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# **Doctoral Thesis:**

# **Diagnosis and therapeutic relationships: the perspectives of service users with a Borderline Personality Disorder diagnosis**

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# Word Count

| Section | Words | Appendices (including abstracts, tables, figures and references) | Total |
|---|---|---|---|
| Thesis abstract | 265 | - | 265 |
| Systematic Literature Review | 7,998 | 9,241 | 17,239 |
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| Ethics | 2,613 | 7,591 | 10,204 |
| **Total** | **22,769** | **25,385** | **48,154** |

# Thesis Abstract

This thesis begins with a literature review exploring how individuals who have a diagnosis of Borderline Personality Disorder (BPD) experience the therapeutic relationship during psychological therapy. A systematic literature search identified 15 papers which were synthesised using a meta-ethnographic approach. Three third order themes emerged; *valuing a therapeutic relationship*, *building a connection (based on trust)*, and *coming together to navigate the therapeutic relationship.* These findings highlight the importance of the therapeutic relationship across psychological therapies for people with a BPD diagnosis and that positive therapeutic relationships are needed for successful therapy. Clinical implications are discussed.

The research paper explores service-user perceptions of how receiving a diagnosis of BPD affects wellbeing. Nine participants were interviewed, and data were analysed using a constructivist grounded theory method. A model was developed which highlighted two key processes that influenced participants' wellbeing. Firstly, the way in which the diagnosis was communicated, as this laid foundations for participants' perceptions of the diagnosis. Secondly, participants' experiences of the perceived advantages and disadvantages of living with the diagnosis, which included the responses of services, the influence on participants' social relationships and impact of stigma. The findings are discussed in relation to the existing literature surrounding mental health diagnosis and contributes by highlighting the specific processes and mechanisms which occur for people who receive a diagnosis of BPD. From the developed model clinical implications and areas of future research are proposed.

The critical appraisal focuses on the findings of the empirical paper and processes of carrying out a grounded theory investigation. Issues around conducting research during the Covid-19 pandemic are also considered.

# Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at the Division of Health Research at Lancaster University from December 2019 to March 2021. The work presented here is the author's own, expect where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Sophie Green

Signature:

Date: March 2021

# Acknowledgements

I would firstly like to thank all the people who took part in this research, for giving your time and sharing your experiences and reflections with me. I was humbled and inspired by the journey each of you had been on.

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To my family and friends, particularly my Mum, Dad and Charlotte, despite becoming more distant from you during this process, I have felt your love and support more than ever. I am so incredibly lucky to have you all and I would not be where I am today without your unwavering belief in me.

To Ben, you gave me reassurance, brewed endless cups of tea and provided me with laughter and perspective. Thank you for keeping me grounded when things felt completely overwhelming.

# Contents

# Section One: Systematic Literature Review

## What are the experiences of the therapeutic relationship for people with a diagnosis of Borderline Personality Disorder?

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Prepared for - Psychology and Psychotherapy: Theory, Research and Practice (see Appendix 1-B)

# Abstract

*Purpose:* People with a diagnosis of Borderline Personality Disorder (BPD) experience difficulties which impact upon relationships and can require significant support from mental health services. Due to the nature of the difficulties experienced and associated stigma, clinicians often report difficulties when working with these individuals. However, the therapeutic alliance has been identified as a key factor in successful therapy. The aim of this study is to create an understanding of how people with a diagnosis of BPD experience the therapeutic relationship during psychological therapy.

*Methods:* A systematic search of PsycInfo, CINAHL, AMED, Medline and Web of Science databases was completed. This resulted in 15 qualitative studies being identified for inclusion. Studies were synthesised using a meta-ethnographic approach.

*Results:* Three new themes emerged from the analysis; *valuing a therapeutic relationship, building a connection (based on trust)*, and *coming together to navigate the therapeutic relationship.*

*Conclusions:* Positive therapeutic relationships were highly valued by participants and seen as necessary for successful therapy, of the upmost importance for participants was the development of trust. However, these features were not always present and for many their absence impacted negatively on the quality of the therapeutic relationship. Clinical implications and areas for future research are discussed.

*Keywords: Borderline Personality Disorder, Therapeutic Alliance, Working Relationship, Psychotherapy.*

Borderline Personality Disorder (BPD) is a diagnostic category found in the Diagnostic and Statistical Manual for Mental Disorders (DSM). The DSM 5th edition defines BPD as “a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, beginning by early adulthood and present in a variety of contexts”; this is considered against nine specific criteria relating to difficulties within relationships, self-identity and difficulties in regulating emotions (American Psychiatric Association, 2013, p. 663).

## The medical model and BPD diagnosis

The classification and diagnosis of mental health difficulties is based on a Westernised medical model of illness. This proposes that there are ways to scientifically observe, describe and differentiate symptoms of illness in order to identify causal factors and administer specific treatments to cure a person’s illness (Shah & Mountain, 2007). This medical model underpins the diagnostic manuals for mental health, and has been criticised for promoting a reductionist narrative which overlooks the wider context and experience of individuals (Gambrill, 2014; Sedler, 2016). This approach also assumes there are distinctions between ‘normal’ and ‘abnormal’ which can be objectively categorised; however this can vary over time, between cultures, and the social norms of society (Jacob et al., 2014).

BPD is one particularly contentious diagnostic category. Criticism includes the grouping and definition of ‘symptoms’ of a BPD diagnosis which pathologises distress and ways of coping which are seen as less socially acceptable by that society (Choudhary & Gupta, 2020; Shaw & Proctor, 2005). The diagnosis is also inherently gendered, as approximately 75% of those diagnosed are women (Sansone & Sansone, 2011). It has been argued that the diagnostic construct of BPD pathologises and individualises women’s distress by labelling it a ‘disorder’ (Bjorklund, 2006; Shaw & Proctor, 2005). Furthermore critics have argued that BPD is strongly linked to childhood trauma and that a diagnosis of complex post-traumatic stress disorder would be a more accurate and less stigmatising way of understanding people's difficulties (Ball & Links, 2009; Ford & Courtois, 2014; Lewis & Grenyer, 2009). These criticisms do not take away from the distress which is experienced by people who have been diagnosed with BPD, but instead question the validity of diagnosing this distress as a 'personality disorder'.

## Difficulties associated with a BPD diagnosis

The difficulties associated with having a diagnosis of BPD are significant and life threatening. It is estimated that 60-70% of people with a diagnosis of BPD have attempted to take their own life, with approximately 10% of people with this diagnosis completing suicide (Black et al., 2004; Oldham, 2006). Difficulties also extend to other areas of life, including physical health and disability, with high co-occurrence of mood and anxiety related difficulties (Grant et al., 2008; Leichsenring et al., 2011).

From the service-user perspective, living with a diagnosis of BPD has been associated with struggling with the 'symptoms' of the diagnosis, including feelings of chronic emptiness and constantly struggling with emotional pain, which is difficult to control and understand (Ntshingila et al., 2016; Perseius et al., 2005). To manage these difficulties some people with a diagnosis of BPD report engaging in self-harm as a way to relieve distress and regulate emotional pain (Kleindienst et al., 2008; Nehls, 1999). Service-users also report that the diagnosis of BPD in itself is not helpful, as it brings judgements rather than useful treatments (Nehls, 1999).

## Working therapeutically with people with a BPD diagnosis

People with a BPD diagnosis are often frequent users of mental health services (Comtois et al., 2016), with medication and psychiatric hospital admissions being more common in this group of people compared to people with other personality disorder diagnoses (Bender et al., 2006; Hörz et al., 2010). Yet despite the significant contact people with a BPD diagnosis have with the health system, working therapeutically with people with this diagnosis can be experienced as challenging for staff (Dickens et al., 2016). This may be due to the nature of the difficulties associated with a BPD diagnosis being centred around interpersonal relationships, emotional regulation and self-harm and suicidal behaviours.

The majority of research from staff perspectives has focused on psychiatric nurses' views on working with people with a BPD diagnosis. Findings suggest people with this diagnosis are viewed as 'difficult to treat' (Cleary et al., 2002; James & Cowman, 2007) and that staff feel unable to help (Woollaston & Hixenbaugh, 2008). This sense of difficulty and subsequent helplessness may be one of the reasons why people with a BPD diagnosis are more likely to be viewed negatively, as staff are left feeling frustrated and angry following interactions (Nehls, 1994). These views have also been shown to be held by allied health professionals, including psychologists, social workers, occupational therapists and psychiatrists (Treloar, 2009). However, a 15-year comparison has shown that mental health staff held more positive attitudes towards people with a BPD diagnosis in 2015 than they did in 2000, demonstrating a more explanatory understanding of self-harming behaviours and the influence of early life trauma (Day et al., 2018). Furthermore, research has also shown that staff report a desire for more funding, education, training and specialist services for people with a BPD diagnosis (Bodner et al., 2011; Stroud & Parsons, 2013). This suggests that negative attitudes may be improving, and demonstrates an understanding that improving knowledge and skills to work with individuals with a BPD diagnosis is likely to be beneficial to both staff and service-users.

Research has also focused on the personal experiences of people with a BPD diagnosis and the care they receive from services. Negative experiences for people accessing accident and emergency departments is common and individuals report being made to feel undeserving of inpatient care (Fallon, 2003; Rogers & Dunne, 2011). The care offered to people with a BPD diagnosis is also affected by stigma associated with the label; services are more likely to view people with a BPD diagnosis as ‘difficult’ rather than being in distress or unwell (Morris et al., 2014) and mental health services treat people with this diagnosis differently to other service-users (Vandyk et al., 2019). On the other hand, research has reported that positive experiences of inpatient care were centred around communication and support from nursing staff during hospital admissions (Helleman et al., 2014). Similar to professionals, people with a BPD diagnosis have also noted some improvements in their care over time, however this was related to improved communication and being more involved in their own care planning rather than changing attitudes from professionals (Fallon, 2003).

## Interventions for people with a diagnosis of BPD

National Institute for Health and Care Excellence (NICE) guidelines suggest that community mental health teams should be responsible for the ‘routine assessment, treatment and management’ of people with a BPD diagnosis and emphasise psychological therapy over pharmacological interventions (National Institute for Health Care Excellence, 2009). Comprehensive reviews have looked at the range of psychological therapy available for the difficulties associated with a BPD diagnosis, with Dialectical Behavioural Therapy (DBT) the most extensively researched, demonstrating “reductions in inappropriate anger, a reduction in self-harm and an improvement in general functioning” (Stoffers-Winterling et al., 2012, p. 2). Other psychological therapies which have been researched include Schema Therapy (Sempértegui et al., 2013), Transference-Focused Therapy (TFT) (Giesen-Bloo et al., 2006), Mentalisation-Based Therapy (MBT) (Vogt & Norman, 2019) Structured Clinical Management (SCM) (Bateman & Fonagy, 2009) and democratic therapeutic communities (Pearce et al., 2017). These kind of specialised psychological therapies have shown medium effects on overall severity of the difficulties associated with a BPD diagnosis when compared to treatment as usual (Oud et al., 2018).

### Therapeutic alliance

Common factors refer to the variables or aspects of therapy which are common across most therapies or modes of treatment. It has been estimated that common factors account for more clinical improvement (30%) than specific therapy techniques (15%) (Lambert & Barley, 2001). The therapeutic alliance is a technical term, defined as “the collaborative and affective bond between therapist and patient” (Martin et al., 2000, p. 438), and is the most heavily researched common factor in psychotherapy, often cited as the most important factor for outcomes (Barber et al., 2010; Clarkson, 2003). Factors associated with the therapist which are deemed important include the therapist’s interpersonal style, relational skills and experience in working with the particular difficulties (Nissen-Lie et al., 2010). For the client, important factors in establishing a positive therapeutic alliance include motivation, being pro-treatment, and demonstrating capacity to address their difficulties (Holdsworth et al., 2014).

As the difficulties experienced by people with a BPD diagnosis are often centred around interpersonal relationships and intense emotional states (Giffin, 2008), this may influence the development and maintenance of the therapeutic alliance, which has been documented as an important factor when working with people with personality related difficulties (Lingiardi et al., 2005). It may be that due to the nature of the difficulties experienced by people with a BPD diagnosis, compounded by unhelpful narratives from staff and stigma associated with the diagnosis, the development of a positive and helpful treatment relationship may be affected (Richardson-Vejlgaard et al., 2013). Furthermore a review of specialised psychological therapies for people with a BPD diagnosis highlighted the importance of the treatment relationship across all psychological therapies reviewed

(Weinberg et al., 2011). To date, research has focused on gathering quantitative data about the predictors of the therapeutic alliance and its implications for people with a diagnosis of BPD (Barnicot et al., 2012; Richardson-Vejlgaard et al., 2013) and more generally how people with a BPD diagnosis experience interactions with mental health services (Fallon, 2003; Rogers & Dunne, 2011). However, what is less clear from this literature is how people with a diagnosis of BPD experience the therapeutic alliance.

## Aim of the Review

This review aimed to understand how people with a diagnosis of BPD experienced the therapeutic relationship during psychological therapy, by undertaking a systematic review and meta-synthesis of published qualitative research.

It was important to consider that the therapeutic alliance is a technical term often found in research literature and unlikely that this term or definition described above would be routinely used by service users when describing their relationships with clinicians. Therefore, the therapeutic alliance was conceptualised in a broader sense as the therapeutic relationship that exists between service-user and mental health professional.

This review included the many types of psychological therapy offered by mental health services, due to the nature of the therapeutic alliance being recognised as a common factor across intervention modalities. This included psychological therapies such as DBT, MBT and Schema Therapy, which combine both individual and group therapy.

Data were extracted from papers which referred to the participants’ therapeutic relationship with the relevant individual professional, therefore, in the case of group therapy only the relationship described between service-user and professional was considered.

# Method

## Design

A meta-synthesis was conducted as this enables researchers to develop an "overarching interpretation emerging from the joint interpretation of the primary studies included in the synthesis" (Lachal et al., 2017, p. 2). This was conducted in line with seven phases of meta-ethnographic research as proposed by Noblit and Hare (1988) enabling the results to be "something more than the parts alone imply" (p. 28).

## Study Selection

The following inclusion criteria were applied to papers returned by the systematic search:

1) primarily focused on the experiences of people with a BPD diagnosis when receiving psychological therapy; that being an intervention grounded in psychological theory aiming to produce change.

2) use qualitative empirical methods;

3) results have partial or full reference to the therapeutic relationship; that being the relational, affective or working connection between service-user and professional arising from being together in therapy.

4) participants aged 16+;

5) studies were published in peer-reviewed journals, as these are considered these are of a higher quality;

6) English language.

The following exclusion criteria were applied:

1) papers which integrate experiences of people with a diagnosis of BPD with other individuals (e.g people with other mental health diagnoses or professionals);

2) research conducted with people with intellectual disabilities or forensic populations as therapies are likely to have adaptations specific for the population.

## Search Strategy

The SPIDER tool (Cooke et al., 2012) was used to develop a search strategy which included both index terms and free text searches (Table 1). A systematic search of PsycInfo, CINAHL, AMED, Medline and Web of Science databases was completed in November 2020. An exhaustive search strategy of titles and abstracts, combining free text search and indexed terms, was conducted.

The search returned a total of 1550 papers; 698 after duplicates were removed. Titles and abstracts were screened against the inclusion and exclusion criteria. This resulted in 648 papers being removed. 50 papers were read in full, with 15 meeting the inclusion criteria (reasons for exclusion and flow of paper selection in Figure 1). These papers consisted of; five DBT studies, four studies in which participants had accessed a range of therapies, three MBT studies, one group psychotherapy study, one individual psychotherapy study and one Schema Therapy study. (Characteristics of included papers in Table 2).

## Quality Appraisal

The Critical Appraisal Skills Programme (2018) checklist was used to determine the strengths and limitations of each paper. This 10-item tool is used to evaluate the credibility of qualitative studies, with the first two items acting as screening questions and a further eight questions evaluating the overall quality of the research. These eight questions were scored using the rating scale developed by Duggleby et al. (2010) with a maximum total score of 24. Scores for the papers were generally high, with only two papers scoring below 16. However, the critical appraisal was not used to exclude papers, but as a way to quality-check the synthesis to consider the contributions of each paper to this current synthesis. (Scores for each paper in Table 3).

## Data Synthesis

Data were synthesised using the seven stages of conducting a meta-ethnography (Appendix 1-A), as described by Noblit and Hare (1988). The first two phases of *'getting started'* and *'deciding what is relevant'* are covered in earlier sections of this paper. The third phase of *'reading the studies'* involved the researcher re-reading the 15 identified papers to become familiar with the data and extract key concepts and themes which referenced the therapeutic relationship. Tables were constructed with first order interpretations i.e. participant quotes, and second order interpretations i.e. the interpretations of the study's author (Table 4). For the fourth phase of *'determining how the studies are related'*, Noblit and Hare (1988) describe three ways in which papers can be related to one another; reciprocal translation, refutational synthesis and line of argument synthesis. The data gathered from the papers were reviewed, with similar concepts and themes appearing in relation to the therapeutic relationship. Therefore, a reciprocal translation was used to synthesise data in this study. In the fifth phase *'translating the studies into one another'* the identified key concepts and themes were mapped onto each other, identifying similar themes between papers, maintaining the second order interpretations at this stage. The sixth phase of *'synthesising translations'* allowed for second order interpretations to be refined and developed into third order interpretations i.e. the interpretations of the meta-synthesis author, these new interpretations and the original papers which contributed to them are displayed in Table 5. This created the overarching set of key concepts and themes, presented below according to phase seven *'expressing the synthesis'*.

# Results

Through the process of reciprocal translation and synthesis, three themes were developed; valuing a therapeutic relationship, building a connection (based on trust), and coming together to navigate the therapeutic relationship.

## Valuing a therapeutic relationship

This theme focuses on the importance participants placed on having a positive relationship with their therapist and is something which they actively sought in therapy. However, this appeared to vary, with participants valuing the relationship with the individual therapist over and above the relationship with the group therapist. Despite this, participants perceived there to be negative consequences when there was not a positive therapeutic relationship in place.

Participants reported valuing elements of the therapeutic alliance which have been noted in the literature, highlighting the importance of a relationship which was collaborative (Hodgetts et al., 2007), and where participant and their therapist were felt to be working together toward the same goal (Cunningham et al., 2004). One study described participants needing to actively ‘find’ the right therapist for them (Carrotte et al., 2019), suggesting that the therapeutic relationship is something which is not always present and has to be sought out. For some participants, psychological therapy was their first experience of a positive therapeutic relationship with a professional in health care services (Katsakou et al., 2019; Perseius et al., 2003).

In some DBT and MBT studies, which incorporated individual and group therapy elements, having a positive relationship with an individual therapist tended to be “prized very highly” by participants, over and above the group elements of the therapy (Lakeman & Emeleus, 2020). The positive effects of the individual therapy relationship was seen, by participants, as a key element in successful therapy (Cunningham et al., 2004; Gardner et al., 2020). In other studies of MBT approaches, participants' accounts reflect individual therapists being idealised whereas group therapists were denigrated (Dyson & Brown, 2016), participants seemed to not want to criticise their individual MBT therapist (Gardner et al., 2020). Similarly in another MBT study, participants also reported to find it easier to establish a therapeutic relationship with a therapist in individual therapy compared to in group therapy, and for those participants who had their individual therapist present in group sessions, their therapist was perceived to be an 'ally' (Lonargain et al., 2017). However, Tan et al. (2018) found the majority of participants spoke highly of their relationship with both their individual and group therapists when accessing Schema Therapy, with one participant reporting "the relationship between therapist and patient in my opinion is the most important thing for the whole thing [schema therapy] to work" (p. 12). It seems that where participants experienced both individual and group therapy, they were able to compare the experiences of the therapeutic relationship in both settings, with the therapeutic relationship being experienced as particularly important and highly valued when engaging in individual therapy.

Participants spoke of the difficulties when a positive relationship with the therapist was not in place and experienced this to have negative consequences as recovery was impeded. One participant in an MBT study reported; "It was very me therapist, you patient. Like as I said there was no you...there wasn't any relationship to stand on" (Dyson & Brown, 2016, p. 592), with this perpetuating a feeling of 'wrongness' in participants. Participants felt the lack of a positive therapeutic relationship impacted negatively on their recovery, as it was felt to be discouraging of the progress that could be made with that therapist (Katsakou et al., 2019).

**Building a connection (based on trust)**

Positive therapeutic relationships were established from a trusting base, which was developed over time through certain acts demonstrated by the therapist, such as listening and showing their human side. This enabled participants to feel genuinely cared for by their therapist and allowed a deep emotional connection to be forged, which in turn allowed hope for the future to be developed.

A connection to a therapist needed to be built on a foundation of trust, and can be thought of as an essential factor in developing a connection, which then allowed successful therapy to take place (Duarte et al., 2019; Gardner et al., 2020). Feelings of trust within the therapeutic relationship were described as the foundation or core (Langley & Klopper, 2005; Romeu-Labayen et al., 2020). This implies that trust was something which needed to be felt by participants before they could experience a "realisation of the benefits of openness and honesty during therapy" (Lonargain et al., 2017, p. 20). This is explained by one participant; "I've got a sense of a relationship with someone who I can trust... [when you] start off it's a little bit nerve-wracking...you can't really trust them" (Lakeman & Emeleus, 2020, p. 6). This suggests that participants need to feel trust in the therapist but also in the process of therapy. Participants also acknowledged that trust in itself had psychotherapeutic value, despite having difficulties in relating to others (Romeu-Labayen et al., 2020).

Participants recognised that a connection with a therapist is not something that was automatically present, but emerged over a period of time. Participants reported differences in how long this took, with some taking "a long time, a very long time" and "a good couple of years to even trust her [therapist]" (Langley & Klopper, 2005, p. 29) while others were able to feel "unbelievably comfortable with their therapist after the first few sessions" (Lonargain et al., 2017, p. 20).

Participants were able to build a sense of trust when they felt their therapist was listening actively to them. Participants perceived their therapists’ listening to be free from judgement (Duarte et al., 2019) and demonstrated an ability to attend to what they were saying with clear concern and interest (Langley & Klopper, 2005). This sense of trust allowed participants to feel able to freely ‘speak their minds’ and experience being heard by a therapist (Tan et al., 2018) allowing them to feel safe and able to open up to their therapist. Participants noted that this was not simply passive listening, instead trust was developed where therapists demonstrated understanding and connecting with what was being said, as one participant indicated “I don’t mean listening like here [signals to her ears] I mean listening with your mind and with your heart” (Goldstein, 2020, p. 138). This listening was felt to have an emotional component, as they experienced their therapist as connecting emotionally with what was being said. Participants in other studies found that this deeper listening had therapeutic qualities in itself, enabling participants to clarify events, thoughts and feelings (Langley & Klopper, 2005), which contributed to processes of reflection, allowing participants to be observers of their own experiences (Romeu-Labayen et al., 2020). However, those participants who took part in group therapy found that having enough time to feel heard and listened to was particularly difficult in these settings (Gardner et al., 2020). It may be that in these settings a trusting connection was harder to establish, as participants were less able to feel the therapist could connect with what each individual was saying.

The development of trust was aided by participants being able to connect with their therapists on a human level, this showed participants that therapists were real, genuine and not simply doing a job. One participant noted that this human connection was manifested by sharing; “the sharing that goes on in, like in individual therapy, is it’s really human”, giving a sense of authenticity not just limited to a job role for participants engaging with their DBT therapist (Hodgetts et al., 2007, p. 175). A connection which goes beyond the typical roles of therapist and client, allowing a “genuine manifestation of emotions and affections” was described by one participant who experienced long-term outpatient psychotherapy (Duarte et al., 2019, p. 455). This indicated to participants that their therapist was sincere, as another participant highlighted “you’re a human being before you’re a therapist.” (Goldstein, 2020, p. 144). This humanness allowed participants to place trust in their therapist as participants felt they were being real, allowing them to open up and share more within the relationship. Therapists were perceived to be human when they “allowed the relationship to transcend the therapy hour” (Goldstein, 2020, p. 144). This seemed to increase feelings of connection to a therapist, as one participant having Schema Therapy reported that having contact “in between the sessions, sometimes even in the weekend…really surprised me positively, because therapists deserve to have weekend. I thought it was huge, because the effort was a little bigger” (Tan et al., 2018, p. 12). Although this contact was not specified within the Schema Therapy intervention, it may reflect factors relating to the individual therapist rather than the intervention protocol. In contrast, rigidity and overly boundaried approaches hindered this sense of humanness and connection. Some therapists’ rigidity was perceived to block a human connection; “it was all very, um, like I’m here for the hour and then, be like...to see you like next week or see you whenever” (Dyson & Brown, 2016, p. 592) which served to create an ‘Us and Them’ dynamic making it harder for participants to view their therapist as human and forge a trusting connection with them.

