not acceptable to those decided that it was not right for them: although they weren't willing to invest time on the OSG they did not find it inappropriate or harmful. It is also interesting to note that the presence of dental professionals was considered a positive by many, whereas many in the PPI focus group positioned dentists as, if not the cause of their DA, certainly a key contributor. For most participants, using an OSG is a balance between reassuring and distressing content, and some participants found that the balance was not in their favour, which does not negate some of the positives or benefits they may have gained from it. Conversely, it is important to understand that even those who did engage more with the OSG and found it a beneficial resource were still exposed to distressing content.

A very encouraging finding from these data is that participants found the forum friendly and supportive, with many of the commonly reported negatives around OSGs such as misinformation, misinterpretation or flaming (Allen et al., 2016; Shoebotham & Coulson, 2016) not being reported, and the anticipated negatives that participants had feared not materialising. It is also encouraging that participants were able to deploy mitigation strategies to minimise the distress caused by some of the more triggering content.

It is contradictory that some people found the OSG easy to navigate, whilst others did not. One possible explanation for this could be the method of usage, specifically the challenges of a small screen on a phone as opposed to a bigger screen on a laptop, or possibly existing familiarity with the forum format (not necessarily OSGs, for example tech forums), and overall digital skills.

Whilst a good rapport was established with participants during the interview, which I believed facilitated the discussions and encouraged honest exploration of participants' experience, the extent to which participants felt a duty towards the study, and even towards me as researcher was an unexpected theme in the analysis. The extent to which this rapport would be replicable in a wider RCT needs to be considered. A wider limitation that has become apparent from this analysis is that when considering the barriers and facilitators to initiation, it is important to recognise that in a truly naturalistic situation, the barriers would remain unchanged, but several facilitators (the reminders and the sense of duty towards the study and the researcher) would no longer apply. This could limit people's interaction with the forum and therefore their opportunity to experience its benefits. Chapters 7 (Section

7.7.1) and 8 (Section 8.4.3) will consider whether in the context of a randomised control, the same facilitators could apply and to the same extent.

6.8 Conclusion

Although some participants resolutely decided that the OSG was *“not for me”*, overall, the qualitative evidence seems to indicate that the OSG is acceptable to most of them. Even those who decided that the OSG is not what they needed currently reserved the right to return to it in the future and acknowledged its potential benefits to others. Furthermore, the qualitative evidence would indicate that although the content can be distressing at times, participants perceived that there are wide-ranging and clear benefits to engagement, some of which could not be achieved through factual information alone. This fine balance between positive and negative aspects of the OSG is fairly typical of participants’ experience as no participants described their experience as either wholly positive or wholly negative. Therefore, in the context of a randomised control trial, the OSG seems to be an acceptable intervention to participants. The next chapter will now focus on the effectiveness of the recruitment, the acceptability to participants of different elements of the study (such as sign-up, randomisation and the questionnaires), and the overall feasibility of the study processes.

Chapter 7: Process Evaluation

7.1 Chapter summary

The aim of this chapter is to evaluate the feasibility of the recruitment for a Randomised Control Trial (RCT) based on the existing participant recruitment and retention rates. In addition, it is to ascertain whether the randomisation and the measures were acceptable to participants, and to understand what modifications (if any) may be needed for a future RCT protocol. Both the timescales and limited financial cost of recruitment would indicate that the recruitment strategy and chosen platforms were effective. Furthermore, the sample was reasonably diverse, although some improvements could be made in this area, particularly with regards to educational levels. Recruitment for this feasibility study highlighted the risk of imposter participants in research, although effective steps were taken to minimise that risk and these should be carried forward to an RCT. Participants who took part in the semi-structured interviews found the sign-up and randomisation processes acceptable. Retention was unusually high compared to the published literature on attrition rates in online studies, and in this chapter, I will examine some of the factors that may have contributed to this.

In terms of quantitative data collected for the study, there were some issues with the data around participants’ usage of the Online Support Group (OSG), but participants found the baseline and outcome measures acceptable. In summary, whilst some modifications to the protocol may be beneficial, the evidence seems to indicate that an RCT would be feasible.

7.2 Effectiveness of recruitment

7.2.1 Adverts

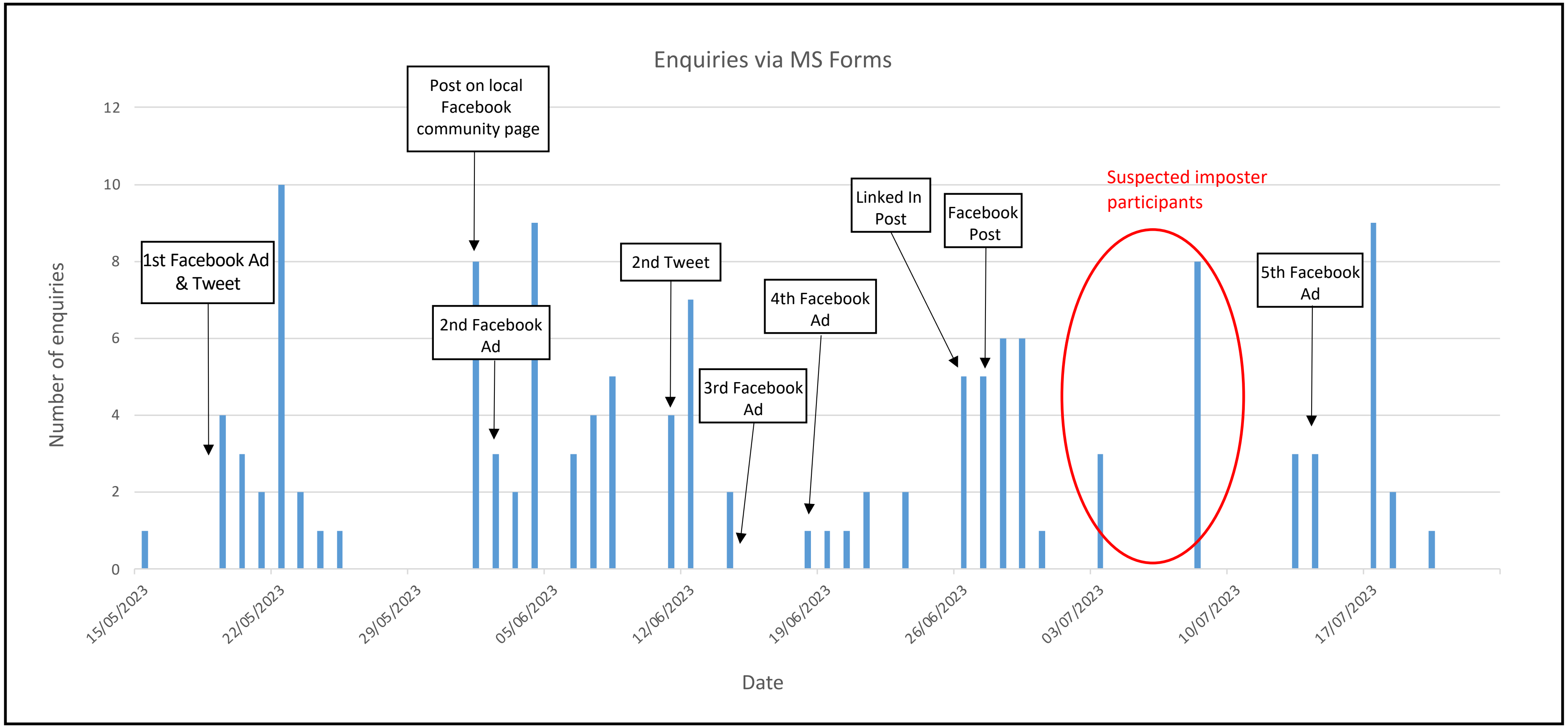
As previously described in the Methods (Chapter 4, Section 4.4.5), a Facebook page was created for the study, from which the study was advertised through both paid and unpaid adverts. Facebook provides the advertiser with the choice of also showing the paid adverts on Instagram.

This option was selected for all the adverts to broaden the study's reach, as Instagram attracts a younger demographic compared with Facebook (Statista, 2025). As can be seen in Figure 7.1, the response rate to the adverts varied.

Although it is not possible to categorically link an enquiry to a specific advert, most of the paid adverts were followed by an increase in enquiries a few days after the adverts went live. For most of the unpaid adverts (tweets, posts on a local Facebook page and Linked-in posts), the response was more immediate. Not all paid adverts were equally effective. Facebook allows the advertiser to choose whether to target more clicks (as measured by the number of Facebook users who click on a link within the post or advert) or more engagements (which includes clicks, but also likes, comments and shares). Both types of adverts were used, with no discernible difference in recruitment.

Across the adverts, two different images were used (see Appendix 4). The first was a cartoon picture of a tooth, which was chosen for being positively received by the PPI group as being non-threatening, and because a previous study by Hui et al. (2015) found that a Facebook advert using a happy face when recruiting for participants in a study on depression was more effective than an advert using a sad face. The second image featured the University of Nottingham logo alongside the question "Are you anxious about going to the dentist?". This second image aimed to communicate the study's affiliation with an academic institution, which felt important in the context of social media where users may be weary of scams or data harvesting (Alkhalil et al., 2021), and because participants in the consent calls asked about the context of the study and its links to a university. However, the responses to the advert showed that there was no discernible difference in recruitment based on the image.

Figure 7.1: Enquiries received via MS Forms during recruitment period



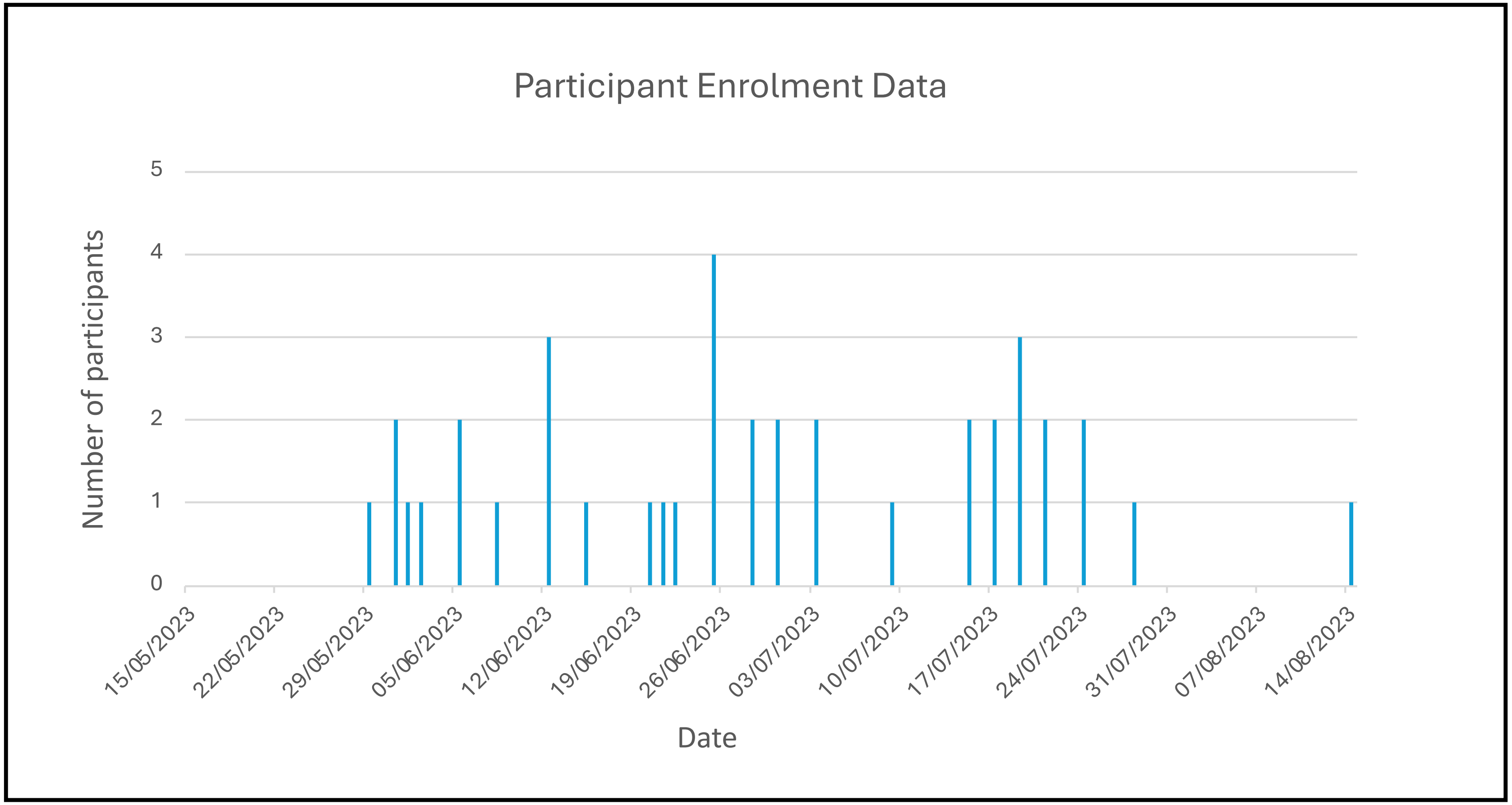
The most effective advertising activities appeared to be the first paid Facebook advert, followed by the unpaid advert on a local community Facebook page. However, to be able to confidently establish the most effective recruitment strategy, a more robust testing procedure would have been needed, taking into account the timing of posts (day of the week and time of day), choice of image, and type of advert selected (clicks or engagement). In hindsight, my approach to this aspect of the PhD was rather naïve and although I learnt a lot as the recruitment went on, an RCT that might recruit over a longer period of time and with a greater number of adverts should be set up to test the effect on recruitment of individual adverts, to respond and repeat those that yielded the highest number of enquiries. Furthermore, as Meta (the company that operates Facebook, Instagram and WhatsApp) develop their advertising capability, they have also developed their support tools for small advertisers, and use of these newly available resources would be of benefit to the researchers involved in an RCT to ensure that they understand and maximise the available functionality of Facebook and Instagram adverts.

The effectiveness of Facebook as a recruitment tool is corroborated by the feedback from the qualitative interviews: of the 13 participants who were able to recall where they saw the study advertised, ten reported seeing the study advertised on Facebook, of which two recalled that it was a local page, and one recalled that it had been shared by a friend. Two participants stated that they had seen the study advertised on X (formerly known as Twitter). None of the participants reported seeing adverts on Instagram. One participant was recruited through an email that was sent to people who applied to take part in the PPI focus group but were not selected for it and agreed to be contacted again about the study. Participants were asked during the consent call where they had seen the advert, but this information was not recorded as they had not at that point signed a consent form. On reflection, I could have collected this data from the entire sample and at an earlier stage in the process to provide a more accurate understanding of recruitment effectiveness, as participant recall was limited at the end of the study. For example, a question could have been added to the initial enquiry form on MS Forms, asking them where they had seen the advert. This would not only help overcome any issues with recall but would also allow analysis to understand which advert location (e.g. Facebook, LinkedIn or X) generates the highest level of enquiries, as well as whether one location has a higher follow-through to study sign-up than the others.

7.2.2 Recruitment timescales

In total, 131 individuals used the enquiry form (see Appendix 6) to express an interest in the study and request more information, of which 128 were sent a link to complete the MDAS (three were duplicate or invalid emails), 78 completed the MDAS and were screened for eligibility, and 50 received a Teams or a phone call to explain the study and to provide an opportunity to ask any questions. Of those 50, 40 subsequently completed a consent form and were enrolled in the study (for a CONSORT diagram see Chapter 5, Section 5.2). Recruitment was achieved within the expected 3-month timeframe, with the first participant enrolled in the study 14 days after the Facebook page went live and 12 days after the first advert was launched (see Figure 7.2). The target number of participants (N=38) was achieved within 75 days of the Facebook page going live. At the end of the three-month recruitment window, consent forms had been received for 39 participants. One additional participant who was recruited via email (as described above in Section 7.2.1) expressed an interest in mid-July, but their enrolment was delayed as they required reasonable adaptations (participant information sheet in large font printed on green paper and posted to them). Unfortunately, this was difficult to do using University resources. However, I was still able to enrol them when their consent form was received in early September (which was within the additional contingency period of one month that had been allowed for recruitment). Two other consent forms were received in September, but the participants were advised that enrolment had already closed.

Figure 7.2: Participant enrolment during 3-month window



7.2.3 Cost of recruitment

The recruitment was achieved with limited spend on Facebook adverts. The total cost of £31.24 equated to a net cost of less than £1 per recruited participant. Two systematic reviews of recruitment to studies using social media (Reagan et al., 2019; Sanchez et al., 2020) found high levels of variation in cost per participant where the data were included, with the average cost per participant varying from less than a dollar to around $68 (circa £55) per participant, depending on the country and the type of study. According to Sanchez et al.'s (2020) systematic review of recruitment for participants in mental health research, Facebook was the most common platform for recruitment, specifically paid adverts, and the average cost per participant for RCTs was $42.82 (circa £35). They also note that recruitment speed was often faster using social media compared to more traditional recruitment methods (such as flyers, adverts and print media). Most of the studies included in their review were conducted in the US, Australia and the UK and between 2012 and 2017, which could mean that some of their findings are out of date, given that social media is a fast-evolving medium. The relative low-cost per participant of this feasibility trial could be due to the prevalence of Dental Anxiety (DA) in the general population, making any paid advert relevant to a wide audience. Indeed, Sanchez et al. (2020) highlight the rarity of potential participants in the general population as a key factor that drives recruitment costs on social media.

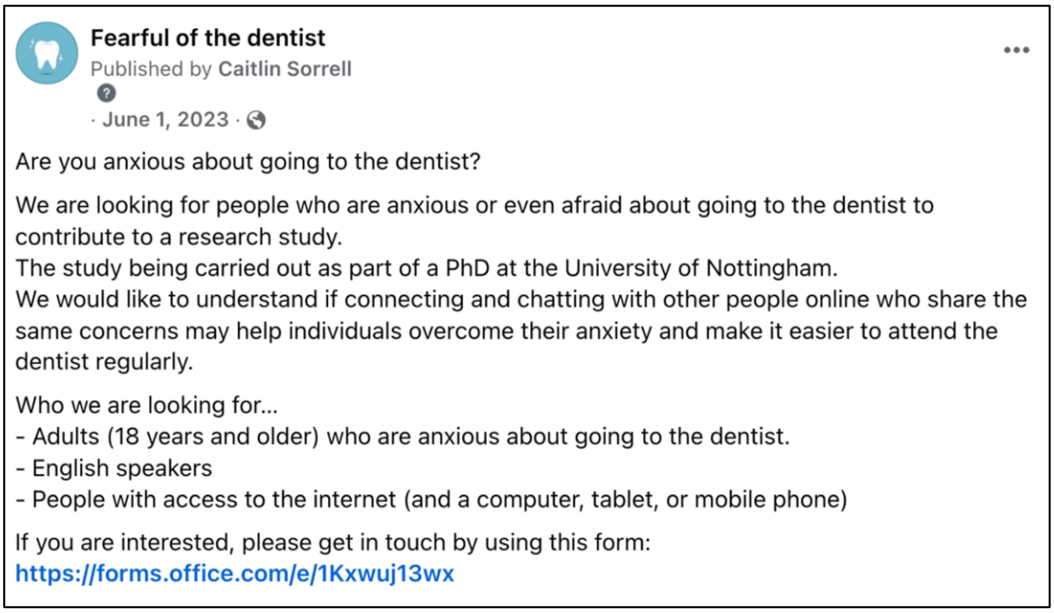
7.2.4 Sample diversity

At 22%, the sample had a higher proportion of non-white British participants than the population average of 18% (ONS, 2022b), indicating that the strategy of targeting the adverts at major urban areas may have been successful at increasing diversity. However, the sample was predominantly female, and whilst DA affects more women than men (Office for Health Improvement and Disparities, 2024), the bias towards women was higher than prevalence alone would explain. To address this issue, the final Facebook advert was set up to explicitly target men, although enquiries that followed this final advert were exclusively female, indicating that for a full

RCT a different advertising strategy would need to be employed, perhaps stating in the advert itself that the study is looking for male participants. Data collected during the interviews indicated that 60% of the participants in the Online Support Group (OSG) condition were educated to bachelor's or post-graduate level, compared to a 33% national average (ONS, 2022a). This bias may have been introduced by the tweets and posts placed on my own social media profiles (X and Linked-in), which were then shared by others within the academic community.

Analysis of the baseline data (see Chapter 5, Section 5.3) showed that the mean scores on the MDAS in both conditions (OSG and Wait List Control or WLC) were high, with a mean across both conditions of 22.1. A score above 19 is considered indicative of high DA (Office for Health Improvement and Disparities, 2024). This raises the question of whether the adverts may have been perceived as more relevant by people who have higher levels of anxiety, or whether people with higher DA are simply more motivated to seek help. Whilst the message in the adverts themselves asked "are you anxious about going to the dentist?", the post will have appeared preceded by the name of the Facebook page "Fearful of the dentist" (see Figure 7.3). It is unclear whether use of the word fearful may have made the advert appear more relevant for people with a higher level of anxiety.

Figure 7.3: Example of text on Facebook advert



Fearful of the dentist
Published by **Caitlin Sorrell**
· June 1, 2023 ·

Are you anxious about going to the dentist?

We are looking for people who are anxious or even afraid about going to the dentist to contribute to a research study.
The study being carried out as part of a PhD at the University of Nottingham.
We would like to understand if connecting and chatting with other people online who share the same concerns may help individuals overcome their anxiety and make it easier to attend the dentist regularly.

Who we are looking for...
- Adults (18 years and older) who are anxious about going to the dentist.
- English speakers
- People with access to the internet (and a computer, tablet, or mobile phone)

If you are interested, please get in touch by using this form:
https://forms.office.com/e/1Kxwuj13wx

7.2.5 Imposter participants

According to Wang (2024), imposter participants (also sometimes referred to as fake participants or fraudulent participants) are participants who fabricate identities and untruthfully claim to meet eligibility criteria to participate in research, often for financial gain. Ridge et al. (2023) argue that whilst this issue is not entirely new in qualitative research, it appears to be an increasing phenomenon which they attribute to the COVID-19 pandemic and the move to online research methods, as well as the cost-of-living crisis in the UK and elsewhere. Prompted by the behaviour of one of the participants in the PPI focus group (see Chapter 4, Section 4.3.2.4), I searched for information on this topic. During recruitment, I was therefore aware of the potential risk of imposter participants in qualitative research, particularly when recruiting through social media (Woolfall, 2023).

On two dates in July, a total of 11 participant enquiries were received, with 3 enquiries on July 3rd, followed by 8 enquiries five days later, during a period without any advertising activity (see Figure 7.1). These enquiries were often clustered within minutes of each other, with similar email formats: all gmail addresses, with interchangeable first and second names or famous peoples' names, and numbers after the names (e.g., Johnjames2500@gmail.com or Michaeljackson11@gmail.com[5]). These participants were predominantly male and in their twenties, with enquiries received in short succession often stating the same age. Ridge et al. (2023) identify multiple emails in quick succession, similar email configurations, and similar demographic features as three of fifteen potential characteristics of imposter participants, and whilst these participants were not removed from the study at this stage, I noted them as potentially suspicious. Upon further investigation, an additional four email addresses were identified that followed a similar suspicious pattern and had been received a few days earlier, and some a few days later. This took the total of suspected imposter participants to 15. Five of these did not complete the MDAS. A further five completed the MDAS questionnaire but did not respond to the invitation to take part in a Teams or phone call. Five

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[5] These are not the actual email addresses used, but illustrations of the type of format that appeared suspicious.

responded, but were reluctant to provide a phone number, and arranged a Teams call. A reluctance to provide a phone number is another one of Ridge et al.'s (2023) characteristics of imposter participants. Three of the participants who arranged Teams calls failed to attend, and two joined the call as agreed. Both Ridge et al. (2023) and Martino et al. (2024) recommend that researchers take active steps to identify imposter participants, and that these steps are built into research protocols. Although the protocol for this feasibility study did not include any contingencies for dealing with potential imposter participants, recommendations based on the nascent literature on this topic were followed. These included asking participants to briefly turn their cameras on and asking more questions about geographic location (Martino et al., 2024), asking more probing questions about lived experience (Wang, 2024) whilst paying particular attention to the richness of detail provided (Ridge et al., 2023). The two suspected imposter participants who attended a Teams call were asked to turn their cameras on briefly under the pretext of needing to verify that they were indeed over 18. Both were reluctant but agreed to turn their cameras on. When both participants were asked where in the UK they were from, they replied “London”. When asked for the first part of their post-code, there was a delay as they visibly typed on their computers before replying ‘W1’, the postcode for the City of London, an experience which is very similar to the one described by Martino et al. (2024), which led them to exclude the participant’s data from their research. Both participants asked questions about the compensation and payment methods before the study had been described fully, which is another of Ridge et al.'s (2023) characteristics of imposter participants. One participant ended the call abruptly on hearing that compensation was in the form of Amazon vouchers. The other participant was asked whether they had lived with DA for a long time, and they responded that it was a recent development. When asked if they felt that a particular incident had triggered their DA, they appeared hesitant and avoided answering by asking again about compensation. At that point, I advised them that they would not be enrolled in the study as they did not meet the eligibility criteria, and they ended the call. After both calls, I made notes in my reflexive diary as I was concerned that I wanted to capture the experience, not least so that I could justify why I had excluded a potential participant.