Building a connection was aided by the therapist maintaining a sense of professionalism. This included maintaining confidentiality, remaining calm but demonstrating empathy during emotive discussions (Langley & Klopper, 2005) and being able to demonstrate appropriate confidence and strength, which was identified by Goldstein (2020) who interviewed participants who had engaged in a variety of therapy approaches for problems relating to BPD. This helped participants to feel a sense of security in the relationship and develop trust with the therapist. Unfortunately, some participants recounted times when therapists had acted with little professionalism, including confidentiality breaches and being asked if they were ‘stupid’ (Carrotte et al., 2019), which would likely undermine the sense of trust this participant could place in their therapist.

A connection with their therapist culminated in participants feeling they were genuinely cared for, which was described by Langley and Klopper (2005) who interviewed participants who had outpatient individual and group therapy. This was sometimes manifested in particular acts, such as gestures of kindness (Goldstein, 2020), not giving up on them despite difficulties (Katsakou et al., 2019) or remembering personal details and information; “you told her something about an ex-boyfriend three months ago and you ask, ‘Do you remember that?’, and she says ‘yes’, and she really does remember” (Romeu-Labayen et al., 2020, p. 873). To participants this seemed to indicate that the connection with their therapist had been established, they felt genuinely cared for and were able to feel safe and trust in them. This was not universal however, some participants described not receiving appropriate care or being made to feel undeserving of care. This included feeling rejected by the therapist in a group MBT setting (Gardner et al., 2020) and perceiving group psychodynamic therapists as passive (Hummelen et al., 2007), which did little to foster a feeling of being connected with or cared for by the therapist.

When there was an established connection based on trust participants were able to develop hope that the therapy could be helpful for them. Participants began to slowly believe that their therapist might help them (Langley & Klopper, 2005), and one young adult accessing DBT reflected “once you see results with all the skills then slowly I place my trust in them” (Lakeman & Emeleus, 2020, p. 6). This implies that participants started to believe change, recovery and the achievement of goals may be possible through therapy as they began to trust in their therapist.

### Coming together to navigate the therapeutic relationship

Successful therapeutic relationships were typified by the service-user and therapist being able to come together and navigate the therapeutic relationship itself, through open communication with each other. It was important for participants and their therapists to be able to adequately balance and negotiate aspects of the relationship, including boundaries, accessibility and difficulties within the relationship, with the therapist encouraging participants to play an equal part in ownership of this navigation as therapy progresses. Although participants felt this was difficult at times, doing so was acknowledged as helpful for participants as it enabled them to stay in therapy and work through difficulties which arose.

Participants noted the importance of knowing the limits of accessibility to their therapist, in one DBT study participants reported that simply knowing their therapist was available helped, even if they did not use the phone coaching available to them (Lakeman & Emeleus, 2020). This was also highlighted as important by participants who had accessed a range of therapies, as having access to their therapist outside of regular therapy sessions was described as containing and helped to ease distress (Langley & Klopper, 2005). However, participants noted that this needed to be an open conversation with their therapist, as there was a need for a balance to be struck in terms of the "therapeutic relationship and with regard to their behaviour" and acknowledged that it was not humanly possible for therapists to be available at all times (Langley & Klopper, 2005, p. 27). This felt like a clear boundary which needed to be set by the therapist and respected by the participants.

Participants found that as their relationships developed it was helpful to have a therapist who relinquished some control and was able to promote autonomy within the therapeutic relationship, which meant giving participants choice and independence. Positive experiences included participants having “clear, honest and sensitive communication throughout their treatment pathways” (Carrotte et al., 2019, p. 530), having their opinions listened to, engaging in transparent discussions about treatment (Romeu-Labayen et al., 2020) and collaborative reworking of the therapy structure (Goldstein, 2020). In Cunningham et al. (2004) the successful establishment of autonomy meant participants in an assertive outreach service were more empowered to take responsibility of their own DBT therapy. This suggests autonomy is something which is given by the therapist and promoted to the participant as therapy progresses, needing to create a sense of oneness at the beginning but separateness by the end (Dyson & Brown, 2016). Participants who had accessed a range of specialised therapies acknowledged how “support needed to be balanced with promoting independence in therapy” (Katsakou et al., 2019, p. 610).

Some participants noted times when their therapist had been unsuccessful in establishing accessibility and promoting autonomy, leaving them unhelpfully dependant within the therapeutic relationship. One participant reflected on the intensive support from being able to access direct therapy and out-of-hours crisis support; “I was having somebody who I was relying on...DBT hadn’t identified that I was over-reliant on my therapist” (Katsakou et al., 2019, p. 610). Some participants also reported times when they had less autonomy and felt controlled and powerless in relation to therapists (Goldstein, 2020). It was acknowledged that therapists had a particularly difficult job navigating the therapeutic relationship, managing to make participants feel comfortable enough, but also challenging their behaviour and pushing them to work harder (Cunningham et al., 2004). Some participants felt like they were not being pushed enough or conversely, too hard, as one recalled “He pushes and he will get me to the point where I start to cry.... He is trying to push me to achieve more but I am not really ready yet” with therapy itself deemed to be less helpful in these situations (Cunningham et al., 2004, p. 251).

Participants valued therapists who could navigate difficulties which may arise within the therapeutic relationship, and it was felt that this was generally the role of the therapist to address and manage. Some participants discussed experiences of conflict with their therapist, but that conflict did not necessarily negatively impact on the therapeutic relationship. This appeared to be mediated by the therapist's ability to manage and address the conflict, as one study highlighted:

> In every case in which the participant perceived her therapist as making an active and discernible effort to address the rupture, the outcome was favourable. And in each of these cases, the relationship, from the participant's perspective was not just maintained but meaningfully enhanced. (Goldstein, 2020, p. 147)

Participants experienced being encouraged to openly discuss difficulties in the therapeutic relationship and navigate this together with their therapist, enabling participants "to stay, and work through it" (Katsakou et al., 2019, p. 610) which was a new and helpful experience for them. Furthermore, participants who had disengaged from group therapy reported therapists' passivity as a factor in their disengagement and a wish for therapists who were able to deal differently with criticism by admitting shortcomings and working on problems in a more active way (Hummelen et al., 2007). Suggesting that when therapists do not actively address difficulties which may arise, participants may disengage as a consequence.

Participants perceived therapists who had specialist knowledge as being better at navigating the therapeutic relationship. Some participants perceived professionals as having a lack of specialist knowledge about BPD (Perseius et al., 2003), which was a barrier to successfully negotiating the therapeutic relationship, as these professionals lacked the insight into how the difficulties associated with this diagnosis may impact a relationship (Carrotte et al., 2019). However, some participants reported professionals who had knowledge of different therapeutic strategies and an ability to use this “flexibility rather than demonstrate expertise in any particular school of therapy” as particularly helpful (Langley & Klopper, 2005, p. 29). Participants emphasised the benefits of accessing psychological support from specialist services, with practitioners who have more training and understanding of working with people with a BPD diagnosis, compared to the lack of empathy and understanding offered by some clinicians in more generalist services (Carrotte et al., 2019).

The ability to navigate the therapeutic relationship also encompassed the importance of managing the ending of the therapeutic relationship. Endings appeared to be a difficult event for participants, which was associated with feelings of grief and loss, as summarised by one participant who finished her course of MBT; "I really, really struggled with the ending of particularly the individual, but also the group and was really grieving and found erm that really tough" (Dyson & Brown, 2016, p. 592). Endings that had not been well managed felt like a betrayal on the therapist’s part (Perseius et al., 2003). The ending stage of therapy could be viewed as a delicate negotiation, needing to be handled well by the therapist. This was a particularly important time for therapists to demonstrate their ability to navigate the relationship and promote autonomy. Some participants noted therapists “did not manage successfully the transition between encouraging a degree of dependence and attachment in the beginning with fostering more independence towards the end” (Katsakou et al., 2019, p. 610). In the reviewed studies only one study explicitly discussed the relationship extending beyond the ending of therapy, where it was noted that although the therapy process might end, the relationship that has developed with a therapist remained (Duarte et al., 2019).

## Discussion

This study aimed to create an understanding of how people with a BPD diagnosis experience therapeutic relationships during psychological therapy. This was done through a meta-ethnographic meta-synthesis of qualitative studies, which generated three themes relating to participants' experiences. Positive therapeutic relationships were highly valued and sought after by participants and seen as necessary for successful therapy to take place. Positive therapeutic relationships were felt to be established from a trusting base, which was established over time, through therapist acts such as listening and being human. Participants highlighted the need to jointly come together with therapists to skilfully navigate the relationship, by addressing difficulties and, as therapy progressed, by promoting autonomy. However, these features were not always present and their absence impacted negatively on the therapeutic relationship.

In this review, participants' experiences of positive therapeutic relationships appeared to mirror aspects of the therapeutic alliance, which is often used to measure the strength of the therapeutic relationship. Definitions and ideas around the therapeutic alliance have evolved over time (Ardito & Rabellino, 2011). There are now a wide range of clinical measures which primarily seek to quantify and objectify the therapeutic alliance into a tangible and measurable construct, measuring a few key concepts, based on the work of Bordin (1979). These aspects of the 'working alliance' are the agreement between therapist and client on; 1. the goals of therapy, 2. the tasks to achieve the goals, 3. the development of a relational bond. In this review there was mention of relationships with therapists which were collaborative (Hodgetts et al., 2007) and within which the participant and their therapist were working together toward the same goal (Cunningham et al., 2004). Within the theme of "Coming together to navigate the therapeutic relationship" participants made reference to the negotiation of accessibility and autonomy, which may reflect the need to agree on tasks and goals of therapy which are ‘allocated’ to the therapist and service-user (Dyson & Brown, 2016; Goldstein, 2020; Katsakou et al., 2019). Furthermore, there were times when participants reported disagreements about the tasks in therapy, such as being pushed too much or not enough (Cunningham et al., 2004), which impacted negatively on the therapeutic relationship.

Of particular importance for participants in this study was the emphasis of the relational bond over the other concepts described by Bordin (1979), as indicated by the theme “Building a connection (based on trust).” This is novel and significant compared to existing literature where the three concepts of the therapeutic alliance are equally weighted in common outcome measures (Duncan et al., 2003; Horvath & Greenberg, 1986). The factors perceived to be needed for “Building a connection (based on trust)” link to Rogers (1957) necessary and sufficient conditions, who highlighted the importance of the genuineness of a therapist who displays unconditional positive regard and feels empathy for the client. These results also challenge existing literature which indicates therapists need to maintain strict boundaries and limit setting when working with people with a BPD diagnosis (McGrath & Dowling, 2012; McMain et al., 2015).

This emphasis on trust as the foundation may be reflective of the difficulties people with a diagnosis of BPD describe experiencing in the establishment and maintenance of relationships in their wider lives (Ntshingila et al., 2016) and the importance placed on a relationship within which they are able to feel trust and security. Participants’ emphasis on the need for trust could be understood by considering the influence of developmental traumas often experienced by people with a diagnosis of BPD and the impact this has on attachment and trust (Ford & Courtois, 2014). It is widely acknowledged that developmental traumas impact on a person’s internal working model of others and their ability to form trusting relationships (Williams, 2006). It may be that therapists working with individuals with a diagnosis of BPD need to do more to create a connection based on trust, so the therapist can be viewed as a secure base from which a client can explore difficulties with appropriate support (Bowlby, 1988). For participants in this review this included showing a human side, deeper listening and demonstrating genuine care. It may be that service-users with positive therapeutic relationships begin to perceive the therapist as a secure base, which fits with wider literature acknowledging that a secure base in therapy can provide a corrective emotional experience to internal working models (Berry & Danquah, 2016).

However, as indicated by participants in this study, trusting relationships were not always established and may be reflective of negative views sometimes held by clinicians. Research has shown therapists negatively evaluate the impact of individuals with a diagnosis in the ‘cluster B’ of personality disorders (which includes BPD) on the development of the therapeutic alliance (Lingiardi et al., 2005), and therapists may distance themselves from clients with a diagnosis of BPD and not allow this close bond to be established (McGrath & Dowling, 2012; Stroud & Parsons, 2013). These could partly explain difficulties captured within the themes “Building a connection (based on trust)” and “Coming together to navigate the therapeutic relationship”, whereby some participants experienced their therapists as overly rigid, lacking humanness and struggling to adequately balance boundaries and autonomy.

## Clinical implications

Of the therapies experienced by participants in this review, the majority were manualised treatment approaches, including DBT, MBT and Schema Therapy, which have been specifically developed to address the difficulties associated with a diagnosis of BPD (Choi-Kain et al., 2017). Although therapists delivering these interventions are likely to be highly trained in their specific modality, there have been arguments made to move away from overly rigid manualised treatments to use more integrative person-centred approaches (Livesley, 2012). The overly rigid application of some of the approaches was highlighted by participants in this review as being a barrier to the development of a positive therapeutic relationship. An individualised approach is something which could be facilitated by clinical psychologists through supervision and formulation with therapists, as clinical psychologists are trained in a range of interventions to generate a person-centred approach (The British Psychological Society, 2014). This could also help therapists to develop skills in navigating therapeutic relationships with individuals who have a diagnosis of BPD.

A further implication is the need for therapists, and therapies, to allow for active and open discussion about the therapeutic relationship, including managing ruptures, autonomy, boundaries and endings. Being able to have these discussions was highly valued by participants in this review, who also noted the negative impact of not being able to discuss when difficulties had arisen. Therefore, promoting these discussions within therapy may be particularly helpful for people with a BPD diagnosis. Although the therapeutic relationship is seen as important across therapies for people with a BPD diagnosis (Weinberg et al., 2011), approaches such as Cognitive Analytic Therapy (CAT) encourage the therapist to reflect on and actively address the therapeutic relationship with the client (Ryle, 2004). Effective use of CAT may offer therapists a way of noticing and addressing potential threats to the therapeutic relationship and improve the effectiveness of treatment (Bennett et al., 2006).

Despite the continued use of training and educational interventions aimed at decreasing negative perceptions of people with a BPD diagnosis, increasing empathy and understanding of their difficulties (Davies et al., 2014; Shanks et al., 2011), some professionals still distance themselves from clients with a BPD diagnosis and do not allow a close bond to be established (McGrath & Dowling, 2012; Stroud & Parsons, 2013). Some participants in this review still describe encountering therapists who were distant, passive and on occasion unprofessional. It is therefore important for individual clinicians and services to continue with training and educational interventions to mitigate the negative perceptions and stigma, and be considerate of the difficulties associated with a BPD diagnosis that may continue to impact on the therapeutic relationship.

### Strengths and limitations

A strength of this review is that it offers the first synthesis of the experiences of the therapeutic relationship for people with a diagnosis of BPD. It offers something new to the literature, as the wide range of countries, services, and therapies included in the reviewed papers has revealed commonalities across different psychological therapies. This is important to consider, as reviews can sometimes focus on the experiences of a particular psychological intervention in isolation. Looking at how the therapeutic relationship is experienced across different therapies is novel and has shown how this is of considerable importance to participants with a BPD diagnosis.

One issue which could be conceptualised as both strength and limitation, is the definition of the therapeutic alliance. This is a technical term found in the research literature and not often a phrase used by participants. Sticking to this rigidly may have meant that some participants' experiences would not have been included in this review. However, it felt important that the concept of the 'therapeutic alliance' remained central, with also a need to recognise that participants' language on this topic may vary. To strike a balance between these issues the term 'therapeutic relationship' was felt to be an appropriate choice. This would allow for the inclusion of participants' experiences which may fall outside of the technical definition of the "the collaborative and affective bond between therapist and patient" (Martin et al., 2000, p. 438). However, this also meant that a level of author interpretation was needed in order to decide what constituted the ‘therapeutic relationship’. For example Ditlefsen et al. (2020) was excluded from the review as the theme ‘It gave me more trust in the therapy’ was felt to relate to the confidence in the therapeutic approach itself, rather than a relationship with a therapist.

Another aspect to consider is that thirteen studies were excluded from the review as the results did not include data which related to the therapeutic relationship, despite meeting all other inclusion criteria. This raises questions about whether participants did not mention the therapeutic relationship in these studies because they were not asked directly about it, or whether they did not perceive it to be important. For example in McSherry et al. (2012), the topic guide comprised of “(1) helpful/unhelpful components of the programme, (2) experiences of participating in an adapted DBT programme and (3) treatment impact”, however there was no mention of the therapeutic relationship in the findings.

A limitation of this review is, as described in table 2, the vast majority of participants in the reviewed studies were female. This is reflective of the gendered aspect of BPD diagnoses which has been critiqued in the wider literature (Bjorklund, 2006; Sansone & Sansone, 2011; Shaw & Proctor, 2005) but also means that a predominantly female view of the therapeutic alliance was captured. It is likely gender plays a role in how therapeutic relationships are experienced for both therapists and clients (Schapiro-Halberstam et al., 2020). Furthermore, in the included papers, there was very limited reporting on the gender of therapists which may also influence the therapeutic relationship.

A further limitation is the lower quality appraisal scores for some papers included in this review, with two, (Cunningham et al., 2004) and Goldstein (2020), having scores of 11 and 13 respectively, which is particularly low in comparison to the rest of the papers. However, in order to account for this apparent lack of quality, contributions to the development of themes which came from these papers were always considered alongside more highly appraised papers and, where possible, original quotes were used from participants rather than author interpretations.

## Future research

To get a more rounded view of the therapeutic alliance it would be important to consider the views of therapists when establishing a relationship with a person with a BPD diagnosis. It would be particularly helpful for future research to focus on the experiences of clinicians who have established positive therapeutic relationships when working with a person with a BPD diagnosis and the factors which have contributed to this, how clinicians manage the navigation of the boundaries of relationships without having to resort to rigid boundaries.

In addition, future research could investigate how people with a BPD diagnosis experience other forms of therapeutic relationships, not limited to the single relationships with a therapist. This could include the relationships between group members, the relationships in therapeutic communities, peer and family support.

## Conclusion

In conclusion, this review considered the experiences of the therapeutic relationship for people with a diagnosis of BPD. The themes identified highlight the vast differences in experience but also commonalities which participants value and see as contributing to successful therapy. The experience of the therapeutic relationship could be enhanced for people with a diagnosis of BPD if therapists are supported to openly discuss relational difficulties with service users during therapy and support from clinical psychologists could encourage more flexibility in therapy than manualised treatment approaches currently allow.

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## Tables and Figures

### Table 1: Example search terms in EBSCO databases

| | **SPIDER Heading** | | | | |
|---|---|---|---|---|---|
| | Sample | Phenomenon of Interest | Design | Evaluation | Research Type |
| **Description** | People with a diagnosis of Borderline Personality Disorder | The therapeutic relationship during psychological therapy | Any qualitative or mixed methods | How this is experienced | Qualitative or mixed methods |
| **Search Terms** | Borderline Personality Disorder (DE),<br>Borderline States (DE),<br>Borderline Personality Disorder,<br>Borderline Personality,<br>BPD,<br>Emotionally Unstable Personality Disorder,<br>Emotionally Unstable Personality,<br>Emotionally Unstable,<br>EUPD | Cognitive Therapy (DE),<br>Psychotherapy (DE),<br>Schema Therapy (DE),<br>Therapeutic Community (DE),<br>Therap*<br>Psychotherap*<br>Psycholog*<br>Treatment*<br>Intervention*<br>Pathway*<br>Support,<br>DBT,<br>Dialectic* Behaviour* Therapy,<br>MBT,<br>Mentali*ation Based Therapy,<br>CBT,<br>Cognitive Behaviour* Therapy,<br>Schema,<br>CAT,<br>Cognitive Analytic* Therapy,<br>Psychodynamic,<br>Therapeutic Communit* | | Perception*<br>Perspective*<br>Experience*<br>View*<br>Opinion*<br>Response*<br>Journey*<br>Insight*<br>Narrative*<br>Voice*<br>Understanding*<br>Attitude* | Qualitative Methods (DE),<br>Qualitative,<br>Phenomenol*<br>IPA,<br>Narrative*<br>Discourse Analysis,<br>Discursive,<br>Thematic*<br>Grounded Theor*<br>Content Analysis,<br>Focus Group,<br>Interview |

N.B. Search terms within columns combined with OR, search terms in rows combined with AND.

**Table 2: Study Characteristics**

| Study Number | Author(s) and Year | Sample | Intervention modality | Country | Primary Aim | Method of Data Collection | Method of Analysis |
|---|---|---|---|---|---|---|---|
| **1.** | Carrotte et al. (2019) | 11 participants* (75% female, M age = 39.9, SD = 11.7), nine with lived experience of BPD, having accessed at least one treatment or support service for reasons relating to the personality disorder<br>Eight participants* with BPD, and one participant reporting BPD traits | | Australia | To investigate (a) treatment and support services that are accessed by people living with BPD and their carers, (b) perceived benefits and challenges associated with these services, and (c) changes these individuals would like to see with regards to service provision and access | Semi-structured interviews<br>Focus groups | Framework Approach |
| **2.** | Cunningham et al. (2004) | 14 participants (100% female, M age 38.7), diagnosed with BPD, participants in a DBT programme | | USA | To understand, from the perspective of the client, what is effective about DBT and why | Semi-structured interviews | Ethnographic Methods |
| **3.** | Duarte et al. (2019) | One female service user diagnosed with BPD, participating in long-term psychotherapy* | | Chile | To identify aspects of psychotherapy that contribute to therapeutic change based on the experience of a patient and her therapist | Semi-structured interviews | Grounded Theory Construction of the Self in Biographical Narration Model |
| **4.** | Dyson & Brown (2016) | Six participants (100% female) diagnosed with BPD, completed a minimum of 6 months MBT | | UK | To explore the experience of MBT for individuals diagnosed with BPD | Open-ended interviews | Interpretative Phenomenological Analysis |

| | | | | | | |
|---|---|---|---|---|---|---|
| **5.** | Gardner et al. (2020) | Eight participants (100% female, aged 22-64) experiencing difficulties associated with BPD, attending MBT for at least six months | UK | To understand service users' lived experiences of MBT, including their experiences of change | Semi-structured interviews | Interpretative Phenomenological Analysis |
| **6.** | Goldstein (2020) | Seven participants (100% female, aged 28-45) with a diagnosis of BPD, having at least three treatment or therapy encounters for BPD | USA | To explore the nature and quality of patients' interactions with clinicians, while receiving services in various settings | a) Interviews<br>b) Administration of the Core Conflictual Relationship Theme (Relationship Anecdotes Paradigm)<br>c) Relational Space Mapping | Phenomenological Analysis |
| **7.** | Hodgetts et al. (2007) | Five participants (three female, two male, aged 24-48) with experience in a DBT programme | UK | To explore the experience of Dialectical Behavioural Therapy for people with a diagnosis of Borderline Personality Disorder | Semi-structured interviews | Interpretative Phenomenological Analysis |
| **8.** | Hummelen et al. (2007) | Eight participants (100% female) diagnosed with BPD, having dropped out from outpatient group psychotherapy | Norway | To explore the reasons for patients' premature termination of outpatient group therapy | Interviews | Philosophical Hermeneutics |
| **9.** | Katsakou et al. (2019) | 48 participants* (39 female, 9 male, mean age: 36.5, range: 18–58) with a diagnosis of BPD, contact with mental health services | UK | To explore how recovery in BPD occurs through routine or specialist treatment, as perceived by service users and therapists | Semi-structured interviews | Framework Approach |

| | | | | | | |
|---|---|---|---|---|---|---|
| **10.** | Lakeman & Emeleus (2020) | Six participants (mean age: 20, range: 17-25) diagnosed with BPD, participating in a DBT programme for youth | Australia | To explore the experience of recovery from BPD in the context of participation in a comprehensive DBT programme | Semi-structured interviews at three timepoints | Grounded Theory |
| **11.** | Langley & Klopper (2005) | Six participants* (five female) diagnosed with BPD, with experience of inpatient and outpatient services, and attendance at individual and group therapy | South Africa | To explore what factors patients and clinicians living with or caring for people with BPD consider helpful in facilitating their mental health | Conversational interview | Interpretive Descriptive Approach |
| **12.** | Lonargáin et al. (2017) | Seven adults (five female, age range: 26-52) accessing MBT for BPD between 2 and 15 months | UK | To explore how adults with difficulties associated with BPD experience intensive out-patient MBT | Semi-structured interview | Interpretative Phenomenological Analysis |
| **13.** | Perseius et al. (2003) | Ten participants (100% female, age range: 22-49), with a diagnosis of BPD, having at least 12 months of DBT intervention | Sweden | To investigate patients and therapists perception of receiving and giving dialectical behavioural therapy | Semi-structured interview | Qualitative Content Analysis |
| **14.** | Romeu-Labayen et al. (2020) | 12 participants (100% female, age range: 20-46) with a diagnosis of BPD, under the care of mental health nurses (care consisted of unstructured weekly or fortnightly individual visits and participation in a nurse-led DBT group) | Spain | To identify the actions of mental health nurses that, according to people with BPD, have contributed to their recovery | Semi-structured interview | Qualitative Descriptive Design |

| | | | | | | |
|---|---|---|---|---|---|---|
| **15.** | Tan et al. (2018) | 36 participants (28 females, eight males) diagnosed with BPD, having at least 12 months of Schema Therapy | Multi centre –<br>Australia<br>The Netherlands<br>Germany | To explore BPD patients' experiences of receiving schema therapy, in intensive group or combined group-individual format. | Semi-structured interview | Qualitative Content Analysis |

*Studies also recruited other participants, including therapists and parents/carers, where data was presented separately

**Table 3: CASP ratings**

| | **Study** | **CASP** | | | | | | | | **Total** |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Research Design | Recruitment | Data Collection | Reflexivity | Ethical Issues | Data Analysis | Findings | Value of Research | |
| **1.** | **Carrotte et al. (2019)** | 2 | 3 | 3 | 2 | 3 | 2 | 2 | 2 | 19 |
| **2.** | **Cunningham et al. (2004)** | 2 | 1 | 2 | 1 | 1 | 2 | 1 | 1 | 11 |
| **3.** | **Duarte et al. (2019)** | 3 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 16 |
| **4.** | **Dyson & Brown (2016)** | 3 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 17 |
| **5.** | **Gardner et al. (2020)** | 2 | 2 | 2 | 2 | 2 | 3 | 3 | 3 | 19 |
| **6.** | **Goldstein (2020)** | 2 | 2 | 2 | 2 | 1 | 2 | 1 | 1 | 13 |
| **7.** | **Hodgetts et al. (2007)** | 2 | 2 | 1 | 1 | 2 | 3 | 2 | 3 | 16 |
| **8.** | **Hummelen et al. (2007)** | 1 | 3 | 2 | 2 | 1 | 2 | 3 | 2 | 16 |
| **9.** | **Katsakou et al. (2019)** | 3 | 3 | 3 | 3 | 2 | 3 | 3 | 2 | 22 |
| **10.** | **Lakeman & Emeleus (2020)** | 2 | 1 | 2 | 2 | 2 | 2 | 3 | 2 | 16 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **11. Langley & Klopper (2005)** | 2 | 2 | 3 | 2 | 2 | 3 | 2 | 2 | 18 |
| **12. Lonargáin et al. (2017)** | 3 | 3 | 3 | 3 | 2 | 3 | 2 | 2 | 21 |
| **13. Perseius et al. (2003)** | 2 | 2 | 2 | 2 | 3 | 3 | 3 | 2 | 19 |
| **14. Romeu-Labayen et al. (2020)** | 3 | 3 | 2 | 2 | 2 | 3 | 2 | 2 | 19 |
| **15. Tan et al. (2018)** | 2 | 3 | 3 | 3 | 2 | 3 | 3 | 2 | 21 |

**Table 4: Second order constructs from synthesised papers**

| **Study** | **2nd Order Constructs** | **Description** |
|---|---|---|
| Carrotte et al. (2019) | Finding what works (for me) | Finding the right clinician who was validating, non-judgmental and skilful, and able to challenge. |
| | (Mis)communication | Importance of clear, honest and sensitive communication throughout their treatment pathways. |
| | Complexities of care | Needing more experienced/specialised services, to be able to understand the severity of attachment-related difficulties, boundary-setting and other interpersonal challenges. |
| Cunningham et al. (2004) | Individual therapy | Emphasising the smooth working relationship they had with their therapist, characterized by clients as friendships or partnerships in which the therapist and client are on the same level, working together toward the same goal. |
| Duarte et al. (2019) | Context | The therapeutic setting, the goals and tasks expected from the therapist and the patient. |
| | Relation of trust between patient and therapist | Allowing patient and therapist to work together and establish a trust-based relationship. |
| | Therapeutic listening | The feeling that the therapist listens, an activity characterized as judgment-free and soothing. |
| | Emotional experience | The importance of the “person-to-person” encounter beyond the therapist and client roles. |
| | The therapy finishes, the relationship remains | Closing therapy and the reconfiguration of the therapeutic relationship. |
| Dyson & Brown (2016) | We are one (but not together) | Negotiating the relationship with their therapist between their desire for attachment and implicit sense that their desire for connection cannot last. |
| Gardner et al. (2020) | My therapist and me | The importance of the therapeutic relationship and therapist qualities such empathy, stability, consistency, and trust. |
| | Being in the group | Feeling there was not enough time for each to explore issues in depth, and this led to feelings of frustration and rejection by the group therapist. |
| Goldstein (2020) | To be seen and heard | The experience of ‘real listening’ which has an emotional component wherein two people are joined in an experience |
| | To be cared for | A need to feel cared for by their clinicians, engendered by a therapist’s way of communicating or listening. |
| | To balance structure and flexibility | Participants described the ideal clinician as compassionate and caring without being indulgent or permissive. |

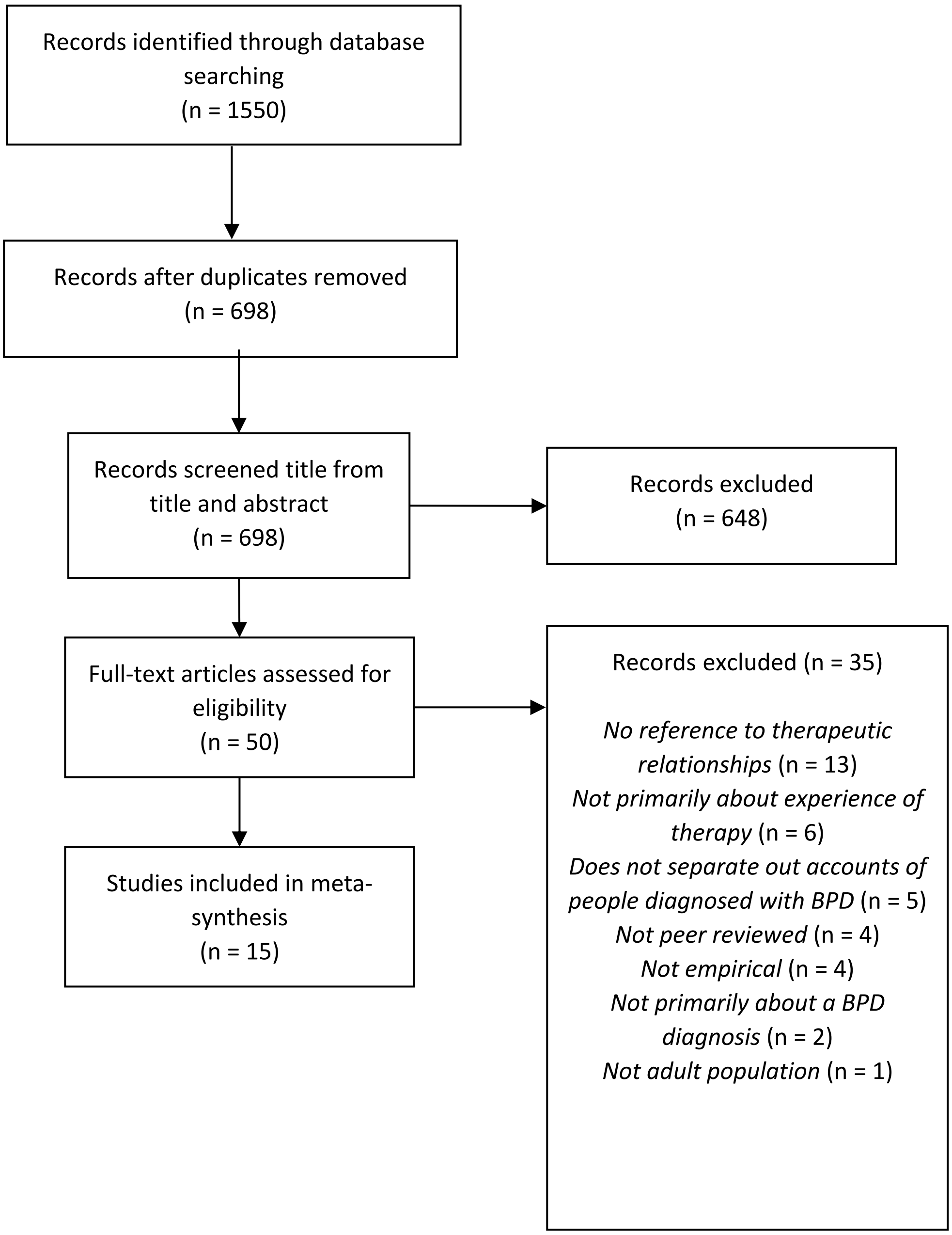
| | | |
|---|---|---|
| | To be real: transparency, action, and humanity | The experience therapist neutrality and inactivity as a barrier that discouraged the development of closeness and safety in the relationship. |
| | To address tension and conflict head-on | The experiences of specific conflicts with their therapists and whether these were ultimately experienced as therapeutic. |
| Hodgetts et al. (2007) | Non-specific factors of DBT | The relationship with individual DBT therapists, in relation to the therapist's qualities and support, but also the collaborative working relationship including self-disclosures. |
| Hummelen et al. (2007) | Negative Aspects of the Patient–Therapist Relationship | Experiencing therapists' passivity and lack of understanding, wishing for therapists to deal differently with criticism, notice distress and responded to it more actively. |
| Katsakou et al. (2019) | Confronting interpersonal difficulties and practicing new ways of relating | Appreciating the opportunity to openly discuss and repair conflicts in their relationship with their therapist(s). |
| | Balancing support and independence | Valuing the feeling of being understood and accepted by therapists, however, support needed to be balanced with promoting independence, especially towards endings. |
| Lakeman & Emeleus (2020) | Elements of Success | Elements such as the relationship with the individual therapist tended to be prized very highly. |
| Langley & Klopper (2005) | Trust, a foundation | Trust was described by every patient as a foundation, the essential requirement for the establishment and maintenance of any relationship. |
| | Available & accessible | Acknowledging that being available all times was not humanly possible, but being able to negotiate contacting the therapist at set times. |
| | Caring | Believing that the person cared if he or she was perceived as trying to understand, by really listening, by being available and by accepting them as they were. |
| | Trying to understand | Listening did not imply that the person did understand, but to focus on the tone of the message and try to clarify the content for the patient. |
| | Professional | The importance of therapists that were honest, maintained confidentiality, able to apply different therapeutic strategies with flexibility, remained calm but empathetic. |
| | Trust takes time | Patient participants emphasized that trust took time to develop. |
| | Hope | As trust develops, so they begin to trust themselves and the world around them and hope emerges. |
| Lonargáin et al. (2017) | Building trust: a gradual but necessary process during MBT | Learning to trust and feel comfortable with therapists was an essential process in order to benefit from MBT, achieved with much more ease in individual sessions than group sessions. |
| | Building trust in individual sessions with minimal difficulty | Despite initially feeling uncertain about their individual therapists participants seemed to quickly build trust with them. |
| | The impact of programme structure and duration of attendance on building trust | The impact of having their individual therapist in group sessions generally valued this, therapists are an "ally" in the group and this helped to feel more comfortable. |

| | | |
|---|---|---|
| Perseius et al. (2003) | Respect and Confirmation is the Foundation | The patients narrated the great respect, understanding and confirmation they have encountered in the DBT-therapists. |
| | Discontinuity and Betrayal | Some of the patients stress the experience of discontinuity and feelings of betrayal by therapists and attendants, which for different reasons have ended the contact with them. |
| Romeu-Labayen et al. (2020) | Building trust: Perceiving the interest of the nurse | Perceiving that the mental health nurse was interested in them, in their personal histories and in their distress. |
| | Perceiving the nurse’s empathy | Empathy allows the participants to trust the nurse. It shows the ability of the nurse to be present, to help the person with BPD contain her emotions, to take up what she has said, and to support her. |
| | Feeling listened to | Putting distress into words to reflect and narrative construction that allowed them to position themselves as observers of their own experiences and view them from a different perspective. |
| | Being empowered through validation: Feeling validated | Experiences of feeling emotionally recognized, respected and valued. |
| | Participating in treatment decisions | Is the recognition that the nurse listened to the service user’s opinion and informed her about her treatment transparently. |
| Tan et al. (2018) | Email access to therapists outside working hours | The value of having email contact with therapists outside office hours, reflect a sense of security and support from this form of therapist accessibility. |
| | Extent to which patients feel supported by their therapists | Having a good fit in the therapeutic relationship where they felt emotionally connected and appropriately supported. Group therapists were non-imposing and non-judgmental, attuned, creating a sense of safety. |

## Table 5: Third order constructs

| Third order constructs | Translated themes (from second order constructs) | Contributing papers |
|---|---|---|
| **Valuing a relationship** | Wanting a relationship | Carrotte et al. (2019), Cunningham et al. (2004), Hodgetts et al. (2007), Katsakou et al (2019), Perseius et al. (2003) |
| | Individual vs group relationships | Cunningham et al. (2004), Dyson & Brown (2016), Gardner et al. (2020), Lakeman & Emeleus (2020), Lonargain et al. (2017), Tan et al. (2018) |
| | When a relationship isn't present | Dyson & Brown (2016), Katsakou et al. (2019) |
| **Building a connection (based on trust)** | Trust | Duarte et al. (2019), Gardner et al. (2020), Lakeman & Emeleus (2020), Langley & Klopper (2005), Longarian et al. (2017), Romeu-Labayen et al (2020) |
| | Time | Langley & Klopper (2005), Longarian et al. (2017) |
| | Listening | Duarte et al. (2019), Gardner et al. (2020), Goldstein (2020), Langley & Klopper (2005), Romeu-Labayen et al. (2020), Tan et al. (2018) |
| | Connecting on a human level | Duarte et al. (2019), Dyson & Brown (2016), Goldstein (2020), Hodgetts et al. (2007), Tan et al. (2018) |
| | Professionalism | Carrotte et al. (2019), Goldstein (2020), Langley & Klopper (2005) |
| | Feeling cared for | Goldstein (2020), Gardner et al. (2020), Hummelen et al. (2007), Katsakou et al. (2019), Langley & Klopper (2005), Romeu-Labayen et al. (2020) |
| | Developing hope | Lakeman & Emeleus (2020), Langley & Klopper (2005) |
| **Coming together to navigate the therapeutic relationship** | Accessibility | Lakeman & Emeleus (2020), Langley & Klopper (2005) |
| | Promoting autonomy | Carrotte et al. (2019), Cunningham et al. (2004), Dyson & Brown (2016), Goldstein (2020), Katsakou et al. (2019) Romeu-Labayen et al. (2020) |
| | Rupture and repair | Goldstein (2020), Hummelen et al. (2007), Katsakou et al. (2019) |
| | Specialist knowledge | Carrotte et al. (2019), Langley & Klopper (2005), Perseius et al (2003) |
| | Managing endings | Duarte et al. (2019), Dyson & Brown (2016), Katsakou et al. (2019), Perseius et al. (2003) |

**Figure 1: Flowchart of study selection**



## Appendix 1-A: Seven Phases of Meta-Ethnography

Seven phases of Meta-Ethnography byNoblit and Hare (1988)

Phase 1: Getting started - 'identifying an intellectual interest that [synthesis of] qualitative research might inform' [pp.26]. The focus of the synthesis may be revised through reading the individual qualitative studies

Phase 2: Deciding what is relevant to the initial interest - study selection should be 'driven by some substantive interest derived from comparison of any given set of studies' [pp.28]. Searches for studies need not be exhaustive because 'unless there is a substantive reason for an exhaustive search' [pp.28]

Phase 3: Reading the studies - the repeated reafing of studies and noting of concepts or themes with close attention to the detail in the studies and what they tell you about your area of interest [pp.28]

Phase 4: Determinging how the studies are related - by creating a 'list of key metaphorsm phrases, ideas and/or concepts (and their relations) used in each account and to juxtapose them' [pp28] or order to make an intial assumption about how the studies relate to one and other.

Phase 5: Translating the studies into one and other - the concepts and themes in each study account and their interactions are systematically compared or 'translated' while retaining the structure of relationships between central concepts/themes within accounts.

Phase 6: Synthesising translations - translations can be compared to one and other to see if there are common types of translation or if some translations encompass those from other studies. In these cases, a second level of synthesis is possible, to reach new interpretations/conceptual understandings.

Phase 7: Expressing the synthesis - tailoring the communication of the synthesis to the intended audiences culture and laguage so that it is intelligible and useful to them

## Appendix 1-B: Author Guidelines (Psychology and Psychotherapy: Theory, Research and Practice)

# PAPTRAP AUTHOR GUIDELINES

**Sections**

### 1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

**Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at http://www.editorialmanager.com/paptrap**

Click here for more details on how to use **Editorial Manager**.

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This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

### 2. AIMS AND SCOPE

*Psychology and Psychotherapy: Theory Research and Practice* is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders.

Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies and Registered Reports. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

All papers published in *Psychology and Psychotherapy: Theory, Research and Practice* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

## 3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

- Articles should adhere to the stated word limit for the particular article type. The word limit excludes the abstract, reference list, tables and figures, but includes appendices.

Word limits for specific article types are as follows:

- Research articles: 5000 words
- Qualitative papers: 6000 words
- Review papers: 6000 words
- Special Issue papers: 5000 words

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## Appendix 1-C: Practitioner Points for Journal Submission

Practitioner points:

- The therapeutic relationship is known to be a key factor in contributing to successful therapy outcomes, however no systematic reviews has considered how the therapeutic relationship is experienced for people who meet criteria for a diagnosis of BPD.

- Across the different psychological interventions reviewed, the therapeutic relationship was found to be particularly important to people with a diagnosis of BPD, with an emphasis on building a trust-based relationship with their therapist.

- Therapists' rigid adherence to treatment protocols and not showing a 'human side' impacted negatively on the therapeutic relationship, more person-centred and individualised approaches in therapy could help to address this.

- Open discussion about the nature of the therapeutic relationship were beneficial to participants and should be encouraged by practitioners as part of psychological therapy.
-

Noblit, G. W., & Hare, D. R. (1988). *Meta-ethnography synthesizing qualitative studies*. Sage Publications.

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## Section Two: Research Paper

# How does receiving a personality disorder diagnosis affect wellbeing? A grounded theory investigation.

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Prepared for - Psychology and Psychotherapy: Theory, Research and Practice (see Appendix 2-B)

## Abstract

*Objectives:* Receiving a mental health diagnosis is a significant moment for many service-users. However, the diagnosis of Borderline Personality Disorder (BPD) is particularly contentious and laden with stigma, therefore it is particularly important to understand how receiving this diagnosis affects individuals. This study aims to explore service-user perceptions of how receiving a diagnosis of BPD affects wellbeing.

*Design:* A constructivist grounded theory method was used to analyse data from qualitative interviews.

*Methods:* Nine people who had received a diagnosis of BPD in the last five years participated in semi-structured interviews.

*Results:* Two key processes were highlighted as important in considering how receiving a diagnosis of BPD is thought to have affected the wellbeing of participants. Firstly, the way in which the diagnosis was communicated, as this laid foundations for participants' perceptions of the diagnosis. Secondly, participants' experiences of the perceived advantages and disadvantages of living with the diagnosis, which included the responses of services, the influence on participants' social relationships and impact of stigma.

*Conclusions:* Although participants reported benefits of being able to access therapy, there was significant negative impact on wellbeing associated with receiving a diagnosis of BPD. Clinical implications to improve the experiences and wellbeing of people with a diagnosis of BPD are discussed. Limitations and areas for future research are also considered.

*Keywords: Borderline Personality Disorder, Diagnosis, Wellbeing, Stigma.*

Receiving a mental health diagnosis is accompanied by a range of individual responses including relief and validation (Milton & Mullan, 2014), but also stigma, perceived powerlessness and limited access to services (Rose & Thornicroft, 2010; Van Den Tillaart et al., 2009), all of which will likely impact a person's subsequent wellbeing. The act of disclosing a mental health diagnosis has received much attention recently and is seen as a particularly important event to service-users (Perkins et al., 2018).

Borderline personality disorder (BPD) is one of the most commonly used diagnoses in mental health settings (Beckwith et al., 2014). It is associated with significant difficulties, including risk of suicide, a struggle to regulate emotions and difficulties controlling impulses, often meaning people with a BPD diagnosis have significant support from mental health services (Aviram et al., 2006; Larivière et al., 2015). Prevalence rates in studies vary, with estimates suggesting between 10% and 40% of service-users in outpatient and primary care settings have this diagnosis (Lieb et al., 2004; Newton-Howes et al., 2010; Zimmerman et al., 2005). However, there are arguments and controversies surrounding the diagnosis. It has been argued that people who are labelled with BPD by mental health services are made to feel as if "they are deserving of care and traditional professional paternalism but they are actually scorned and disliked" (Pilgrim, 2001, p. 258). The impact of receiving a BPD diagnosis is therefore important to understand, as it is associated with significant stigma, difficulties when accessing services and a lack of understanding from professionals (Stalker et al., 2005)

## Psychological perspectives

The difficulties associated with a BPD diagnosis can be understood from a psychological perspective, drawing on trauma and attachment theories. This may help to understand the aetiology of contributing factors which lead to difficulties that are conceptualised as 'BPD'. For example, the impact of developmental trauma has been highlighted as significant (Linehan, 1993) as it is widely acknowledged that abuse and neglect are closely linked to the development of difficulties associated with a BPD diagnosis (Ball & Links, 2009; Pietrek et al., 2013; Widom et al., 2009). However, these studies are only correlational, suggesting additional factors such as resilience, opportunities for positive interactions and the development of adaptive coping strategies may mediate the development of difficulties (Alwin et al., 2006; Runtz & Schallow, 1997). Nevertheless, some theories about the mechanisms of why developmental trauma may lead to difficulties associated with a BPD diagnosis have been proposed. One such theory proposes that traumatic and abusive environments may mean that emotional responses in children are invalidated (Linehan, 1993), and parents and carers in these environments may find it difficult to teach children how to regulate and tolerate emotions (Hughes et al., 2012; Kuo et al., 2015).

The development of the difficulties associated with a BPD diagnosis can also be understood using attachment theory. Attachment theory, as proposed by Bowlby (1969, 1973), suggests the bond which develops between child and caregiver is rooted in survival and comfort-seeking and interactions between child and caregiver will shape the ‘internal working model’ of the self and others. Ainsworth et al. (2015) classified children’s attachment as either, secure, avoidant or anxious/ambivalent, with disorganised being added later (Main & Solomon, 1986). Research has shown a consistent negative correlation between measures of ‘BPD symptoms’ and measures of secure attachment (Levy, 2005). An attachment framework could be useful for understanding the difficulties associated with BPD. The attachment behaviours seen in children with an anxious/ambivalent attachment style, such as fearing abandonment and the seemingly extreme efforts taken to avoid this, are captured in the diagnostic symptoms of BPD (Mosquera et al., 2014). Furthermore, disorganised attachment is typified by an approach-avoidance dilemma, whereby to seek comfort a child may need to approach an abusive or threatening figure, and displays an apparent ‘freeze’ response to stressful situations (Holmes, 2004; Main, 1995). It has been hypothesised that the approach-avoidance dilemma may mean a consistent internal working model for the self and others is not developed, and the sense of self and others is incoherent (Liotti, 2000). This may account for some of the difficulties associated with a BPD diagnosis, such as the lack of a stable sense of self and stress related dissociation (Liotti, 2014).

Taking a psychological perspective and using formulation is an important step in considering the development of difficulties and can offer a more individualised understanding than can be described by a diagnostic label alone (Carey & Pilgrim, 2010; Macneil et al., 2012). Psychological formulation is based on the assumption “that however unusual, confusing, risky, destructive, overwhelming, or frightening someone’s thoughts, feelings, and behaviours are, there is a way of making sense of them” (Johnstone, 2018, p. 32). This has been shown to be an important step for service-users, increasing feelings of being understood and developing insight into difficulties (Halpin et al., 2016; Pain et al., 2008; Redhead et al., 2015). For someone with a BPD diagnosis, psychological formulation could offer a more individualised understanding of their difficulties and person-centred approach to interventions (Kramer & Zanarini, 2019).

### Impact of a mental health diagnosis

Although psychological formulation can offer understanding and insight into how difficulties may have arisen, labelling the difficulties with a diagnosis is commonplace (Basco et al., 2000; Frances, 2013). There is much research into the impact of receiving a mental health diagnosis, with it being described as a “double-edged sword” (Penn & Wykes, 2003, p. 203). People with a mental health diagnosis describe experiences of stigma including; internalising stigma by believing they are ‘not normal’, experiencing stigma from others and also institutional stigma in the form of ignorance, culture and a lack of understanding (Huggett et al., 2018). On the other hand some people find having a mental health diagnosis validating of their distress, aiding feelings of containment and see this as an important step in getting support (Milton & Mullan, 2014; Perkins et al., 2018).