Whilst there can be no guarantee that the remaining participants did not still include imposters, most were keen to talk about their DA during the consent call, to the extent that I needed to gently and empathetically return the discussion to the study and what was involved. In addition, most participants asked questions about the study itself and showed limited interest in the compensation and the form which it would take or how promptly it would be paid. For the participants in the OSG condition, their descriptions of the OSG and of their lived experience of DA during the semi-structured interviews contained the richness of detail that Ridge et al. (2023) describe as providing reassurance on the authenticity of a participant.

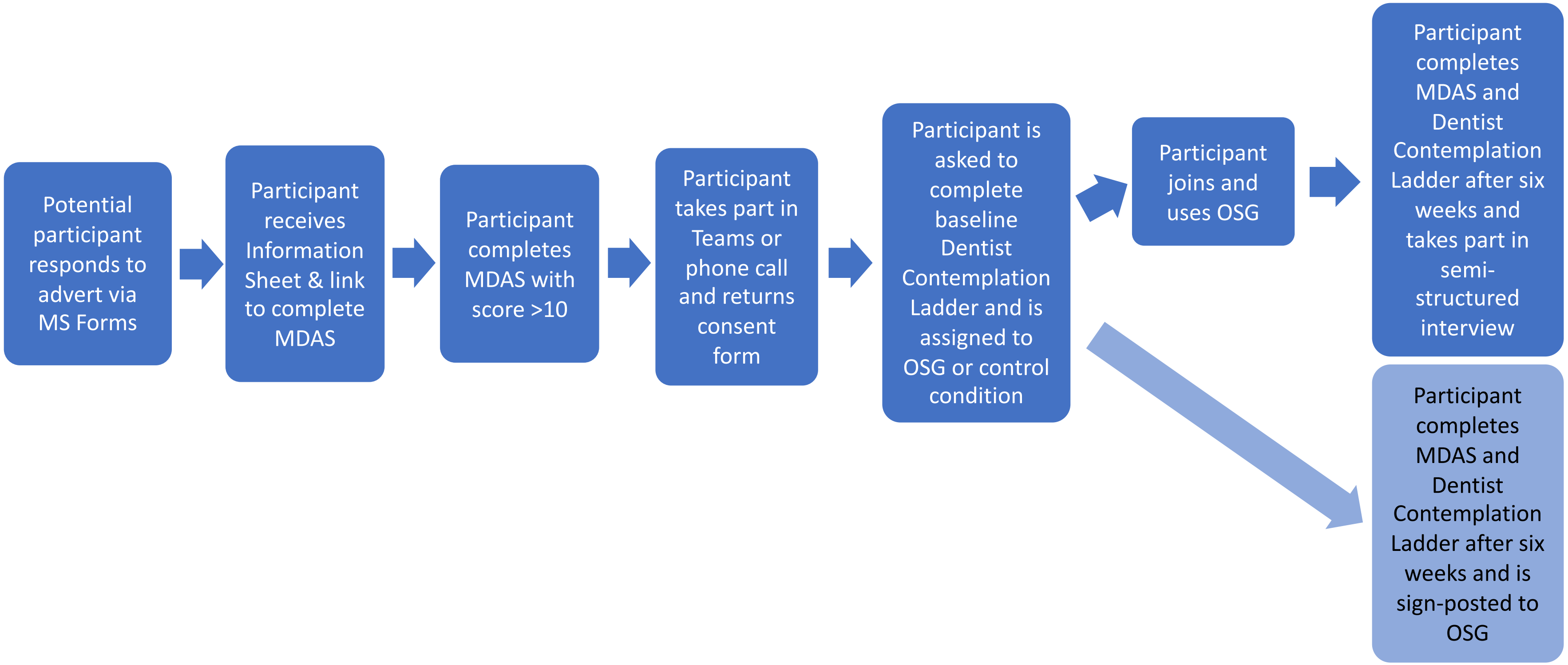
7.3 Sign up and randomisation process

7.3.1 Sign up to the study

Of the 50 participants who received a phone or Teams call, 80% signed up. Of those who received a phone call but were not enrolled in the study, two were identified as imposter participants (see Section 7.2.5), two returned their consent forms after the study had closed, and two decided during the call that they did not want to participate, one because they did not feel that it would help their DA, the other because they felt it would be too great a time commitment for them. Four did not return their consent forms after the call and did not respond to the follow-up email they were sent (see Appendix 9.7), therefore their reasons for non-participation are not known.

During the interviews, participants allocated to the OSG were asked for feedback on the sign-up process (see Figure 7.4 for details of participant progress through the study, including sign-up). Some participants admitted that they had limited recall on the detail of the sign-up process, which a few then interpreted as meaning that it must have proceeded smoothly: "*the fact that I don't actually remember it's probably a good thing because I remember not having any issues" (participant 37, female age 32)*.

Figure 7.4: Participant progress through study



However, eight participants described the process of signing-up to the study as *"easy"* or *"very easy"* and an additional six participants described the process as *"straightforward"*. A couple of participants reflected on the amount of *"private details" (participant 33, female age 31)* that they had been asked to provide at the point of enquiring and at the point of signing up and observed that it was not *"too invasive" (participant 20, female age 37)*, and that they *"didn't feel like, um, there was any problem with this" (participant 33, female, age 31)*.

They were also asked whether they felt that they had a clear understanding of what was involved in the study before they returned the consent sheet. Participants confirmed that they did have a clear understanding, with a few participants reporting that this increased their confidence in taking part in the study or helped alleviate their anxiety about participating:

> *"Yes, I felt like on that call you were really, really clear and explicit on everything. And I think that helps, um, especially if you do have, you know, things like… Yeah, like if, if you're concerned or if you have anxiety, then I think going through that step by step, was really, really, er, helpful." (participant 37, female age 32).*

One participant mistakenly assumed that the purpose of the call was to screen participants, which they saw as a positive step to increase diversity and ensure that only engaged participants were signed up. More generally, several participants offered positive feedback about the communications they had received regarding the study, from clarity about what was involved in the different steps of the study to guidance around logging on and resolution of issues:

> *"No, it's been-, genuinely not, not, not just saying this. It was very well run. Start to finish, so..." (participant 116, female age 47)*
>
> *"The way that you approached it all and your speed of replying to anything that-, you know, queries or, or, or problems that ensued along the way" (participant 59, female age 71).*

7.3.2 Randomisation

Participants who were allocated to the OSG condition and who took part in a follow-up interview were asked about the randomisation process. Because of this approach, there is an inherent bias in the data collected as only participants in one of the conditions were asked about the randomisation. However, the low attrition rate for those randomised to the WLC condition could indicate that any concerns or dissatisfaction about the randomisation were insufficient to lead to participants leaving the study. Furthermore, no responses (either positive or negative) were received to the email allocating participants to the WLC condition.

Participants in the OSG condition provided feedback on their reaction to the randomisation, with most participants reporting positive feelings on being allocated to the OSG condition. These positive feelings were often ascribed to the prospect of taking steps towards helping with their DA, and they described feeling positive about accessing support:

> *"Oh I thought I was really lucky, actually! I got the-, I got the intervention group so I thought, yeah, I get a bit of help for this and that's obviously what motivated me to join so…" (participant 64, female age 30).*
>
> *"It felt nice to know that there was gonna be somebody else I could talk to" (participant 20, female age 37).*

A small minority of participants reacted with apprehension, and even those who expressed positive feelings on being allocated to the OSG condition sometimes described it as being tinged with apprehension or curiosity:

> *"I worried a bit, then immediately about oh what will I have to do?" (participant 101, female age 47)*
>
> *"I was very excited about it, um, but I didn't know what to expect" (participant 33, female age 31).*

A third of participants described their views as neutral, or admitted that they "*didn't actually, um, think about that too much, to be honest." (participant 59, female age 71).* Some participants explained this lack of emotional reaction to the allocation to the OSG condition by their understanding of the process and their awareness that this was a possible outcome, as they were *"prepared for that to be the case" (participant 23, female age 56).* In addition, some of the participants who expressed positive emotions about being allocated to the OSG condition also stated that the opposite outcome would have been met with neutral rather than negative emotions:

> *"not that that I would have felt anything, having been assigned to the control" (participant 64, female age 30).*

7.4 Participant retention

In total, 40 participants were enrolled in the study, of which 37 completed all measures, equating to an attrition rate of 7.5%. This attrition rate is significantly lower than both the attrition rate target of 33% that was set out in the study protocol, and the median attrition rate of 40% outlined in a systematic review of app-based studies for health-related interventions by Meyerowitz-Katz et al. (2020). Although the levels of attrition in this review were highly variable, the lowest recorded rate for an included study was 9%, making the attrition rate of 7.5% in this feasibility study noteworthy. One potential contributing factor to the lower attrition rate could be the recruitment method. As Sanchez et al. (2020) identified in their systematic review, studies that recruited participants through Facebook had lower attrition rates than other social media, and most of the participants in the OSG condition reported seeing the advert on Facebook. Furthermore, a systematic review and meta-analysis of RCTs for mental health Linardon & Fuller-Tyszkiewicz (2020) found that short follow-ups (less than 8 weeks) reduced attrition, therefore the six-week intervention period may have contributed to the low attrition but does not fully explain it. Their data also indicated that studies that offered financial incentives and provided reminders to participants about the intervention saw lower attrition rates. In this feasibility study, participants were only provided with vouchers once they had completed follow-up questionnaires and/or interviews. Furthermore, the emails with the links to the final questionnaires or asking them to confirm the date and time of the interview (see Appendices 9.10 and 9.11) reminded them of the financial incentive that they would receive upon completion. Finally, Linardon & Fuller-Tyszkiewicz (2020) found that trials which involved an element of personal contact with a researcher, either over the phone or in person, also had lower attrition rates. They hypothesised that two factors could be involved in the reduced attrition with direct contact. Firstly, participants who have personal contact with researchers have a greater understanding of what is expected of them and the amount of effort involved in taking part in the study from the onset. Secondly, studies which do not rely on purely online enrolment attract more motivated participants. Whilst all these factors (timeframe, financial incentives, reminders, and phone or Teams contact) no doubt played a part in reducing attrition, the extent to which I built rapport during the initial phone call may also have contributed to the lower attrition rate. Emails to arrange the call were sent from my named university email address (rather than a generic study address) and the text of the email made it clear that the call would be with me personally, rather than an anonymous member of the study team (see Appendix 9 for emails sent to participants). During the call, participants were made aware that this research was conducted as part of my PhD, which may have further contributed to a sense of commitment from participants as they may have felt some accountability for the success or failure of my studies. Finally, the tone in the emails and during the call aimed to be warm and conversational rather than formal, which may have also helped to build rapport with participants. However, this additional element of the sign-up process was time consuming, therefore consideration needs to be given to its scalability in a larger RCT.

7.5 Participant feedback on online support group usage

7.5.1 Guidance on using the online support group

Participants were asked to engage with the OSG in a naturalistic manner and received no guidance on how often they should be logging on, or how long they should spend on the OSG. There was no requirement for them to engage with, respond to, or initiate any posts. The participant information sheet (see Appendix 7), the phone or Teams call, and the guidance that was emailed out to participants when they had been allocated to the OSG condition (see Appendix 9.4) all made it clear that it was up to them to use the OSG in a way that suited them, and all participants were reminded during the phone call that if they were allocated to the OSG condition and encountered any distressing content, they should feel free to step away from the OSG. However, in the qualitative interviews it became apparent that opinions were divided about being given *“complete free reign” (participant 88, female age 31)* to explore the OSG. Some participants stated that they were confident using online forums, with one participant outlining that *“somebody* *who was new to forums"* might benefit from *"a little bit more support and guidance" (participant 1, female age 45)*. However, others highlighted that the visual instruction sheets provided on how to navigate their way around the OSG (see Appendix 12) were *"helpful" (participant 11, male age 43)* and *"very, very clear" (participant 116, female age 47)*. Some described how they were confused by the *"lack of expectations" (participant 116, female age 47)* and were concerned that they might not be engaging enough with the OSG to meet the needs of the study. They felt that they would have benefited from more explicit guidance and clearer targets *"because that way I feel like I'm not letting you down but I'm like doing what you want from me" (participant 88, female age 31)*. Some felt that guided exploration would have been beneficial, with *"suggestions or again prompts as to what to look at on the site" (participant 119, female age 52)*, perhaps on a weekly basis. However, others felt that their exploration of the OSG was *"entirely my journey and my experience and that whatever that looked like was what you were interested in" (participant 116, female age 47)*. To reconcile these conflicting opinions, more guidance could be provided, with a clear statement that it is intended as guidance only and that participants should feel free to either follow the prompts or engage in whatever way they feel comfortable.

7.5.2 Reminders

As mentioned in Section 7.4, reminders may have played an important role in supporting usage of the OSG for participants in that condition. In Chapter 6 (Section 6.3.2), the thematic analysis of the semi-structured interviews highlighted how for many participants email prompts and reminders to use the OSG (both those sent as part of the study and those sent by DFC) facilitated and encouraged engagement with the OSG. During the interviews, participants were also asked about their perceptions of these reminders and provided direct feedback on the tone, content and frequency of reminders. More than a third of participants stated that they would have liked *"more of a nudge" (participant 23, female age 56)* or felt that they would have benefited from a higher frequency of reminders, with several participants suggesting that a reminder *"once a week" (participant 119, female age 52)* would have been beneficial as it would have encouraged more engagement with the OSG:

> *"if it had been a… weekly reminder, have you, have you checked into the forum this week? Is there anything it could help you with? That perhaps would have triggered me to go, oh, actually yes, I have got a question" (participant 101, female age 47).*

A small number of participants who wanted more reminders suggested that these should be linked to content on the OSG, either highlighting *"what's new on the forum" (participant 20, female age 37) or "this is what's been happening on the topic of…" (participant 36, male age 41)*. One participant suggested that reminders based on a combination of trending and personalised content would provide the greatest incentive to visit the OSG:

> *"So something that kind of is somewhere in between, just here are the top trending topics, and here's something very specifically targeted to you." (participant 119, female age 52).*

However, there were also a small number of participants who found the number of reminders appropriate, and some who explicitly stated that they did not want more:

> *"I think had there been more, it would have started to feel like I was being compelled." (participant 116, female age 47).*

Participants were keen to clarify that whatever the frequency, reminders should be *"just a nudge" (participant 20, female age 37)*, and not make them feel chastised for not engaging with the OSG:

> *"I think there are ways and means of, you know, just prompting people, you know, even by questions, it makes people think crikey, I haven't been in there, I need to go back in." (participant 4, female age 55).*

However, the value of this feedback is limited as it is difficult to establish how many reminders each participant received, as one was sent from the study to all participants around the half-way point of their six-week intervention, but Dental Fear Central (DFC) also sent messages approximately every 18 days to those participants who had not actively opted out of this functionality when signing up to the OSG. These messages were focused on recent trending topics on DFC. Participants did not distinguish between reminders sent from the study and those sent from DFC. Going forward, participants could be instructed not to opt-out of these reminders to ensure greater consistency between participants in the frequency of messages received. The importance of reminders as an external prompt also contributes to an understanding of why just over 60% of the logons occurred within the first week of participation in the study, when all participants had received the instructions about joining the OSG and taking part in the study.

7.5.3 Issues with data on online support group usage

The analysis of logon data shows that the mean number of days logged on by participants during their six-week period after signing up to DFC was 3.6 (ranging from 0 to 13 days). Being able to capture data on usage frequency from the OSG rather than relying solely on participant self-report is a significant positive, as it provides an objective measure. However, triangulation of the qualitative and quantitative data reveals a discrepancy. During the interviews, participants often reported higher levels of interaction than those captured through the quantitative data. There could of course be an element of over-reporting driven by demand characteristics and a desire to be perceived as "good participants", or simply a lack of recall on behalf of participants. However, there is also an inherent issue with the way that the data were captured. The logon data were based on screenshots of a section of the OSG showing which usernames had logged on during the last 24 hours, when it was in fact possible to use all "passive" functions of the OSG (browsing the site and reading posts) without logging on. Participants only need to be logged on to react or to post, but most participants described themselves in the semi-structured interviews as "readers" rather than "posters". Whilst participants were shown how to check they were logged on in the guidance notes (see Appendix 12), the need to logon every time the participant used the OSG could have been made more explicit. Several participants reported that the OSG was *"very easy to go on… it remembered my login details" (participant 62, female age 21)* and that they were repeatedly able to access the content without the need to login again. One participant believed that if they clicked on a link from an email from DFC, this bypassed the need to logon:

> *“that's when I clicked into the site and I noticed that when I got those emails, it didn't automatically take you to log in. So you were able to view the content without creating an account or having to log in, which, I actually really did like.” (participant 37, female age 32).*

The website however does not remember people’s logon details and does require them to logon afresh each visit if they want to post, respond or comment. These participants would have been using the OSG and accessing all the content they felt they needed, without being listed as one of the usernames that had logged on. Therefore, the data are likely to under-report the number of times participants used the OSG.

One participant experienced technical difficulties as they did not receive and click on the link in the confirmation email needed to complete registration with DFC. The email sent by DFC may have gone to this participant’s junk folder, but they were unsure how to retrieve it from there. I tried to assist them with repeating the logon process, but without success. However, this participant still accessed the OSG and was able to give a detailed account of their usage, of the topics they read about on the site, and they did not feel that their experience had been compromised by the absence of logon. This participant’s frequency of usage however was recorded as zero. The issues around participants’ engagement with the OSG and the data collection for it will be further considered in the discussion in Chapter 8 (Section 8.3.4).

7.5.4 Duration of intervention

Participants allocated to the OSG condition were asked during the interviews about the duration of the intervention. More than two thirds of the participants felt that a six-week period was an appropriate duration, which allowed them to find time to use the OSG without it being an excessive commitment, so that it *“feels natural to use the, the forum, but it's not so pressured” (participant 64, female age 30).* In addition, participants described how the six-week period enabled them to ascertain whether the OSG was of value or not to them, and enabled them to provide informed feedback in the context of the study:

> *“…anywhere between maybe 4 weeks to six weeks, it's enough to discover if this is a community that benefits you or not.” (participant 33, female age 30).*

> *"…six weeks is, is a reasonable length of time to give it, you know, for you to be able to find the time to actually spend some time, you know, reasonable amount of time in there browsing and having look around enough to give you some feedback" (participant 4, female age 55).*

However, a small number of participants felt that the six-week period was not long enough or would only have been sufficient with more reminders. One participant highlighted that the window was *"possibly a bit short because appointments are so far away" (participant 101, female age 47)*, and they felt there was benefit in using the forum around a dental appointment. Another participant felt that the timing of the study during school holidays made the six-week window feel short.

7.6 Questionnaires

7.6.1 Participants' experience of the questionnaires

During the semi-structured interviews, participants were asked about their experience of completing the questionnaires. Almost all participants reported finding the questionnaires simple, quick and easy to complete, and that it was clear to them why these questions were being asked:

> *"They were really quick to fill in. They were really clear. I wasn't confused about what any of the questions were asking at all." (participant 37, female age 30).*
>
> *"I mean it linked to the research question and also linked to what the, um, whole forum was about." (participant 62, female age 21).*

However, one participant reported how completing the questionnaire *"kind of did remind me a bit of the anxiety that I get" (participant 1, female age 45),* but not to the extent that they felt *"triggered as such".* More than a quarter of participants highlighted that an inherent issue with completing the questionnaire is that their DA is not a constant, but instead will vary from day to day, which may or may not be linked to dental appointments or dental issues:

> *"I think the ladder one kind of threw me a bit because I think it will change day-to-day depending on how I feel." (participant 88, female age 31)*

Interestingly, more than a quarter of participants also reported how completing the questionnaires had prompted them to reflect on their DA in a way that they had not previously done:

> *"But it was a moment of reflection for me to say OK. I like-, I hear myself, I see myself. I am a bit nervous and it's there in front of you in black and white." (participant 64, female age 30)*

Finally, one participant who stated that the questionnaires were easy to complete also demonstrated some confusion about the Dentist Contemplation Ladder, reporting that *"ten was the lowest and one was the highest. Which suddenly makes your brain sort of half confused and then try and work out well, ten's the best, but it's not. It's the worst." (participant 36, male age 41)*. The way the questionnaire should be interpreted is that a score of 10 would indicate the highest likelihood of attending a dental appointment. However, it is not clear whether this was indicative of an issue with their understanding or with their recall of the ladder.

7.6.2 Timing of questionnaires

The first two interviews were completed before participants had returned their outcome measure questionnaires. This proved to be problematic for two reasons: firstly, because participants had limited recall of the questionnaires they had completed more than six weeks previously. Secondly, the discussion about DA during the interview may have led them to reflect more deeply on their DA and their experience of using the OSG, which could have influenced their score. The usage of the OSG for a six-week period would then no longer have been the only difference between the OSG condition and the WLC condition, and it would have been difficult to attribute any changes in scores to the OSG usage alone. This issue could have been exacerbated by the rapport that was initially built during the consent calls and then strengthened during the interviews, which may have increased the risk of bias through demand characteristics, with participants allowing their scores to be influenced in response to the expectations of the study and the researcher.

Therefore, after the first two interviews that were completed in very short succession, participants were asked to complete the outcome measures before the interview, and all participants complied with that request, returning the questionnaires before the interview. The risk of participants not completing questionnaires was hopefully reduced by sending the link to complete the questionnaires in the same email that reminded them of their approaching interview appointment (see Appendix 9), reminding them of the need to complete the questionnaires ahead of the interview, and reminding them of the financial incentive as the vouchers would be sent once the questionnaires were completed.

This is an important consideration that should be taken forward and included in the protocol of a full RCT, and whilst similar steps should be taken to encourage completion of the questionnaires ahead of the interview, it seems unlikely that this would be achieved in all cases.

7.7 Discussion

7.7.1 Feasibility of Teams or phone call

The telephone or Teams call that formed part of the sign-up process for the study was initially intended to ensure informed consent, by ensuring that participants had an understanding of what the study involved as well as the opportunity to ask any questions they might have. It seems to have been effective in fulfilling that purpose, although evidence suggests that it could have been strengthened even further through the use of a test/feedback or teach-back component (Glaser et al., 2020). In this instance, requesting a phone number and including an element of personal contact appears to have also been a useful step in identifying and avoiding imposter participants, which is in keeping with findings from previous research (Loebenberg et al., 2023; Ridge et al., 2023). Furthermore, according to both Sanchez et al. (2020) and Linardon & Fuller-Tyszkiewicz (2020), recruitment methods that involve phone calls or in-person appointments require higher motivation to participate as they involve longer wait times and require more effort than those with purely online methods, which in turn may have contributed to the low attrition rate. Therefore, it could be that this feasibility study combined the ease of online recruitment through social media with an additional element of in-person contact over the phone or on Teams, thus reaping the benefits of both approaches. However, it is unclear whether the attrition was reduced by the phone call itself, or by the rapport building that took place during the phone call, which may be a more difficult element to replicate in a scaled-up RCT. Furthermore, this process was time consuming not just in terms of the calls themselves, but also in terms of the time required to arrange each individual call at a mutually convenient time to both the researcher and the participant. Many of these calls took place in the evening and at weekends, which suited the context of a part-time PhD student, but may be less appropriate for a full study.

7.7.2 Financial compensation

At the request of the Faculty of Medicine and Health Sciences' Research Ethics Committee at the University of Nottingham, participant compensation was not publicised on any of the adverts, although the enquiry form mentioned an allowance for participation and the patient information sheet (see Appendix 7) indicated the monetary value of the vouchers. On the one hand, there is evidence that remuneration, even of low monetary value, can improve recruitment and retention, as well as improve sample diversity (Abdelazeem et al., 2022; Linardon & Fuller-Tyszkiewicz, 2020). However, remuneration also increases the risk of imposter participants (Wang, 2024), as witnessed during this study. Furthermore, the ethical implications of participant remuneration or compensation in clinical and qualitative research have been much debated (Head, 2009; Permuth-Wey & Borenstein, 2009). On balance, I would argue that the university's decision not to advertise remuneration on the adverts was highly appropriate. As none of the participants enrolled in the study focused on compensation during the consent calls, it did not appear to be the main motivator of participation. This is consistent with Largent et al.'s (2022) findings from a study investigating participants' perceptions of financial incentives in clinical studies. They argue that whilst many participants reported that financial incentives had been a motivation, they were not the main motivation, and participants did not feel unduly influenced by them. In the context of this feasibility study however, it may have acted as an incentive to complete questionnaires or take part in the interview at the end of the study, thus contributing to the low attrition rate. The reaction of one of the imposter participants would also indicate that the value of the vouchers on offer was insufficient to provide a significant incentive for someone motivated purely by financial gain. Furthermore, it could be argued that researchers have a moral obligation to acknowledge the contribution of participants and encourage participation, and that compensation is one way of achieving this (Largent et al., 2017; Różyńska, 2022).

7.7.3 Feasibility of achieving recruitment for a randomised control trial

Based on the effect size and the power calculation carried out in Chapter 5 (Section 5.6), the sample size required for a full RCT would be 36 in each condition. However, this is the final number of participants required post-attrition. If attrition were to be as low as in the current study, a recruitment target of 78 would be required. However, based on the factors described in Section 7.4 above, this low attrition rate may be optimistic. Assuming an attrition rate of 20.5% which would be halfway between the target of 33% (based on the literature for online interventions – see Chapter 4, Section 4.4.3) and the actual attrition rate of 7.5%, a recruitment target of 88 participants would be required. Given that 75 days were required to achieve the initial target of 38 participants, and assuming similar rates of recruitment (based on similar spend levels and similar platforms being used), the required number of participants could be achieved within a six-month period. To reduce the risk of not achieving the recruitment target, another social media platform such as Reddit or TikTok could be used (Lee et al., 2024), although the evidence for TikTok's effectiveness as a recruitment platform is still limited. Given the success of recruitment for the PPI focus group through NIHR's 'People in Research' website, a full RCT could be advertised on the NIHR website for research participants, 'Be Part of Research'. In addition, to reduce costs per participant, more use could be made of free adverts on local

Facebook pages. Furthermore, if an additional social media platform is used, or if the NIHR website ‘Be Part of Research’ is used, posts on researcher’s own social media profiles may not be required., which could in turn avoid the bias towards a highly educated population as occurred with the sample for this feasibility study.