When considering the impact of receiving a BPD diagnosis, similar themes have been found. Research has shown discrepancies between service-users' perceptions of the helpfulness of the diagnosis, ranging from it being derogatory and exclusionary, to feeling it provided relief and explains struggles well (Horn et al., 2007; Stalker et al., 2005). However, there is much literature surrounding experiences of discrimination and stigma for people with a BPD diagnosis. Service-users report that having the label of BPD means that services perceive them as 'difficult' rather than in distress (Morris et al., 2014) and that people with a BPD diagnosis are treated differently by mental health services (Vandyk et al., 2019). It appears that for people with a BPD diagnosis, the experiences of stigma are then internalised and are reported to impact negatively on their own self-image (Veysey, 2014).

Despite a move towards collaborative patient centred care, the diagnosis of BPD is still being given in less than collaborative ways (Sisti et al., 2016). It has been highlighted that clinicians may not disclose to an individual that a diagnosis of BPD has been made, believing that service-users may feel hopeless at the sense of stigma and perceptions of BPD as being untreatable (Lequesne & Hersh, 2004; Sulzer et al., 2016). In Sulzer et al. (2016) it was highlighted that when service-users later learnt of their diagnosis, they ended their treatment, potentially perpetuating the stigma by becoming more ostracised. It therefore appears that the way in which a diagnosis is disclosed, or otherwise discovered, may influence a persons' responses to the diagnosis and subsequent mental health and wellbeing (Horn et al., 2007).

## Aim of the study

Previous research has focused on the impact of a diagnosis of BPD on a person's sense of self (Veysey, 2014), views on how the diagnosis conceptualises difficulties (Horn et al., 2007; Stalker et al., 2005), and service-user experience of services (Fallon, 2003; Hörz et al., 2010). However as far as the author is aware there has been no research into the specific process of receiving a diagnosis of BPD and how this impacts an individual's wellbeing. Therefore, the aim of this study is to explore service-user perceptions of how receiving a diagnosis of BPD affects wellbeing. For the purposes of this study the term "wellbeing" is understood as a dynamic concept encompassing the psychological, social and physical resources and challenges a person faces (Dodge et al., 2012).

# Method

## Design

A qualitative design was used to explore the perceptions of participants in this study, with a constructivist grounded theory approach employed to collect and analyse the data (Charmaz, 2006). Unlike positivist grounded theory (Glaser & Strauss, 1967), this approach assumes there is no objective truth to be discovered, instead seeking to explore *how* people construct their experiences. This was felt to be the most appropriate way to address the aims of the study, as this provides a framework to understand a particular phenomenon (wellbeing) and develop a theory about the phenomenon which is grounded in the data.

## Participants

Participants were recruited from adult mental health services, including a specialist Personality Disorder Management Service and a Community Mental Health Team in two separate NHS trusts in the North West of England, and via advertising the research on social media sites Facebook and Twitter. This was to ensure a range of participants were selected and including those who may not be currently accessing services.

The inclusion and exclusion criteria were;

*Inclusion criteria* -

- Aged 18+ at the time of diagnosis
- Have a formal diagnosis of BPD or emotionally unstable personality disorder (EUPD)
- Have been informed of their diagnosis
- Received their diagnosis in the last 5 years
- Living in the UK

*Exclusion criteria* -

- Individuals still undergoing assessment for BPD or EUPD or with an informal, redacted or queried diagnosis

These criteria were chosen to ensure that participants could accurately recall the events surrounding their diagnosis being communicated to them and ensure that a diagnosis would have been made using the latest edition of both the Diagnostic and Statistical Manual of Mental Disorders (2013) and International Statistical Classification of Diseases (2004) diagnostic manuals. Although the diagnosis of ‘BPD’ is most common in the literature, after liaison with services, the decision was made to recruit both people with a diagnosis of BPD and EUPD as services vary between which diagnostic terminology is used but the diagnoses are considered analogous (Lai et al., 2012).

## Procedure

### *Recruitment*

Potential participants contacted the researcher via details on social media adverts or study information sheets, which were handed out to eligible service-users at recruitment sites. 13 individuals expressed an interest in participating, 10 completed demographic information forms (see Ethics Section) and nine completed an interview. All participants identified as female and were below the age of 40. Table 1 illustrates the demographic features of the participants; pseudonyms have been used to protect anonymity. The first three individuals who made contact were initially interviewed and following this, recruitment was conducted on the basis of theoretical sampling (Charmaz, 2006). This involved reviewing the demographic information forms completed by participants and liaison with recruitment sites to focus recruitment efforts on those individuals with experiences which, it was hoped, would provide data that would refine emerging themes and categories.

### *Data collection*

Participants attended an interview via telephone or online video platform Microsoft Teams, which was arranged at a time of their preference. Participants were interviewed with the aid of a flexible topic guide which was developed following liaison with supervisors and people with lived experience of difficulties associated with a BPD diagnosis (see Ethics Section). Semi-structured interviews allowed for structure but also enabled flexibility for participants to raise topics they felt were relevant to them. The topic guide was adapted and refined as the research progressed to ensure subsequent interviews covered emerging themes and categories. The interviews included recording consent, the interview itself and debriefing. Following the interview participants were asked if they would like a copy of the findings. Interviews lasted between 48 and 76 minutes and were recorded using a digital audio-recorder.

## Ethical Considerations

This study was approved by Lancaster University and the project was given full ethical approval by the Oxford-B Research Ethics Committee and corresponding Research and Development Departments for the recruiting NHS trusts.

Prior to participating in the interview all participants provided informed consent. Names given in this report are pseudonyms to protect participants' anonymity. In addition, information that was deemed to be identifiable, such as services or locations was retracted from interview transcripts. At the end of each interview the researcher checked how the participant had found taking part in order to offer a debrief and signposting as appropriate, no participants reported being distressed by the interview process.

## Data analysis

In line with constructivist grounded theory methods, data analysis was conducted alongside data collection (Charmaz, 2006). Interviews were transcribed and initially analysed using line-by-line coding to produce initial codes. The most frequent or significant initial codes were then grouped into focused codes which represented more comprehensive segments of data (Table 2). During this process memos were recorded by the researcher which captured reflections and ideas about how codes may relate to the emerging model (Appendix 2-A). The use of memos allowed for consideration of areas which needed to be explored in greater depth in subsequent interviews and gaps in the emerging model. This process was iterative and completed in groups of three interviews at a time with the researcher using constant comparison methods between already coded and raw data.

The analysis of this data aimed for the principle of ‘theoretical sufficiency’ (Dey, 1999), whereby enough data has been generated to suggest categories sufficient enough to build a theory. This is also in keeping with a constructivist approach which would argue that it would not be possible to achieve ‘theoretical saturation’ as is often the aim of positivist grounded theory (Corbin & Strauss, 2015).

### Quality and reflexivity

The role and influence of the researcher are important considerations when taking a constructivist grounded theory approach (Charmaz, 2006). Throughout the research process the researcher engaged in frequent supervision with two research supervisors. One research supervisor listened to a recording of the first interview to ensure rigor and quality of the interviews. Both research supervisors were consulted throughout the generation of line by line and focused coding, reflections gathered in memos and the developing model. The field supervisor working in a specialist ‘Personality Disorder’ service was consulted to check the final model.

The researcher kept a reflective diary, where they examined their own position in relation to the research. This included identifying their role as a trainee clinical psychologist and experiences of working with people with a BPD diagnosis. Assumptions identified included that people with a BPD diagnosis would have negative experiences when encountering mental health services and personal views on the usefulness of diagnoses in general. To mitigate the effects of these assumptions interview questions were framed neutrally and discussions held with supervisors to ensure transparency during data collection and interpretation. Excerpts from the interviews and analysis process are included in the results and appendices to ensure transparent data interpretation (see Table 3 for example development of conceptual category). However, taking a constructivist approach means acknowledging and being aware of the influence of the researcher's experiences on process and outcomes of the research and that this will affect the generated data (Etherington, 2004; Finlay, 2002). For example, by the researcher identifying themselves as a trainee clinical psychologist, this may communicate to participants some knowledge of mental health systems and structures, assuming shared language and understandings when experiences of divergence and difference may have been underexplored.

## Results

A theoretical model was developed from the interviews and data analysis (Figure 1). This provides a diagrammatic representation of events and processes, beginning with participants' reflections on their lives before the BPD diagnosis, their experiences of receiving a diagnosis of BPD and how these impact on wellbeing. Two key mechanisms were identified as influencing how receiving a diagnosis of BPD is thought to have affected the wellbeing of participants. Firstly, the way in which the diagnosis was communicated, as this laid foundations for participants' perceptions of the diagnosis and subsequent information seeking. Secondly, participants' ongoing experiences of the perceived advantages and disadvantages of living with the diagnosis. These mechanisms culminated in participants being able to evaluate the impact of receiving a diagnosis of BPD on their wellbeing.

### Life pre-diagnosis – "every day was a battle"

Participants contextualised their experiences by reflecting on their life in the weeks, months and sometimes years before receiving a diagnosis. All participants described struggling with their mental health to some extent prior to diagnosis, with some having had significant contact with mental health services and needing to frequently utilise support in times of crisis. Lucy spoke about being "in and out of A&E and hospital" and Megan had been "struggling on and off for years". For some participants the difficulties they were experiencing meant they were actively suicidal, Sandra reported she "just didn't want to be here anymore" and Katy had "planned everything to…end my life."

Participants had a sense that their difficulties were more significant than their diagnoses at that time were capturing. Some participants reported being given other mental health diagnoses in the past, however these diagnoses did not feel like they adequately described the difficulties participants were experiencing. As Rachel explained; "I've not actually got a diagnosis other than depression, which was from 2010, I’m like this is, this isn't depression what I'm going through, like I want to know what is wrong with me". Steph felt her previous diagnoses had not “fully captured what I had been experiencing and almost kind of invalidating because I always wanted to say ‘no, it’s more than that’.” This left participants feeling significantly concerned about their mental health, feeling that there was something seriously wrong with them and making them concerned they were ‘going mad’ (Sandra and Lala).

### Receiving the diagnosis – a myriad of experiences

The experiences of receiving a diagnosis of BPD varied greatly between participants. Two main methods of communicating the diagnosis were used; direct, where the diagnosis was given in a face-to-face setting such as an appointment with a mental health professional, or indirect, where the diagnosis was given via a secondary source such as a letter.

Five participants (Steph, Lala, Megan, Rachel and Katy) received their diagnosis directly from a mental health professional, such as a psychiatric nurse, psychotherapist, or a psychiatrist. Lala and Rachel discussed how direct communication of the diagnosis enabled them to describe difficulties to a professional using their own words and allowed for an “opportunity to explain to her [psychotherapist] everything that had been happening in my life” (Lala). Megan’s experience was distinctly collaborative, with her psychiatrist discussing diagnostic criteria for “PTSD, BPD, Bipolar and Autism” asking her, “do you agree with this, would you say this is you?” before they both agreed on a diagnosis of BPD as fitting best. Participants valued these collaborative conversations as it meant they could get information about potential treatments such as therapy and medication. Having the diagnosis communicated face-to-face enabled participants to have conversations within which they felt reassured and had their worries about the diagnosis contained. Lala remembers her therapist saying “what’s happened is not my fault and that everybody has different ways of dealing with things and it’s just something that happens basically and there is nothing wrong with me.” Megan was told by her diagnosing psychiatrist “it is treatable, you have options”. However, Katy felt that despite being given her diagnosis in a face-to-face meeting, professionals were “not really explaining anything to it [the BPD diagnosis]”.

Four participants (Jess, Tia, Sandra and Lucy) described receiving their diagnosis indirectly. Participants seemed to come across their diagnoses inadvertently, Tia saw the term ‘EUPD’ appear on her GP computer screen and Lucy discovered the diagnosis on legal paperwork. For Jess and Sandra their diagnoses came, unexpectedly, via discharge letters in the post. These participants’ experiences were characterised by being distinctly uncollaborative, with these participants receiving no explanation of what a diagnosis of BPD meant, no opportunity to offer their own perspectives on the difficulties or contribute to an assessment process. Lucy recalled when she read her diagnosis she had "never even heard of it [BPD] before, I was like, what is that?" The uncollaborative nature of how these diagnoses were made and given left participants feeling as though “the label was given and that’s it” (Jess), this was explained by Sandra as being like; “telling someone, oh you know you’ve got cancer…how do you know you haven’t even assessed me?…well we just know, we just know you’ve got it.”

### Responding to the diagnosis – from “thank you” to “what’s wrong with my personality”

Regardless of the way in which the diagnosis was given, every participant spoke of an initial sense of relief when they received the diagnosis. Being given a diagnosis allowed participants to feel relieved as they believed this meant mental health professionals finally understood what was happening and that this would lead to more appropriate and helpful support.

> I almost was relieved as well when he gave me the diagnosis at that point because, it's not a label I particularly wanted, I wasn’t overjoyed, like yes, I've got personality disorder how amazing, but it felt like, OK, so this is what it is and now we know what it is, I’m going to get a treatment that is going to help. (Megan)

After this initial sense of relief participants’ responses seemed to be influenced by the way in which the diagnosis was given. For those participants who were given the diagnosis directly, many had a chance to talk through what the diagnosis meant, have the difficulties associated with the diagnosis explained clearly and discuss potential treatment options with professionals and were more likely to recall positive responses to the diagnosis. This helped participants feel as though receiving the diagnosis was a helpful and necessary step in getting the right support for the difficulties they were experiencing. Participants also recalled the containing nature of having a diagnosis which helped them to make sense of their experiences, Steph recalled her responses to the diagnosis as “like almost like a thank you, that makes sense” and for Lala “getting the diagnosis, hearing the words, somebody trying to explain to me what exactly it is that I am going through, you know I think that saved my life.”

However, for participants who had received the diagnosis indirectly, relief was often accompanied by feelings of anger, frustration and worry. For some this was at the way in which the diagnosis was communicated, Lucy reflected on her anger at “the fact that you are just letting me find that out on a piece of paper.” For others the phrasing of the diagnosis led to worry about being seen as “crazy” and wondering “what is wrong with my personality” (Tia). Participants’ negative responses seemed linked to the diagnosis being evaluated as being less helpful for these participants as they did not perceive there to be benefits associated with receiving the diagnosis, and feeling as though the diagnosis of BPD was not accurate as they were unable to offer professionals their own perspectives on their difficulties.

### Finding out more about the diagnosis – “google is probably the worst”

Every participant discussed how they purposefully found out more about the diagnosis of BPD, apart from Steph who already had knowledge of BPD through her work. Most participants used the internet, using sites operated by the NHS and mental health charities, which were felt to be more trustworthy. However, participants felt that the information here was overly clinical and not reflective of the real-life difficulties they were facing. Some participants reported this meant turning to online forums, where they came across highly judgemental and negative content and found significant stigma surrounding the diagnosis online. Participants reported reading descriptions of someone with a BPD diagnosis as being “so manipulative, they can’t handle relationships, they’re hard to live with” (Lucy) and despite knowing such descriptions were not helpful to read, felt compelled to do so, describing it as “going down the rabbit hole” (Megan). For some this meant their psychological wellbeing was affected, as the initial relief and hope in the helpfulness of the diagnosis disappeared, leading them to believe there was little chance of recovery after what they had read online. For those who had not had much information given to them about the diagnosis, researching online felt like their only option; “I think if it had maybe been explained to me before I googled it I might not have even googled it but I think because I didn’t really know that much about it I just went and looked it up” (Jess).

However, those participants who already had a sense of the diagnosis being helpful for them and a positive effect on their future wellbeing actively chose to stay away from forums or less trusted sites and focused on finding information which would be helpful, such as coping strategies and how to access support (Rachel and Katy). These participants were seemingly bolstered against the negative information they came across online. As Lala described;

> I’ve read a lot of things online you know, I don’t know if they are true or not but I’ve heard things like psychotherapists don’t like working with people with BPD or you know it’s impossible to work with somebody with that type of diagnosis because they are very manipulative and they are this and they are that, so it does have a lot of stigma around it, it’s not nice to hear these things…I’m still waiting for the therapy [laughs] so I don’t have any issues with any psychotherapists or anything at the moment and I don’t think they have any issues with me but I am quite sure time will tell, we will see. (Lala)

It appears that the way in which the diagnosis was initially communicated to participants influenced their actions and responses when finding out more about the diagnosis. Participants who were given the diagnosis directly, with a chance to discuss treatment options, reported positive initial responses and were able to counteract the negative information they later found online. These participants were more likely to maintain the view that receiving the diagnosis was helpful for them and their wellbeing. However, those who had been given the diagnosis indirectly, with no chance for discussion or exploration, reported more negative responses and were more affected by the negative information they found online. In turn this seemed to confirm to them that the diagnosis was not a helpful thing for them and negatively impacted on their wellbeing.

### Experiencing the advantages and disadvantages of the diagnosis

Participants described living with their BPD diagnosis, and how having this diagnosis seemed to influence the responses of services and their social relationships and contributed to experiences of societal stigma.

### *Gaining access to support / Changing responses from services*

Every participant who took part in this study was either currently accessing therapy, or was on a waiting list for therapy. Participants evaluated receiving a diagnosis of BPD as being helpful for their psychological wellbeing when it led to timely and appropriate access to specialist support. Participants spoke of feeling as though they needed the diagnosis in order to access therapy, which was not present or available prior to their diagnosis. Jess, Lucy and Katy all referred to being unable to access therapy “without the label”. Having access to therapy was helpful for participants’ wellbeing and some viewed finally being to access therapy, after years of struggling with mental health difficulties, as lifesaving.

However, for many participants there was often a long wait associated with being able to access therapy and this wait was particularly difficult to manage. Participants reported having to manage significant mental health difficulties during the wait for therapy, often being told that going to A&E would be their ‘only option’ at this time. Participants reflected on the impact of being given a significant mental health diagnosis and then feeling abandoned by the services who diagnosed them, after receiving her diagnosis, Sandra felt “my mental health [got] worse if anything just by not receiving that follow on support.” Megan described feeling; “I’ve just got this label, but I’ve got no medication. I've got no follow up, I've got nothing…that’s a hell of a bombshell to drop on someone to then not see them for months.”

For some participants, receiving the diagnosis led to them experiencing more ‘unhelpful’ responses from services. Some participants felt as though services they were accessing were less supportive of their difficulties once they had the diagnosis of BPD, feeling dismissed as “everyone was just kind of discharging me” (Jess) and that the label of BPD meant that professionals were perceiving their distress differently; “they do just see you as being too sensitive and you know overreacting” (Lucy). Once participants were diagnosed, some recalled feeling as though their follow-up care and follow-up support was badly co-ordinated, for example not being given copies of their own care plans and experiences of being “batted from hospital to case worker, back to another case worker, back to a CBT therapist” (Sandra). It was also felt that once participants had the BPD diagnosis, this overshadowed other difficulties which they wanted help with. This made participants feel as though the diagnosis was not helping their wellbeing, as they were left feeling as though services no longer supported them in the ways they needed. “I do struggle with like things that have happened in the past and like there was like no one really wants to talk about that now that that label is there” (Jess).

### *Feeling connected / Feeling disconnected*

Participants discussed the impact the diagnosis had on their social relationships and times when it made them feel more connected to others or disconnected from others. For some, having the diagnosis meant that they could now connect with others who had also been diagnosed, knowing they shared similar experiences and difficulties. Participants reported using social media to connect with others and take an interest in other people’s experiences. This connection helped participants to “actually talk about your experience and not feel alone in the world” (Sandra) and realise that “it’s not just me” (Rachel) when managing the difficulties associated with a BPD diagnosis. However, for Megan, connecting with others with a BPD diagnosis left her wondering “am I this bad?” and impacted negatively on her wellbeing as she reported feeling “paranoid” about how others perceived her distress.

There were different experiences when participants considered talking to their family and friends about the diagnosis. This was experienced as a ‘trade-off’, with participants knowing it may be helpful for other people to understand the difficulties associated with a diagnosis of BPD and would aid connection. However, participants anticipated risks due to the stigma and misinformation about the diagnosis if family and friends were to search for information online, which fuelled a sense of disconnection. Steph reflected how she “didn’t tell anyone because…if you google it great things do not come up.” Katy pre-empted this by actively giving her friends and family specific websites so they had “something to read as well so they could understand you more.” Ultimately, most participants made the decision to only disclose their diagnosis to a few people, and when participants did make the decision to tell others, this was usually just close family members and friends. For Steph, she chose to tell only two people who were perceived to “understand what it [BPD] is and they understand the stigma associated with it.”

Some participants experienced a sense of disconnection from others in relation to romantic relationships, wondering how future partners would react to or be accepting of their BPD diagnosis. Some participants described a decision to avoid relationships for worry of having to explain their diagnosis. Megan questioned “how do you tell somebody that you are emotionally unstable?” This was accompanied by a fear that “if I confide in that person and I tell them about my mental health are they just going to run away?” (Lala). Thus, this concealment fuelled a sense of being disconnected from others by being unable to openly discuss their mental health difficulties.

### *Managing impact of stigma / Struggling with impact of stigma*

Participants reflected on the experience of societal stigma in relation to the diagnosis on areas of their life including work and general life ambitions. Most participants experienced struggling with the impact of the stigma that came with a diagnosis of BPD.

Despite participants’ differences in preferences using either ‘Borderline Personality Disorder’ or ‘Emotionally Unstable Personality Disorder’ to describe their difficulties, most participants reflected on the language of the diagnosis perpetuating stigma and having to manage this. Some participants considered ‘EUPD’ to present an image of a person who does not fit within societal norms, is unbalanced and unreliable, and depicts someone as being “a hysterical woman” (Megan). It was felt that generally people in society were perceived to be unaware of what a diagnosis of BPD meant, and participants felt the language used perpetuated misunderstandings instead of offering explanations. This was felt by Lala who described “when you say borderline and then you mention personality disorder it just sounds like a freak show…I’m not just this crazy person who has multiple personalities.”

For those participants in work they discussed the difficulties with their employer knowing about their diagnosis of BPD due to perceived stigma. To mitigate this, participants sometimes used terms such as ‘anxiety and depression’ when describing their mental health to employers. However, participants felt as though they had no choice in telling their employer about the diagnosis when they needed time off to access therapy as appointments could often be in the middle of the day. Some participants anticipated stigma from employers about the term ‘personality disorder’ as this was thought to convey a difficulty which was not going to get better. Lala reported; “I haven’t told them [employer] about my diagnosis because I feel like the minute I do they’re gonna feel like well she’s never going to be capable of coming back to work”. Even after disclosing their diagnosis to employers, participants’ awareness of the stigma surrounding the diagnosis meant they felt under pressure to present themselves in particular ways at work;

> I worry now about showing any form of emotion, erm and but I also equally worry that if I am not showing emotion they think that I am hiding things so it’s kind of get that balance of how do I present myself with this diagnosis (Steph).

Some participants reported the impact of stigma surrounding the diagnosis on other areas of their life, for example Sandra was now unable to “secure…life insurance because to help my kids if [anything] does happen to me.” Megan wondered about the impact of the diagnosis on her plans to adopt; “I know that now I’ve got this on my medical records it’s going to be extremely hard.”

However, some participants reported that although they were aware of the societal stigma associated with a diagnosis of BPD they felt able to embrace life and were still able to pursue their life ambitions. Jess reported her diagnosis “might make things a bit harder, how I feel, but [it’s] not stopped me from doing what I want”. These participants seemed to draw upon other life events to put their diagnosis into perspective, looking at their role as an employee, parent, partner, daughter or student. This appeared to help them manage the impact of stigma by focusing on their life outside of mental health difficulties. For example, Katy felt the diagnosis meant “realising your potential and what you can do with it…I think I can do anything I want career wise, whatever, as long as you manage in the right way, you know you can…be fine and live a healthy life.”

### Evaluating the impact of the diagnosis – “worth it in the long run?”

The two mechanisms, the way in which the diagnosis was communicated and ongoing experiences of the perceived advantages and disadvantages of living with the diagnosis, culminated in participants evaluating the impact of a diagnosis of BPD on their wellbeing, which appeared to be a spectrum from more helpful to more unhelpful.

For some participants having a diagnosis was seen as fundamentally helpful for their wellbeing, as it fostered a sense of understanding and control over their difficulties which they did not have prior to diagnosis. This meant having a sense of containment to previously uncontainable and confusing emotions by being able to recognise and label them, as Rachel described “it helped me to realize that, ah okay that's impulsivity, that's abandonment issues, and then I can deal with that…rather than be like what are all these things?”

Conversely, some participants believed that receiving their diagnosis negatively impacted their wellbeing, these participants spoke about not wanting to have the diagnosis or having it removed in the future due to the negative impact it was having on them. This was in part due to responses of services and sense of hopelessness that a diagnosis of a 'personality disorder' conveys. Lucy reflected "I don't want the diagnosis and that's just me being honest…it's left me feeling quite hopeless a lot of times, it still does because I'm still in need of treatment…because [having BPD] it means you are not taken seriously."