7.7.4 Use of questionnaires

Participants’ experiences of the questionnaires were overall positive, with only one participant reporting mild anxiety during completion. Most found them short and easy, and many found that they were an opportunity to reflect on their DA. One participant expressed confusion around the Dentist Contemplation Ladder and its use of a 1 to 10 scale. This participant stated in the interview that their experience of using the OSG was positive and beneficial, and they talked about strategies that helped them ensure they did indeed attend dental appointments. However, when their individual ladder scores were examined, their baseline score was a 7 (high likelihood to attend) whereas their six-week score completed immediately before the interview was a zero (lowest likelihood to attend an appointment). This might indicate that the explanation provided on how to complete the Dentist Contemplation Ladder could be clarified or improved for an RCT to reduce any confusion. This issue notwithstanding, the data from participants collected during the semi-structured interviews would indicate that they found the questionnaires appropriate and acceptable.

7.8 Conclusion

The adverts and the 12-week window for recruitment delivered the target number of participants, and whilst many aspects of the recruitment process could be repeated for an RCT, some minor adjustments would provide greater confidence of achieving the recruitment required for a full-scale study. The learnings gained during this feasibility study around detecting and avoiding imposter participants should be replicated where possible for a full RCT. Participants found the questionnaires acceptable and easy to complete, although some minor amends may be required to avoid any confusion with the Dentist Contemplation Ladder. The attrition rate in this study was very low, some of which may be linked to the steps taken, but some of which may be due to the rapport established between the participants and the researcher, which may not be easily replicated. However, based on the evidence reviewed in this chapter, an RCT appears feasible, with some minor modifications to the protocol.

Therefore, the next chapter will review and triangulate both qualitative and quantitative data and compare this to the existing literature. It will also seek to address any remaining unresolved questions and areas for further investigation and consider the strengths and limitations of this feasibility study. Finally, it will conclude on the feasibility of an RCT and make recommendations for any future protocol.

Chapter 8: Discussion

8.1 Chapter summary

In this final chapter, the evidence so far will be brought together and summarised to evaluate whether a Randomised Control Trial (RCT) is feasible and should be carried out. A summary of the main results is presented and considered, and outstanding questions are addressed. Participants in the Wait List Control (WLC) condition also reported improvement in outcome measures, for which the qualitative data may provide some explanation. Comparison of the qualitative data with the existing literature on empowerment and social comparison allows some hypothesising about the mechanisms of action that might have facilitated changes in outcome measures for the Online Support Group (OSG) condition. The existing literature on both OSGs and digital interventions indicates that usage is perhaps a less appropriate measure than engagement for a future RCT. The strengths of this study include the Patient and Public Involvement (PPI) contribution, and the novel findings it has generated. However, it also has limitations around the role of the researcher and the risk of demand characteristics, as well as some limitations based on the participant sample.

Finally, an argument is presented to show that an RCT should proceed, that an RCT is feasible, and recommendations are made on how an RCT should be conducted.

8.2 Summary of main findings

As outlined in Chapter 4 (Section 4.2.2), the purpose of a feasibility study is to establish “whether something can be done, should we proceed with it, and if so, how.” (Eldrige et al., 2016, p.1). Therefore, this study aimed to evaluate the feasibility of a Randomised Control Trial (RCT) on the effects of engagement with a Dental Anxiety (DA) Online Support Group (OSG) in a dentally anxious adult population. More specifically, this included the following objectives:

- To assess the feasibility of recruitment
- To understand whether participants were willing to be randomised
- To assess the attrition rate amongst participants
- To explore whether the usage of an OSG is acceptable to adults with DA
- To understand whether the chosen measures are appropriate, and which might serve as a primary measure for a full RCT
- To determine the sample size required for a full RCT

Several of these individual objectives have been discussed in previous chapters, but this chapter aims to summarise the findings already discussed and triangulate findings from different chapters to elaborate on some of these objectives.

8.2.1 Quantitative results

In terms of participant recruitment, 40 participants were recruited to the study during the target period of 13 weeks, compared to a target of 38. Three participants were lost to follow-up, which equates to an attrition rate of 7.5%, which compares favourably to the original target of 33%. As a result, the final sample size of 37 participants was greater than the target of 24 that was outlined in the protocol. On average participants logged on 3.6 times during the study period. No target or minimum amount was mandated for this.

In terms of outcomes, the MDAS mean score was reduced in both the OSG condition and the WLC condition, but the reduction in score (which represents a reduction in DA) was greater in the OSG condition. The Dentist Contemplation Ladder mean scores increased (which indicates an increased readiness to attend a dental appointment) in both conditions but was greater in the OSG condition. A Cohen D’s effect size of 0.68 was detected for the MDAS based on a t-test, but no effect size was detected for the Dentist Contemplation Ladder. A power calculation indicated that a sample size of 36 participants in each condition would be required for a full RCT.

8.2.2 Qualitative results

Four main themes were developed through thematic analysis, from the transcripts of the semi-structured interviews. The theme of “initiation” explored the barriers and facilitators to accessing the OSG. The theme of “exploration” outlined participants’ initial interactions, how they browsed and gained familiarity with the OSG. The theme of “engagement” considered the different approaches to the OSG: the minority who consciously disengaged from the OSG and those who were willing to engage. The final theme explored the “benefits and outcomes” that participants reported experiencing by using the OSG.

Participants recognised that the OSG had both positive and negative aspects, and whilst they encountered distressing content, most perceived that there were clear benefits to engaging with the OSG. Although the purpose of a feasibility study is not to evaluate the efficacy of an intervention, it is worth noting that both the qualitative and quantitative data provide encouraging evidence that points towards the value of an OSG for DA.

From a process perspective, participants reported finding the sign-up process straightforward and the questionnaires easy to understand and to complete. None of the participants reported any issues with the randomisation, although it should be noted that only those who were allocated to the OSG were asked.

8.3 Reflections

8.3.1 Reduction in outcome measures for wait list control

One intriguing finding that remains unexplained is why participants in the WLC condition also saw improvements in their MDAS scores, and (albeit to a lesser extent) in their Dentist Contemplation Ladder scores. Although the MDAS reduction in the OSG condition (-3.1) was greater than the reduction in the WLC (-1.6), this is still an interesting result. The Dentist Contemplation Ladder score saw an increase of 1.1 in the OSG condition, which is greater than the 0.7 increase in the WLC condition. This is where triangulation of the data across the qualitative and the quantitative may help elaborate on these findings. These changes in the WLC condition could simply be down to random variation, and indeed participants in the follow-up interviews highlighted how their DA was not a constant and was likely to change day to day (see Chapter 7, Section 7.6.1). Although the interviews were carried out with participants allocated to the OSG condition, this would most likely equally be applicable to participants in the WLC condition. However, only three of the WLC participants reported an increase of one on their MDAS score, and 12 of the 19 participants saw a decrease, making random variation seem an unlikely or at least insufficient explanation. There is a risk that some participants in the WLC used an OSG for DA which influenced their scores (although they were asked not to until they were sent the link to DFC upon completion of their final questionnaires). There is also a risk that participants were already users of an OSG, as this was not screened for at sign-up, which in retrospect was an oversight. A future RCT would be well-advised to specify existing users of an OSG for DA are excluded from the study. However, during the interviews none of the participants were existing users or had previously used an OSG for DA, mostly because they were not aware that such a thing existed or had not felt the need to seek one out. It therefore seems unlikely that enough participants in the WLC condition would have used an OSG during the study period to have influenced the overall outcome of scores in the condition.

Previous research has argued that completion of the MDAS does not increase state anxiety amongst the general population (Humphris et al., 2006), and that it does not increase state anxiety amongst the dentally anxious (Humphris & Hull, 2007). The data from Humphris & Hull’s (2007) study in particular showed a small reduction in state anxiety amongst participants who scored 19 or above on the MDAS and were therefore classified as phobic, however this was neither clinically nor statistically significant. This raises the question of whether the decrease in MDAS scores could indeed be indicative of a reduction in anxiety. Once again, the data from the interviews may provide some insight: participants reported how even just completing the questionnaires provided them with an opportunity to reflect on their DA, a topic that they otherwise seldom engage with and avoid thinking about. There is evidence that mindfulness interventions can reduce general anxiety (Hofmann & Gómez, 2017), as well as evidence that they can influence DA (Beltes et al., 2024; Turer et al., 2023). The two key elements of mindfulness interventions are attention regulation and non-judgemental observation of one's own experiences (Beltes et al., 2024). Perhaps the completion of the questionnaires, separated from the stress-inducing stimulus of a dental visit, prompted some of the participants allocated to the WLC condition to engage in non-judgemental observation of their DA, which in turn helped reduce their anxiety. However, another potential explanation is that the initial scores were influenced by natural variation, and that the follow-up scores are in fact more typical and simply represent a regression to the mean (Field, 2018) without any real reduction in anxiety. A future RCT could therefore also conduct interviews with the control condition to understand more about their experience of completing the questionnaires, and whether participants felt that this provided them with any benefits.

8.3.2 Potential mechanisms of action of online support group

8.3.2.1 Empowerment

As discussed in Chapter 2 (Section 2.8), empowerment is one theoretical perspective that explains the psychosocial benefits experienced by OSG users. Participation in an OSGs can help lead to a greater sense of well-being, control and self-confidence, which in turn generates a feeling of independence and can contribute to increased optimism (Barak et al., 2008; Van Uden-Kraan et al., 2008a). Empowerment has also been shown to improve confidence in relationships with health professionals (Mo & Coulson, 2014; Van Uden-Kraan et al., 2008a). In this study, the sub-themes of "the OSG as an information resource", "realising dental anxiety is a widespread condition" and "feeling less anxious or more confident" constructed through thematic analysis of the semi-structured interviews (see Chapter 6, Section 6.6) could be interpreted as evidence of empowerment processes and outcomes.

Firstly, in "the OSG as an information resource" sub-theme, participants outlined how the OSG had enabled them to gain new information about potential tools, treatments or solutions. Whilst some of that information was gained from the articles and factual content on the DFC website, participants highlighted how they also benefited from learning from people they could relate to in the OSG. Secondly in the sub-theme of “realising dental anxiety is a widespread condition” participants explained how the OSG provided reassurance that DA was more common than they thought, which in turn made them feel less isolated and helped them normalise their anxiety. This relates closely to the two empowerment processes of “exchanging information” and “finding recognition and understanding” which Van Uden-Kraan et al. (2008a) identified in their study of empowerment across OSGs for multiple conditions. However, it is worth noting that the other empowerment processes identified by Van Uden-Kraan et al. appear to be absent in this feasibility study. None of our participants reported experiencing “amusement” (where OSG users share humour or aspects of their daily lives that are unrelated to their condition), which could be a feature of the focused and moderated nature of DFC (where unrelated content is not encouraged and may be removed). Although our participants reported finding the OSG a friendly and supportive place, this was mostly based on reading responses to other people’s posts, and only a small number viewed the OSG as a community. Those that did view it as a community and did engage spoke about “encountering social support” and “sharing experiences and helping others”, two more empowering processes identified by Van Uden-Kraan et al. (2008a). This could be related to the limited engagement that our participants had with the OSG, as participants on average only accessed the forum 3.6 times, and most participants described themselves as readers rather than posters. However, some participants reported that they would continue to use the OSG and that although they had not yet done so, they may build up their confidence and actively post, which could indicate that for some people six weeks is not a sufficient length of time for them to experience all the potential benefits an OSG can offer.

Nonetheless, in terms of empowerment outcomes, participants reported that their usage of the OSG would make them feel more confident in future interactions with dental professionals, enabling them to disclose their anxiety, ask questions and even challenge their dental team. As well as being consistent with the literature on empowerment in OSGs (Mo & Coulson, 2014; Van Uden-Kraan et al., 2008a) this is also consistent with some of the findings from the systematic review on the experiences of users of OSGs for DA (see Chapter 3, Section 3.6), where both studies found that participants felt empowered by the OSG, leading them to take action towards a dental appointment and feel more confident when talking to their dental team (Buchanan et al., 2010; Buchanan & Coulson, 2007).

Furthermore, Van Uden-Kraan et al. (2008b) found that OSG participants who read other people's posts without actively posting themselves (which they refer to as "lurkers") still experienced empowering outcomes such as "feeling more confident in their relationship with their physician" and "increased optimism and control", which is consistent with our findings that empowerment in some form was not limited to those who viewed the OSG as a community and shared their own experiences.

8.3.2.2 Social comparison

Festinger's Social Comparison Theory (1954) outlines how individuals self-evaluate by comparing themselves to similar others (see Chapter 2, Section 2.7 on Theoretical Perspectives). According to the identification and contrast model (Buunk & Dijkstra, 2017), positive identification or comparison can impact positively on psychological well-being, whereas negative identification or comparison can have a negative impact. Several studies have shown that social comparison can be one of the mechanisms of action driving outcomes for users of OSGs (Barta et al., 2023; Batenburg & Das, 2015; Dibb & Yardley, 2006; Malloch et al., 2023). The data from this study could indicate that social comparison may have influenced the outcome measures of both DA and readiness to attend a routine dental appointment.

Social comparison appears to play a part in the sub-themes of "reflexivity and perspective" and "validation" from the thematic analysis (see Sections 6.6.1.3 and 6.6.1.4 in Chapter 6). It could be argued that lateral comparison (comparison that is with someone who is neither better nor worse off) enabled participants to feel validated by realising that they are not alone and that their DA is not an overreaction or something that should be dismissed. Barta et al. (2023) argue that validation and normalisation of experience by similar others are part of the social comparison processes in OSGs. Furthermore, downward contrast may have increased participants' self-esteem by enabling them to reflect on how others faced greater challenges with their DA and their dental issues, which is consistent with Malloch et al.'s (2023) findings from a weight management OSG which showed that downward comparison enhanced self-esteem. However, this study did not measure self-esteem, therefore limited conclusions can be drawn on the role it plays. In their study on the psycho-social impact of DA, Locker (2003) found an association between low self-esteem and DA, but their analysis cannot determine the direction of that association, which leaves interesting questions for further research to understand whether usage of an OSG for DA does indeed increase self-esteem, and whether this could in turn help reduce DA.

Furthermore, some participants in the study reported that reading about other people's positive outcomes and experiences of potential solutions had helped them think about their non-attendance behaviour, as captured in the sub-theme "moving closer to an appointment" (see Section 6.6.2.1 in Chapter 6). This is consistent with findings from both Diel & Hofmann (2019) who found that moderate upward comparison (or positive identification), provided a boost to an individual's motivation to pursue physical activity behavioural goals. Other participants stated that it was gaining perspective on their anxiety and their dental issues that had helped them contemplate making a dental appointment. This is consistent with Malloch et al. (2023) who argue that downward contrast supports self-esteem, which in turn affects health efficacy, contributing to health behaviour intentions.

Finally, for social comparison to take effect, individuals need to feel that they are comparing themselves to similar others (Barta et al., 2023). Some of the participants who decided that the OSG did not meet their needs gave as an additional reason not to engage the difference between their DA and the DA levels of other OSG users. The lack of perceived similarity between themselves and the other users may have prevented them from experiencing any positives or negatives associated with social comparison.

8.3.3 Issues of dental anxiety as distinct from dental avoidance

One of the challenges presented by the findings of this feasibility study is the overlapping, yet distinct concepts of DA and dental avoidance. As previously discussed in Chapter 1 (Section 1.5.1) and Chapter 5 (Section 5.7.2), Berggren's (2001) model highlights how dentally anxious individuals avoid or postpone treatment, and there is evidence that avoidance increases with DA (Armfield, 2013b). However, according to Armfield (2013b) this is only true of 38% of people with moderate to high DA, which indicates that most people with DA still manage to attend appointments. This contributes to our understanding of why 27% of our participant sample with high DA still reported their score on the Dentist Contemplation Ladder as 10 at baseline (which indicates that they are already taking action to attend a dental appointment), which in turn highlights that there is most likely a ceiling effect with this measure (as discussed in Chapter 7, Section 7.7.4).

This could lead us to question whether a measure of readiness to attend a dental appointment is appropriate or necessary in a future RCT. However, a larger sample size as part of an RCT may enable sub-analysis of those not yet ready to attend vs those who are ready. Furthermore, from the beginning of this project, participants in the Patient and Public Involvement (PPI) group highlighted how reducing DA (rather than eliminating it) could make a dental visit less stressful, which would encourage them to attend on a more regular basis, an outcome that they felt was important. In an ideal world, we would measure actual attendance, although the Adult Oral Health Survey (Office for Health Improvement and Disparities, 2024) indicates that only 46% of adults attend every six months, and a further 28% attend one a year, making measuring of change in actual attendance a difficult one to operationalise. Therefore, whilst there are problems with intention to attend, we should persevere with trying to measure it and use PPI to help ensure whatever measure is meaningful from a patient perspective.

8.3.4 Reflections on online support group usage and data capture

8.3.4.1 Usage of online support group

Most feasibility studies consider adherence to the intervention a key measure. In this feasibility study, participants were asked to use the OSG in a naturalistic manner, with no prescribed minimum number of times they needed to access the OSG and no minimum amount of time they needed to spend on the OSG. In addition, participants were not asked to post or react to other people’s posts. Therefore, whilst adherence is not a key metric on which feasibility should be measured in this instance, there is still value in understanding how participants engaged with the OSG, and what role engagement may have played.

As discussed in Chapter 5 (Section 5.4), usage of the OSG was weighted towards the start of the study period, with more than 60% of logons occurring with the first week of participation. This is of course affected by the fact that all participants logged on initially to create their usernames with the study team as requested in the guidance they received but could also have been affected by the fact that some subsequent visits may not have been recorded as participants failed to logon to use the site (see Chapter 7, Section 7.5.3). This skew towards the early part of the study can also in part be explained by information from the interviews which shows that some participants rapidly decided that the OSG did not meet their needs (see Chapter 6, Section 6.5.1) and stopped using it. This can potentially also be explained by the initial phase of exploratory browsing (see Chapter 6, Section 6.4.2) in which participants invested time trying to gain an overview of the OSG and understand its norms. For some participants, this initial stage was a precursor to then using the OSG in a more interactive manner, with one participant reporting that they were still building up to posting their own story. There may therefore be value in extending the duration of the study, and adding a later follow-up to understand how engagement has evolved over time. A small number of participants did report that a six-week period was a too short, implying that they may have returned to it had they been given a longer period (see Chapter 7, Section 7.5.4).

The data from the interviews indicate that most of our participants were readers rather than posters (see Chapter 6, Section 6.6.1). According to Mo & Coulson (2010a), there is some evidence that what they refer to as "lurkers" (and this thesis has referred to as "readers") do not experience as many empowerment processes as those who engage more actively by posting, yet still experience OSGs as an empowering experience. These findings are consistent with (van Uden-Kraan et al., 2008b) who found that reading without posting was sufficient to have a profound effect on participants self-reported feelings of empowerment. Specifically, they found that that although not all empowerment processes were present amongst "lurkers", both groups had almost all the same empowerment outcomes. Although the quantitative data may under-report the frequency of usage of the OSG by our participants (see Chapter 7, Section 7.5.3) the qualitative data seems to confirm that the number of times each user accessed the OSG was still low, which raises the question of whether frequency of use matters. It is also important to note that participants stated that at times they made a conscious decision to step away from the OSG so as not to exacerbate their anxiety by exposure to triggering content (see Chapter 6, Section 6.5.2.1). According to a systematic review by Sieverink et al. (2017), whilst an assumption of dose-response effect is often a key premise of studies on adherence in digital interventions in general, the theoretical justification for that assumption appears to be lacking. For research that has focused on OSGs, Eysenbach et al. (2004) argue that some, but not all of the studies included in their systematic review observed an association between greater use of an OSG and better outcomes. However, they recognised that none of the studies could establish a direction of causation, and that it could be that those participants who experience greater benefits are driven to use the OSG more frequently. No analysis has been conducted to compare individual usage of the OSG with any improvement in scores on the outcome measures, firstly because the purpose of this feasibility study is not to explore the efficacy of the OSG, and secondly because the small sample size does not lend itself to this level of analysis. With the benefit of a larger sample size, this may be an interesting topic for an RCT to explore.

However, Kelders et al. (2020) argue that there is a conceptual difference between adherence and engagement, and that a participant’s motivation and reasons for using the intervention lie at the heart of this difference. They outline how a participant may be using an intervention in the way that the researcher intended and therefore considered adherent but may be doing so because the researcher has asked them to rather than because they feel it is beneficial. Reversely, a participant may be engaged and using the intervention in a way that they feel is beneficial, but with less frequency than expected and in a way that the researcher would classify as non-adherent. They also argue that existing research has prioritised measuring adherence over engagement as the former is easier to conceptualise and quantify, when in fact engagement is not strongly correlated to the number of times a participant has used the intervention. Furthermore, it would appear that there is evidence to suggest a link exists between engagement measures and behavioural outcomes. Therefore, it could be argued that the low levels of usage of the OSG are less relevant than the levels of engagement of our participants which are currently unknown.

Eysenbach et al. (2004) highlight that an intrinsic desire to participate in an OSG may be a pre-requisite for benefits to occur. The data from the interviews in our study show that some participants decided quite early that the OSG did not meet their needs and disengaged (see Chapter 6, Section 6.5.1). However, several of these participants still acknowledged that there could be value in the OSG, and recognised that it had provided them with the opportunity to reflect and gain perspective on their DA. A fully powered RCT might be used to establish whether this limited involvement was still sufficient to deliver some benefit in terms of quantitative outcome measures, or whether the data confirms Eysenbach et al.’s assertions.

8.3.4.2 Capture of online support group usage data

Logon data is one of the most commonly used measures of adherence in digital interventions (Donkin et al., 2011), and whilst there are limitations to the concept of adherence in research generally, and in the context of this study, there is still value in capturing data to understand how participants engaged with the OSG. Usage of the OSG is one area where the qualitative interviews and the quantitative data are discrepant, with participants reporting higher usage than the logon data would indicate. As discussed in Chapter 7 (Section 7.5.3), participants were able to access most of the features of the OSG they wanted to use as readers without logging on, meaning that the logon data were most likely an under-report of participants’ frequency of use. On the one hand, improvements could be made to the instructions given to participants to emphasise the importance of logging on. However, the manual screenshot capture of the logon information on a daily basis was a complex and time-consuming process and, as described in Chapter 4 (Section 4.5.2), led to one day’s worth of missing data. If a full RCT were to be carried out using DFC as the OSG, the research team would ideally work in closer collaboration with the team at DFC to investigate whether it is possible to access the data directly from their systems, and what would need to be true to enable that access. As discussed in Chapter 4 (Section 4.4.8), DFC was chosen because it is a moderated, public forum with over 30,000 members, meaning it generates a sustainable level of interaction between participants. Creating an OSG for the purposes of a study would most likely not be a viable option.

In addition, as the body of research on digital interventions increases, more complex ways of capturing engagement (rather than just adherence) through self-report are becoming more developed. A full RCT therefore may want to consider adding a measure of engagement to the study protocol. Two such measures that might be considered are the Digital Behaviour Change Intervention – Engagement Scale (DBCI-ES) (Perski et al., 2018) and the TWente Engagement with Ehealth Technologies Scale (TWEETS) (Kelders et al., 2020). Both are validated self-report scales that are designed to measure multiple facets of engagement, taking into account behaviours, cognitions and affect. The TWEETs in particular allows for fluctuation of usage to reflect the needs of the participant at that current moment, which could make it particularly relevant in light of the fluctuating nature of DA. However, both scales were designed for app-based digital interventions and there does not appear to be any literature that has used either of these scales in a study on OSGs. Furthermore, consideration needs to be given to the burden of completion of these scales, and some Patient and Public Involvement (PPI) work could help assess this.

8.4 Strengths and limitations

8.4.1 Contribution of patient and public involvement

One of the strengths of this feasibility study is the important part that PPI played in the initial planning stages. As a researcher without lived experience of DA, it was particularly important to me to ensure that I tried to understand more about the condition from people who did. Some of the points raised by the PPI focus group were indeed echoed by participants in the follow-up interviews of the study. For instance, that an OSG for DA is a solution that some people might not want to engage with, and that for others who are willing, lack of time could be the biggest barrier to engagement. They also highlighted that DA was something that they preferred to avoid thinking about, which again is consistent with the findings of the thematic analysis on the interview data.

The concerns that were raised in the focus group around the time commitment required and around the content of an OSG for DA being potentially triggering were influential in my decision to choose naturalistic participation, rather than requiring minimum levels of participation in the OSG. Their concerns were also translated into the participant information sheet and the sign-up calls, which emphasised how participants should feel under no obligation to read or engage with distressing content. In addition, the focus group gave positive feedback on the MDAS, confirming its use in this study, but also gave a strong steer towards adding a second measure. I have already discussed how the behaviour of a single participant in the online focus group alerted me to the concept of imposter participants (see Chapter 4, Section 4.3.2.4, and Chapter 7, Section 7.2.5), enabling me to take action to reduce the risk of unwittingly including them in the feasibility study. From the focus group, I also became aware of how some participants wanted to talk about their past traumatic experiences with dentists, and that early experience helped me navigate those conversations respectfully and sensitively, without allowing them to dominate the sign-up calls or the follow-up interviews.