Other participants sat somewhere in the middle and felt that receiving the diagnosis had not made a difference as it had not brought about discernible changes to their lives. They reported still struggling with the same difficulties, and the label of BPD had not altered that. Some wondered whether it was the support which came alongside the diagnosis, rather than the diagnosis itself, which made the difference to their wellbeing. As Katy pondered "does a diagnosis make a difference or is it just that I'm now in a better place, because I'm taking better care of myself?"

## Discussion

Participants in this study saw receiving a BPD diagnosis as impacting on their wellbeing in both helpful and unhelpful ways. Direct communication from health professionals at the point of diagnosis, with the opportunity for the diagnosis to be explored and explained, resulted in participants feeling contained and understood, and bolstered against negative information participants later came across online. However, indirect communication often left participants feeling angry and confused and subsequently found it harder to dismiss negative information they found about the diagnosis. All participants experienced living with the advantages and disadvantages of the diagnosis in relation to service responses, social relationships and experiences of stigma. These experiences contributed to the overall perceived helpfulness of receiving a BPD diagnosis.

The findings from this study fit with previous research into the impact of how mental health diagnoses are communicated. Participants in research by Milton and Mullan (2017) discussed the importance of face-to-face communication about a serious mental health diagnosis, reporting lowest satisfaction when stigma was not actively tackled, fears and concerns about the diagnosis were not addressed, and when additional web-based information was not given. Furthermore, in a systematic review into a range of mental health diagnoses including anxiety, depression, schizophrenia, personality disorders and bipolar, Perkins et al. (2018) discussed the importance of the ‘functional value’ of receiving a diagnosis and that it should be a tool for recovery. This was also viewed as important for the participants in the present study who reported that having a BPD diagnosis enabled them to access therapy. This study adds to previous research by exploring the mechanisms by which these factors go on to influence wellbeing for people with a BPD diagnosis. This study has emphasised the importance of open conversations around mental health diagnosis, as diagnosis was experienced more positively when it emerged out of a conversation, particularly when the conversation was collaborative and participants had a say in whether they want a particular diagnosis.

These findings fit with the model of wellbeing proposed by Dodge et al. (2012). This considers wellbeing to be a dynamic concept whereby there is a “balance point between an individual’s resource pool and the challenges faced” (p. 230). This study adds to this understanding by highlighting the specific challenges faced by people when receiving a BPD diagnosis, and the resources they need to draw on to manage these challenges. The challenges which were highlighted in this study included coming across negative information online, experiencing changing responses from services, feeling disconnected and experiencing stigma. It may be that participants’ resource pool improved when they were provided with containment and understanding of the difficulties and given timely support, meaning participants were better able to manage the challenges faced when receiving a diagnosis of BPD.

## Limitations

Participants in this study were all female and of a younger age. This clearly limits the transferability of the findings reported here. It may be that males who receive a diagnosis of BPD are affected in different ways to females. However, this sample highlights the wider gendered aspect of the BPD diagnosis and in fact may accurately represent the service-users who are often given this label by mental health services (Sansone & Sansone, 2011).

A further limitation is the small sample size for a grounded theory methodology. Due to the influence of Covid-19 pandemic advertising of the study and recruitment was particularly impacted. Services from which participants were recruited were offering few face-to-face contacts and researchers were not able to visit sites to promote the study. Despite the limitations of a small sample, a fairly robust model was developed from participants’ interviews, and in line with constructivist grounded theory methodology, this study seeks to offer understanding rather than explanation of how participants' wellbeing is affected following a diagnosis of BPD.

### Clinical implications

A primary factor which contributed to positive wellbeing following diagnosis was the perception that a BPD diagnosis was needed in order to access psychological therapy. However, in some cases participants reported long waiting times in order to access therapy and having little or no follow up support after they received their diagnosis, which impacted negatively on their mental health and wellbeing. The mental health and wellbeing of any service-user is of importance to clinical psychologists, but is of significant importance given the difficulties associated with a BPD diagnosis. Clinical psychologists are in a unique position to bring together their psychological understanding of the difficulties associated with this diagnosis to influence and improve services for these service-users, through policy development, organisational development and service redesign. This research gives empirical support to clinical psychologists influencing services by highlighting that if a diagnosis is going to be given, services need to ensure that adequate support be given alongside diagnosis, such as timely follow up, open discussion around the stigma associated with the diagnosis and an emphasis on treatment options.

Furthermore, some participants in this study felt that a BPD diagnosis offered a sense of understanding of and containment for the difficulties experienced, but also led to experiences of stigma and prejudice. As NHS services often require a diagnosis to be made (Court et al., 2017) there are alternatives to a BPD diagnosis, with arguments that 'complex PTSD' would be more accurate, less stigmatising diagnosis that incorporates an understanding of aetiology of the difficulties (Lewis & Grenyer, 2009). For clinical psychologists it is important to highlight these alternatives in services which may use BPD diagnoses and appropriately challenge or seek compromises within services in which the medical model is deeply embedded (Cooke et al., 2019).

It was also notable that none of the participants discussed psychological formulation as occurring alongside diagnosis, this is despite guidance from the Royal College of Psychiatrists (2020), acknowledging that “diagnosis alone is insufficient and good care should be guided by a co-constructed biopsychosocial formulation which gives patients an experience of being understood” (p. 10). The use of psychological formulation alongside diagnosis could help to provide service-users with the benefits described by the participants here (feeling contained and understood) while allowing for stigma and prejudice associated with the diagnosis to be challenged. Psychological formulation could also be used to tackle some of the disadvantages experienced by participants in this study, by supporting staff teams to understand the relational aspects of the difficulties associated with a BPD diagnosis, providing a more psychological understanding of the difficulties experienced and contribute to more person-centred treatment.

## Future research

There are aspects of the model developed here which could be expanded on through further research. Although touched upon in this study, future research could explore the more detailed aspects of a communication of a diagnosis of BPD, for example the language used by the clinician, how the diagnosis was broached and exploration of the diagnosis. This could highlight what the specific processes which mean direct communication is helpful to participants wellbeing. This could also help to improve knowledge about helpful ways to communicate a diagnosis of BPD and culminate in practice driven theory about the most helpful ways to make and communicate these diagnoses and inform the development of more collaborative approaches to use of diagnosis.

To further build on the findings and model developed in this study it would be important for future research to focus on understanding the interaction between the different aspects of the advantages and disadvantages of living with the diagnosis. This would help to develop a more dynamic and interactive understanding than was possible here by using a qualitative approach to consider how service-users manage the challenges faced when receiving a BPD diagnosis. This could explore how participants resources may mitigate challenges faced and if there is a certain threshold which needs to be reached for someone to ultimately view the diagnosis as helpful or unhelpful for their wellbeing.

Based on the findings and clinical implications of this study, it would be important to capture how experiences of psychological formulation fit with the model developed here, as this is something which should be occurring for service-users according to good-practice guidelines but was not discussed by participants in this study. It may be that formulation influences the mechanisms described in this study, for example by helping service-users to make sense of their difficulties, or mitigating some of the disadvantages of living with the diagnosis of BPD by tackling internalised stigma or giving participants a different framework for discussion within social relationships.

## Conclusion

In conclusion, in this study nine participants with a BPD diagnosis were interviewed about their experiences of receiving this diagnosis and how this impacted on their wellbeing. Although varied, their experiences highlighted common mechanisms and challenges which impacted on their overall wellbeing. Clinical psychologists are in a unique position to influence and improve services for people with a BPD diagnosis and to continue to promote alternative narratives to psychiatric diagnosis.

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**Figure 1: Model representing how receiving a diagnosis of BPD affects wellbeing**

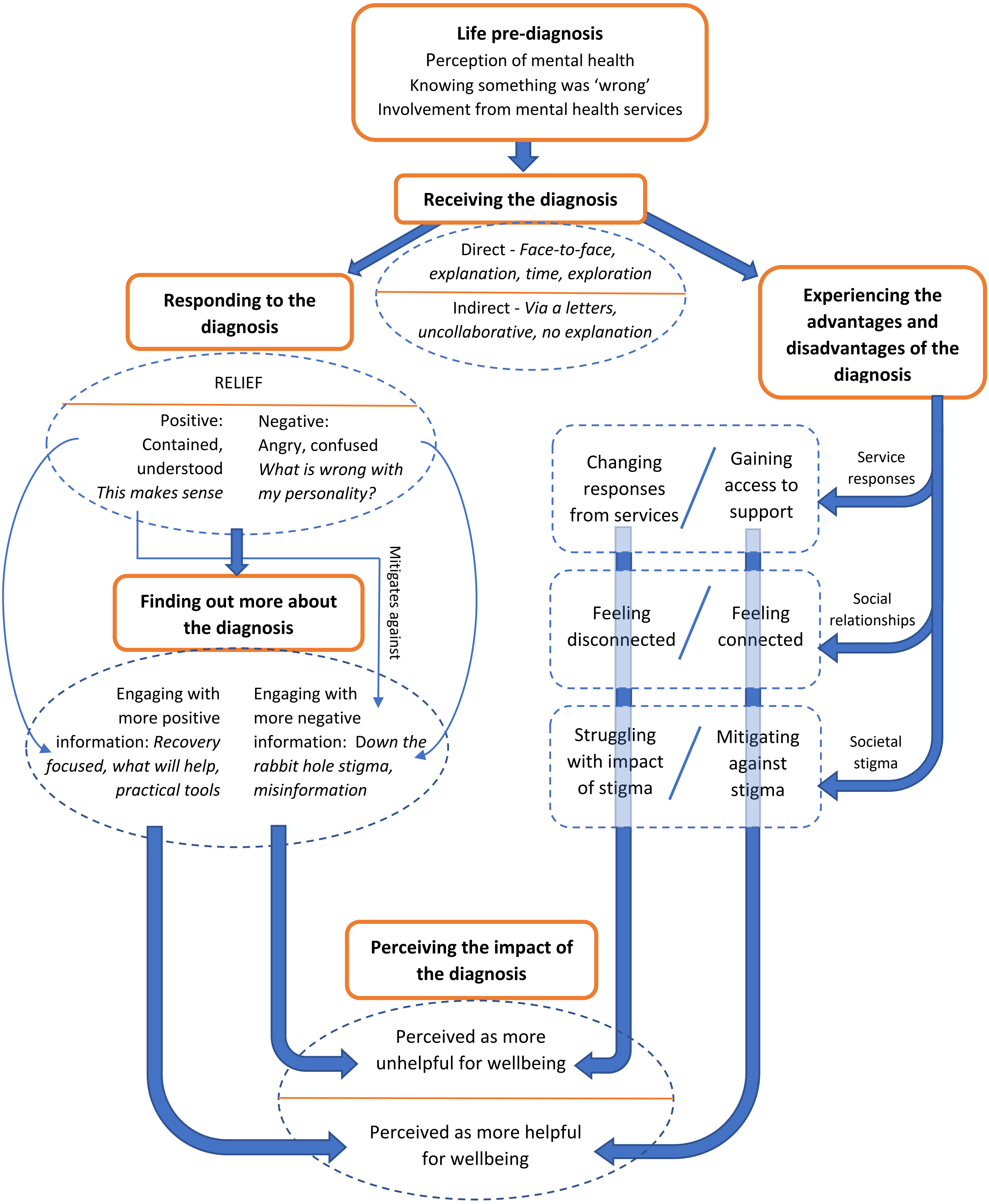

**Table 1: Participant Demographic Information**

| Pseudonym | Age | Gender | Ethnicity | Time since diagnosis | Method of communication | Disclosing individual | View of wellbeing now |
|---|---|---|---|---|---|---|---|
| 1. Steph | Female | 18-29 | White British | <1 year | Face to face | Psychiatric Nurse<br>Psychiatrist | Okay |
| 2. Lala | Female | 30-39 | Mixed race – African/British | 1-2 years | Face to face | Psychotherapist | Very poor/poor |
| 3. Jess | Female | 18-29 | White British | <1 year | Indirect | A&E discharge letter | Poor |
| 4. Tia | Female | 18-29 | White British | <1 year | Indirect | GP records | Poor |
| 5. Sandra | Female | 18-29 | White British | 3-4 years | Indirect | Psychiatric hospital discharge letter | Okay |
| 6. Lucy | Female | 18-29 | White British | 2-3 years | Indirect | Court report letter | Poor |
| 7. Megan | Female | 30-39 | White British | 1-2 years | Face to face | Psychiatrist | Good |
| 8. Rachel | Female | 30-39 | White British | 1-2 years | Face to face | Psychiatrist | Good |
| 9. Katy | Female | 30-39 | White British | 2-3 years | Face to face | Psychiatrist | Good |

## Table 2: Sample transcript with initial line-by-line codes

| Line | Person | Transcript | Initial Codes | Focused Codes |
|---|---|---|---|---|
| 41. | I | I just wonder for you, what was that like, what was the impact of sort of that experience for you? | | |
| 42. | P | It meant that I had to wait longer to get help, it took longer to actually understand what was going wrong with me, erm, so it took longer to actually, for us as a family unit, to try and help me, the best way we could, like in a helpful way erm so it's no good letting me just stay upstairs for two weeks, not that that's ever happened, this is just example, but you know, it's no good saying, you know we don't know what's going on with her, she needs to be in her room for two weeks, that's what she feels like but that's not, that's not something helpful, you know you need to, so being able to like label it, like why is that person in the room, it's like no idea, well find out why, it's like yeah we're trying to find out but you know so there still in room, is like yeah erm yeah | Waiting to get help<br>Taking time to understand what was wrong<br>Figuring out how to help self<br>Working out what is helpful<br>Being left isn't helpful<br>Not knowing what is wrong<br>Not knowing what is helpful<br>Needing to label difficulties<br>Finding out why difficulties are happening<br>Trying to figure it out | Taking time to understand what was wrong<br>Not knowing what is helpful<br>Trying to figure difficulties out |
| 43. | I | So do you see it is having any impact on like your mental health and well-being kind of that wait and having to sort of go so long? | | |
| 44. | P | Sorry now my mom's calling, I've cancelled her you're alright [laughs] erm yeah, I think, I think it did erm by not knowing what was wrong, it's bit like I don't know what difficulties I'm going to be facing erm, like I don't know what to be looking out for, I don't know warning signs or anything even to the point of like I don't know why I keep experiencing this, erm an obviously it's like, even though it's my mental health which is, literally being unstable erm since 2017 is a bit like, it has an impact on my family too, erm, I like I like with my kids and stuff so I am just like why am I pushing them away? I don't get it. And then obviously then you start having all your negative thoughts 'cause you like, I'm a bad mom, and this that and the other and because I can't label nothing, I don't know why I'm in this darkness, because nobody is shining a light onto the tracks, if you will, so yeah, just yeah, being left high and dry for so long, had a really bad impact because I've lowered myself | Not knowing what was wrong<br>Not knowing what difficulties you are facing<br>Not knowing what to look out for<br>Not knowing warning signs<br>Not knowing why experiences are happening<br>Perceiving mental health as unstable<br>Seeing impact on family<br>Questioning pushing family away<br>Having negative thoughts<br>Being unable to label experiences<br>Unable to make sense of difficulties<br>Being left 'high and dry'<br>Experiencing lower self esteem | Lacking knowledge and understanding into difficulties<br>Seeing mental health impact on family<br>Unable to make sense of difficulties |

| | | | | |
|---|---|---|---|---|
| | | esteem even lower than what it was before, I've lowered my self-confidence even lower than what it was before, erm, I effectively stopped parenting and let my husband do it, I lost all confidence in parenting, to the fact that I wouldn't take my kids to bed, I just yeah, couldn't do it, so yeah, it was very impactful. | Experiencing lower self confidence<br>Being unable to parent<br>Losing confidence to parent<br>Being unable to take children to bed | Impacting on self-esteem<br>Losing confidence to parent |
| 45. | I | Very yeah, it sounds like it, and is that something that you notice change then when you had that diagnosis confirmed? | | |
| 46. | P | Yeah, because then I could understand then like I could label it, so I'd know then it's not me pushing people, well it is me pushing people away but it's not, intentionally directed at my children, so it's not like a mother-child kind of pushing away like I experienced with my mum is more of a general, OK I need some space, there's something, things are processing, I need some space, so for me that's an indication that something is brewing, if I'm starting to push people away and it's from that point, like you can then intervene, it'll be like OK, let's talk what's on your mind, and then it doesn't actually have to develop into an even further problem, it can actually be dealt with, erm but that's only once you've got the the insight, so there's obviously a couple of times I've pushed people away, I've no idea I've done it, no idea why, and again, hindsight, it's beautiful, erm we should bottle it and drink it [laughs] hindsight yes I'll drink it every morning, yeah so yeah, it's only it's only with that but yeah. | Being able to understand difficulties<br>Being able to label behaviours<br>Seeing behaviours as not specific to others<br>Seeing behaviours as more general reflections of mental state<br>Noticing things 'brewing'<br>Being able to intervene<br>Talking about what's on your mind<br>Stopping difficulties developing<br>Dealing with difficulty<br>Needing insight<br>Pushing people away<br>Not knowing why<br>Needing hindsight | Being able to understand difficulties<br>Seeing behaviours as more general reflections of mental state<br>Being able to stop difficulties developing<br>Needing insight into difficulties |

## Table 3: Development of Conceptual Category

The table below shows a sample of focused codes which were used to develop the conceptual category “Feeling connected / Feeling disconnected”, the corresponding initial codes, quotes and interviews these codes were developed from.

| Focused Codes | Initial Codes | Participant | Quotes |
|---|---|---|---|
| Explaining lack of disclosure<br>Difficulty explaining diagnosis | Perceiving lack of understanding<br>Explaining lack of disclosure<br>Perception of information about the diagnosis<br>Selecting people to tell<br>Basing decision on others understanding of stigma<br>Explaining lack of disclosure<br>Difficulty in explaining the diagnoses | Steph | “Particularly in my life, my support system around me no one has even heard of it so I didn’t tell anyone because I didn’t want, if you google it great things do not come up so, I didn’t want to”<br>“They’re the only people that know because they understand what it is and they understand the stigma associated with it, but I haven’t told anyone else because you then have to explain what it is and it’s a really strange concept when you have never hear of a personality disorder it doesn’t really make sense, it’s a really odd thing to try and explain” |
| Explaining lack of disclosure<br>Anticipating impact on work | Deciding not to tell people<br>Anticipating other’s responses<br>Anticipating rejection?<br>Taking time off work<br>Not disclosing diagnosis at work<br>Anticipating others perception of ability to work<br>Disclosing the diagnosis<br>Predicting others won’t be accepting | Lala | “Even up until today there are certain people that I know that I haven’t told just because I don’t know how they would receive that bit of information or how they would accept it, if they would accept it you know, so there’s especially with my work place, I mean I am currently off sick long term with my work place which I am very grateful for, even though they know I am off with mental health I haven’t told them about my diagnosis because I feel like the minute I do they’re gonna feel like well she’s never going to be capable of coming back to work” |
| Feeling forced to tell employer<br>Not wanting employer to know about diagnosis | Struggle to fit therapy around work<br>Telling employer about therapy and diagnosis<br>Feeling scared<br>Putting it off<br>Almost not engaging in therapy<br>Not wanting to tell employer | Megan | “Yea the difficult thing is that services aren’t really set up for people who work, so I’ve had to tell my work that I have to go to therapy because I have a personality disorder, and that scared me, I put it off for a long time and I almost didn’t go to, I almost didn’t engage in the therapy because I did not want to have to go to my employer even though I work for XXXX, to tell them I have a personality disorder” |
| Connecting with others with BPD<br>Not feeling alone | Following people on twitter<br>Being interested in others experiences now | Rachel | “So like on my Twitter now like I follow people that also have it so I’m now interested in other peoples’ experiences because then I feel more connected because before I felt really alone and now it's like |

| | | | |
|---|---|---|---|
| | Feeling connected to others<br>Feeling alone before<br>Believing she is not alone<br>Understanding the ‘ups and downs’ | | actually I'm not alone, I don't have to feel it and I now understand that I am gonna feel up and down, up and down, sometimes it's up and down every minute, sometimes it's up and down every couple of hours every couple of days, every couple of weeks, and knowing that I'm on just this up and down, up and down, up and down, what feels like constantly that it’s not just me” |
| Not wanting to tell employer<br>Perceiving judgements<br>Being unwilling to have a romantic relationship | Needing to make therapy appointments<br>Wishing to not disclose to employer<br>Anticipating negative impact<br>Perceiving judgements from lack of understanding<br>Not wanting to be treated differently<br>Not getting into a romantic relationship<br>Anticipating explaining diagnosis to partner<br>Seeing self as a nice person<br>Not willing to be in a relationship | Katy | “Because I needed to make the appointments and you need special leave for it, but for me if there's a choice I probably wouldn’t tell my employer, because of negative, how it could negatively impact, and the judgments from it and do they really understand it and you don't want to be treated different or special, you know if I’ve done something wrong I need to be told, you know, you need to fix it but I don't know if that's your own insecurities and fear"<br>"Because I won't have a relationship because I don't want to get in a relationship because I don't want to have to explain that I've got a personality disorder, even though I'm probably one of the nicest people you could be in relationship, it’s just something that I'm not willing to do, because it's just scary to me that" |

## Appendix 2-A: Sample memo from Jess' interview

*Finding out about the diagnosis*

Jess found out about her diagnosis after receiving a letter following discharge from A&E. This felt like a shock for Jess, there was little anticipation of a diagnosis coming at this point. Jess later reflected that a 'diagnosis' had been mentioned by mental health professionals but that this was not expanded on or discussed further with Jess. The sense that the diagnosis of BPD was kept from her?

*Changing responses to the diagnosis*

Jess talked about not necessarily wanting a diagnosis, but despite this feeling relieved as it meant there was a reason for why she was feeling like she did. However, this relief only lasted until she searched for more information about the diagnosis online, then her relief disappeared. Something about seeing negative information changes people's perspectives on the diagnosis when they become aware of the stigma associated?

*Getting access to therapy*

Jess described the diagnosis enabling her to access to specialist services, but that her CMHT quickly discharged her following the diagnosis. She was anticipating that therapy was going to be helpful despite the fact that she was still waiting to access this.

*Stigma*

Jess wondered out loud whether having the diagnosis was worth it. For Jess it was a toss-up between getting support and perceiving stigma surrounding the diagnosis, that the perception is that things cannot get any better for people with this diagnosis, and that it will always be on her medical records, but perceived the diagnosis to have little impact on her life in the long term once she envisaged being out of mental health services.

## Appendix 2-B: Author Guidelines (Psychology and Psychotherapy: Theory, Research and Practice)

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**Sections**

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*Author Guidelines updated 28th August 2019*

## Appendix 2-C: Practitioner Points for Journal Submission

Practitioner points:

- The diagnosis of BPD is controversial, yet it still regularly diagnosed in people who struggling with emotional regulation, self-harm and suicidal ideation.

- Participants valued receiving this diagnosis when it was given collaboratively, with adequate explanation and an emphasis on treatment.

- However, participants' experiences also highlighted how the diagnosis of BPD is still being given via covert an unhelpful means, which were shown to negatively impact on their wellbeing.

- Alternatives to the diagnosis of BPD, such as complex-PTSD, psychological formulation and open, collaborative conversations about diagnosis should be promoted in settings where the medical model and psychiatric diagnosis are dominant.

# Section Three: Critical Appraisal

## A critical reflection on conducting research into the diagnosis of 'Borderline Personality Disorder'

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# A critical reflection on conducting research into the diagnosis of ‘Borderline Personality Disorder’

In this critical appraisal I will summarise the findings of the research paper and reflect upon the process of conducting the research, “How does receiving a personality disorder diagnosis affect wellbeing? A grounded theory investigation.” This will include my own motivations and personal interest which led me to conducting research in this area, and the discomfort I experienced by seemingly collaborating with the medical model of mental health difficulties. I will then discuss the process of conducting a constructivist grounded theory study and managing the influence of my own views and assumptions. Finally, I will consider issues relating to conducting research during the Covid-19 global pandemic.