Overall, I would conclude that the biggest benefit of the PPI focus group was that it brought to life the concept of stigma that I had read about in the literature, and I feel that this was most apparent in the focus group participants' desire to allocate the locus of control for DA with dentists. This increased my awareness of the need to be empathetic towards my participants, both in the sign-up calls and in the follow-up interviews. I was particularly mindful of avoiding anything that might be seen as either invalidating their DA or apportioning blame. I believe that this early experience with dentally anxious adults contributed to the quality of interaction and the rapport I was able to build with my participants, which in turn contributed to the retention rates of the study.

I feel that PPI involvement could however have been improved, for instance, going back to members of the PPI panel to give feedback on the Dentist Contemplation Ladder would have perhaps been beneficial. As outlined in Chapter 4 (Section 4.3), PPI involvement can vary from consultation, to collaboration, to co-production (NIHR Applied Research Collaboration East Midlands, 2019). In this PhD, the role of PPI was limited to being advisory and consultative but if greater resources (both in terms of time and in terms of financial funds) had been available, it could have been strengthened by a more collaborative approach, for example by involving one or several members of the panel in the qualitative data analysis.

8.4.2 Novel findings

Another strength of this study is that it has robustly tested the processes and measures as an important first step towards a potential RCT to evaluate the effectiveness of an OSG for adults with DA. Through the semi-structured interviews, this study has not only demonstrated the acceptability of the intervention for most participants but also shed light on why some people might chose to participate in OSGs and others not (see Chapter 6, Section 6.5). Encountering distressing content alone does not explain why some participants rejected the OSG, although it is a contributing factor. Being motivated by facts and expert information rather than looking for opinions or support and connection is a key reason to disengage for some participants. This understanding of how these two factors together led participants to decide that the OSG did not meet their needs represents a novel finding, as many studies on OSGs have been conducted with existing users. Thus, participants in previous studies may have been biased towards a sub-group of engaged users, as those who do not benefit from using the OSG are likely to stop using it (Eysenbach et al., 2004; MacLachlan et al., 2020). Furthermore, the interviews provided novel insight into the benefits experienced by participants who had not self-selected to use an OSG. Looking at barriers to engagement with the OSG, existing literature has highlighted concerns around inaccuracy and misinformation (Mo & Coulson, 2014; Moorhead et al., 2013), which is related yet subtly different to the preference for fact over opinion which the findings from the interviews demonstrated. Further research could also validate whether our finding that approximately one third of participants not finding the OSG relevant is common.

Finally, the participants in this study reported that the OSG contains distressing content, which is a recognised negative feature of OSGs in general (Holbrey & Coulson, 2013; Malik & Coulson, 2008; Van Uden-Kraan et al., 2008a). However, understanding how people use coping strategies and manage their exposure to difficult content about dental problems or dental treatments (see Chapter 6, Section 6.5.2.1) is another novel finding as this has not been explored in previous literature on OSGs and DA.

8.4.3 Role of researcher and risk of demand characteristics

The rapport that I believe I established with participants from the beginning of the study through the sign-up Teams and phone calls and maintained through subsequent email communications is both a strength and a potential limitation of this study. The sub-theme of “being a good study participant” from the thematic analysis indicates how participants were motivated to use the OSG because of their sense of duty toward the study and the researcher (see Chapter 6, Section 6.3.2.3). It is also reasonable to assume, based on existing literature (Linardon & Fuller-Tyszkiewicz, 2020) that this desire to be a good participant and the personal contact with the researcher contributed to the low attrition rate (see Chapter 7, Section 7.4). However, there could be a risk that, in their desire to be good study participants, they responded to the demand characteristics of the study (McCambridge et al., 2012). The aims of the study were made clear to all participants, and these were described as investigating whether a larger fuller study can be done, as understanding people’s experience of an OSG for DA, and as trying to understand the appropriateness of the measures. Participants were advised that longer-term, a larger study could investigate whether OSGs were helpful or not (see Appendix 7 for the Participant Information Sheet). However, a feasibility study is not a common lay concept, and participants may have simply understood that the study was looking to see if the OSG had reduced their anxiety and increased their readiness to attend the dentist. This could have influenced (consciously or unconsciously) their self-reported scores on the MDAS and the Dentist Contemplation Ladder as they sought to satisfy what they believed the researcher’s needs to be.

8.4.4 Limitations of the sample

As discussed in Chapter 7, Section 7.2.4, there were some limitations with the diversity of participant sample. Whilst the sample was more ethnically diverse than the population average, there were other aspects where diversity could be improved for a full RCT. Participants were educated to a higher level than the national average, which is probably linked to the use of the researcher’s own social media networks, but may also reflect a feature of research participants more generally, as according to the Health Research Authority (2024), adults from higher social grades are more likely to be willing to participate in research, and are also more likely to be more highly educated. The sample was also predominantly female. Here a combination of factors may be at play: firstly, the Health Research Agency indicates that women are more likely to be willing to participate in research than men. Secondly most of the recruitment advertising was carried out on Facebook whose users in the UK are more likely to be female (Statistica, 2025). Thirdly, women are more likely to be living with DA than men (Office for Health Improvement and Disparities, 2024). Therefore, whilst steps can be taken to improve the diversity of the sample for an RCT, some element of bias towards women at least may be inevitable. The fact that the sample was predominantly female does not invalidate the results of the feasibility study, although the impact of gender on the effectiveness of an OSG for DA may be something an RCT can shed more light on.

A limitation of much of the previous research on OSGs is that has been conducted with existing OSG users (Audrain-Pontevia et al., 2019; Eysenbach et al., 2004; Litchman et al., 2018) and this feasibility study aimed to go some way to addressing this issue by recruiting adults with DA who were not currently users of an OSG for DA and randomising them to either the OSG or the WLC condition. Nonetheless, it is important to recognise that people who are very reluctant to engage with their DA may have ignored the Facebook or Twitter adverts and avoided signing up to the study. Those who were not at all interested in using an OSG may have decided not to participate once they had received the participant information sheet, when it became clear that participation in an OSG may be required. Therefore, despite best endeavours to attract a wide audience of participants, an element of self-selection remains in the sample.

8.5 Recommendations for a randomised control trial

8.5.1 Should we proceed with a randomised control trial?

In summary, the first question any feasibility study needs to address is whether an RCT should be conducted. The literature review in Chapter 1 concluded that more than 50% of the population in England lives with moderate to extreme DA (Office for Health Improvement and Disparities, 2024), and that living with DA can have a range of psychosocial impacts (Cohen et al., 2000; Locker, 2003; Vermaire et al., 2016) as well as being associated with avoidance of dental appointments (Armfield, 2013b; de Jongh et al., 2011). The systematic review in Chapter 2 indicated that adults who use OSGs for DA find them beneficial and OSGs can bring about positive changes. Therefore, there seems to be sufficient evidence to argue that an RCT to examine the effectiveness of engagement with an OSG for DA should be carried out.

8.5.2 Can a randomised control trial be conducted?

8.5.2.1 Recruitment, sign-up and attrition

This feasibility study achieved the required sample within the target three-month time frame. The effect size and power calculations (see Chapter 5, Section 5.6) indicate that a sample size of 72 would be required for a fully powered RCT. The attrition rate of 7.5% from this feasibility study was significantly lower than the target, and a combination of factors seem to have driven this result (see Chapter 7, Section 7.4). These include the recruitment method (Facebook in particular), the short duration of the study, the financial incentives, and the personal contact with the researcher. However, the personal rapport that I built up with the participants may have also contributed, and it cannot be assumed that this will be replicated in a future RCT. Therefore, if we assume an attrition rate of 20.5% (see Chapter 7, Section 7.7.3), a recruitment target of 88 participants would be required for an RCT. This target seems achievable if an additional social media platform is introduced, or if the NIHR ‘Be Part of Research’ website is used, and if the window for recruitment is extended to six months. Finally, participants reported being satisfied with the sign-up process and the information provided, and no concerns were raised regarding the randomisation process (see Chapter 7, Section 7.3). Therefore, there seems to be sufficient evidence to argue that recruitment for a fully powered RCT is achievable and sign-up processes are acceptable.

8.5.2.2 Appropriateness of measures

The participants reported finding both questionnaires quick and easy to complete, and although they prompted participants to reflect on their DA, they did not cause distress. However, some participants highlighted that their DA is not a constant but varies from day to day and can be influenced by external factors such as dental appointments or dental issues (see Chapter 7, Section 7.6.1). The quantitative data from the outcome measures indicates that the OSG condition reported the greatest mean reduction in MDAS score, and the independent t-test showed a medium to large effect size. In addition, nine participants in the OSG condition reported a reduction in MDAS score from above to below the clinical threshold for extreme DA (see Chapter 5, Section 5.5.1). Whilst the sample size from this feasibility study does not allow us to draw any conclusions on the effectiveness of OSGs, this data supports the use of the MDAS as a measure in a future RCT.

The data from the Dentist Contemplation Ladder indicates that the OSG condition reported the greatest mean increase in score (see Chapter 5, Section 5.5.2). However, the confidence intervals for the mean change in the ladder scores fully overlap, and no effect size was detected for the Dentist Contemplation Ladder. Furthermore, the data also appears to indicate a ceiling effect, with more than a quarter of participants already reporting a maximum score of 10 at baseline. Therefore, the evidence seems to indicate that the MDAS, rather than the Dentist Contemplation Ladder, is appropriate as a primary outcome measure.

8.5.2.3 Acceptability of online support group to adults with dental anxiety

The data from the semi-structured interviews indicates that although some participants felt that the OSG did not meet their needs, and although participants encountered content that was at times distressing (see Chapter 6, Section 6.5.2.1 and 6.5.2.2), most participants found the OSG to be a positive experience overall. The OSG helped them realise that they were not alone in living with DA and provided them with perspective and validation. Most participants also found that the OSG was a useful information resource, with the success stories from others providing particular benefit. Some participants also reported feeling more confident and closer to making an appointment (see Chapter 6, Section 6.6). These positive aspects are consistent with the findings from the meta-aggregation in the systematic review (see Chapter 3, Section 3.6), which found that the OSG was a rich and varied source of information, which helped participants realise that DA was not uncommon. The findings also showed that OSG users particularly valued reading other users’ positive experiences and reported increased confidence and empowerment from using the OSG (Buchanan et al., 2010;

Buchanan & Coulson, 2007). Furthermore, most participants highlighted the friendliness of the forum, and the OSG's moderation may have helped avoid the rude or confrontational behaviour sometimes reported in the literature (Attard & Coulson, 2012; Shoebotham & Coulson, 2016; Suler, 2005) Finally, most participants found the OSG easy to navigate, and although one user had technical issues (see Chapter 7, Section 7.5.3), most found it easy to register.

Despite their overall positive experience, most participants accessed the OSG a limited number of times, and most described themselves as readers rather than posters. However, it could be argued that this limited use of the OSG is not important, as there is currently no clear evidence to support a dose-response effect in digital interventions (Sieverink et al., 2017). Furthermore, there is evidence to indicate that readers experience most of the same benefits as posters (Mo & Coulson, 2010a; van Uden-Kraan et al., 2008b), although participants' roles as readers may explain why some of the benefits reported in the systematic review meta-aggregation findings were not present in the semi-structured interview data. Specifically, our participants did not report experiencing the OSG as a source of social support or empathy (Buchanan et al., 2010; Buchanan & Coulson, 2007), which is consistent with Mo & Coulson's (2010) findings that readers experience less social support than posters. The participants' limited frequency of usage or usage as a reader rather than a poster therefore does not appear to detract from the appropriateness of the OSG for the purpose of an RCT, and the evidence overall would therefore indicate that it is acceptable to adults with DA.

8.5.3 How should a randomised control trial be conducted?

The outcomes of this feasibility study appear to indicate that most of the recruitment and sign-up processes have been successful and robust. Nonetheless, some areas could be improved, and some processes could be optimised to ensure the success of a future RCT. Considering the benefit that collaborative PPI brought to this feasibility study, I would start by recommending that researchers looking to conduct an RCT consider how coproduction could benefit a larger and more comprehensive research project and be embedded in all aspects of the project.

8.5.3.1 Recruitment and sign-up process

As outlined in Section 8.5.2.1, to achieve the 88 participants required, the timeframe should be extended and at least one additional platform should be used. Given the success of the recruitment for the PPI focus group through the NIHR’s PPI participant platform (see Chapter 4, Section 4.3.1), a future RCT might consider using ‘Be Part of Research’ for that purpose. I would not recommend the use of flyers and adverts in community locations, as these were not effective. A future RCT could use more unpaid adverts on Facebook community groups and could make better use of the Meta support tools and use a more systematic approach to testing different adverts to optimise their recruitment on Facebook and Instagram. To ensure a diverse sample, I would recommend continuing to target major urban areas as this seems to have achieved ethnic diversity, but more consideration needs to be given on how to attract more male participants, including potentially using an advert calling for male participants only. I would advise caution before any researchers use their personal social media to share the adverts (see Chapter 7, Section 7.2).

The criteria for participation in this feasibility study did not explicitly exclude current users of OSGs for DA. Although the data from the interviews indicate that this was unlikely to have been a confound in this study (see Chapter 6, Section 6.4.1), this omission should be rectified when screening for participants for a full RCT. Although the Teams or phone call was a time-consuming aspect of the sign-up process, there is evidence that it may have served two important processes: it contributed to increased retention and helped reduce the risk of imposter participants. Therefore, a future RCT may want to ensure an element of personal contact is maintained at the sign-up stage.

8.5.3.2 The online support group intervention

8.5.3.2.1 Use of Dental Fear Central

Dental Fear Central (DFC) was chosen because it is an established OSG for DA, and because of its size (over 30,000 members) which helps generate a sustainable level of interaction between users. In addition, it is a well-moderated forum, and participants commented on its friendliness. Although some participants expressed a preference for an app-based OSG, and some found the presence of users from other countries jarring or even confusing, participants also liked the presence of dentists on the forum. As there is no other existing OSG of that scale for DA, and given the importance of size to generate interactions, my recommendation would be to seek DFC's agreement to be used as part of an RCT.

Participants were asked to use the OSG for a period of six weeks, and whilst most found this a sufficient length of time, some felt that a longer period would have given them more chance to interact with the OSG. However, there is evidence that the six-week follow-up may have contributed to the low rate of attrition. Therefore, my recommendation would be to maintain the follow-up at six weeks. However, there may be value in adding an additional follow-up at three months as outlined in Section 8.3.4. Although this additional follow-up may have a higher attrition rate, it could provide insight into how usage evolves over time and how that might affect outcomes.

8.5.3.2.2 Reminders to use the online support group

Overall, participants found reminders helpful and acknowledged that they acted as a prompt to access the OSG. Many participants would have welcomed more frequent reminders, but this opinion was not unanimous. My recommendation would be to ask participants to opt-in to the reminders from DFC as these highlight content available on the OSG and to increase the frequency of reminders sent out by the study. I would also encourage working with DFC to understand the pattern of their reminders so that across both, participants receive weekly reminders, whilst ensuring that the tone of the emails from the study remains encouraging and avoids triggering feelings of guilt for not using the OSG. `

8.5.3.2.3 Guidance on using the online support group

Participants were asked to use the OSG in a naturalistic manner. Whilst the rationale for this remains compelling (it provided greater ecological validity, addressed the PPI group's concerns around time commitment, and mitigated the risk of exposure to distressing content), and whilst some participants were comfortable with this approach, others found this freedom confusing. My recommendation therefore would be to provide some optional guided discovery that suggests to participants what they might want to do on their first visit and on subsequent follow-ups, guiding on how to access the most recent posts, and how to search for specific topics.

8.5.3.3 Process and outcome measures

The MDAS appears to be an appropriate and acceptable measure, and I would therefore recommend using it as a primary outcome measure. Whereas there are issues with the Dentist Contemplation Ladder, I would still argue that it provides an interesting additional measure, particularly given the importance the PPI group placed on regular dental attendance. With a larger sample size, there could also be value in conducting sub-group analysis for those with either low or high intention to attend.

The data on usage is an area where improvements need to be made, as the screenshots used in this feasibility study were burdensome and led to missing data. I would therefore recommend speaking to DFC to see if a more collaborative way of working is possible, and whether it would be possible to access that data from their systems. In addition, as outlined in Section 8.3, I would recommend adding the TWEETS scale (Kelders et al., 2020) as a self-report measure of engagement as there is more evidence for the effect of engagement on behaviour rather than just usage.

Finally, this feasibility study only conducted interviews with the participants randomised to the OSG condition, as an important purpose of those interviews was to establish the acceptability of the OSG and understand the barriers and facilitators to access. However, interviews with participants randomised to the WLC condition may help understand why participants who did not use the OSG still saw improvements in their outcome measures.

8.6 Conclusions

The results of this PhD indicate that an RCT on the effects of engagement with an OSG for DA is both feasible and necessary. The evidence indicates that a sufficient number of participants (n=88) for a fully powered RCT could be recruited through social media within a suitable timeframe. This feasibility study has highlighted the importance of reminders to participants in the OSG condition and suggests that financial rewards and strong communication with participants are important drivers of retention. A future RCT may help understand the role of usage of the OSG on outcomes and enable further sub-group analysis based on willingness to attend dental appointments. Recommendations for a future RCT include using DFC as the OSG intervention, using the MDAS as the primary outcome measure, and ensuring public and patient involvement to further guide the development of the RCT.

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Appendices

Appendix 1: Database search strategies

1.1 ACM digital Library (Association for Computing Machinery)

Search conducted 31.10.2021
Search Strategy:

#	Searches	Results
1	AllField:("fear of dentist*" "dental* phobi*" "dental* fear*" "odontophob*" "dental* anxi*" "dental anxiety")	12
2	AllField:("online chat*" "online discussion*" "online discussion group*" "online forum*" "online communit*" "online health communit*" "patient online communit*" "online peer support" "online support group*" "online social network*" "online network" "social network" "online fora*")	51536
3	AllField:("virtual discussion group" "virtual communit*" "virtual patient communit*" "virtual peer support" "virtual peer support group*")	7
4	AllField:("internet discussion*" "internet discussion group*" "internet forum*" "internet communit*" "internet peer support" "internet support group*")	502
5	AllField:("digital communit*" "digital peer support" "digital support group" "digital health communit*" "computer-mediated support group*" "computer-mediated discussion group*" "web-based support group*" "web-based discussion group*" "web-based communit*" "online fora*" "internet fora*" "chatroom*" "chat-room*")	171419
6	AllField:(OSG ISG)	2170
7	AllField:("online chat*" "online discussion*" "online discussion group*" "online forum*" "online communit*" "online health communit*" "patient online communit*" "online peer support" "online support group*" "online social network*" "online network" "social network" "online fora*""virtual discussion group" "virtual communit*" "virtual patient communit*" "virtual peer support" "virtual peer support group*""internet discussion*" "internet discussion group*" "internet forum*" "internet communit*" "internet peer support" "internet support group*""digital communit*" "digital peer support" "digital support group" "digital health communit*" "computer-mediated support group*" "computer-mediated discussion group*" "web-based support group*" "web-based discussion group*" "web-based communit*" "online fora*" "internet fora*" "chatroom*" "chat-room*" ISG OSG)	214106
8	AllField:("online chat*" "online discussion*" "online discussion group*" "online forum*" "online communit*" "online health communit*" "patient online communit*" "online peer support" "online support group*" "online social network*" "online network" "social network" "online fora*""virtual discussion group" "virtual communit*" "virtual patient communit*" "virtual peer support" "virtual peer support group*""internet discussion*" "internet discussion group*" "internet forum*" "internet communit*" "internet peer support" "internet support group*""digital communit*" "digital peer support" "digital support group" "digital health communit*" "computer-mediated support group*" "computer-mediated discussion group*" "web-based support group*" "web-based discussion group*" "web-based communit*" "online fora*" "internet fora*" "chatroom*" "chat-room*" ISG OSG) AND AllField:("fear of dentist*" "dental* phobi*" "dental* fear*" "odontophob*" "dental* anxi*" "dental anxiety")	8
9	filter: { Publication Date: (01/01/1998 TO 10/31/2021) }	8

1.2 APA PsycInfo 1806 to October Week 2 2021

Search conducted 21.10.2021

Search Strategy:

#	Searches	Results
1	Dental anxiety.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	432
2	odontophob*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	2
3	((fear or afraid or anxious or anxiety or dread* or nervous or phobi*) adj5 (dentist* or dental)) .ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	791
4	1 or 2 or 3	830
5	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 (forum* or fora or group* or communit*)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	13282
6	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 support group*).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	786
7	(discussion forum* or discussion fora).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	1062
8	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 support communit*).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	93
9	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 (self-help or support)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	5145
10	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 peer support).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	186
11	(bulletin or message) adj2 board*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	731
12	chat room* or chatroom*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	756
13	((internet or online) adj4 (discussion group or chat)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	694
14	(OSG or ISG).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	79
15	exp Online Social Networks/	8574
16	social network*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	37494
17	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	53553
18	4 and 17	5
19	limit 18 to yr="1998 -Current"	4

1.3 ASSIA (ProQuest)

Search conducted 02.11.2021
Publication Date: (01/01/1998 TO 31/10/2021)
Peer reviewed only
Search Strategy:

#	Searches	Results
1	(fear OR afraid OR anxious OR anxiety OR dread* OR nervous OR phobi*) NEAR/3 (dentist* OR dental)	220
2	odontophobi*	0
3	MAINSUBJECT.EXACT("Dental anxiety")	4
4	MAINSUBJECT.EXACT("Dental phobia")	12
5	1 OR 2 OR 3 OR 4	220
6	(online OR web OR web-based OR computer-mediated OR internet OR virtual OR digital) NEAR/4 (forum* OR fora OR group* OR communit*)	8212
7	(online OR web OR web-based OR computer-mediated OR internet OR virtual OR digital) NEAR/4 "support group*"	871
8	"discussion forum*" OR "discussion fora"	647
9	(online OR web OR web-based OR computer-mediated OR internet OR virtual OR digital) NEAR/4 "support communit*"	74
10	(online OR web OR web-based OR computer-mediated OR internet OR virtual OR digital) NEAR/4 (self-help OR support)	4364
11	(online OR web OR web-based OR computer-mediated OR internet OR virtual OR digital) NEAR/4 "peer support"	308
12	(bulletin OR message) NEAR/2 board*	853
13	"chat room*" OR chatroom*	727
14	(internet OR online) NEAR/4 (discussion)	1752
15	(internet OR online) NEAR/4 chat	540
16	OSG OR ISG	69
17	"Online Social Network*" OR "online network*" OR "social network"	7179
18	6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17	18258
19	5 AND 18	21

1.4 EBSCOhost CINAHL Plus with Full Text

Search conducted 29.10.2021

Search Strategy:

#	Searches	Results
1	(MH "Dental Anxiety")	1451
2	odontophob*	2
3	((fear or afraid or anxious or anxiety or dread* or nervous or phobi*) N5 (dentist* or dental))	3239
4	1 or 2 or 3	3240
5	((online or web or web-based or computer-mediated or internet or virtual or digital) N4 (forum* or fora* or group* or communit*))	62649
6	((online or web or web-based or computer-mediated or internet or virtual or digital) N4 (support group*))	2896
7	(discussion forum*) or (discussion fora*)	1166
8	((online or web or web-based or computer-mediated or internet or virtual or digital) N4 (support communit*))	1010
9	((online or web or web-based or computer-mediated or internet or virtual or digital) N4 (self-help or support))	36993
10	((online or web or web-based or computer-mediated or internet or virtual or digital) N4 peer support)	1000
11	(bulletin or message) N2 board*	2460
12	chat-room* or chatroom* or (chat room)	289
13	((internet or online) N4 (discussion group or chat))	815
14	OSG or ISG	240
15	(MH "Online Social Networking")	446
16	Online social network	510
17	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	89140
18	4 and 17 (Limiters - Published Date: 19980101-20211031)	73

1.5 Ovid EMBASE 1980 to 2021 Week 41

Search conducted 21.10.2021

Search Strategy:

#	Searches	Results
1	exp Dental Anxiety/	2975
2	odontophob*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	30
3	((fear or afraid or anxious or anxiety or dread* or nervous or phobi*) adj5 (dentist* or dental)) .ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	4786
4	1 or 2 or 3	4793
5	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 (forum* or fora or group* or communit*)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	16271
6	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 support group*).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	1441
7	(discussion forum* or discussion fora).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	1339
8	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 support communit*).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	121
9	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 (self-help or support)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	8141
10	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 peer support).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	356
11	(bulletin or message) adj2 board*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	879
12	chat room* or chatroom*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	528
13	((internet or online) adj4 (discussion group or chat)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	559
14	(OSG or ISG).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	3021
15	exp Social Networking/	20056
16	social network*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	31425
17	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	57267
18	4 and 17	12
19	limit 18 to yr="1998 -Current"	12

1.6 Ovid MEDLINE(R) ALL 1946 to October 2021

Search conducted 21.10.2021
Search Strategy:

#	Searches	Results
1	exp Dental Anxiety/	2776
2	odontophob*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	29
3	((fear or afraid or anxious or anxiety or dread* or nervous or phobi*) adj5 (dentist* or dental)) .ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	4944
4	1 or 2 or 3	4953
5	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 (forum* or fora or group* or communit*)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	11669
6	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 support group*).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	819
7	(discussion forum* or discussion fora).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	903
8	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 support communit*).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	74
9	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 (self-help or support)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	5968
10	((online or web or web-based or computer-mediated or internet or virtual or digital) adj4 peer support).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui	284
11	(bulletin or message) adj2 board*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	580
12	chat room* or chatroom*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	377
13	((internet or online) adj4 (discussion group or chat)).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	404
14	(OSG or ISG).ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	1871
15	exp Social Networking/	4964
16	social network*.ab,hw,kf,ot,sy,ti,fx,nm,ox,px,rx,ui.	22833
17	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	41502
18	4 and 17	12
19	limit 18 to yr="1998 -Current"	11

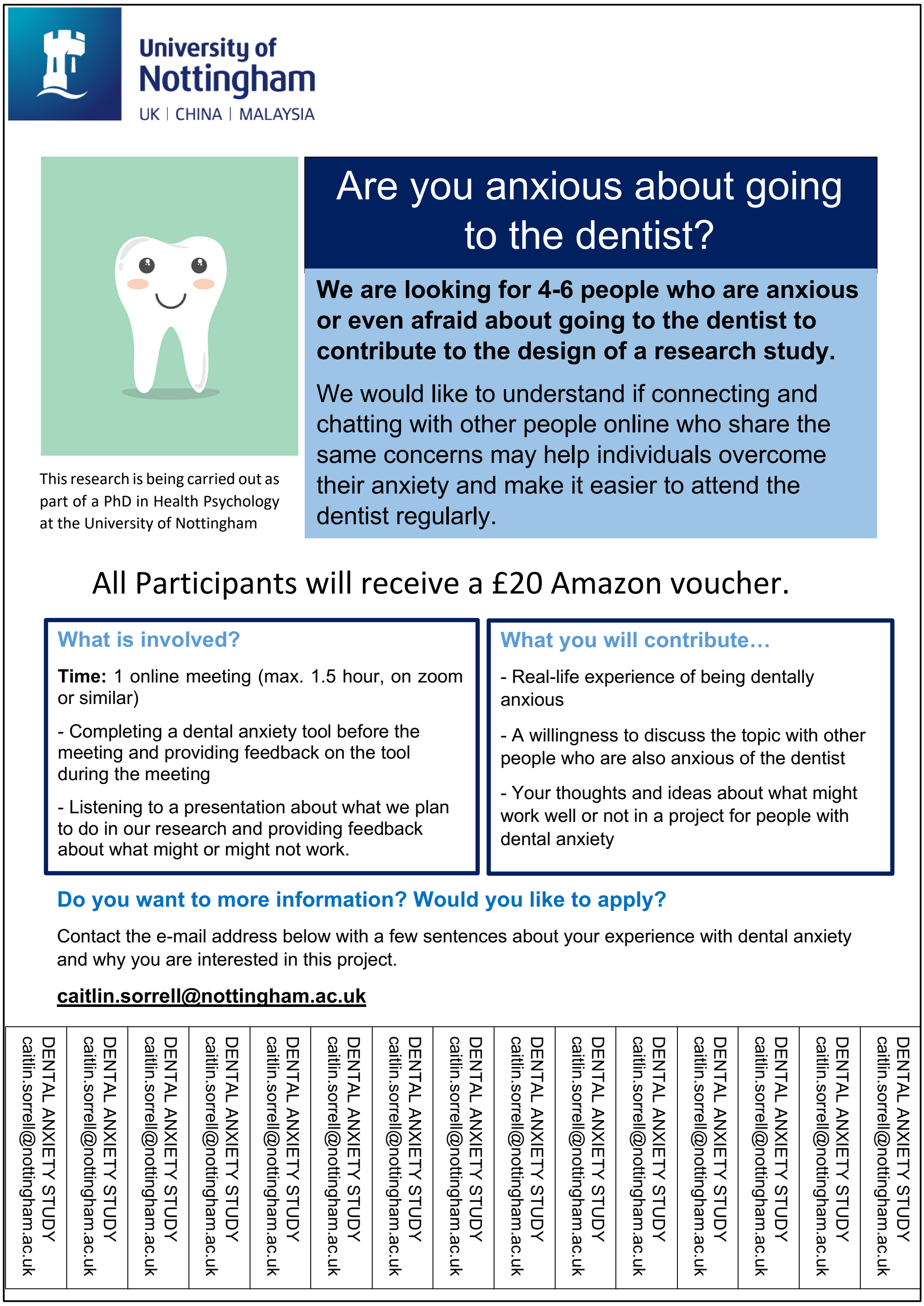
1.7 Web of Science (Clarivate)

Search conducted 02.11.2021
Publication date: 01/01/1998 to 31/10/2021
Search Strategy:

#	Searches	Results
1	ALL=("dental* anxi*" or "dental* fear*" or "dental* phobi*" or "odontophobi*" or "fear of dentist*")	2298
2	All=("online chat*" or "online discussion*" or "online discussion group*" or "online forum*" or "online communit*" or "online health communit*" or "patient online communit*" or "online peer support" or "online support group*" or "online social network*" or "online fora*" or "online network" or "social network")	69618
3	ALL=("virtual discussion group" or "virtual communit*" or "virtual patient communit*" or "virtual peer suport" or "virtual peer support group*")	4446
4	ALL=("internet discussion*" or "internet discussion group*" or "internet forum*" or "internet communit*" or "internet peer support" or "internet support group*")	2200
5	ALL=("digital communit*" or "digital peer support" or "digital support group" or "digital health communit*" or "computer-mediated support group*" or "computer-mediated discussion group*" or "web-based support group*" or "web-based discussion group*" or "web-based communit*" or "online fora*" or "internet fora*" or "chatroom*" or "chat-room*")	1995
6	ALL=(OSG or ISG)	4954
7	#2 or #3 or #4 or #5 or #6	81547
8	#1 and #7	6

Appendix 2 – PPI Communication Materials

2.1 Advert for PPI recruitment



University of Nottingham
UK | CHINA | MALAYSIA

Are you anxious about going to the dentist?

We are looking for 4-6 people who are anxious or even afraid about going to the dentist to contribute to the design of a research study.

We would like to understand if connecting and chatting with other people online who share the same concerns may help individuals overcome their anxiety and make it easier to attend the dentist regularly.

This research is being carried out as part of a PhD in Health Psychology at the University of Nottingham

All Participants will receive a £20 Amazon voucher.

What is involved?

Time: 1 online meeting (max. 1.5 hour, on zoom or similar)

- Completing a dental anxiety tool before the meeting and providing feedback on the tool during the meeting

- Listening to a presentation about what we plan to do in our research and providing feedback about what might or might not work.

What you will contribute…

- Real-life experience of being dentally anxious

- A willingness to discuss the topic with other people who are also anxious of the dentist

- Your thoughts and ideas about what might work well or not in a project for people with dental anxiety

Do you want to more information? Would you like to apply?

Contact the e-mail address below with a few sentences about your experience with dental anxiety and why you are interested in this project.

caitlin.sorrell@nottingham.ac.uk

DENTAL ANXIETY STUDY
caitlin.sorrell@nottingham.ac.uk

DENTAL ANXIETY STUDY
caitlin.sorrell@nottingham.ac.uk

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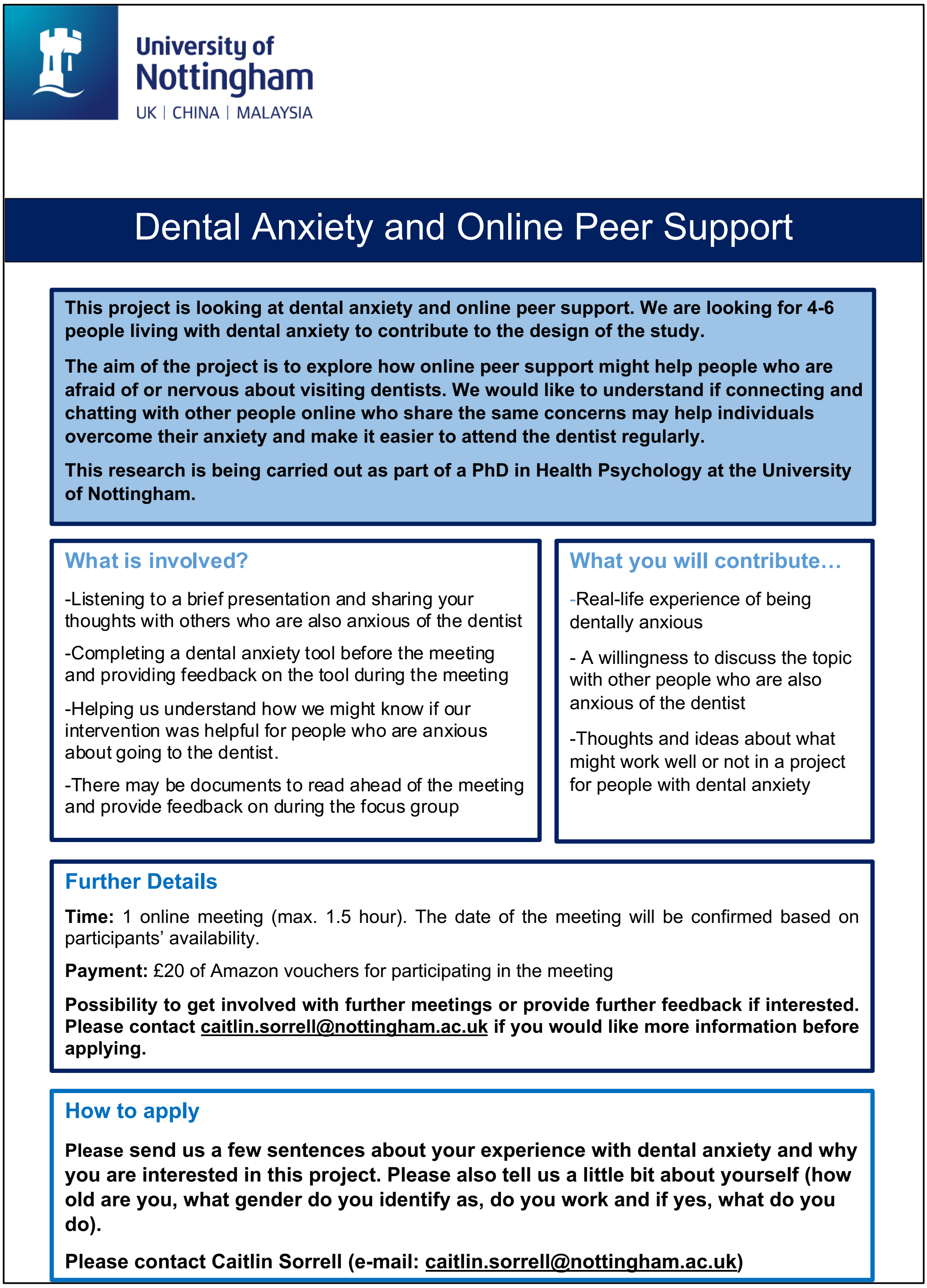
DENTAL ANXIETY STUDY
caitlin.sorrell@nottingham.ac.uk

2.2 Patient Information Sheet for PPI Focus Group



University of Nottingham
UK | CHINA | MALAYSIA

Dental Anxiety and Online Peer Support

This project is looking at dental anxiety and online peer support. We are looking for 4-6 people living with dental anxiety to contribute to the design of the study.

The aim of the project is to explore how online peer support might help people who are afraid of or nervous about visiting dentists. We would like to understand if connecting and chatting with other people online who share the same concerns may help individuals overcome their anxiety and make it easier to attend the dentist regularly.

This research is being carried out as part of a PhD in Health Psychology at the University of Nottingham.

What is involved?

-Listening to a brief presentation and sharing your thoughts with others who are also anxious of the dentist

-Completing a dental anxiety tool before the meeting and providing feedback on the tool during the meeting

-Helping us understand how we might know if our intervention was helpful for people who are anxious about going to the dentist.

-There may be documents to read ahead of the meeting and provide feedback on during the focus group

What you will contribute…

-Real-life experience of being dentally anxious

- A willingness to discuss the topic with other people who are also anxious of the dentist

-Thoughts and ideas about what might work well or not in a project for people with dental anxiety

Further Details

Time: 1 online meeting (max. 1.5 hour). The date of the meeting will be confirmed based on participants' availability.

Payment: £20 of Amazon vouchers for participating in the meeting

Possibility to get involved with further meetings or provide further feedback if interested. Please contact caitlin.sorrell@nottingham.ac.uk if you would like more information before applying.

How to apply

Please send us a few sentences about your experience with dental anxiety and why you are interested in this project. Please also tell us a little bit about yourself (how old are you, what gender do you identify as, do you work and if yes, what do you do).

Please contact Caitlin Sorrell (e-mail: caitlin.sorrell@nottingham.ac.uk)

2.3 Email to potential PPI focus group participants

Hello XXX,

Thank you so much for responding to the advert on People in Research, and for offering up you time to support our research.

About you
Firstly, as I am trying to get a diverse sample of people from different backgrounds and with a spread of ages, could you please tell me a little bit about yourself? I'd like to know how old you are, what gender you identify as (I don't want to make assumptions based on your name!), what your occupation is (or was) and whether you are working, looking for work, retired… I'd also like to know roughly how long it is since you last went to the dentist.

What is involved?
To give you a bit more information about what is required, please check out the attached document, but don't hesitate to contact me if you have any more questions after you've read it. For now, I am asking people to commit to an online focus group (essentially a group chat on Zoom or Teams) that will last between 1 and 1.5 hours. I'll introduce you to what I am planning to do in my research and will ask you for your feedback (positive or negative). I will be asking all participants to complete a very short questionnaire (5 items) before the focus group, and again I'll ask you to give me feedback on what you thought about the questionnaire during the meeting.
If after the first focus group you are interested in doing more, there might be scope for more involvement at a later stage. However, it's equally fine if this is all you are interested in doing.

What's next?
If you are still interested in participating, or if you have any more questions, please let me know.
I have just started advertising both online and off-line, and I need to allow sufficient time for people to respond to both.
I will then be back in touch towards the end of February with an update at which point I will hopefully know who I am going to include. I will then set the date for the online focus group based on people's availability. If I don't include you at this stage, there might be scope for involvement again at a later stage.

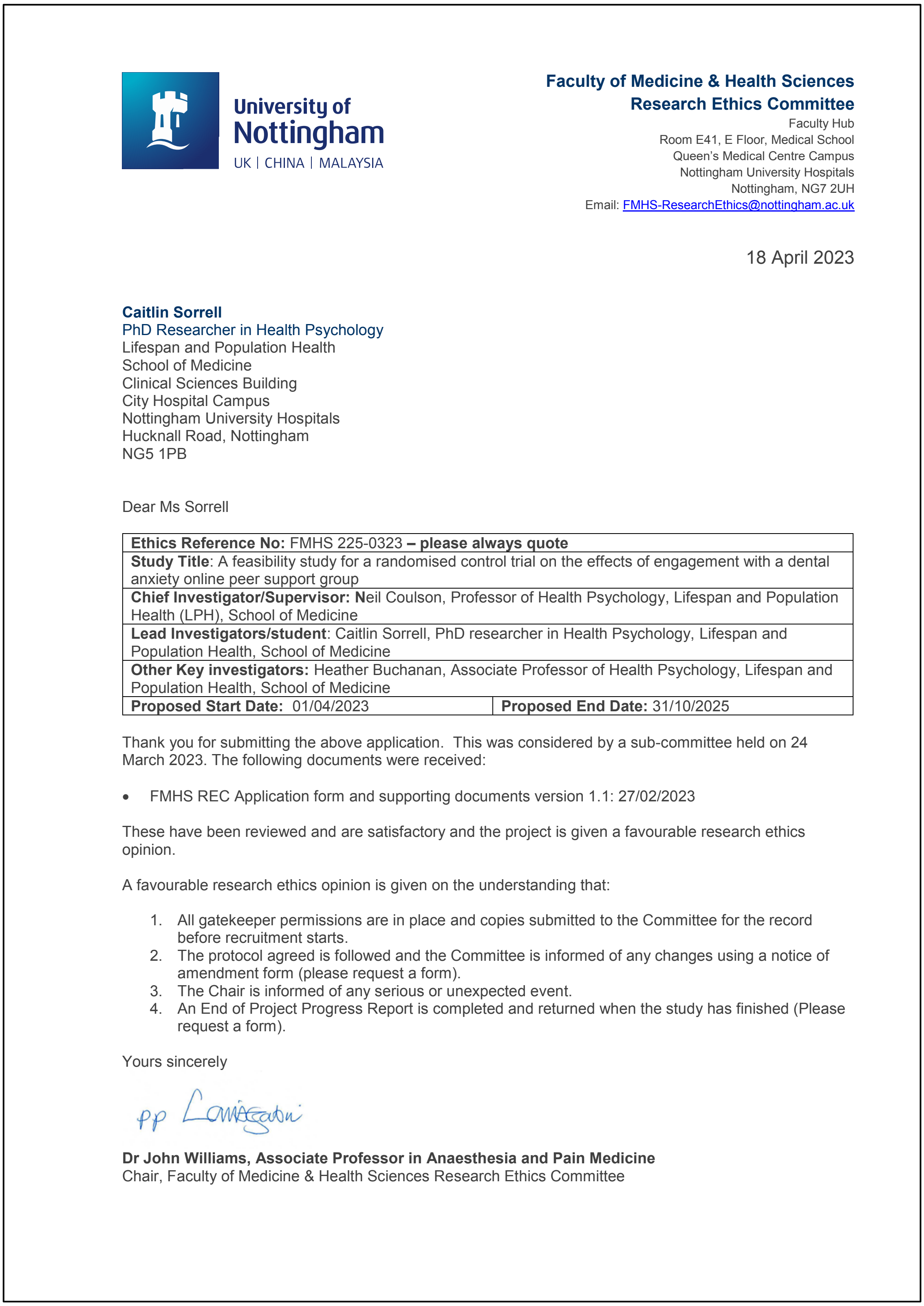
In summary, please read the attached document, please e-mail me back to let me know if you are still interested and let me know a bit more about you. I will then be back in touch in due course.

Thanks again for your interest in this project.

Regards,

Caitlin Sorrell

Appendix 3 – Ethics Approval



University of
Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty Hub
Room E41, E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH
Email: FMHS-ResearchEthics@nottingham.ac.uk

18 April 2023

Caitlin Sorrell
PhD Researcher in Health Psychology
Lifespan and Population Health
School of Medicine
Clinical Sciences Building
City Hospital Campus
Nottingham University Hospitals
Hucknall Road, Nottingham
NG5 1PB

Dear Ms Sorrell

Ethics Reference No: FMHS 225-0323 **– please always quote**	
Study Title: A feasibility study for a randomised control trial on the effects of engagement with a dental anxiety online peer support group	
Chief Investigator/Supervisor: Neil Coulson, Professor of Health Psychology, Lifespan and Population Health (LPH), School of Medicine	
Lead Investigators/student: Caitlin Sorrell, PhD researcher in Health Psychology, Lifespan and Population Health, School of Medicine	
Other Key investigators: Heather Buchanan, Associate Professor of Health Psychology, Lifespan and Population Health, School of Medicine	
Proposed Start Date: 01/04/2023	**Proposed End Date:** 31/10/2025

Thank you for submitting the above application. This was considered by a sub-committee held on 24 March 2023. The following documents were received:

- FMHS REC Application form and supporting documents version 1.1: 27/02/2023

These have been reviewed and are satisfactory and the project is given a favourable research ethics opinion.

A favourable research ethics opinion is given on the understanding that:

1. All gatekeeper permissions are in place and copies submitted to the Committee for the record before recruitment starts.
2. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
3. The Chair is informed of any serious or unexpected event.
4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

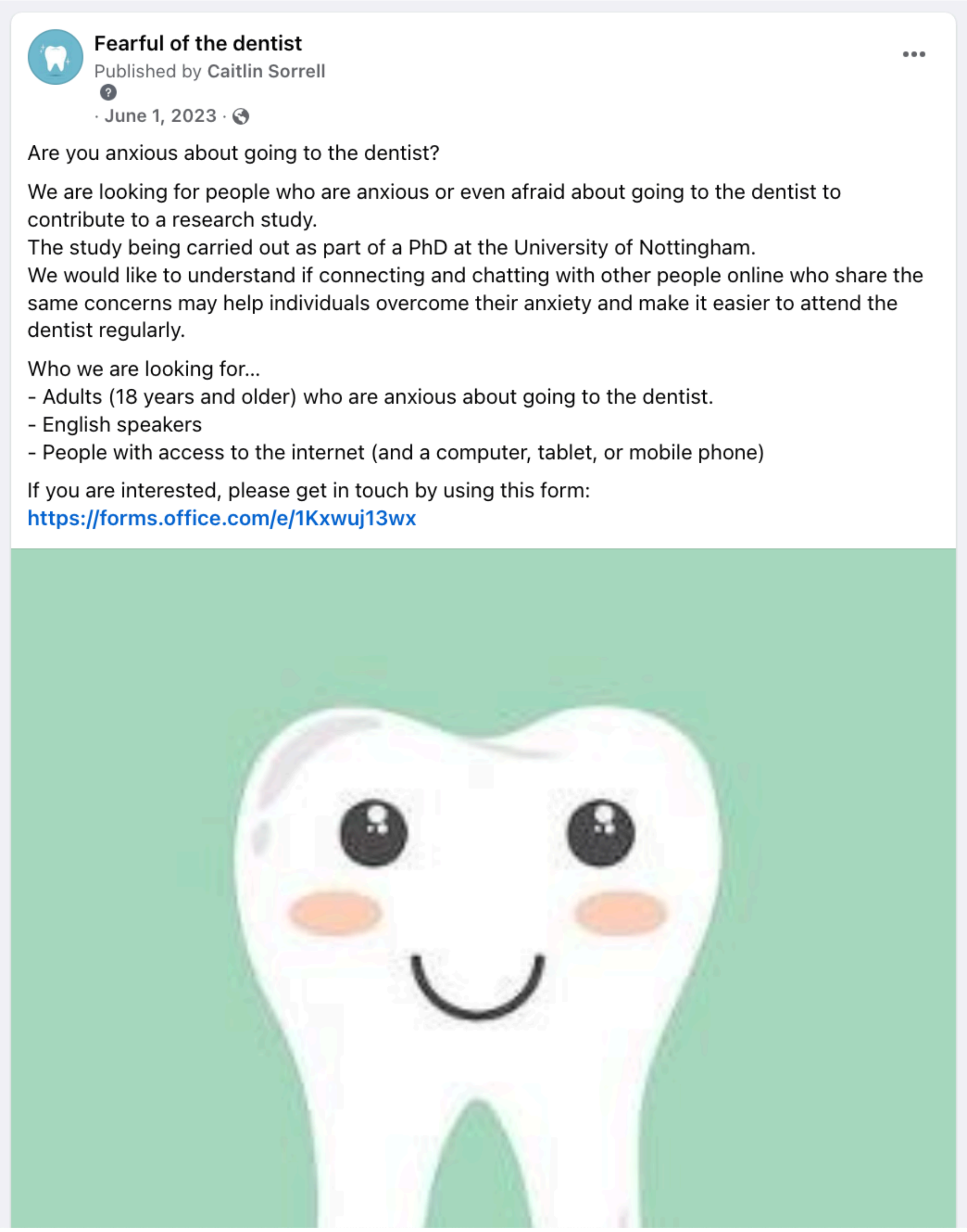
Yours sincerely

pp

Dr John Williams, Associate Professor in Anaesthesia and Pain Medicine
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix 4 – Examples of recruitment adverts

4.1 Boosted post on Facebook



Fearful of the dentist
Published by **Caitlin Sorrell**
· June 1, 2023 ·

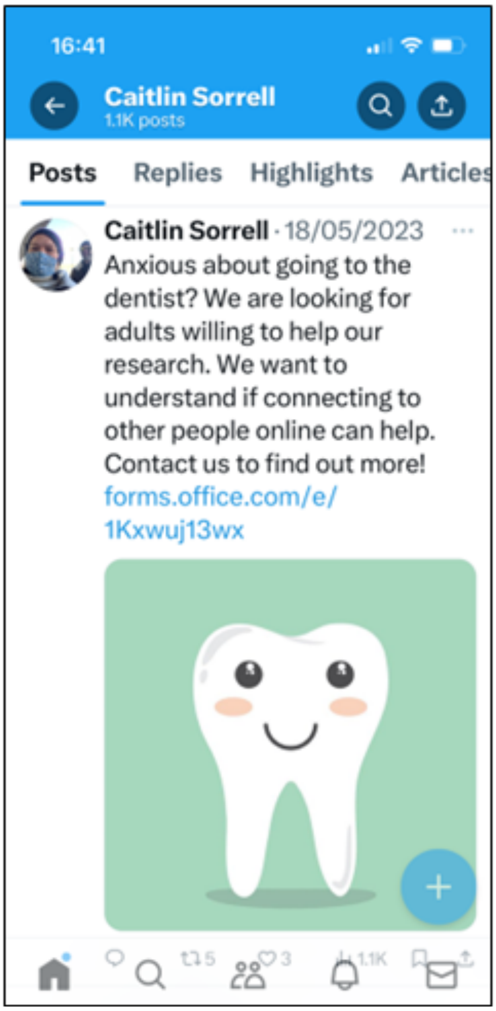
Are you anxious about going to the dentist?