## Outline of the research paper

The aim of the research paper was to explore the experiences of people who had received a diagnosis of Borderline Personality Disorder (BPD) and their perceptions of how receiving this diagnosis had impacted on their wellbeing. Previous research has shown that receiving a diagnosis of BPD contributes to a negative self-image (Veysey, 2014), and had highlighted the discrepancies between service-user accounts of the perceived helpfulness of the diagnosis and how it conceptualises difficulties (Horn et al., 2007; Stalker et al., 2005). These findings emphasise that receiving a diagnosis of BPD is likely to influence a person’s subsequent wellbeing. However, what I found to be missing from these papers was the understanding of the process by which receiving a diagnosis of BPD impacted an individual’s wellbeing. The research paper therefore employed a constructivist grounded theory approach to address this question. Nine participants were interviewed who had received a diagnosis of BPD in the last five years. Interviews were transcribed and analysed to produce a theoretical understanding of how receiving a diagnosis of BPD is thought to impact on a person’s wellbeing. Two key mechanisms were seen to influence this, firstly the way in which the diagnosis was communicated. Direct communication, with the opportunity for the diagnosis to be explored and explained, resulted in participants feeling contained and understood and appeared to bolster these participants against the negative information they later came across online. However, indirect communication of the diagnosis often left participants feeling angry and confused, and when seeking information online, found it harder to dismiss the negative information they found. The second mechanism which influenced wellbeing was participants' experiences of living with the advantages and disadvantages of the diagnosis. This included the responses from services to the diagnosis of BPD, how the diagnosis impacted on social relationships and participants' sense of societal stigma. These mechanisms culminated in participants considering whether receiving a diagnosis of BPD was helpful for their ongoing wellbeing.

## Motivations for the study

My interest in this area stemmed from my experiences working in NHS adult inpatient services as a health care assistant between 2016 and 2017, shortly after completing my undergraduate psychology degree. I worked predominantly into two female acute wards where service-users appeared to be mostly young women struggling with emotional regulation, self-harming behaviours and long-standing suicidal ideation. Many of these young women had already been given a diagnosis of BPD prior to coming to hospital but some were diagnosed during admission. I recall one particular incident where a service-user became extremely distressed following her Care Programme Approach (CPA) meeting with the ward psychiatrist, during which this young woman had been told she had a diagnosis of BPD. Until this point, she had believed that her difficulties were best described using a label of Bipolar and believed the ward psychiatrist had in fact diagnosed her with this previously. The following weeks were very difficult for this young woman and her mental health immediately declined. I wondered what had happened in this CPA meeting to affect this young woman in such a way. When I asked a nurse why this might be, I was told "nobody wants to have a personality disorder, it's much more acceptable to have a mood disorder." I noticed on the ward her behaviours were now looked at in different ways, with some staff believing she was trying to prove she did in fact meet criteria for a diagnosis of Bipolar and not BPD. Still being somewhat naïve and new to acute mental health services I was not entirely aware of the stigma surrounding 'personality disorders', but it felt clear from the reactions of staff and service-users that this was not a diagnosis people wanted to receive.

Following this I have continued to work into NHS services as part of my clinical psychology training and have gradually been exposed to the ongoing stigma associated with this diagnosis, despite continued policies to change this (National Institute for Mental Health in England, 2003; Royal College of Psychiatrists, 2020). However, while on placement within an adult CMHT, I was somewhat surprised to work with a service-user who had been diagnosed with BPD and found the diagnosis extremely helpful for her mental health. This made me reflect on the vastly different responses people have in relation to the diagnosis of BPD and wonder how these different responses were formed. When reviewing the literature there seemed to be a growing field of qualitative research which incorporated service-users' perceptions of the use of the BPD diagnosis (Stalker et al., 2005), the experience of living with the difficulties associated with the diagnosis (Ntshingila et al., 2016) and the experience of accessing services (Fallon, 2003; Vandyk et al., 2019). However, there appeared to be no research into how receiving a diagnosis of BPD influenced a person's mental health. This led me to forming the aim of the research paper "to explore service-user perceptions of how receiving a diagnosis of BPD affects wellbeing."

## Collaborating with the medical model

One issue I have spent time considering while conducting my research project is the collaboration with the medical model for mental health and use of psychiatric diagnosis. I was aware that as a trainee clinical psychologist conducting research into psychiatric diagnosis, this may be viewed as endorsing and perpetuating this way of thinking about people and the difficulties they experience. However, I am aware of the role of clinical psychologists in "remain[ing] engaged in critical debate and to channel uncomfortable feelings into constructive action to improve services" (Cooke et al., 2019, p. 201). I spent time reflecting on the benefits of using a categorical diagnostic framework for research, as it allows for research to occur within populations that experience similar difficulties (Cuthbert & Insel, 2013). This generates the development of knowledge, theory and understanding of the experiences of these individuals, and without a diagnostic label this may not be possible.

However, the diagnosis of BPD is acknowledged to be particularly controversial, with problems with the reliability and validity of the diagnosis (Pilgrim, 2001) and is associated with significant stigma (Morris et al., 2014). My personal stance is that the diagnosis of BPD is a social construction of the distress experienced by people who have often experienced significant interpersonal trauma (Ball & Links, 2009; Widom et al., 2009) and that this should not be labelled as a problem located in someone's personality, as the very nature of the difficulties are often relational (Giffin, 2008). If a diagnosis is needed there are alternatives to the use of BPD, such as complex PTSD (Lewis & Grenyer, 2009) or the term 'trauma induced emotional regulation and interpersonal relational difficulties' (Darongkamas et al., 2020). It is my belief that these labels may be more accurate and less stigmatising than a diagnosis of BPD. There have also been suggestions to change the construct of 'personality disorders' by introducing a dimensional approach to the diagnosis rather than the arbitrary categories which currently exist. This was proposed for the most recent edition of the DSM-V, but was rejected as 'unworkable' despite strong support from professionals in the field about its use and validity (Oldham, 2015). Despite these suggestions the BPD diagnosis is still widely used in mental health services and this present study highlighted how some individuals currently accessing services in the UK are still being given a diagnosis of BPD via covert and uncollaborative means, despite ongoing guidelines to change this (National Institute for Mental Health in England, 2003; Royal College of Psychiatrists, 2020).

I had originally wondered whether my research would help to highlight some of these criticisms with the use of the BPD diagnosis, from the perspective of the service-user, but as the research progressed I was surprised by the number of participants who openly discussed the helpfulness of the diagnosis. This perceived helpfulness has also been documented in the wider literature (Horn et al., 2007; Stalker et al., 2005). This reminded me of the African proverb “when the elephants fight, it is the grass that suffers”, which made me reflect on how clinical psychologists and psychiatrists may differ in their views on the usefulness and validity of psychiatric diagnosis and in particular BPD, but the voice of the service user may be lost in this professional discourse. Listening to the participants themselves and giving power to their voices through doing this research helped me manage my own unease in seeming to collaborate with the medical model and perpetuating the use of the diagnosis of BPD.

## Managing the influence of my own stance while conducting research

When conducting qualitative research, it is important for researchers to ‘bracket’ their own assumptions, experiences, interests or hunches about the topic in question (Fischer, 2009). This is a process by which researchers identify and temporarily set aside or shelve these potential influencing factors. As discussed above, I brought my own motivations, assumptions and experiences to the research, however using a constructivist grounded theory approach enabled me to be reflexive about my position in relation to the study design, data collection and analysis.

During the study design phase, I held open discussions with my research supervisors considering my own position on the use of the BPD diagnosis. Reflecting on my own surprise at meeting a service-user who felt positively about her diagnosis I was able to identify the biases I held, as I had previously implicitly believed people would respond negatively to a diagnosis of BPD. To help me bracket my own assumptions I developed a topic guide in collaboration with my research supervisors, and field supervisor who worked within a specialist ‘Personality Disorder’ service. Interview questions were constructed in a way to promote neutrality, before going on to ask for both positive and negative or helpful and unhelpful reflections and experiences from participants. This topic guide was also further expanded on by two service users who had experiences of the difficulties relating to a diagnosis of BPD. Through reviewing the topic guide with them I was able to consider how questions may be interpreted by potential participants.

While concurrently collecting and analysing data it was important to for me to continually manage the influence of my own assumptions and take steps to mitigate any undue influence. To do this I kept a reflective diary during the process of collecting and analysing data, to document my thoughts and the processes which occurred in each interview. My research tutors listened to my first interview in full, with the corresponding written transcript, line-by-line initial codes and focused codes also checked by one of my research supervisors. Through discussions with my research supervisors and my own reflections it was identified that I had a tendency to shift into interpreting participants’ responses during the earlier interviews instead of taking the time to explore the participants’ experiences in greater depth. For example;

> *Participant 1: …it’s a really odd thing to try and explain so I think that is quite difficult is when you are given that diagnosis obviously everyone knows what bipolar is, it’s not everyone correctly knows, in a way, but everyone, if you say it people understand in a way, but you can’t walk around and tell your friends over coffee (laughs) that you have this diagnosis, so I think that’s quite isolating, in that respect yea*
>
> *Interviewer: Something about the sense of what do you do with that kind of information after you have received it?*
>
> *Participant 1: Yea its not like, you know if you get a medical, erm physical diagnosis you can say ‘oh I’ve got this’ erm and you know friends can, obviously you wouldn’t mind you would kind of maybe encourage them to educate themselves if you wanted to you could say ‘oh just google it’ or ‘here is a link you can read this’.*

Reflecting on this statement I was able to see that this had come from reading done previously about receiving ‘bad news’ in physical health settings where telling others is considered to be important (Baile et al., 2000; Villagran et al., 2010). I also considered how this may have influenced the participant’s response, in seeming to move the conversation on rather than sit with and explore the experience of isolation and perceived misunderstandings. I spent time considering how to explore participants’ experiences in greater depth and in my later interviews I was able to see the more insightful data that was being generated by keeping questions exploratory in nature rather than interpretive;

> *Interviewer: And as you were going through that sort of assessment sort time with him, how did you experience that assessment? What was that like for you to kind of go through?*

> *Participant 7: Erm it was really positive. One of the things that he did was he brought out the actual criteria for BPD and printed that out with some information so we sort of sat and went through the checklist together it was very, erm It was a process I felt involved in rather than rather than label that was just being handed to me, because he was like do you agree with this, would you say this is you, do you have any experience of this? Rather than I've already read your notes, and you've got depression, here's some tablets go away.*
>
> *Interviewer: And when he first off talked about the BPD diagnosis, can you remember what were your sort of thoughts and feelings at that time?*
>
> *Participant 7: Erm well I was aware of BPD, it wasn't brand new information. Erm so it was something that I'd heard and read up on the past because it had been mentioned briefly by a counsellor, but it's not a formal mental health professional, just a counsellor that I had seen for other reasons, and I looked it up, which, I'm sure you know when you Google things like BPD, it's not very nice to see what people wrote about it. Yeah, so again when it was brought up again I was a little bit worried, but it was nothing that he said it was just because of this, these things I've read on the internet before.*
>
> *Interviewer: So I just wonder what your understanding was of BPD, from kind of the information you'd come across…*

The implications of shifting to this more exploratory mindset enabled me to approach the data analysis in a more inductive way also. This was key in the initial coding phase, whereby it was important to emphasise the experiences of the participant so the developing model was grounded in participants' experiences rather than my own interpretations. I did this by selecting initial codes which were close to the generated data, often utilizing participants own words at this stage and ensured to preserve action and active elements rather than interpretation.

### Impact of Covid-19

This research took place during the SARS-CoV-2 global pandemic, which impacted on the study in various ways. This included changes to the way in which the study was promoted to potential participants, recruitment from within services and the use of technology during recruitment. The experiences of which are helpful to reflect on as research in the future may have to adapt to accommodate more flexible ways of working.

During the study design phase in December 2019, and prior to this, I had established working relationships with my field supervisor and agreed to utilise NHS outpatient services where they were based to recruit participants. This included extensive group therapy delivered weekly to groups of between six and eight service-users often experiencing difficulties captured by a BPD diagnosis. Furthermore, I had maintained good links with an adult CMHT where I had been on placement previously, who ran a specialised ‘personality disorder’ pathway, with dedicated practitioners and group therapy session taking place on a weekly basis. I had planned to use these relationships to visit these services, promote my research in person to staff and where appropriate be accessible to potential participants before or after group sessions took place. However, due to the restrictions in place at the time of recruitment I was unable to visit services in person and services were particularly limited in the face-to-face contact they were having with service-users. Furthermore, services were stretched due to staff sickness, shielding and self-isolation during this time. This meant that ultimately it was difficult to promote the research to service-users and have a large pool of potential participants from which to recruit.

To mitigate the difficulties identified with conducting this research during the Covid-19 pandemic, I regularly joined virtual meetings with the services I was recruiting from and kept in touch via email. Through these meetings I was aware that services had switched to using videoconferencing software for the majority of individual and group sessions offered to service-users. I considered how staff could share study information with service users during remote appointments and tried to ensure that any extra work created by recruitment was minimised. I did this by highlighting to staff their support was only needed in handing out study information sheets and the burden was on potential participants to get in touch with myself. To further ease the burden of recruitment on NHS services, and to reach a larger potential participant pool I also promoted the study on social media sites, Facebook and Twitter. This was recommended by one of the experts by experience who had reviewed the study topic guide and information sheets. I was aware from my own presence on Twitter that there are significant discourses relating to the diagnosis of BPD and individuals struggling with the difficulties associated with the diagnosis (Dyson & Gorvin, 2017), and this could be a valuable source of potential participants. I considered that potential participants reached via Facebook and Twitter may also have different experiences to those recruited via NHS services and using social media sites was also a way to ensure that I could reach potential participants who may no longer be in contact with NHS services.

I began planning the research project in December 2019, at this time I had anticipated that the majority of interviews would be conducted face-to-face with telephone interviews being offered as an alternative if needed. However, as the research progressed data collection took place during the national ‘lockdown’ and therefore data collection was also impacted. Due to the Covid-19 pandemic all interviews needed to be conducted remotely and were conducted via Microsoft Teams or telephone. In preparation for this I was able to review the literature surrounding telephone interviews in qualitative research, noting concerns that telephone interviews may result in a loss of non-verbal cues and the ability to interpret responses more deeply (Novick, 2008). I was also aware that telephone interviews may be preferable in some circumstances, when interviewing hard-to-reach groups or to provide more convenient and flexible participation (Fenig et al., 1993). However, telephone interviews have been shown to be an equally viable method of data collection (Cachia & Millward, 2011) and when compared to face-to-face interviews in the same study, telephone interviews yielded similar information (Sturges & Hanrahan, 2004). There was however, much more limited research into the use of videoconferencing technology for qualitative research. I was only able to find two papers which discussed the use of videoconferencing in qualitative research, prior to the Covid-19 pandemic, one of which made helpful explicit recommendations for use (Gray et al., 2020). The other focused on participants’ experiences of using ‘Zoom’ during qualitative interviews (Archibald et al., 2019). In Archibald et al. (2019) participants expressed a preference for videoconferencing over face-to-face interviews or was the ‘next best thing’, stating that the convenience and time-effectiveness of using ‘Zoom’ was particularly advantageous. It could be considered that the Covid-19 pandemic has accelerated the use of this technology in health and research settings (Foley, 2021). However, some have stressed the importance of maintaining face-to-face interviews for research, as this is considered the ‘gold standard’ of qualitative research, by allowing for the researcher and participant to establish rapport, build trust and address potentially sensitive topics (Sy et al., 2020).

When making initial contact with potential participants, the majority expressed their understanding of interviews taking place remotely. However, I was surprised when some participants commented that they would have been unlikely to agree to an interview if it were conducted face-to-face. This is at odds with some of the researcher preferences noted above (Novick, 2008; Sy et al., 2020) but similar to participants preferences noted in other studies

(Archibald et al., 2019). I wondered what potential underlying issues the comments made by participants in this study might be capturing. Firstly, whether remote interviews meant participants felt more private, as they were not taking place physically within the services they were accessing. Secondly, whether this afforded participants a sense of openness, as they may have felt less pressure to reflect a positive experience to me as I was not as closely associated with the service they were accessing. These potential issues were discussed by Cachia and Millward (2011) who interviewed participants about issues relating to their employment. In this study most employees arranged telephone interviews at home or during their lunch break, and the authors considered how this might increase feelings of privacy and potentially enhancing participants’ willingness to share their views and life events.

I was also surprised that the majority of participants, when given the choice, chose telephone interviews over Microsoft Teams. I noted participants seemed to be reluctant to use Microsoft Teams due to technical knowledge which was perceived to be needed to use such technology. Difficultly connecting and technical issues were cited as being the main disadvantage for participants in Archibald et al. (2019). This made me further consider the benefits of participants being interviewed over the phone compared to videoconferencing software, which may have included having a greater sense of anonymity and potentially enabling participants to speak more freely on sensitive topics relating to services. This has been debated in the literature, the nature of the sensitive topic is thought to be important with emotionally painful topics possibly benefitting from face-to-face interviews, whereas embarrassing topics may benefit from anonymity (Sturges & Hanrahan, 2004). Ultimately, I found participants to be extremely open when discussing sensitive issues and was able to gather rich data from the interviews and wondered whether this would have been different if interviews were conducted face-to-face.

## Conclusion

The diagnosis of BPD, despite its controversies, it still frequently used by mental health services in the UK. My research sought to explore how the experience of receiving this diagnosis impacts on a person’s wellbeing. It was particularly important for me to ‘bracket’ my own views on the use of this diagnosis in order to best reflect the experiences and stories of participants. This included neutrality in interviews, ongoing reflective practices and resulted in me having my own assumptions challenged while completing this research.

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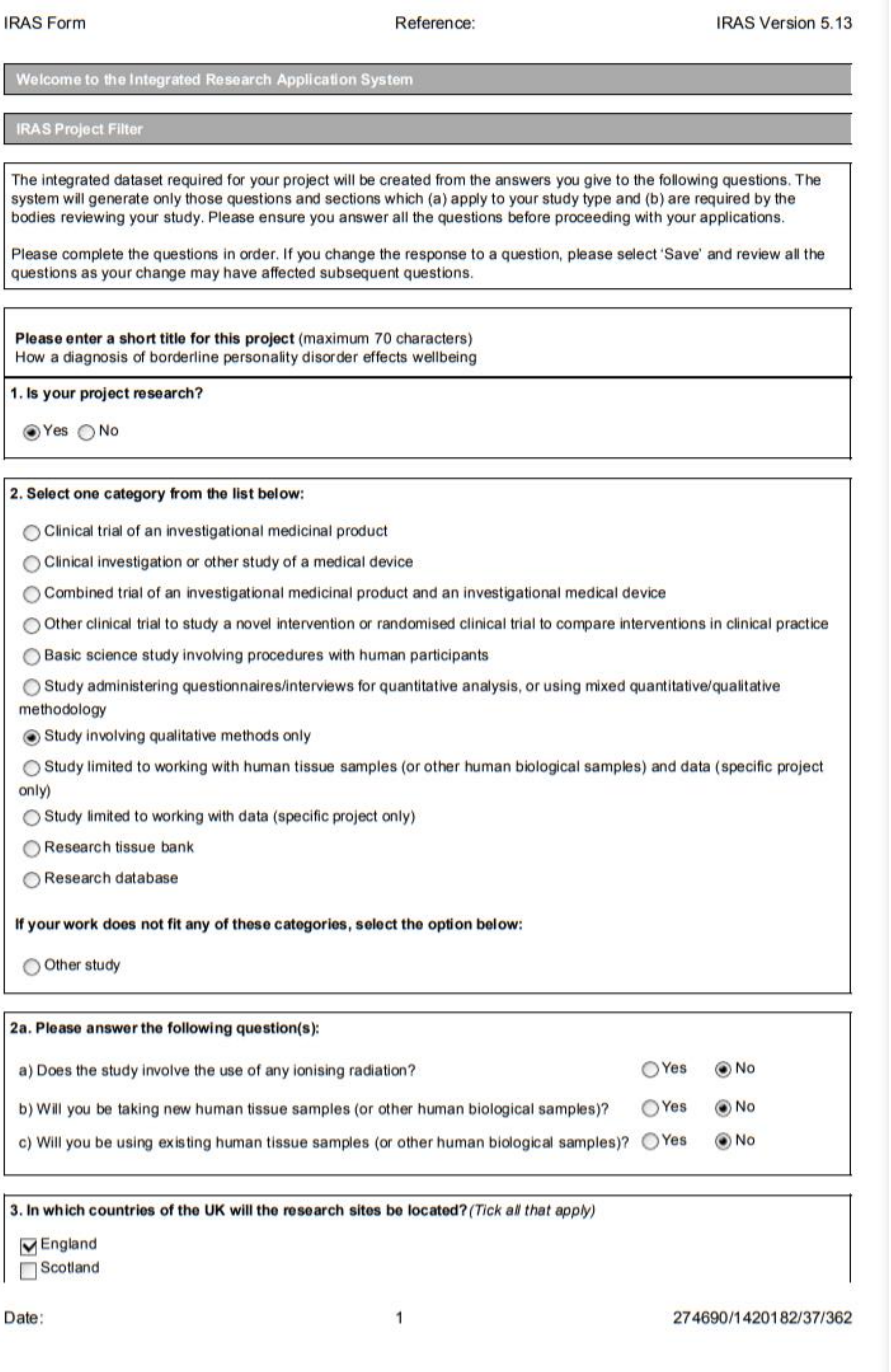
# Section Four: Ethics

Sophie Green
Doctorate in Clinical Psychology
Faculty of Health and Medicine, Lancaster University

All correspondence should be sent to:
Sophie Green
Doctorate in Clinical Psychology
Faculty of Health and Medicine
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT

Email: s.green9@lancaster.ac.uk

## NHS IRAS Application



IRAS Form Reference: IRAS Version 5.13

**Welcome to the Integrated Research Application System**

**IRAS Project Filter**

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

**Please enter a short title for this project** (maximum 70 characters)
How a diagnosis of borderline personality disorder effects wellbeing

**1. Is your project research?**

● Yes ○ No

**2. Select one category from the list below:**

○ Clinical trial of an investigational medicinal product
○ Clinical investigation or other study of a medical device
○ Combined trial of an investigational medicinal product and an investigational medical device
○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
○ Basic science study involving procedures with human participants
○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
● Study involving qualitative methods only
○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
○ Study limited to working with data (specific project only)
○ Research tissue bank
○ Research database

**If your work does not fit any of these categories, select the option below:**

○ Other study

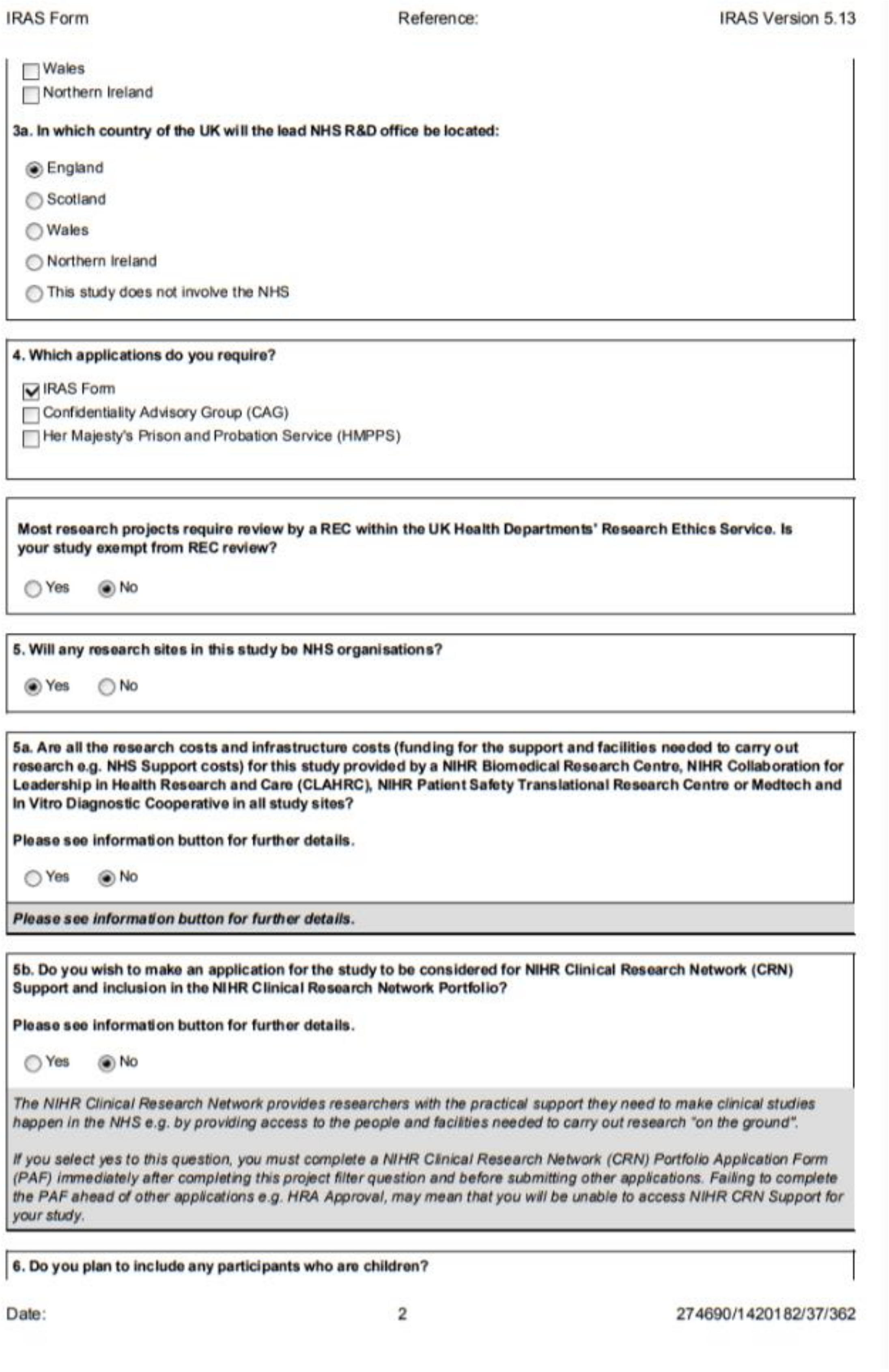
**2a. Please answer the following question(s):**

| | | |
|---|---|---|
| a) Does the study involve the use of any ionising radiation? | ○ Yes | ● No |
| b) Will you be taking new human tissue samples (or other human biological samples)? | ○ Yes | ● No |
| c) Will you be using existing human tissue samples (or other human biological samples)? | ○ Yes | ● No |