We are looking for people who are anxious or even afraid about going to the dentist to contribute to a research study.
The study being carried out as part of a PhD at the University of Nottingham.
We would like to understand if connecting and chatting with other people online who share the same concerns may help individuals overcome their anxiety and make it easier to attend the dentist regularly.

Who we are looking for...
- Adults (18 years and older) who are anxious about going to the dentist.
- English speakers
- People with access to the internet (and a computer, tablet, or mobile phone)

If you are interested, please get in touch by using this form:
https://forms.office.com/e/1Kxwuj13wx

4.2 Adverts on X (formerly known as Twitter)



Caitlin Sorrell · 18/05/2023

Anxious about going to the dentist? We are looking for adults willing to help our research. We want to understand if connecting to other people online can help. Contact us to find out more! forms.office.com/e/1Kxwuj13wx

Caitlin Sorrell · 11/06/2023

I'm still looking for participants for my PhD study. Please retweet! You can find out more and get in touch here forms.office.com/e/1Kxwuj13wx

4.3 Physical Poster and flyers

University of Nottingham
UK | CHINA | MALAYSIA

Are you anxious about going to the dentist?

We are looking for people who are nervous or even afraid about going to the dentist to contribute to a research study.

We would like to understand if connecting and chatting with other people online who share the same concerns may help individuals overcome their anxiety and make it easier to attend the dentist regularly.

This research is being carried out as part of a PhD in Health Psychology at the University of Nottingham

What is involved?

- All participants will be asked to complete some questionnaires about six weeks apart about their dental anxiety and how they feel about attending a dental appointment. The estimated time to complete these is around 15-20 minutes
- Some (but not all) participants will be asked to engage with an online support group for people who are anxious about going to the dentist. It will be up to the participants to decide how and when they use the online support group
- Some (but not all participants) will be asked to take part in interviews lasting around an hour

Who we are looking for…

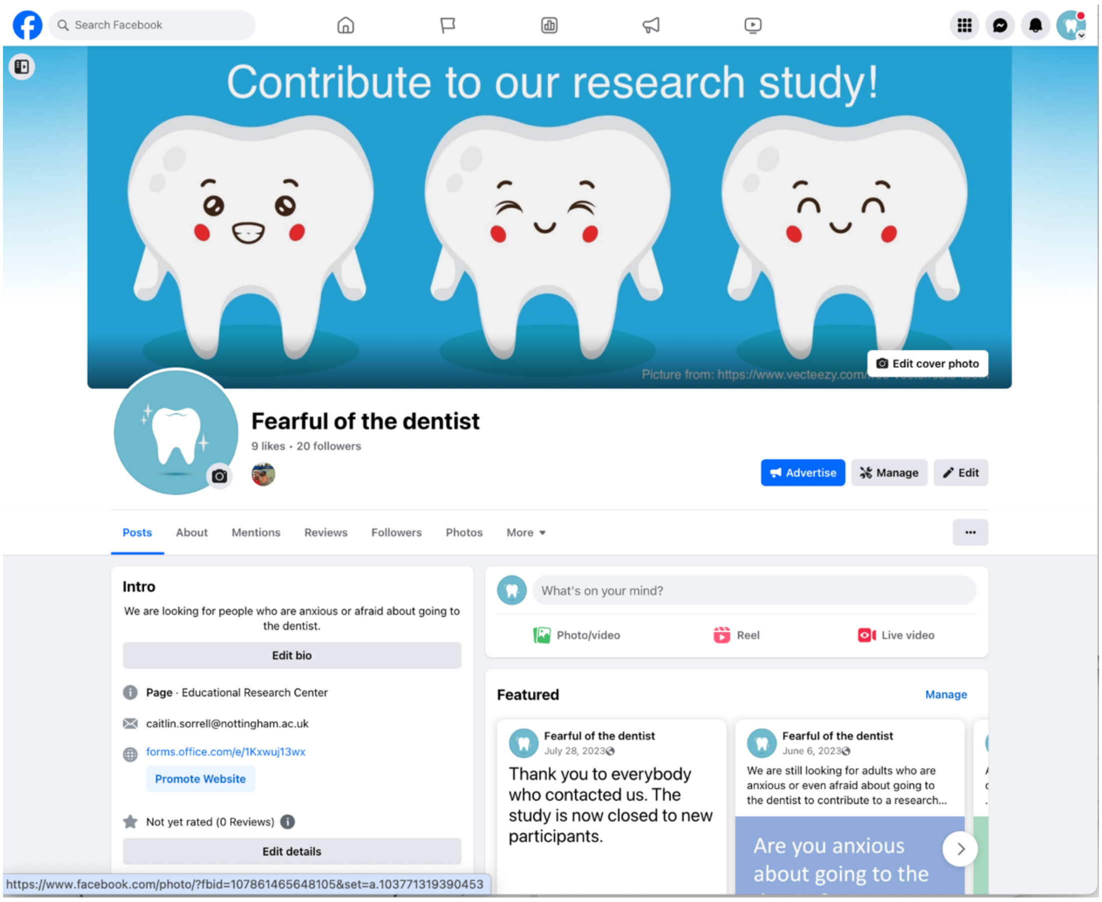
- Adults (18 years and older) who are anxious about going to the dentist
- English speakers
- People with access to an internet-enabled device (computer, tablet, mobile phone)

What you will contribute…

- Real-life experience of being dentally anxious (anxious or afraid of going to the dentist)
- A willingness to discuss the topic online with other people who are also anxious about going to the dentist

Do you want more information?
Would you like to apply?
Scan the QR code or contact
caitlin.sorrell@nottingham.ac.uk

Appendix 5 – Facebook page for the study



Fearful of the dentist

9 likes · 20 followers

Intro

We are looking for people who are anxious or afraid about going to the dentist.

Page · Educational Research Center

caitlin.sorrell@nottingham.ac.uk

forms.office.com/e/1Kxwuj13wx

Not yet rated (0 Reviews)

Fearful of the dentist
July 28, 2023

Thank you to everybody who contacted us. The study is now closed to new participants.

Fearful of the dentist
June 6, 2023

We are still looking for adults who are anxious or even afraid about going to the dentist to contribute to a research...

Are you anxious about going to the

https://www.facebook.com/photo/?fbid=107861465648105&set=a.103771319390453

Appendix 6 – Enquiry Form

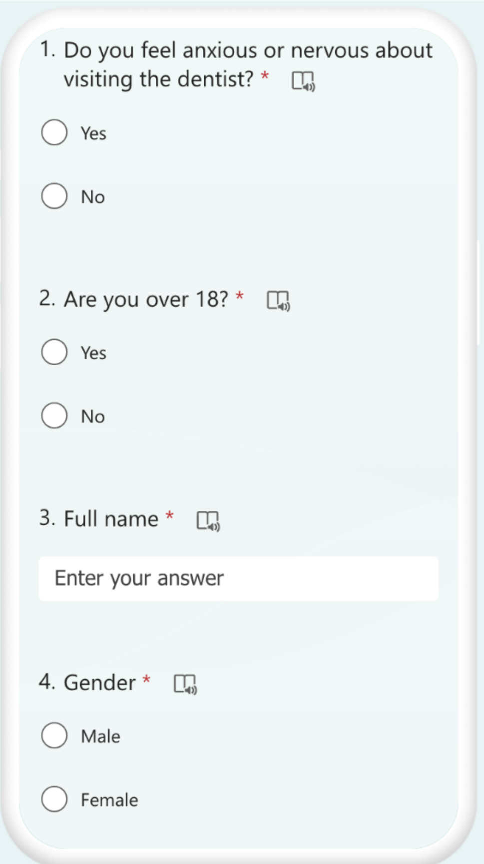
Fearful of the dentist?
A research study.

This research is being carried out as part of a PhD in Health Psychology at the University of Nottingham.
We are looking for people who are anxious or even afraid about going to the dentist to contribute to a research study. We would like to understand if connecting and chatting with other people online who share the same concerns may help individuals overcome their anxiety and make it easier to attend the dentist regularly. Participants will receive an allowance to participate in the study.
This form is just an enquiry form. We will send you more information about the study so you can decide if it is right for you.

UPDATE - THIS STUDY IS CURRENTLY CLOSED TO NEW PARTICIPANTS. THANK YOU FOR YOUR INTEREST!

* Required

1. Do you feel anxious or nervous about



1. Do you feel anxious or nervous about visiting the dentist? *

○ Yes

○ No

2. Are you over 18? *

○ Yes

○ No

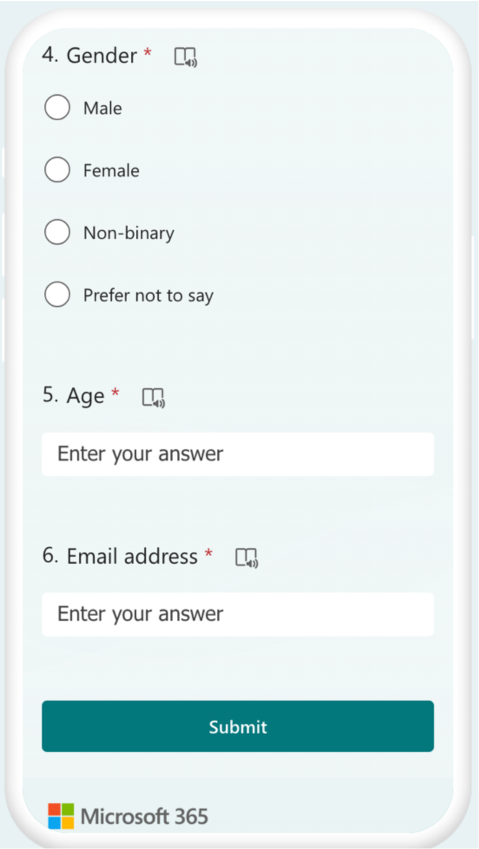
3. Full name *

Enter your answer

4. Gender *

○ Male

○ Female



4. Gender *

○ Male

○ Female

○ Non-binary

○ Prefer not to say

5. Age *

Enter your answer

6. Email address *

Enter your answer

Appendix 7 – Participant Information Sheet

Faculty of Medicine & Health Sciences
School of Medicine
Lifespan and Public Health
Room B126, Clinical Sciences Building
City Hospital, Hucknall Road,
Nottingham, NG5 1PB

Neil Coulson, Professor of Health Psychology (Supervisor)
neil.coulson@nottingham.ac.uk
Caitlin Sorrell, PhD Student (Researcher)
caitlin.sorrell@nottingham.ac.uk

Study Title: A feasibility study for a randomised control trial on the effects of engagement with a dental anxiety online peer support group

PARTICIPANT INFORMATION SHEET

Research Ethics Reference: FMHS 225-0323
Version 1.5 Date: 24.04.2023

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read this carefully and discuss it with others if you wish. Ask us anything that is not clear.

What is the purpose of the research?

Dental anxiety is a commonly used term for fear of going to the dentist or fear of anything being done to the teeth. This study aims to understand more about people's experience of an online support group for dental anxiety. Specifically, the study will investigate what might encourage people to use an online support group, and what might put them off, as well as how they use the online support group.

The study will also measure dental anxiety and how ready or willing people feel to attend dental appointments before and after usage of the online support group. The aim of this is to try and understand if the chosen measures are appropriate.

Overall, the purpose of this small-scale study is to consider whether a larger, fuller study (called a controlled trial) can be done to assess whether online support groups can help people with dental anxiety.

Some studies have carried out interviews or questionnaires with people who use online support groups for dental anxiety, and participants have reported to find them beneficial. This study builds on that knowledge and aims to provide more evidence and understanding. Longer term, we hope to test whether online support groups are effective at helping people with dental anxiety.

Why have I been invited to take part?

- You have been invited to take part in this research because you are over 18 and you have told us that you are anxious about going to the dentist*
- You have told us that you have a device (computer, tablet or phone) that has access to the internet and are comfortable using it.
- You can read and write English (or have assistive technology, for example if visually impaired)

*We will ask you to complete a short questionnaire to assess that your level of dental anxiety is appropriate for the purposes of our study.

Do I have to take part?

It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you online (on Microsoft Teams) to answer any questions you may have. If you agree to participate, we will ask you to sign a consent form and will give you a copy to keep. However, you would still be free to withdraw from the study at any time, without giving a reason, simply by letting the research team know.

What will happen to me if I take part?

In the e-mail that we sent with this document, you were given a unique participant ID number so that your information and data can be collected anonymously.

If you would like to take part, please complete the online questionnaire using your participant ID number. You will find the link to the questionnaire and the participant ID in the e-mail that came with this letter. This questionnaire will ask you a few details about yourself, and how anxious you feel in certain situations that involve a visit to the dentist. The questionnaire is very short and should only take around five minutes to complete. The results from this questionnaire will tell us whether you are eligible for the study as we are looking for a specific level of anxiety. We will then get back in touch to let you know if you are eligible or not.

If you are eligible, a researcher will contact you to arrange a meeting on Microsoft Teams (an online platform for video calls similar to zoom or Skype) at a time that suits you and that should take no longer than 10 minutes. They will go over the information sheet, explain some more about the study and answer any questions you might have. If you are still happy to take part, then you will then be asked to sign a consent form and send it back to us.

When we receive your consent form, you will be asked to complete another online questionnaire about how ready you feel to attend a dental appointment. It should take about 5-10 minutes to complete this second questionnaire. Once again, we will ask you to use your participant ID so that your data remains anonymous.

The study will either involve being asked to use an online support group for dental anxiety or being assigned to a control group (people who don't use the support group so that we can compare results from both groups). In both cases you will be asked to repeat both questionnaires again about 6-8 weeks after the first questionnaires. If you are assigned to the control group, that's all you will be asked to do. Half the participants will be in the control group and half will be asked to take part in an online support group.

If you are asked to take part in the online support group, you will be sent details on how to register and how to use the site. Registration is quick and simple and will allow you to read what other people have posted and comment if you want to. You will be asked to use this support group for a period of six weeks. However, it will be entirely up to you how often you access the site, when you access it and how much time you spend. It will also be up to you whether you just read other people's posts or if you post any comments of your own. We will also ask you to tell us what your username is so that we can record on a daily basis whether you have logged on. We will not be using that information for any other purpose and will not be looking at what you have posted.

At the end of the six weeks, we will contact you to arrange an interview on Microsoft Teams at a time that suits you. The interview will take between 30 minutes and one hour. We will ask you about how you used the online support group (e.g., how often you used the site, what you did when you were on the site). We will ask you about your experience of using the site (e.g., whether you found it enjoyable or useful, whether you found it easy or difficult to use).

After the six weeks, you are more than welcome to continue using the online support group and if you were in the control group, we will send you the relevant details so that you can start using it if you would like to.

What is an Online Support Group?

In this study, participants will be asked to use an online support group that brings together people who all have in common a fear of going to the dentist. Online support groups like this allow people to exchange first-hand experience about their fear of the dentist, or their experiences of going to the dentist. They are sometimes also called discussion forums as people post messages or respond to previous messages, creating threads that others can read with or without adding to. Online support groups can offer a convenient, accessible, and low-cost way of anonymously accessing information, emotional and practical support.

Are there any risks in taking part?

There are few risks involved in taking part in an online support group. However, one possible risk is that you find some of the content discussed in the group distressing, for example, people may discuss their visit to a dentist. If you find a topic on the discussion forum that you find upsetting, please remember that you are under no obligation to engage with that particular online conversation. Look out for conversations that include a trigger warning (which some people use if they are going to describe their treatment for example), as you may want to avoid these. You could also find that other people's behaviour is upsetting, although the risk of this should be reduced as the forum is moderated. Please also remember that you can stop using the online support group altogether if you find it distressing, and this is something that the researchers will be interested in asking you about during an interview if you feel comfortable discussing it.

Another possible risk is that you disclose personal information if you decide to post or reply to a thread on the online support group. Please remember that a discussion forum is public and we recommend that you choose a username that doesn't help identify you, and that you avoid mentioning personal information such as your name, where you live, or where you work.

1. **Are there any benefits in taking part?**

Previous research has shown that some people have found using online support groups for dental anxiety beneficial. However, we cannot say whether there will be a direct benefit to you from taking part in this research. In any case, your contribution may help shape future research to understand whether online support groups are beneficial and for who.

2. **Will my time be reimbursed?**

Participants will receive an allowance to participate in the study. Participants will receive £10 in vouchers after completion of all the questionnaires. Participants will also receive an additional £15 for taking part in an interview.

What happens to the data provided?

Personal data (e.g., gender, age, ethnicity) will be stored confidentially in a password-protected file using the University's One Drive which requires two-factor authentication. The data will be logged against the Participant ID number (assigned at the start of the study) in a password-protected file that only the researcher will have access to. Participants' names and contact details will be linked to their Participant ID number in a separate password-protected file that only the researcher will have access to in order to facilitate communication with the participant and enable removal of their data in the event of their withdrawal from the study. At the end of the study, the personal information and the link to the participant ID number will be deleted. A summary of the demographic make-up (how many men/women, what age range….) of the participant group will be kept.

The **research data** will be stored confidentially on the University's One Drive. For responses to the questionnaires, only the participant ID will be used instead of names. For the interviews, these will be recorded on Teams and the automatic transcription functionality will be enabled. The transcripts will be checked for accuracy and anonymised and any identifying features will be removed from the transcript, at which point the recording will be deleted.

The researcher (Caitlin Sorrell) and the supervisor Neil Coulson will have access to personal data. Only people within the research team authorised by the supervisor will have access to the research data. However, personal data and research data may be made available on request for review by authorised University representatives, and for inspection by relevant regulatory authorities.

We would like your permission to use fully anonymised direct quotes in research publications.
All research data and records will be stored for a minimum of 7 years after publication or public release of the work of the research.

What will happen if I don't want to carry on with the study?

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason. Any personal data will be destroyed and if possible, research data will be removed from the study.
If you withdraw more than 10 days after your interview, we will no longer collect any information about you or from you, but we will keep the anonymous research data that has already been collected and stored as we are not allowed to tamper with study records. This information may have already been used in some analyses and may still be used in the final study analyses.

Who will know that I am taking part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. Electronic storage devices will be encrypted while transferring and saving of all sensitive data generated in the course of the research. All such data are kept on password-protected databases sitting on a restricted access computer system.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (Neil Coulson) is the Data Custodian (manages access to the data).

You can find out more about how we use your personal information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx/

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

Anything you say during an interview will be kept confidential, unless you reveal something of concern that may put yourself or anyone else at risk. It will then be necessary to report to the appropriate persons.

What will happen to the results of the research?

The research will be written up as a thesis for an educational qualification (a PhD in Health Psychology). On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research.

In addition, the research may be published in relevant academic journals.

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

Who is organising and funding the research?

The research is being organised by Professor Neil Coulson, the primary PhD supervisor of Caitlin Sorrell at the University of Nottingham and is being funded as part of Caitlin Sorrell's PhD. No external funders have been involved.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher Caitlin Sorrell or her supervisor Professor Neil Coulson, who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's

Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.
Please quote ref no: FMHS 225-0323

Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Caitlin Sorrell
School of Medicine
Room B126, Clinical Sciences Building
City Hospital, Hucknall Road,
Nottingham, NG5 1PB
Email: caitlin.sorrell@nottingham.ac.uk

Appendix 8 – Participant Consent Form

Participant Consent Form
Version 1.1: 13.02.2023
Title of Study: A feasibility study for a randomised control trial on the effects of engagement with a dental anxiety online peer support group

REC ref: FMHS 225- 0323

Name of Researchers: Caitlin Sorrell, PhD Student; Neil Coulson, Professor of Health Psychology (Primary Supervisor); Heather Buchanan, Associate Professor of Health Psychology (Second Supervisor).

Name of Participant: **Please initial box**

I confirm that I have read and understand the information sheet version 1.1 dated 13.02.23 for the above study which is attached and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without disadvantage. ☐

I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

I understand that the interview will be audio recorded using an automated transcription service and that anonymous direct quotes from the interview may be used in the study reports. The recording will be deleted, and the anonymous transcript will be retained. ☐

I understand that information about me collected during the study will be made anonymous before it is stored in a secure database. Data will be kept for 7 years after the study has ended and then deleted. ☐

I understand that what I say during the interview will be kept confidential unless I reveal something of concern that may put myself or someone else at any risk. It will then be necessary to report this to the appropriate persons. ☐

I agree to take part in the above study. ☐

Optional: I agree that my anonymous research data will be stored and used to support other research during and after 7 years and shared with other researchers including those working outside the University. ☐

Optional: I agree to my contact details being stored for the purpose of being invited to participate in future research studies. ☐

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

Appendix 9 – Email Templates

9.1 Response to Enquiry Form

Dear XX,

Thank you for your interest in our study on dental anxiety.

Attached is an information sheet with all the details about our study. Please take the time to read this before deciding whether to take part or not.

Your unique participant ID is XX

This unique ID number helps us keep your data anonymous.

What is involved?

- All participants will be asked to complete some questionnaires about six weeks apart about their dental anxiety and how they feel about attending a dental appointment. The estimated time to complete these is around 15-20 minutes
- Some (but not all) participants will be asked to engage with an online support group for people who are anxious about going to the dentist. It will be up to the participants to decide how and when they use the online support group
- Some (but not all participants) will be asked to take part in interviews lasting around an hour
- An allowance of £10 will be paid in vouchers to all participants who complete the questionnaires, and a further allowance of £15 to participants who take part in the interviews

What comes next?

First, we would like to click on this link and complete a short questionnaire to check that your level of dental anxiety is appropriate for our study: https://forms.office.com/e/psYUUibYYi

Once we have received those results, I will be back in touch to talk you through the attached information sheet over the phone or on Teams and answer any questions you might have.
At that point, if you are still happy to continue, I will ask you to sign the attached consent form and we will enrol you onto the study.

Please don't hesitate to get in touch if you have any questions, but please note that I am only part time, so there could be a few days' delay before I get back to you.

Thank you again for your interest in our study.

Warm Regards,
Caitlin Sorrell
PhD Researcher
School of Medicine
Nottingham University

9.2 Response to MDAS >10

Dear XX,

Thank you very much for completing the Dental Anxiety questionnaire.

I can confirm that you are eligible for the study, and we would very much like you to take part.

The next step is for us to arrange a quick call, either over the phone or on Microsoft Teams. It should only take 10 minutes, and I will take you through the participant information so that you know what is involved. After that, you can decide if you are still interested in taking part.

If you are still interested after that call, you just need to sign and return the attached consent form.

I currently have the following availability for a call:
xx-xx xx

Please let me know if any of these could work for you, and whether you prefer Microsoft Teams or phone (in which case please advise the best number to call you on). If none of these are suitable, let me know and I'll try and free up some more slots.

Warm Regards,

Caitlin Sorrell
PhD Researcher
School of Medicine
Nottingham University

9.3 Enrolment & Ladder

Hello XXX,

It was lovely to speak to you on xxx and thank you again for taking the time to talk to me.

Firstly, please find attached a counter-signed copy of the consent form. Please keep this for your records. You are now officially enrolled in the study.

The next step is for you to fill-in the second questionnaire. This should hopefully take even less time than the first one. Your participant ID is still number XX.
https://forms.office.com/e/bRxe31nn9F
I would appreciate if you could complete this by xx, but don't worry if it takes you a little bit longer.

In 6-8 weeks, I will be asking you to complete both questionnaires again.

Once I have enough participants, I will do the random allocation and will be back in touch to let you know whether I will be asking you to join the online support group or not.

If you have any questions that the Participant Information Sheet doesn't answer, please don't hesitate to e-mail me.

Warm Regards,

Caitlin Sorrell
PhD Researcher
School of Medicine
Nottingham University

9.4 Allocation to OSG

Hello XXX,
Thank you again for taking part in our study. Your contribution is greatly appreciated.

I am writing to let you know that you have been assigned to the online support group.
Therefore, I would now like you to join the support forum at Dental Fear Central, a UK-based online forum for people with high dental anxiety.
You can go to the website by clicking on or copying this web address: https://www.dentalfearcentral.org/

I have attached a guide on how to register for the support forum on Dental Fear Central. If anything isn't clear or if you have any questions, please don't hesitate to get in touch with me on e-mail.

The forum is moderated, and we ask you to read the site's rules and guidelines**.** To stay safe online, please don't use your actual name as a username.

Once you have registered, **don't forget to send me your username!**

Please check out the forum when you have registered. The attached document might help give you an overview. Have a browse to see if there is anything on there that might be of interest to you. After that, it is up to you how much or how little you use it, or how often you log on during the next six weeks. I will send you an occasional prompt to remind you, but it's still up to you.

I will be back in touch to arrange an interview at a convenient time once the six weeks is over.

Let me know if you have any questions, and I look forward to hearing your thoughts during the interview.

Thank you again for taking part.

Caitlin Sorrell
PhD Researcher
School of Medicine
Nottingham University

9.5 Allocation to WLC

Hello XXX,

Thank you again for your ongoing participation in our research study!

I can now confirm that you have been allocated to the wait list control.

After 6-8 weeks, I will send you another link to complete the two questionnaires again. You will also be signposted to the online support group at that time, and you will be free to sign up if you think that it might be of interest to you.

That means that for the next six weeks, you don't have to do anything, but you will still be helping our research!

Once you have completed the questionnaires, you will receive an electronic voucher for £10 and will be sent all the details of the online support group.

I'll be back in touch in early August for the repeat questionnaires. If you have any questions in the meantime, just let me know.