**3. In which countries of the UK will the research sites be located?** *(Tick all that apply)*

☑ England
☐ Scotland

Date: 1 274690/1420182/37/362



IRAS Form Reference: IRAS Version 5.13

☐ Wales
☐ Northern Ireland

**3a. In which country of the UK will the lead NHS R&D office be located:**

● England
○ Scotland
○ Wales
○ Northern Ireland
○ This study does not involve the NHS

**4. Which applications do you require?**

☑ IRAS Form
☐ Confidentiality Advisory Group (CAG)
☐ Her Majesty's Prison and Probation Service (HMPPS)

**Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?**

○ Yes ● No

**5. Will any research sites in this study be NHS organisations?**

● Yes ○ No

**5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or Medtech and In Vitro Diagnostic Cooperative in all study sites?**

**Please see information button for further details.**

○ Yes ● No

***Please see information button for further details.***

**5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?**

**Please see information button for further details.**

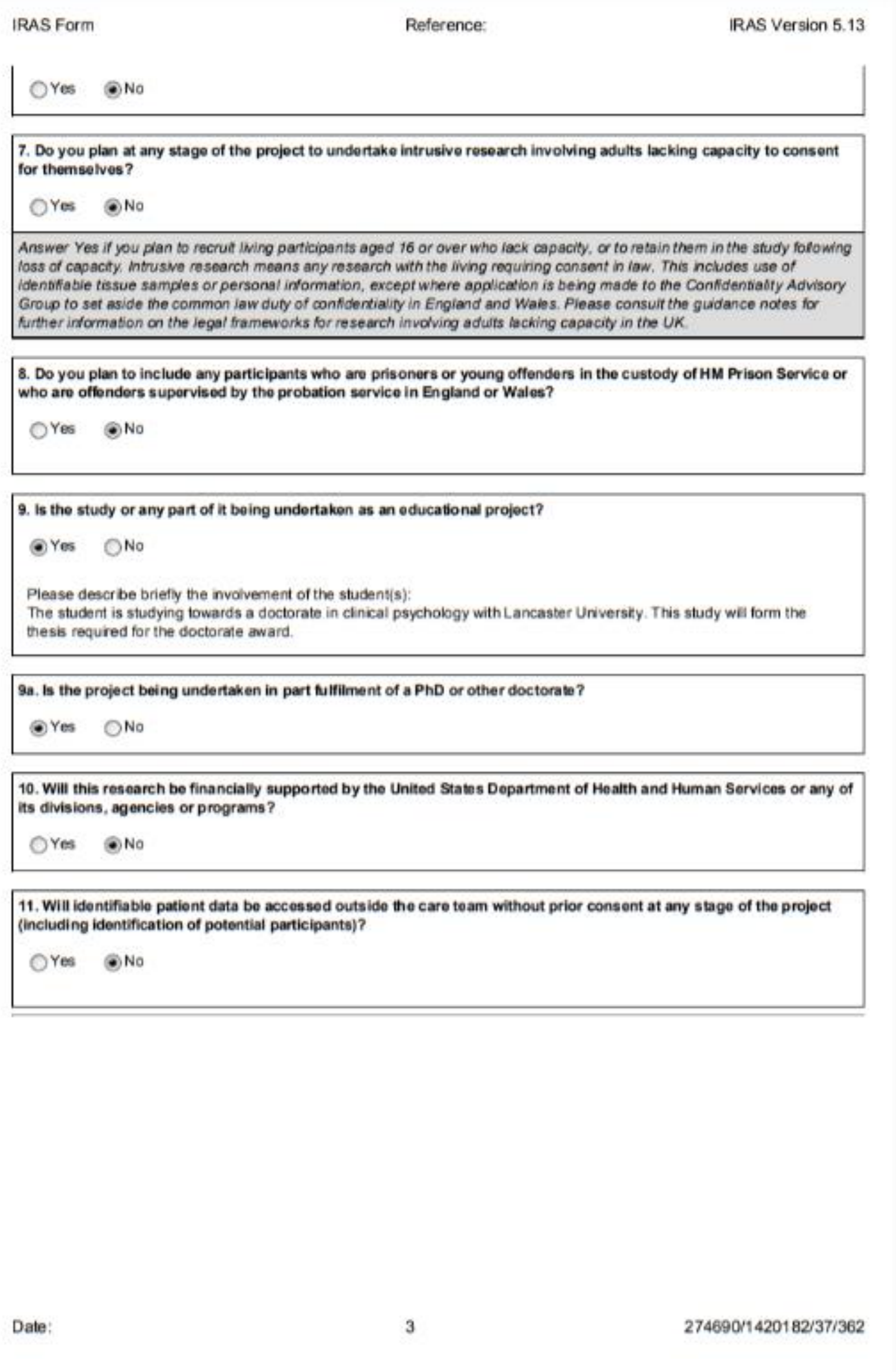
○ Yes ● No

*The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".*

*If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.*

**6. Do you plan to include any participants who are children?**

Date: 2 274690/1420182/37/362



○ Yes ● No

**7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?**

○ Yes ● No

*Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.*

**8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?**

○ Yes ● No

**9. Is the study or any part of it being undertaken as an educational project?**

● Yes ○ No

Please describe briefly the involvement of the student(s):
The student is studying towards a doctorate in clinical psychology with Lancaster University. This study will form the thesis required for the doctorate award.

**9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?**

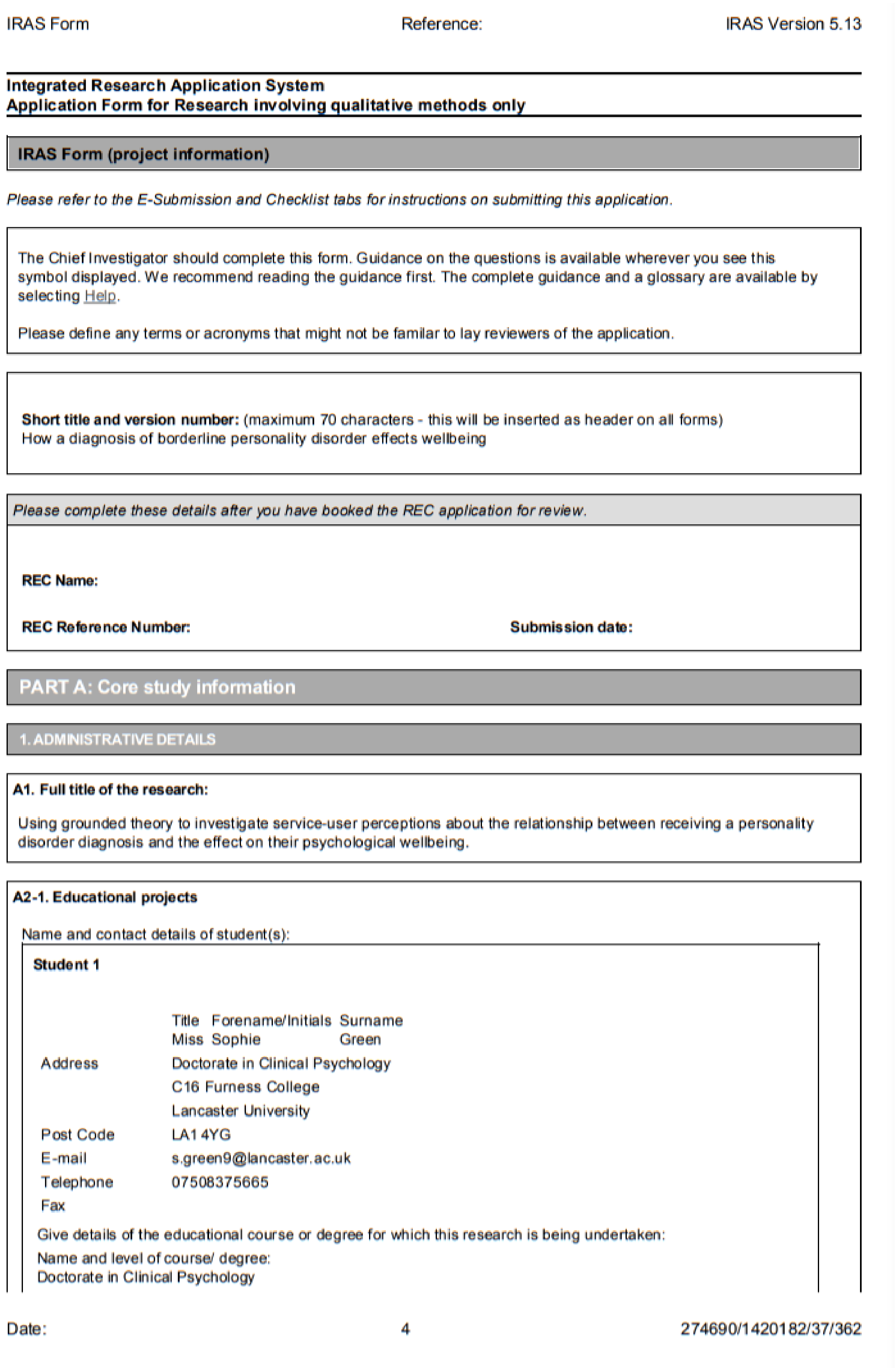
● Yes ○ No

**10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?**

○ Yes ● No

**11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?**

○ Yes ● No



**Integrated Research Application System**
**Application Form for Research involving qualitative methods only**

**IRAS Form (project information)**

*Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.*

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)
How a diagnosis of borderline personality disorder effects wellbeing

*Please complete these details after you have booked the REC application for review.*

**REC Name:**

**REC Reference Number:**

**Submission date:**

**PART A: Core study information**

**1. ADMINISTRATIVE DETAILS**

**A1. Full title of the research:**

Using grounded theory to investigate service-user perceptions about the relationship between receiving a personality disorder diagnosis and the effect on their psychological wellbeing.

**A2-1. Educational projects**

Name and contact details of student(s):

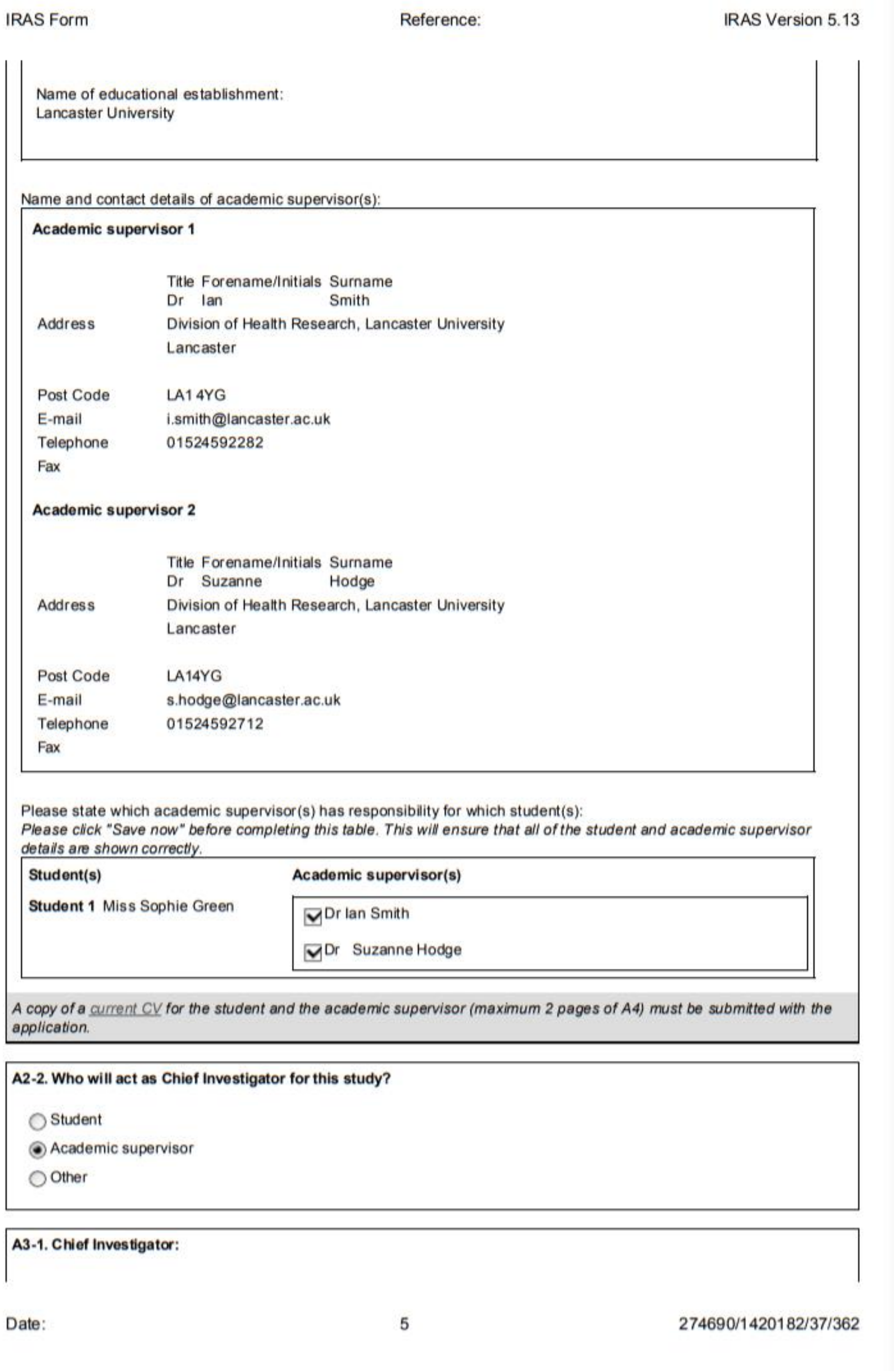
**Student 1**

| Title | Forename/Initials | Surname |
|---|---|---|
| Miss | Sophie | Green |

Address
Doctorate in Clinical Psychology
C16 Furness College
Lancaster University
Post Code LA1 4YG
E-mail s.green9@lancaster.ac.uk
Telephone 07508375665
Fax

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology



Name of educational establishment:
Lancaster University

Name and contact details of academic supervisor(s):

**Academic supervisor 1**

| | |
|---|---|
| | Title Forename/Initials Surname |
| | Dr Ian Smith |
| Address | Division of Health Research, Lancaster University<br>Lancaster |
| Post Code | LA1 4YG |
| E-mail | i.smith@lancaster.ac.uk |
| Telephone | 01524592282 |
| Fax | |

**Academic supervisor 2**

| | |
|---|---|
| | Title Forename/Initials Surname |
| | Dr Suzanne Hodge |
| Address | Division of Health Research, Lancaster University<br>Lancaster |
| Post Code | LA14YG |
| E-mail | s.hodge@lancaster.ac.uk |
| Telephone | 01524592712 |
| Fax | |

Please state which academic supervisor(s) has responsibility for which student(s):
*Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.*

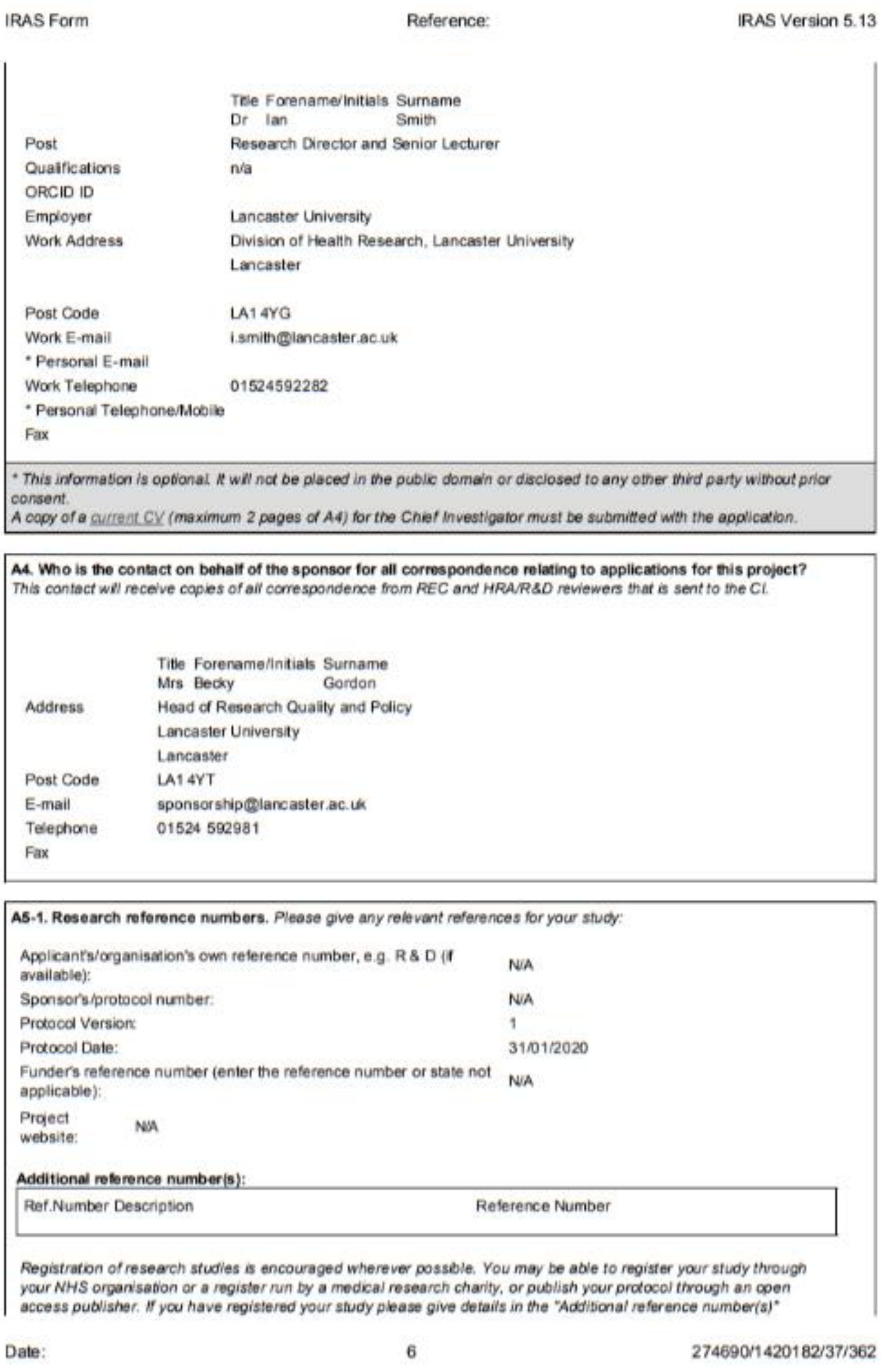
| **Student(s)** | **Academic supervisor(s)** |
|---|---|
| **Student 1** Miss Sophie Green | ☑ Dr Ian Smith<br>☑ Dr Suzanne Hodge |

*A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.*

**A2-2. Who will act as Chief Investigator for this study?**

○ Student
● Academic supervisor
○ Other

**A3-1. Chief Investigator:**



Title Forename/Initials Surname
Dr Ian Smith

| | |
|---|---|
| Post | Research Director and Senior Lecturer |
| Qualifications | n/a |
| ORCID ID | |
| Employer | Lancaster University |
| Work Address | Division of Health Research, Lancaster University<br>Lancaster |
| Post Code | LA1 4YG |
| Work E-mail | i.smith@lancaster.ac.uk |
| * Personal E-mail | |
| Work Telephone | 01524592282 |
| * Personal Telephone/Mobile | |
| Fax | |

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
*A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

**A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?**
*This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.*

Title Forename/Initials Surname
Mrs Becky Gordon

| | |
|---|---|
| Address | Head of Research Quality and Policy<br>Lancaster University<br>Lancaster |
| Post Code | LA1 4YT |
| E-mail | sponsorship@lancaster.ac.uk |
| Telephone | 01524 592981 |
| Fax | |

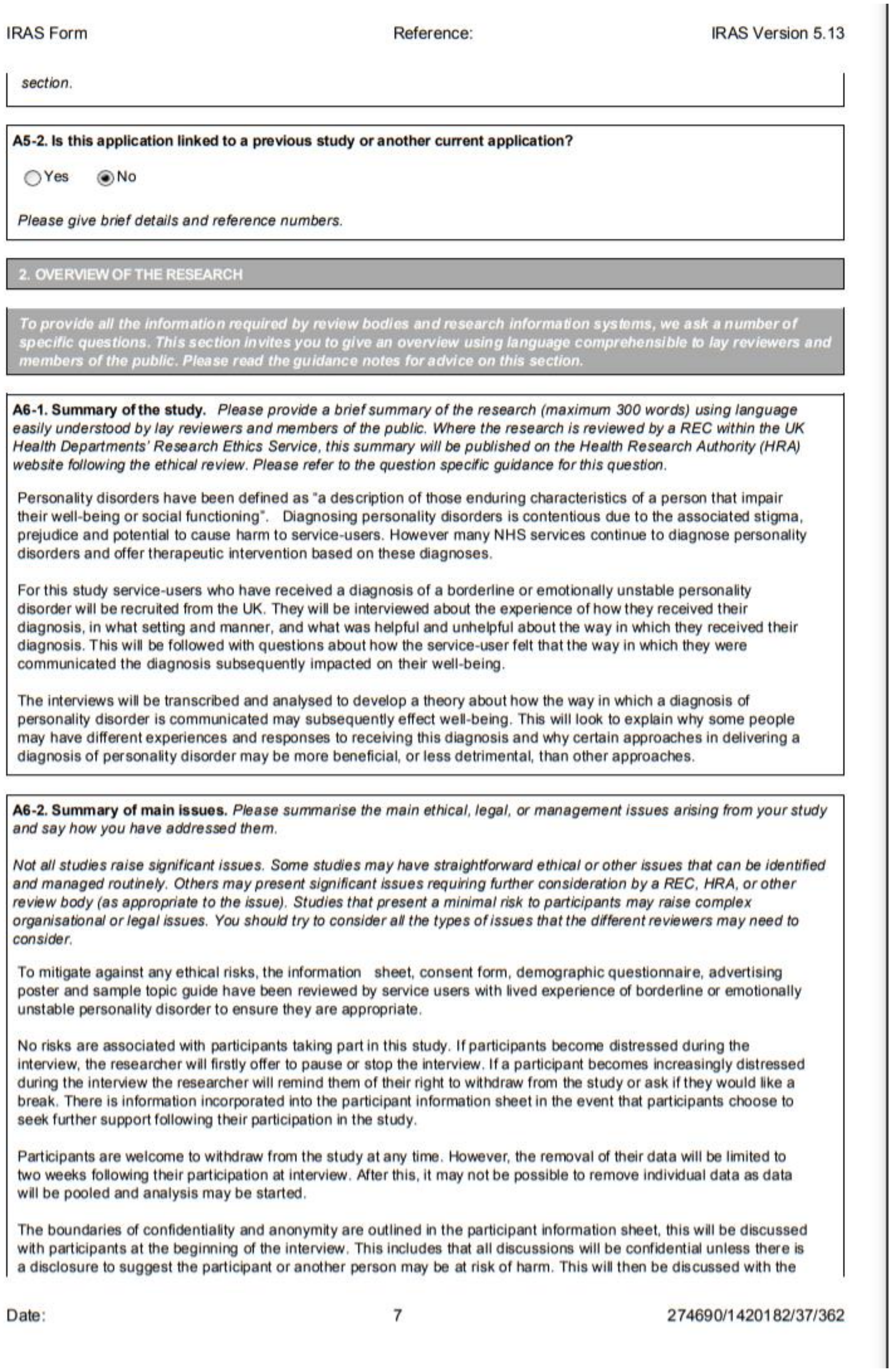
**A5-1. Research reference numbers.** *Please give any relevant references for your study:*

| | |
|---|---|
| Applicant's/organisation's own reference number, e.g. R & D (if available): | N/A |
| Sponsor's/protocol number: | N/A |
| Protocol Version: | 1 |
| Protocol Date: | 31/01/2020 |
| Funder's reference number (enter the reference number or state not applicable): | N/A |
| Project website: | N/A |

**Additional reference number(s):**

| Ref.Number Description | Reference Number |
|---|---|

*Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)"*



*section.*

**A5-2. Is this application linked to a previous study or another current application?**

○ Yes ● No

*Please give brief details and reference numbers.*

## 2. OVERVIEW OF THE RESEARCH

*To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.*

**A6-1. Summary of the study.** *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

Personality disorders have been defined as "a description of those enduring characteristics of a person that impair their well-being or social functioning". Diagnosing personality disorders is contentious due to the associated stigma, prejudice and potential to cause harm to service-users. However many NHS services continue to diagnose personality disorders and offer therapeutic intervention based on these diagnoses.