Warm Regards,

Caitlin Sorrell
PhD Researcher
School of Medicine
Nottingham University

9.5 Reminder email MDAS

Hello XX,

If you are still interested in taking part in the study, it's not too late! Attached is an information sheet that tells you more about the study.

If you are interested, you need to complete an eligibility check via this link, using your participant ID which is XX.
https://forms.office.com/e/psYUUibYYi

If you are no longer interested in taking part, you can let me know and I will remove your details from my database.

Warm Regards,

Caitlin Sorrell

9.6 New Dates PIS Call

Hello XX,

If you are still interested in taking part in the study, it's not too late! Attached is an information sheet that tells you more about the study.

If you are interested, I need to arrange a quick 10-minute call to explain what's involved and answer any questions you may have.

I have the following slots available next week:

Monday 3rd 8.00-9.00am
Wednesday 5th 4.30-5.30pm
Thursday 6th 12am-1pm or 5.00-6.00pm
Saturday 8th 2pm-4pm
Sunday 9th 4pm-6pm

Please let me know if any of those are suitable for you or let me know if you need some later dates.

If you are no longer interested in taking part, you can let me know and I will remove your details from my database.

Warm Regards,

Caitlin Sorrell

9.7 Reminder email Consent

Hello XX!

If you are still interested in taking part in the study after our recent chat, I just need you to complete the consent form attached. If you have any problems completing the form, let me know.

However, if you are no longer interested in taking part, you can let me know and I will remove your details from my database.

Either way, thank you very much for taking the time to speak to me.

Warm Regards,

Caitlin Sorrell

9.8 Reminder email ladder

Hello XX,

This is just a gentle reminder to ask if you could complete the second questionnaire at your earliest convenience.

Your participant ID is still number XX
https://forms.office.com/e/bRxe31nn9F

If you have any problems using the form, please let me know.

Warm Regards,

Caitlin Sorrell

9.9 Reminder OSG & Interview dates

Hello XXX,

I am writing firstly to remind you to logon to the Dental Fear Central support forum and have a look around. If you are already using it, that's great. You have a few more weeks to use it before we reach the end of the study period.

As I told you at the beginning, it's entirely up to you how you use Dental Fear Central. This is simply a reminder because I know that people have busy lives!

I would also like to schedule an interview to talk about your experiences of using Dental Fear Central. This shouldn't take more than one hour and will be conducted on Microsoft Teams.

Please can you let me know if any of the following slots would work for you:

- XXX
- XXX

If none of these are suitable, let me know when could work for you.
I am really looking forward to chatting to you about your experience.

Warm Regards,

Caitlin

9.10 Final questionnaires (and interview reminder)

Dear XX,

Thank you for taking part in our study, your input has been incredibly valuable to us. Now that you are reaching the end of the study period, could I please ask you to fill-in the following two questionnaires.

These are a repeat of the ones that we asked you to fill-in at the start of the study. Your participant ID is still number XX

1. Dental anxiety questionnaire
https://forms.office.com/e/XJU0myGSHy

2. Thinking about going to the dentist
https://forms.office.com/e/j9VTE9Dk4F

I would be really grateful if you could complete both of these by XX.
Once your responses have been received and checked, we will be sending you a £10 voucher to say thank you for your contribution.

If you have any questions, please don't hesitate to contact me.

Warm Regards,

Caitlin Sorrell

9.11 Final questionnaires & interview reminder

Dear XX,

Thank you for taking part in our study, your input has been incredibly valuable to us. Now that you are reaching the end of the study period, could I please ask you to fill-in the following two questionnaires.

These are a repeat of the ones that we asked you to fill-in at the start of the study. Your participant ID is still number XX.

1. Dental anxiety questionnaire
https://forms.office.com/e/XJU0myGSHy

2. Thinking about going to the dentist
https://forms.office.com/e/j9VTE9Dk4F

I would be really grateful if you could complete both of these before your interview on INSERT DATE.
Once your responses have been received and checked, we will be sending you a £10 voucher to say thank you for your contribution.

If you have any questions, please don't hesitate to contact me.

Warm Regards,

Caitlin Sorrell

9.12 Vouchers

Dear XX,

Thank you for taking part in the interview on XX.
Your input is highly valuable to the research team.
Please find attached an Amazon voucher to the value of £10/15 as a token of our appreciation.

Warm Regards,

Caitlin Sorrell

9.13 WLC free to use OSG

Hello XXX,

Thank you again for taking part in our study. Your contribution is greatly appreciated.

As your involvement with the study is now officially over, you are free to join the support forum at Dental Fear Central, a UK-based online forum for people with high dental anxiety.
You can go to the website by clicking on or copying this web address: https://www.dentalfearcentral.org/

I have attached a guide on how to register for the support forum on Dental Fear Central.
The forum is moderated, and we ask you to read the site's rules and guidelines**.** To stay safe online, please don't use your actual name as a username.

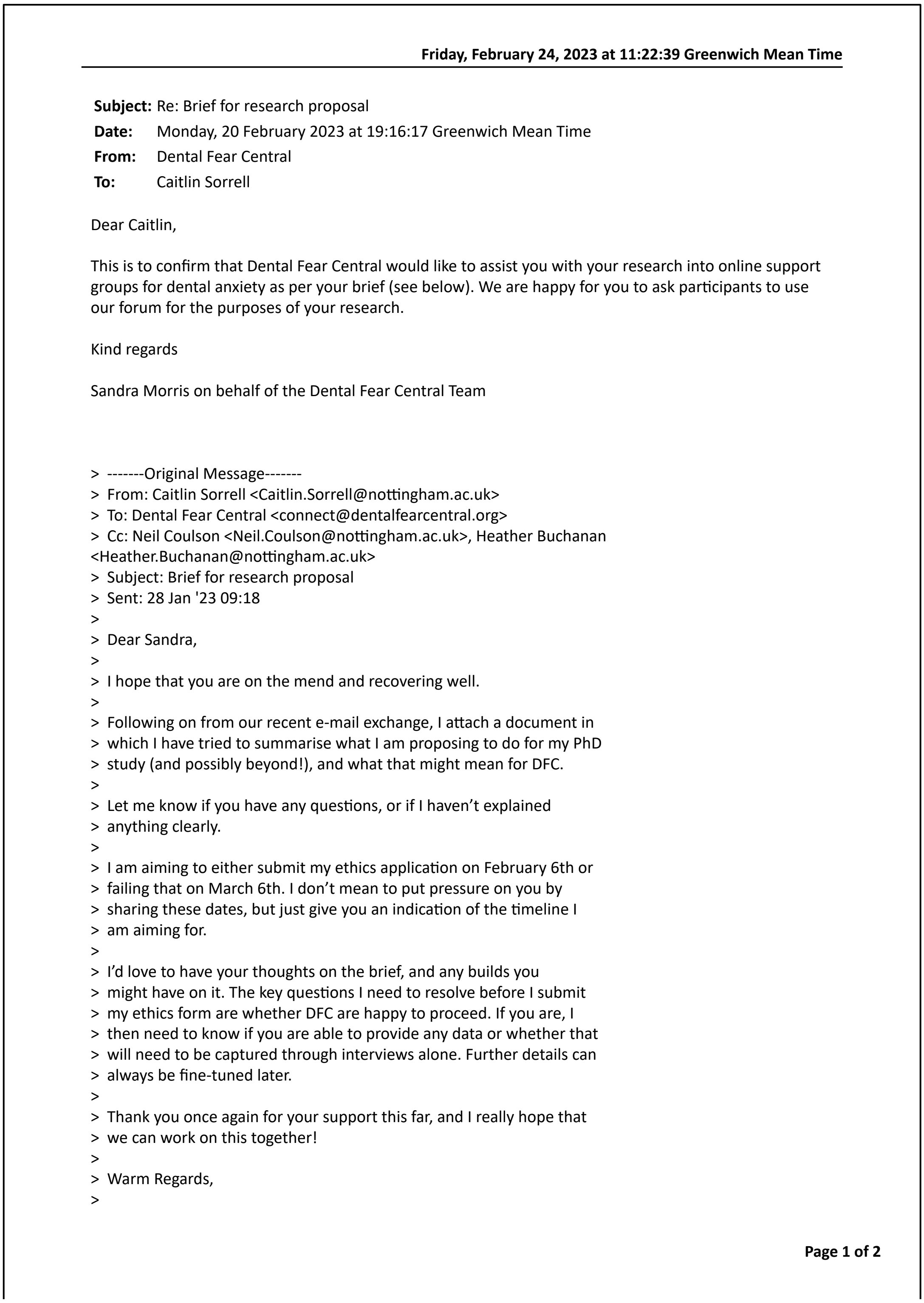
The attached document might help give you an overview of the forum. Feel free to have a browse to see if there is anything on there that might be of interest to you.
It is of course entirely up to you whether you join Dental Fear Central or not.

If you would be interested in receiving a copy of the results from the study (in about 18 months' time), please let me know.

Thank you again for taking part.

Caitlin Sorrell
PhD Researcher
School of Medicine
University of Nottingham

Appendix 10 – DFC Authorisation



Friday, February 24, 2023 at 11:22:39 Greenwich Mean Time

Subject: Re: Brief for research proposal
Date: Monday, 20 February 2023 at 19:16:17 Greenwich Mean Time
From: Dental Fear Central
To: Caitlin Sorrell

Dear Caitlin,

This is to confirm that Dental Fear Central would like to assist you with your research into online support groups for dental anxiety as per your brief (see below). We are happy for you to ask participants to use our forum for the purposes of your research.

Kind regards

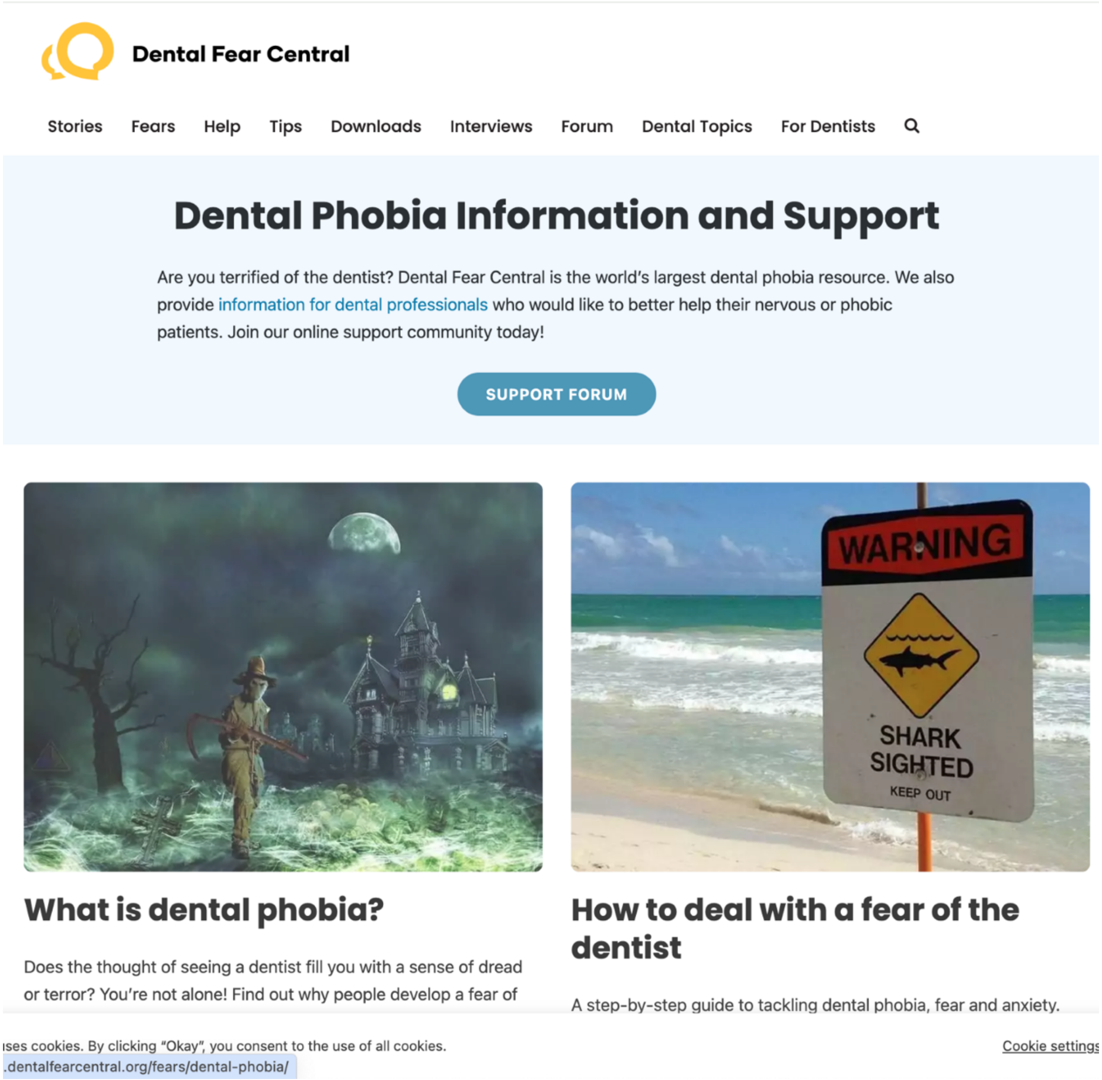
Sandra Morris on behalf of the Dental Fear Central Team

> -------Original Message-------
> From: Caitlin Sorrell <Caitlin.Sorrell@nottingham.ac.uk>
> To: Dental Fear Central <connect@dentalfearcentral.org>
> Cc: Neil Coulson <Neil.Coulson@nottingham.ac.uk>, Heather Buchanan <Heather.Buchanan@nottingham.ac.uk>
> Subject: Brief for research proposal
> Sent: 28 Jan '23 09:18
>
> Dear Sandra,
>
> I hope that you are on the mend and recovering well.
>
> Following on from our recent e-mail exchange, I attach a document in which I have tried to summarise what I am proposing to do for my PhD study (and possibly beyond!), and what that might mean for DFC.
>
> Let me know if you have any questions, or if I haven't explained anything clearly.
>
> I am aiming to either submit my ethics application on February 6th or failing that on March 6th. I don't mean to put pressure on you by sharing these dates, but just give you an indication of the timeline I am aiming for.
>
> I'd love to have your thoughts on the brief, and any builds you might have on it. The key questions I need to resolve before I submit my ethics form are whether DFC are happy to proceed. If you are, I then need to know if you are able to provide any data or whether that will need to be captured through interviews alone. Further details can always be fine-tuned later.
>
> Thank you once again for your support this far, and I really hope that we can work on this together!
>
> Warm Regards,
>

Page 1 of 2

Appendix 11 – Visuals of DFC

11.1 Website Home Page



Dental Phobia Information and Support

Are you terrified of the dentist? Dental Fear Central is the world's largest dental phobia resource. We also provide information for dental professionals who would like to better help their nervous or phobic patients. Join our online support community today!

What is dental phobia?

Does the thought of seeing a dentist fill you with a sense of dread or terror? You're not alone! Find out why people develop a fear of

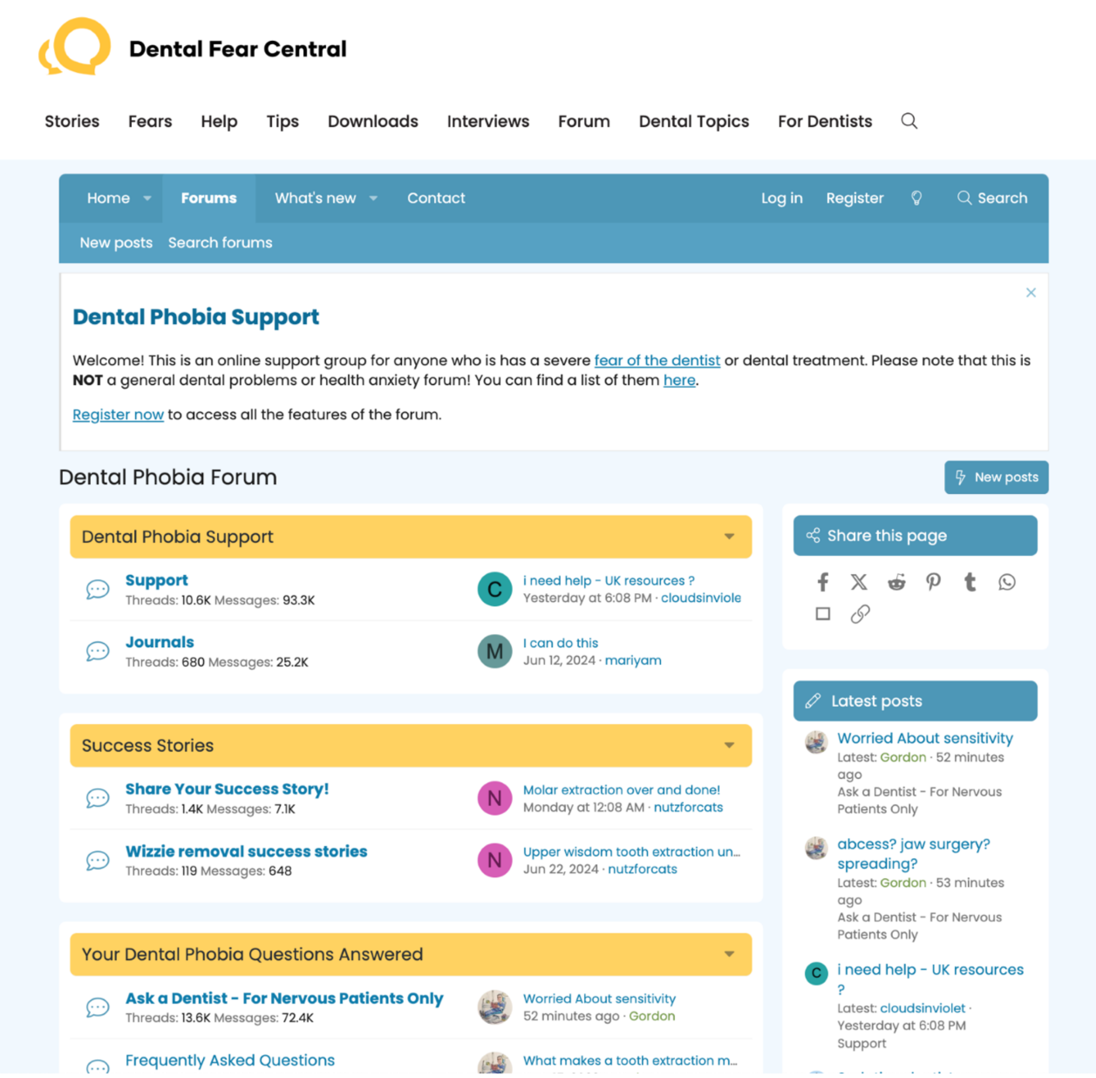
How to deal with a fear of the dentist

A step-by-step guide to tackling dental phobia, fear and anxiety.

ses cookies. By clicking "Okay", you consent to the use of all cookies.

.dentalfearcentral.org/fears/dental-phobia/

11.2 Dental Fear Central Support Forum



Dental Phobia Support

Welcome! This is an online support group for anyone who is has a severe fear of the dentist or dental treatment. Please note that this is **NOT** a general dental problems or health anxiety forum! You can find a list of them here.

Register now to access all the features of the forum.

Dental Phobia Forum

Dental Phobia Support

Support
Threads: 10.6K Messages: 93.3K
i need help - UK resources ?
Yesterday at 6:08 PM · cloudsinviole

Journals
Threads: 680 Messages: 25.2K
I can do this
Jun 12, 2024 · mariyam

Success Stories

Share Your Success Story!
Threads: 1.4K Messages: 7.1K
Molar extraction over and done!
Monday at 12:08 AM · nutzforcats

Wizzie removal success stories
Threads: 119 Messages: 648
Upper wisdom tooth extraction un...
Jun 22, 2024 · nutzforcats

Your Dental Phobia Questions Answered

Ask a Dentist - For Nervous Patients Only
Threads: 13.6K Messages: 72.4K
Worried About sensitivity
52 minutes ago · Gordon

Frequently Asked Questions
What makes a tooth extraction m...

Worried About sensitivity
Latest: Gordon · 52 minutes ago
Ask a Dentist - For Nervous Patients Only

abcess? jaw surgery? spreading?
Latest: Gordon · 53 minutes ago
Ask a Dentist - For Nervous Patients Only

i need help - UK resources ?
Latest: cloudsinviolet · Yesterday at 6:08 PM
Support

Appendix 12 – Visual guide to participants for using DFC

A three-page document that was sent to participants once they had been allocated to the OSG to help them register and navigate the site.

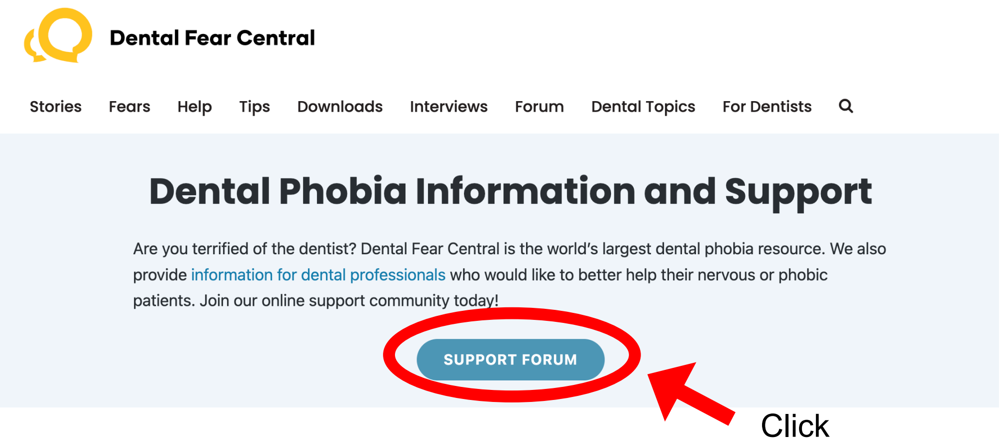
Dental Anxiety Research Project

Guidance for signing up to the online support group

Thank you again for taking part in our study!
The online support group that we would like you to use is called Dental Fear Central.
You can find it online by clicking on this link:
https://www.dentalfearcentral.org

The first thing we need you to do is register by creating a username and password. Please remember not to use your real, full name as your username. This protects your identity and helps keep you safe online.

When you click on the link, you will see this page:

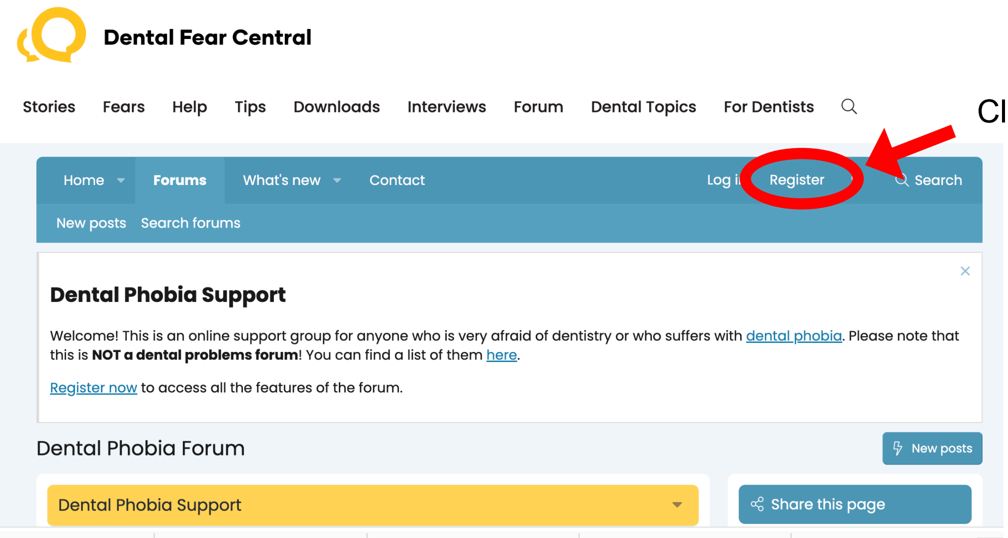


Dental Phobia Information and Support

Are you terrified of the dentist? Dental Fear Central is the world's largest dental phobia resource. We also provide information for dental professionals who would like to better help their nervous or phobic patients. Join our online support community today!

Click

Feel free to have a browse around the site, but to get to the next step, I need you to click on "Support Forum". This will take you to the following page, where you can register.



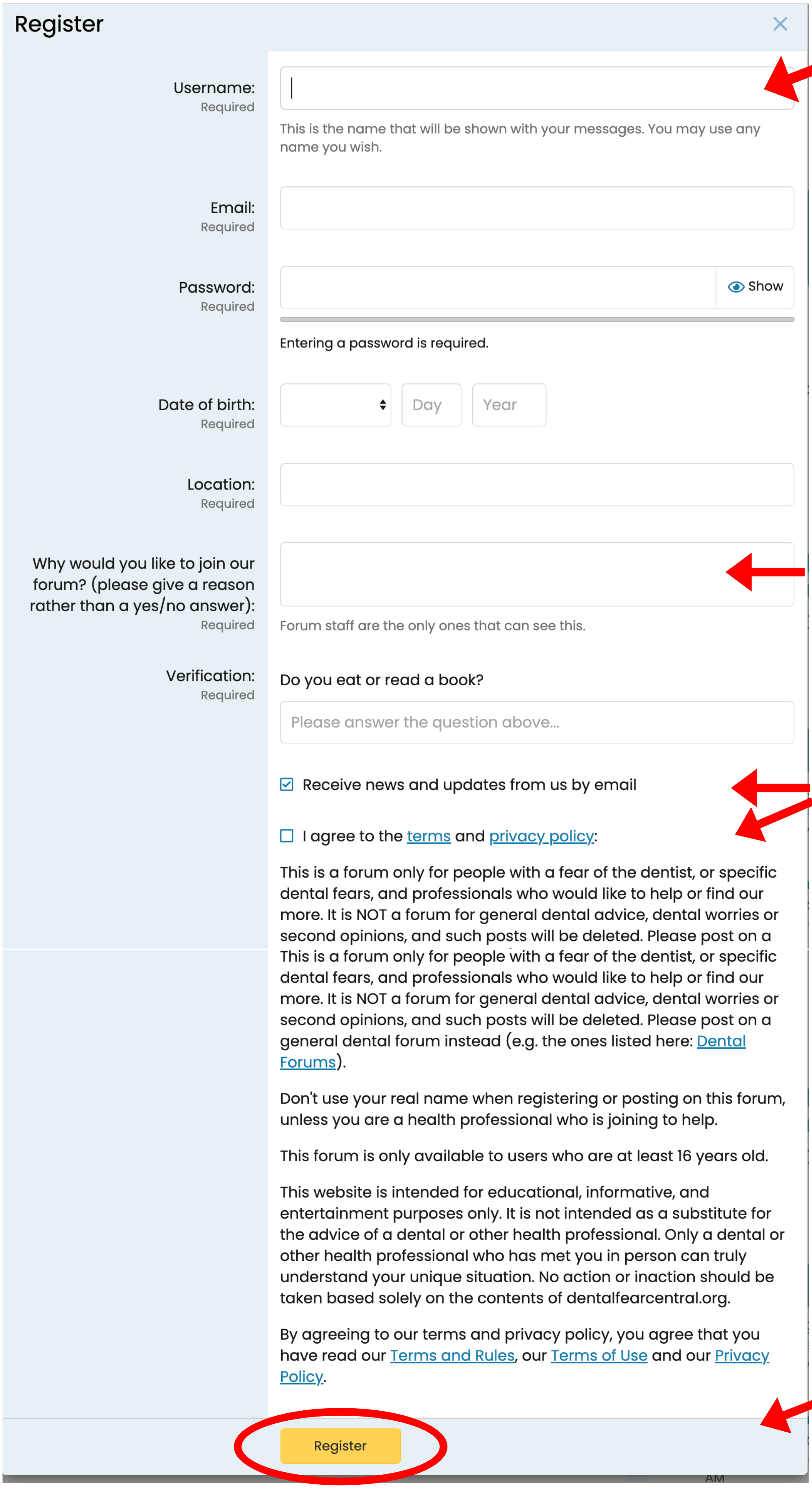
Dental Phobia Support

Welcome! This is an online support group for anyone who is very afraid of dentistry or who suffers with dental phobia. Please note that this is **NOT a dental problems forum**! You can find a list of them here.

Register now to access all the features of the forum.

Click

Registration Process



Register

Username:
Required

This is the name that will be shown with your messages. You may use any name you wish.

Email:
Required

Password:
Required

Show

Entering a password is required.

Date of birth:
Required

Day Year

Location:
Required

Why would you like to join our forum? (please give a reason rather than a yes/no answer):
Required

Forum staff are the only ones that can see this.

Verification:
Required

Do you eat or read a book?

Please answer the question above...

☑ Receive news and updates from us by email

☐ I agree to the terms and privacy policy:

This is a forum only for people with a fear of the dentist, or specific dental fears, and professionals who would like to help or find our more. It is NOT a forum for general dental advice, dental worries or second opinions, and such posts will be deleted. Please post on a This is a forum only for people with a fear of the dentist, or specific dental fears, and professionals who would like to help or find our more. It is NOT a forum for general dental advice, dental worries or second opinions, and such posts will be deleted. Please post on a general dental forum instead (e.g. the ones listed here: Dental Forums).

Don't use your real name when registering or posting on this forum, unless you are a health professional who is joining to help.

This forum is only available to users who are at least 16 years old.

This website is intended for educational, informative, and entertainment purposes only. It is not intended as a substitute for the advice of a dental or other health professional. Only a dental or other health professional who has met you in person can truly understand your unique situation. No action or inaction should be taken based solely on the contents of dentalfearcentral.org.

By agreeing to our terms and privacy policy, you agree that you have read our Terms and Rules, our Terms of Use and our Privacy Policy.

Register

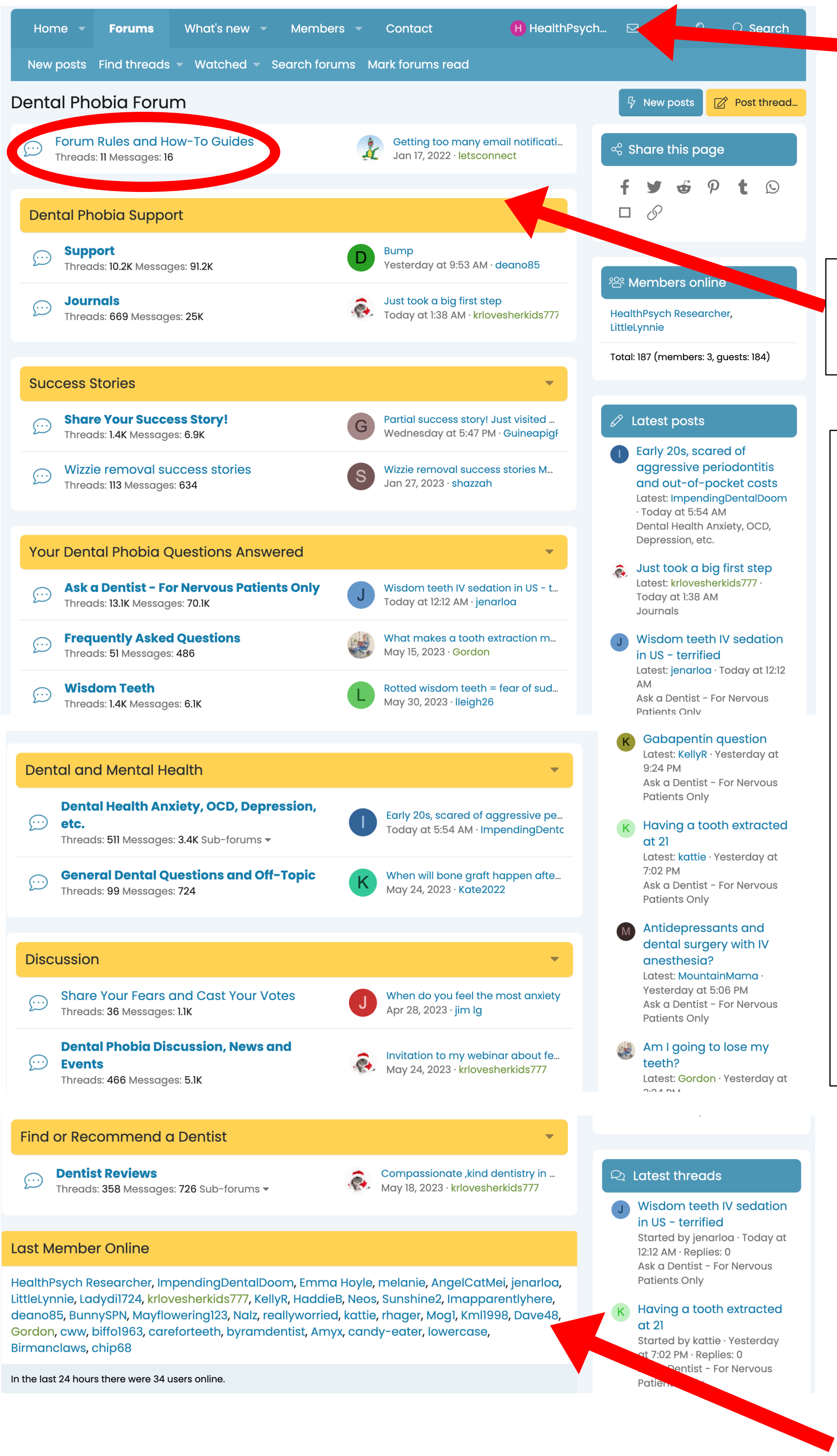
Please don't use your real name! Please e-mail your chosen username to Caitlin.sorrell@nottingham.ac.uk

If you want, you can put "Dental Anxiety Research Study", or you can give your own reasons for wanting to join.

You can untick the box about receiving e-mails, but you must tick the box to agree to the terms and privacy policy (scroll down to read it in full)

Click here to register! The administrators will then send you a verification e-mail and review your request.

Overview of the Forum



Dental Phobia Forum

Forum Rules and How-To Guides
Threads: 11 Messages: 16
Getting too many email notificati...
Jan 17, 2022 · letsconnect

Dental Phobia Support

Support
Threads: 10.2K Messages: 91.2K
Bump
Yesterday at 9:53 AM · deano85

Journals
Threads: 669 Messages: 25K
Just took a big first step
Today at 1:38 AM · krlovesherkids777

Success Stories

Share Your Success Story!
Threads: 1.4K Messages: 6.9K
Partial success story! Just visited ...
Wednesday at 5:47 PM · Guineapigf

Wizzie removal success stories
Threads: 113 Messages: 634
Wizzie removal success stories M...
Jan 27, 2023 · shazzah

Your Dental Phobia Questions Answered

Ask a Dentist - For Nervous Patients Only
Threads: 13.1K Messages: 70.1K
Wisdom teeth IV sedation in US - t...
Today at 12:12 AM · jenarloa

Frequently Asked Questions
Threads: 51 Messages: 486
What makes a tooth extraction m...
May 15, 2023 · Gordon

Wisdom Teeth
Threads: 1.4K Messages: 6.1K
Rotted wisdom teeth = fear of sud...
May 30, 2023 · lleigh26

Dental and Mental Health

Dental Health Anxiety, OCD, Depression, etc.
Threads: 511 Messages: 3.4K Sub-forums
Early 20s, scared of aggressive pe...
Today at 5:54 AM · ImpendingDentc

General Dental Questions and Off-Topic
Threads: 99 Messages: 724
When will bone graft happen afte...
May 24, 2023 · Kate2022

Discussion

Share Your Fears and Cast Your Votes
Threads: 36 Messages: 1.1K
When do you feel the most anxiety
Apr 28, 2023 · jim lg

Dental Phobia Discussion, News and Events
Threads: 466 Messages: 5.1K
Invitation to my webinar about fe...
May 24, 2023 · krlovesherkids777

Find or Recommend a Dentist

Dentist Reviews
Threads: 358 Messages: 726 Sub-forums
Compassionate ,kind dentistry in ...
May 18, 2023 · krlovesherkids777

Last Member Online

HealthPsych Researcher, ImpendingDentalDoom, Emma Hoyle, melanie, AngelCatMei, jenarloa, LittleLynnie, Ladydi1724, krlovesherkids777, KellyR, HaddieB, Neos, Sunshine2, Imapparentlyhere, deano85, BunnySPN, Mayflowering123, Nalz, reallyworried, kattie, rhager, Mog1, Kml1998, Dave48, Gordon, cww, biffo1963, careforteeth, byramdentist, Amyx, candy-eater, lowercase, Birmanclaws, chip68

In the last 24 hours there were 34 users online.

Members online

HealthPsych Researcher, LittleLynnie

Total: 187 (members: 3, guests: 184)

Latest posts

Early 20s, scared of aggressive periodontitis and out-of-pocket costs
Latest: ImpendingDentalDoom · Today at 5:54 AM
Dental Health Anxiety, OCD, Depression, etc.

Just took a big first step
Latest: krlovesherkids777 · Today at 1:38 AM
Journals

Wisdom teeth IV sedation in US - terrified
Latest: jenarloa · Today at 12:12 AM
Ask a Dentist - For Nervous Patients Only

Gabapentin question
Latest: KellyR · Yesterday at 9:24 PM
Ask a Dentist - For Nervous Patients Only

Having a tooth extracted at 21
Latest: kattie · Yesterday at 7:02 PM
Ask a Dentist - For Nervous Patients Only

Antidepressants and dental surgery with IV anesthesia?
Latest: MountainMama · Yesterday at 5:06 PM
Ask a Dentist - For Nervous Patients Only

Am I going to lose my teeth?
Latest: Gordon · Yesterday at

Latest threads

Wisdom teeth IV sedation in US - terrified
Started by jenarloa · Today at 12:12 AM · Replies: 0
Ask a Dentist - For Nervous Patients Only

Having a tooth extracted at 21
Started by kattie · Yesterday at 7:02 PM · Replies: 0
Ask a Dentist - For Nervous

This tells you that you are logged in and can post if you want. I'm logged in as "HealthPsych Researcher"

Please read the Forum Rules and How-to Guides

This is what the forum looks like, with all its different threads and discussion topics.

Have a browse! Remember, it's up to you how you use this forum.
You can just read posts, you can respond to others, or you can post your own thread.

You can pop back here when you want. There is no minimum amount of time I need you to spend here. It's up to you.

Once again, please remember not to use your real full name as a username!

Please send me your username via e-mail. This is where I will making a note of who logged in on any given day.

So please go ahead and register then let me know what your username is once you have registered. If you have any questions, just drop me an e-mail at caitlin.sorrell@nottingham.ac.uk
I will get back in touch in about six weeks to arrange an interview on Microsoft Teams.

Appendix 13 – MDAS (Full questionnaire)

1. **If you went to your Dentist for TREATMENT TOMORROW, how would you feel?**

Not *Slightly* *Fairly* *Very* *Extremely*
Anxious ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵

2. **If you were sitting in the WAITING ROOM (waiting for treatment), how would you feel?**

Not *Slightly* *Fairly* *Very* *Extremely*
Anxious ☐🕵 *Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵

3. **If you were about to have a TOOTH DRILLED, how would you feel?**

Not *Slightly* *Fairly* *Very* *Extremely*
Anxious ☐🕵 *Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵

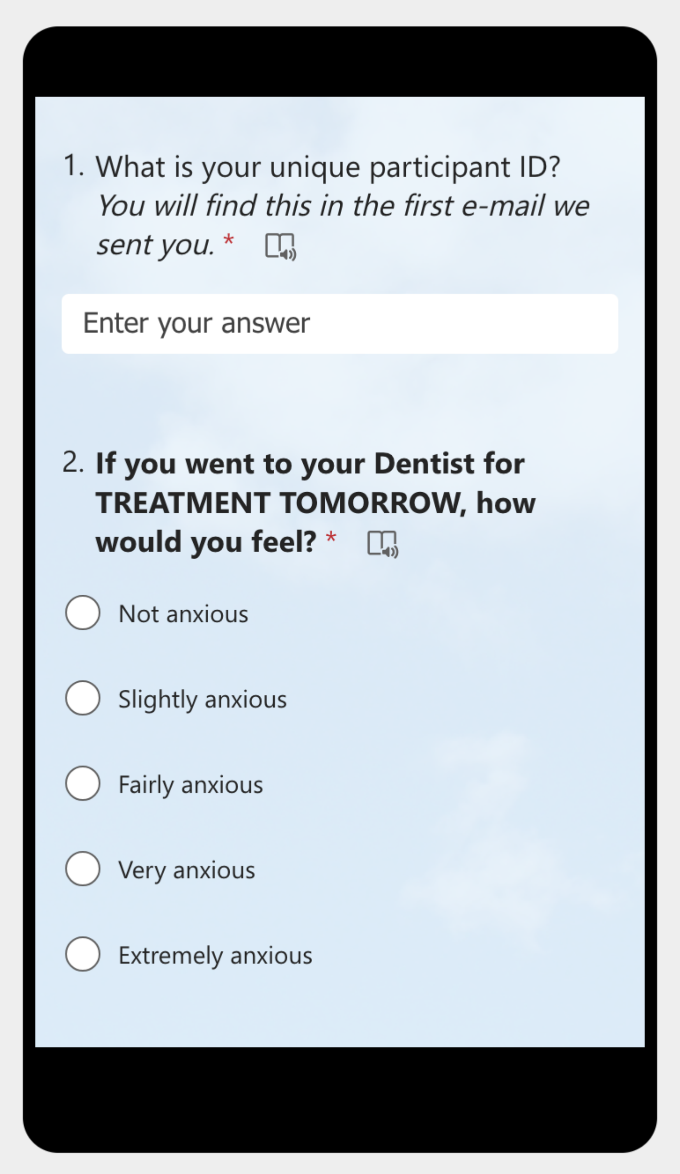
4. **If you were about to have your TEETH SCALED AND POLISHED, how would you feel?**

Not *Slightly* *Fairly* *Very* *Extremely*
Anxious ☐🕵 *Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵

5. **If you were about to have a LOCAL ANAESTHETIC INJECTION in your gum, above an upper back tooth, how would you feel?**

Not *Slightly* *Fairly* *Very* *Extremely*
Anxious ☐🕵 *Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵*Anxious* ☐🕵

Appendix 14 – MDAS and Dental Contemplation Ladder as they appeared on screen



1. What is your unique participant ID? *You will find this in the first e-mail we sent you.* *

Enter your answer

2. **If you went to your Dentist for TREATMENT TOMORROW, how would you feel?** *

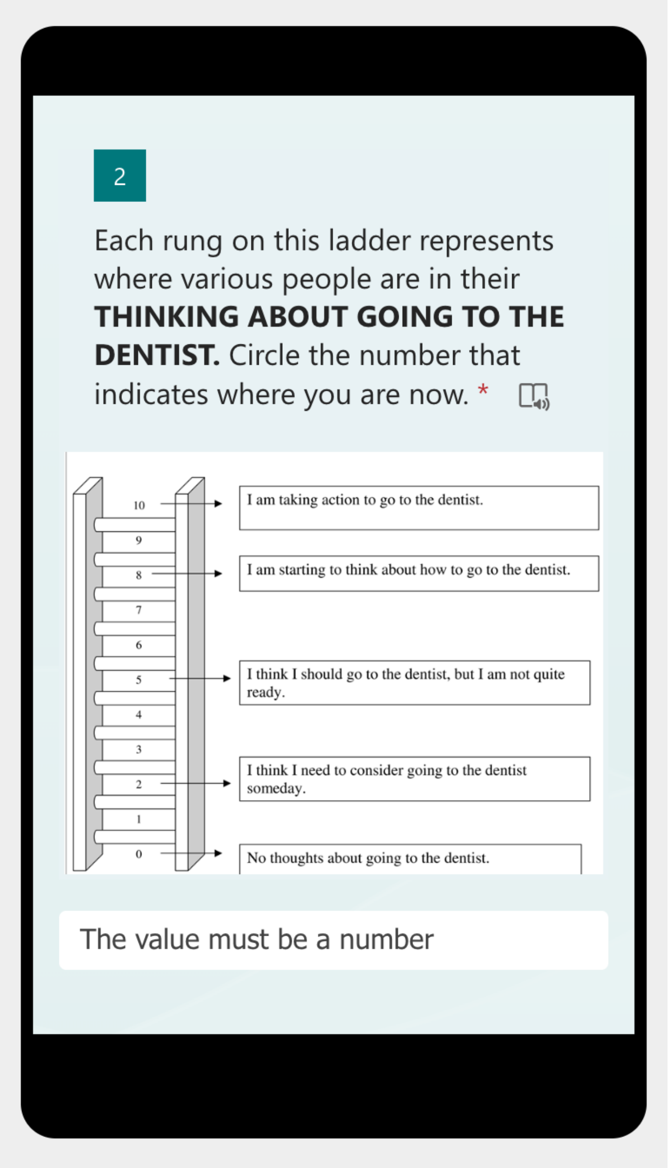
○ Not anxious

○ Slightly anxious

○ Fairly anxious

○ Very anxious

○ Extremely anxious



2

Each rung on this ladder represents where various people are in their **THINKING ABOUT GOING TO THE DENTIST.** Circle the number that indicates where you are now. *

I am taking action to go to the dentist.

I am starting to think about how to go to the dentist.

I think I should go to the dentist, but I am not quite ready.

I think I need to consider going to the dentist someday.

No thoughts about going to the dentist.

The value must be a number

Appendix 15 – Interview Discussion Guide

Recruitment and allocation process	
Initial Question	**Follow-ups**
• Where did you see the study advertised and what prompted you to sign-up?	
• Was using an OSG for DA something you had considered before the study?	• If not, why not?
• How did you find the sign-up process?	• How did you feel about having a call before signing up? Was it clear what was involved?
• How did you find the questionnaires?	• How easy were they to complete? Did they make sense to you?
• How did you feel about being allocated to the OSG?	
Using the online support group	
Initial Question	**Follow-ups**
• After I sent you the information about Dental Fear Central and you logged on, what did you do next?	• Can you tell me a bit more about how you used it? • How often did you use it & when? • Did your usage change over time?
• How did you decide which posts to read or where to go first?	• Did you just read other people's posts or did you make posts of your own?
• If you replied or made a post of your own, what prompted you to do that?	• Did you talk about yourself or your own experiences? • If you thought about telling your story, but didn't, what stopped you?
• What prompted you to visit the forum? • What stopped you visiting the forum?	
• Did the reminder make a difference?	• Would you want more reminders / fewer reminders?
• Did you find it easy or difficult to use the support group?	• Did it help having control over how you used it, or would you have preferred to be given guidance?
• Was there anything that made it easy / difficult to use the OSG?	

Reflecting on the experience as a whole	
Initial Question	**Follow-ups**
• Did you find any aspects of the OSG beneficial? • Were there any aspects of using the OSG that weren’t so positive? • Do you think the OSG made you feel differently? • Do you think it made you think differently? • Do you think it made you act differently?	• Which and why? • Which and why? • How did you deal with that?
• How do you feel about the six-week period? • Do you think you will continue to use the OSG? • Is the OSG something that you would recommend to other people who are fearful of the dentist?	• Do you think it should have been longer or shorter? • Are there particular times when you think you might use it in future?

Appendix 16 – Data from Questionnaires

16.1 MDAS Data

	Participant ID	MDAS Pre	MDAS Post
OSG	33	16	12
OSG	131	17	13
OSG	116	15	15
OSG	59	20	15
OSG	23	21	16
OSG	62	24	16
OSG	88	22	17
OSG	78	20	18
OSG	1	21	18
OSG	17	21	18
OSG	119	23	18
OSG	36	24	18
OSG	101	19	19
OSG	64	21	19
OSG	20	23	20
OSG	37	20	21
OSG	11	23	22
OSG	4	25	25
	MEAN	**20.8**	**17.8**

	Participant ID	MDAS Pre	MDAS Post
WLC	44	14	13
WLC	7	19	15
WLC	18	21	17
WLC	60	20	18
WLC	130	22	18
WLC	6	19	19
WLC	80	22	19
WLC	96	20	20
WLC	10	22	20
WLC	118	22	20
WLC	50	25	20
WLC	89	20	21
WLC	73	23	21
WLC	63	23	22
WLC	68	25	22
WLC	5	22	23
WLC	49	22	23
WLC	61	24	24
WLC	**14**	25	25
	MEAN	**21.6**	**20.0**

16.2 Dentist Contemplation Ladder Data

	Participant ID	Ladder Pre	Ladder Post
OSG	1	8	8
OSG	4	1	10
OSG	11	4	8
OSG	17	8	10
OSG	20	4	10
OSG	23	4	8
OSG	33	8	9
OSG	36	7	0
OSG	37	5	7
OSG	59	10	10
OSG	62	4	8
OSG	64	2	5
OSG	78	5	2
OSG	88	2	6
OSG	101	10	9
OSG	116	10	10
OSG	119	5	2
OSG	131	8.0	2.0
	MEAN	**5.8**	**6.9**

	Participant ID	Ladder Pre	Ladder Post
WLC	5	10	7
WLC	6	6	6
WLC	7	1	6
WLC	10	2	8
WLC	14	2	3
WLC	18	2	5
WLC	44	10	10
WLC	49	7	9
WLC	50	5	2
WLC	60	10	9
WLC	61	3	4
WLC	63	10	9
WLC	68	0	2
WLC	73	5	5
WLC	80	10	10
WLC	89	4	5
WLC	96	8	8
WLC	118	10	10
WLC	130	10	10
	MEAN	**6.1**	**6.7**

Appendix 17 – Effect size calculations in SPSS

17.1 Independent t-test and effect size calculation for MDAS

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Diff MDAS	Equal variances assumed	.817	.372	2.064	35	.023	.046	1.47661	.71541	.02426	2.92896
	Equal variances not assumed			2.050	32.106	.024	.049	1.47661	.72032	.00955	2.94367

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Diff MDAS	Cohen's d	2.17503	.679	.010	1.338
	Hedges' correction	2.22306	.664	.010	1.309
	Glass's delta	2.43678	.606	-.078	1.274

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control (i.e., the second) group.

17.2 Independent t-test and effect size calculation for Dental Contemplation Ladder

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Diff Ladder	Equal variances assumed	5.282	.028	-.345	35	.366	.732	-.37135	1.07671	-2.55718	1.81449
	Equal variances not assumed			-.340	26.242	.368	.737	-.37135	1.09269	-2.61639	1.87370

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Diff Ladder	Cohen's d	3.27349	-.113	-.758	.533
	Hedges' correction	3.34578	-.111	-.741	.521
	Glass's delta	4.07968	-.091	-.735	.556

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control (i.e., the second) group.