For this study service-users who have received a diagnosis of a borderline or emotionally unstable personality disorder will be recruited from the UK. They will be interviewed about the experience of how they received their diagnosis, in what setting and manner, and what was helpful and unhelpful about the way in which they received their diagnosis. This will be followed with questions about how the service-user felt that the way in which they were communicated the diagnosis subsequently impacted on their well-being.

The interviews will be transcribed and analysed to develop a theory about how the way in which a diagnosis of personality disorder is communicated may subsequently effect well-being. This will look to explain why some people may have different experiences and responses to receiving this diagnosis and why certain approaches in delivering a diagnosis of personality disorder may be more beneficial, or less detrimental, than other approaches.

**A6-2. Summary of main issues.** *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

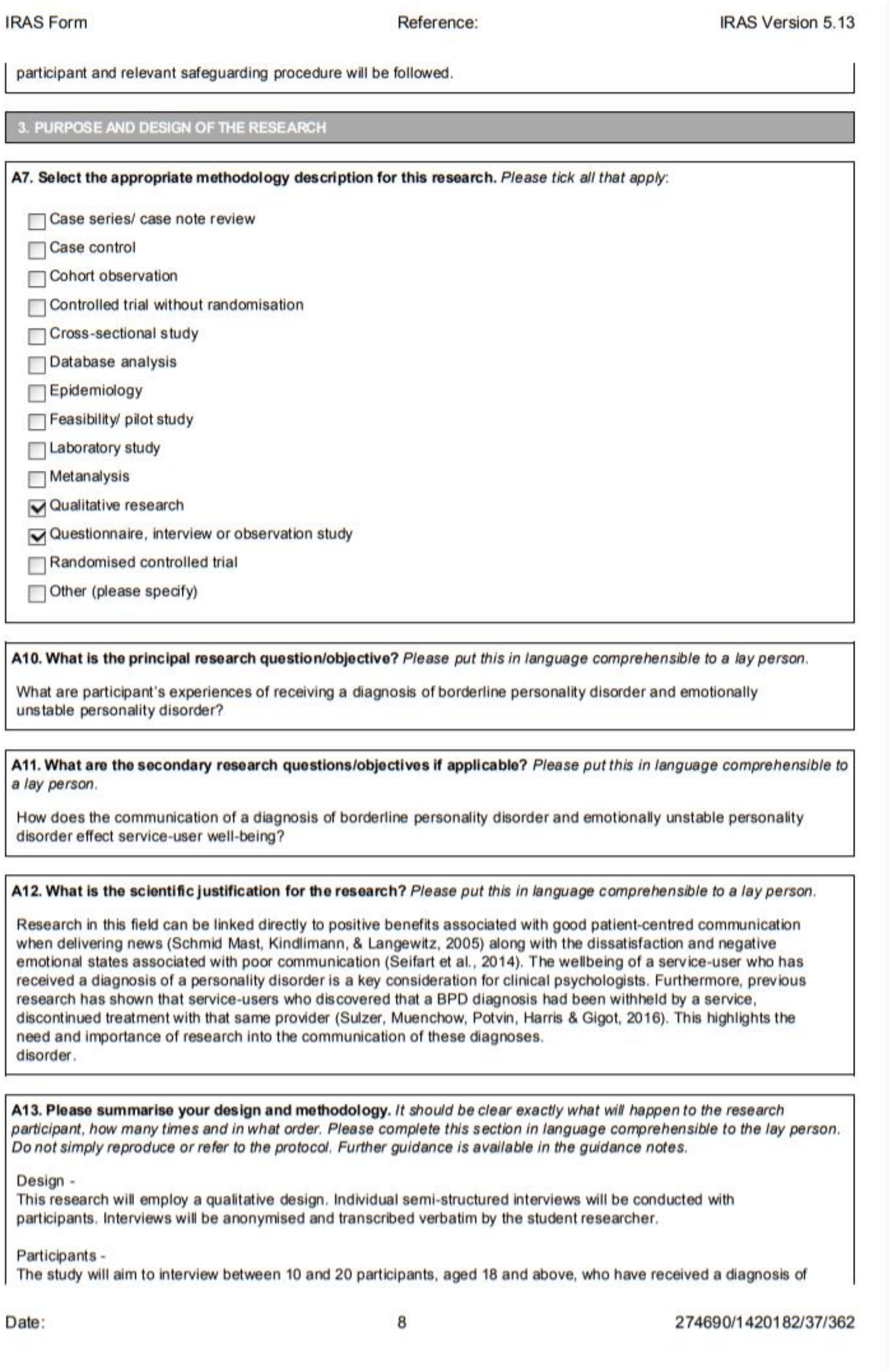
*Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.*

To mitigate against any ethical risks, the information sheet, consent form, demographic questionnaire, advertising poster and sample topic guide have been reviewed by service users with lived experience of borderline or emotionally unstable personality disorder to ensure they are appropriate.

No risks are associated with participants taking part in this study. If participants become distressed during the interview, the researcher will firstly offer to pause or stop the interview. If a participant becomes increasingly distressed during the interview the researcher will remind them of their right to withdraw from the study or ask if they would like a break. There is information incorporated into the participant information sheet in the event that participants choose to seek further support following their participation in the study.

Participants are welcome to withdraw from the study at any time. However, the removal of their data will be limited to two weeks following their participation at interview. After this, it may not be possible to remove individual data as data will be pooled and analysis may be started.

The boundaries of confidentiality and anonymity are outlined in the participant information sheet, this will be discussed with participants at the beginning of the interview. This includes that all discussions will be confidential unless there is a disclosure to suggest the participant or another person may be at risk of harm. This will then be discussed with the



participant and relevant safeguarding procedure will be followed.

**3. PURPOSE AND DESIGN OF THE RESEARCH**

**A7. Select the appropriate methodology description for this research.** *Please tick all that apply:*

☐ Case series/ case note review
☐ Case control
☐ Cohort observation
☐ Controlled trial without randomisation
☐ Cross-sectional study
☐ Database analysis
☐ Epidemiology
☐ Feasibility/ pilot study
☐ Laboratory study
☐ Metanalysis
☑ Qualitative research
☑ Questionnaire, interview or observation study
☐ Randomised controlled trial
☐ Other (please specify)

**A10. What is the principal research question/objective?** *Please put this in language comprehensible to a lay person.*

What are participant's experiences of receiving a diagnosis of borderline personality disorder and emotionally unstable personality disorder?

**A11. What are the secondary research questions/objectives if applicable?** *Please put this in language comprehensible to a lay person.*

How does the communication of a diagnosis of borderline personality disorder and emotionally unstable personality disorder effect service-user well-being?

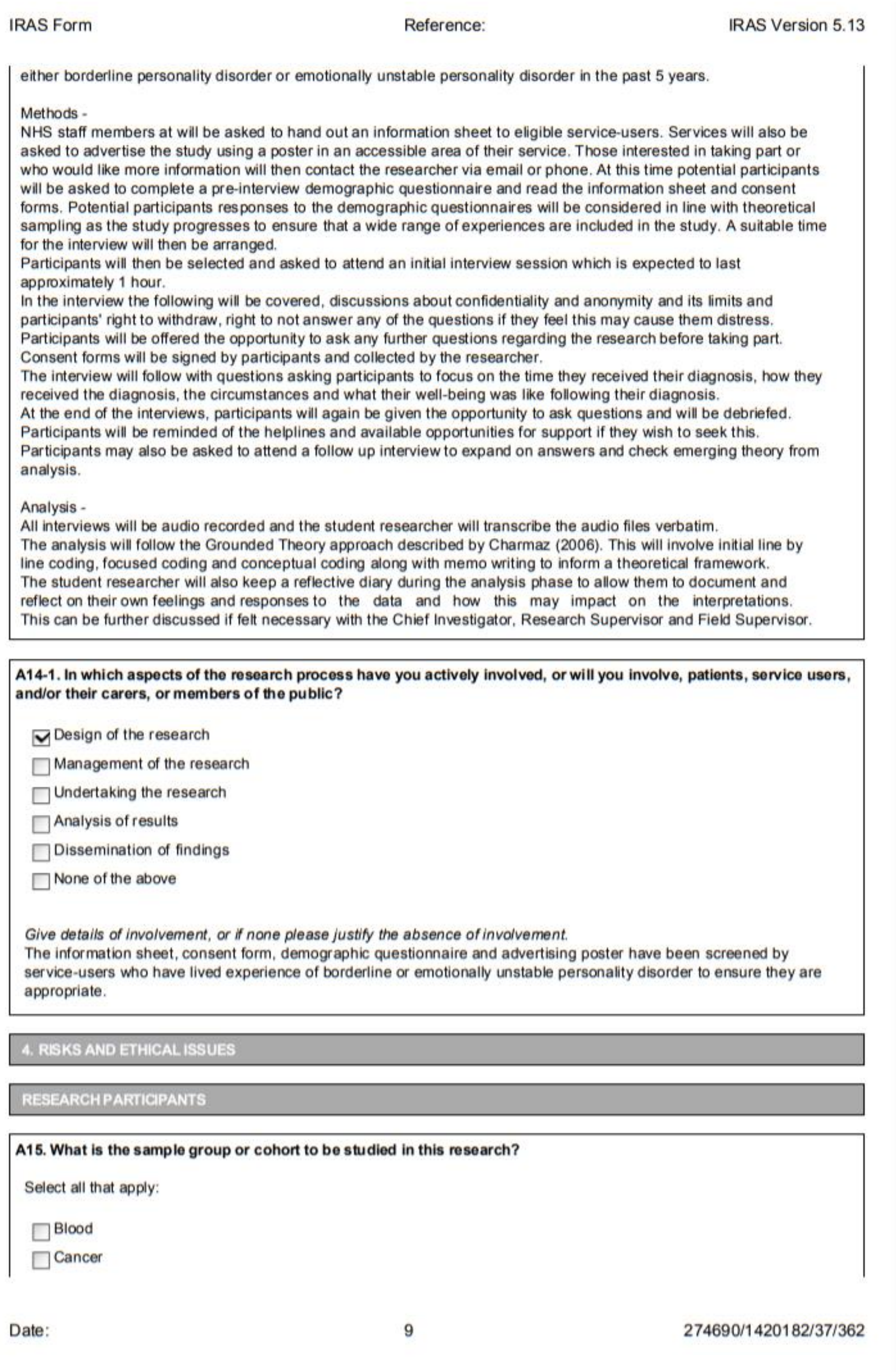
**A12. What is the scientific justification for the research?** *Please put this in language comprehensible to a lay person.*

Research in this field can be linked directly to positive benefits associated with good patient-centred communication when delivering news (Schmid Mast, Kindlimann, & Langewitz, 2005) along with the dissatisfaction and negative emotional states associated with poor communication (Seifart et al., 2014). The wellbeing of a service-user who has received a diagnosis of a personality disorder is a key consideration for clinical psychologists. Furthermore, previous research has shown that service-users who discovered that a BPD diagnosis had been withheld by a service, discontinued treatment with that same provider (Sulzer, Muenchow, Potvin, Harris & Gigot, 2016). This highlights the need and importance of research into the communication of these diagnoses.
disorder.

**A13. Please summarise your design and methodology.** *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Design -
This research will employ a qualitative design. Individual semi-structured interviews will be conducted with participants. Interviews will be anonymised and transcribed verbatim by the student researcher.

Participants -
The study will aim to interview between 10 and 20 participants, aged 18 and above, who have received a diagnosis of



either borderline personality disorder or emotionally unstable personality disorder in the past 5 years.

Methods -
NHS staff members at will be asked to hand out an information sheet to eligible service-users. Services will also be asked to advertise the study using a poster in an accessible area of their service. Those interested in taking part or who would like more information will then contact the researcher via email or phone. At this time potential participants will be asked to complete a pre-interview demographic questionnaire and read the information sheet and consent forms. Potential participants responses to the demographic questionnaires will be considered in line with theoretical sampling as the study progresses to ensure that a wide range of experiences are included in the study. A suitable time for the interview will then be arranged.
Participants will then be selected and asked to attend an initial interview session which is expected to last approximately 1 hour.
In the interview the following will be covered, discussions about confidentiality and anonymity and its limits and participants' right to withdraw, right to not answer any of the questions if they feel this may cause them distress. Participants will be offered the opportunity to ask any further questions regarding the research before taking part. Consent forms will be signed by participants and collected by the researcher.
The interview will follow with questions asking participants to focus on the time they received their diagnosis, how they received the diagnosis, the circumstances and what their well-being was like following their diagnosis.
At the end of the interviews, participants will again be given the opportunity to ask questions and will be debriefed. Participants will be reminded of the helplines and available opportunities for support if they wish to seek this. Participants may also be asked to attend a follow up interview to expand on answers and check emerging theory from analysis.

Analysis -
All interviews will be audio recorded and the student researcher will transcribe the audio files verbatim.
The analysis will follow the Grounded Theory approach described by Charmaz (2006). This will involve initial line by line coding, focused coding and conceptual coding along with memo writing to inform a theoretical framework.
The student researcher will also keep a reflective diary during the analysis phase to allow them to document and reflect on their own feelings and responses to the data and how this may impact on the interpretations. This can be further discussed if felt necessary with the Chief Investigator, Research Supervisor and Field Supervisor.

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

☑ Design of the research
☐ Management of the research
☐ Undertaking the research
☐ Analysis of results
☐ Dissemination of findings
☐ None of the above

*Give details of involvement, or if none please justify the absence of involvement.*
The information sheet, consent form, demographic questionnaire and advertising poster have been screened by service-users who have lived experience of borderline or emotionally unstable personality disorder to ensure they are appropriate.

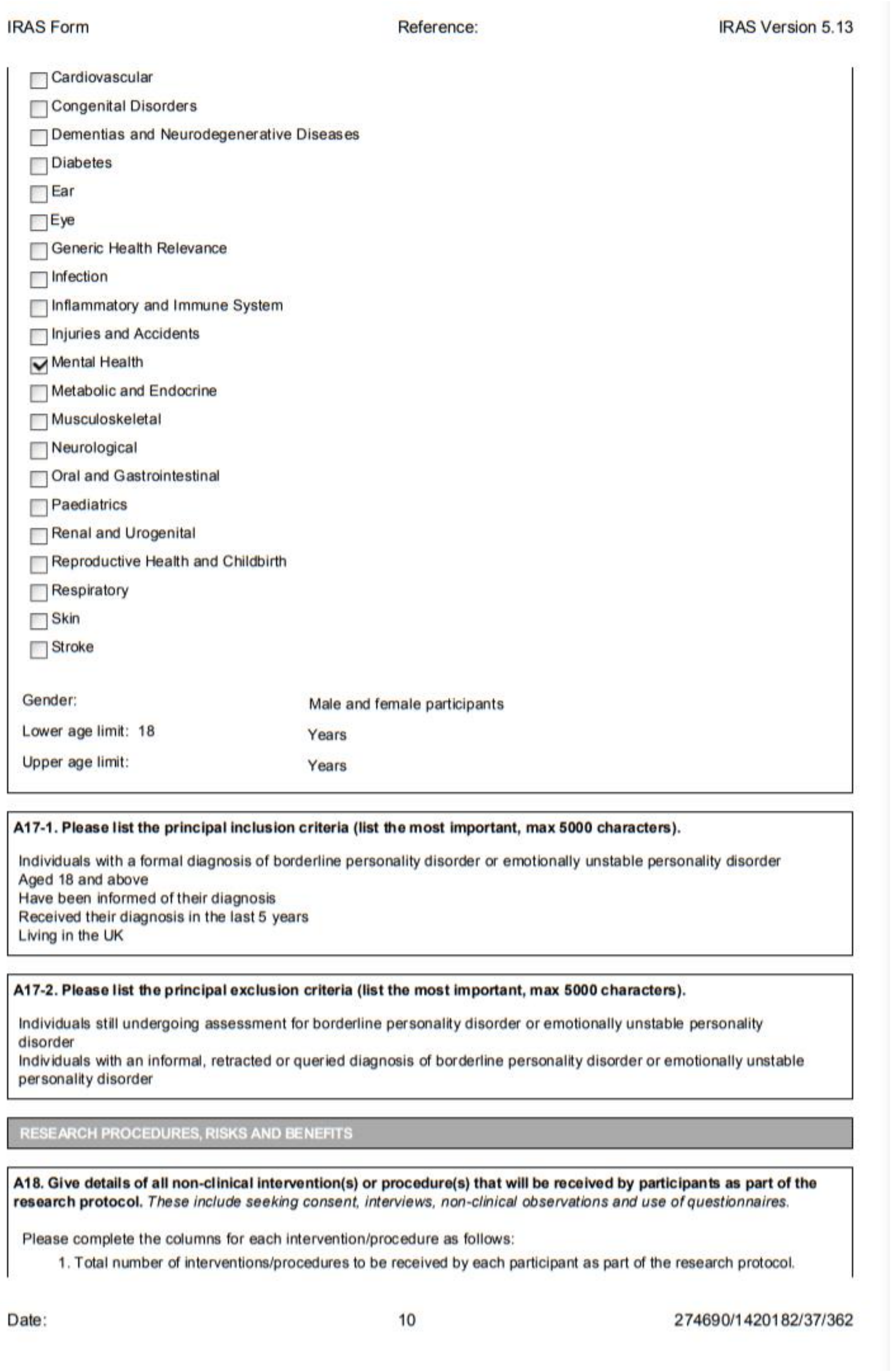
## 4. RISKS AND ETHICAL ISSUES

## RESEARCH PARTICIPANTS

**A15. What is the sample group or cohort to be studied in this research?**

Select all that apply:

☐ Blood
☐ Cancer



☐ Cardiovascular
☐ Congenital Disorders
☐ Dementias and Neurodegenerative Diseases
☐ Diabetes
☐ Ear
☐ Eye
☐ Generic Health Relevance
☐ Infection
☐ Inflammatory and Immune System
☐ Injuries and Accidents
☑ Mental Health
☐ Metabolic and Endocrine
☐ Musculoskeletal
☐ Neurological
☐ Oral and Gastrointestinal
☐ Paediatrics
☐ Renal and Urogenital
☐ Reproductive Health and Childbirth
☐ Respiratory
☐ Skin
☐ Stroke

| | |
|---|---|
| Gender: | Male and female participants |
| Lower age limit: 18 | Years |
| Upper age limit: | Years |

**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

Individuals with a formal diagnosis of borderline personality disorder or emotionally unstable personality disorder
Aged 18 and above
Have been informed of their diagnosis
Received their diagnosis in the last 5 years
Living in the UK

**A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

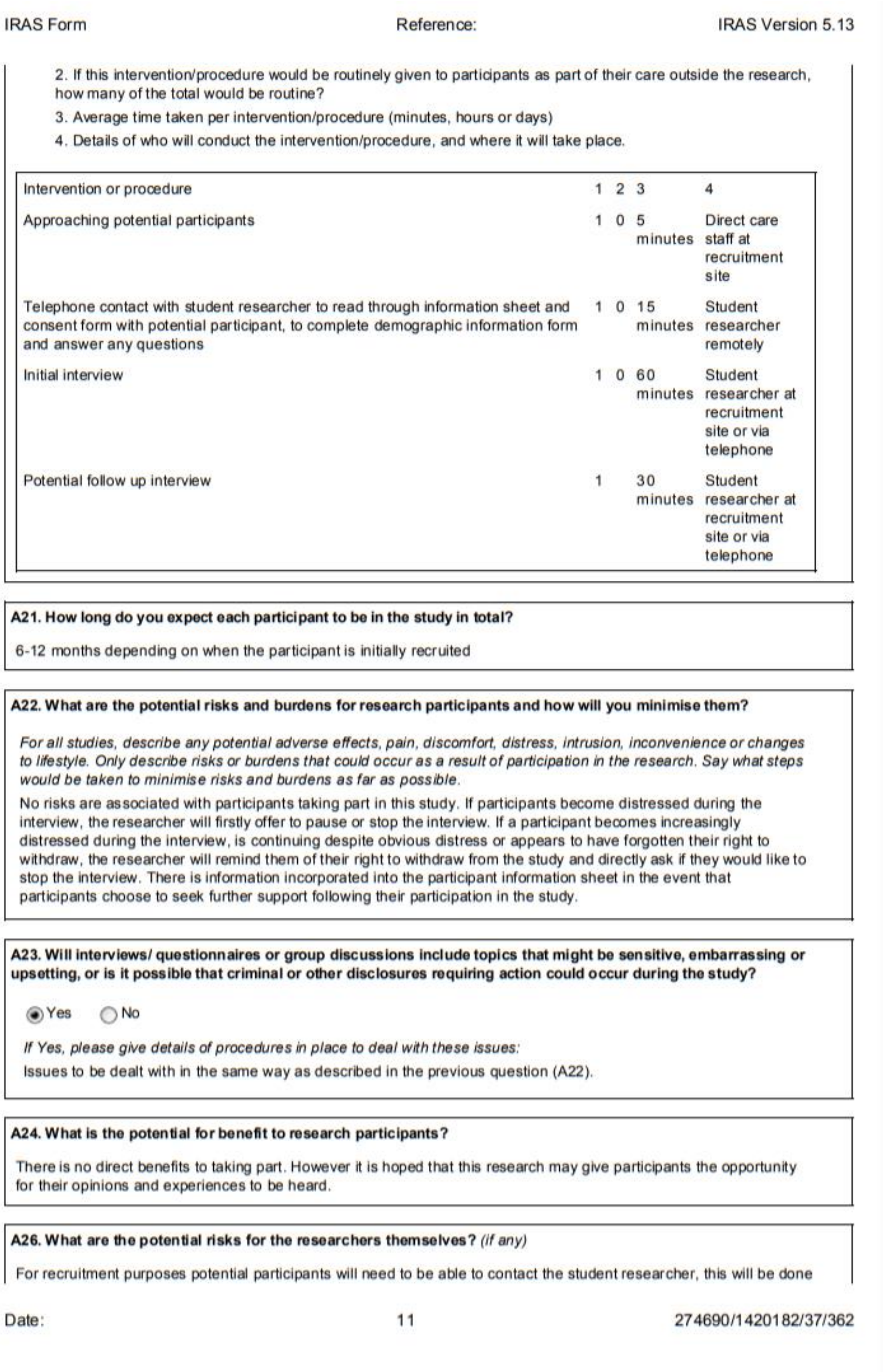
Individuals still undergoing assessment for borderline personality disorder or emotionally unstable personality disorder
Individuals with an informal, retracted or queried diagnosis of borderline personality disorder or emotionally unstable personality disorder

## RESEARCH PROCEDURES, RISKS AND BENEFITS

**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol.** *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.



2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

| | | | | |
|---|---|---|---|---|
| Intervention or procedure | 1 | 2 | 3 | 4 |
| Approaching potential participants | 1 | 0 | 5 minutes | Direct care staff at recruitment site |
| Telephone contact with student researcher to read through information sheet and consent form with potential participant, to complete demographic information form and answer any questions | 1 | 0 | 15 minutes | Student researcher remotely |
| Initial interview | 1 | 0 | 60 minutes | Student researcher at recruitment site or via telephone |
| Potential follow up interview | 1 | | 30 minutes | Student researcher at recruitment site or via telephone |

**A21. How long do you expect each participant to be in the study in total?**

6-12 months depending on when the participant is initially recruited

**A22. What are the potential risks and burdens for research participants and how will you minimise them?**

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

No risks are associated with participants taking part in this study. If participants become distressed during the interview, the researcher will firstly offer to pause or stop the interview. If a participant becomes increasingly distressed during the interview, is continuing despite obvious distress or appears to have forgotten their right to withdraw, the researcher will remind them of their right to withdraw from the study and directly ask if they would like to stop the interview. There is information incorporated into the participant information sheet in the event that participants choose to seek further support following their participation in the study.

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

● Yes ○ No

*If Yes, please give details of procedures in place to deal with these issues:*

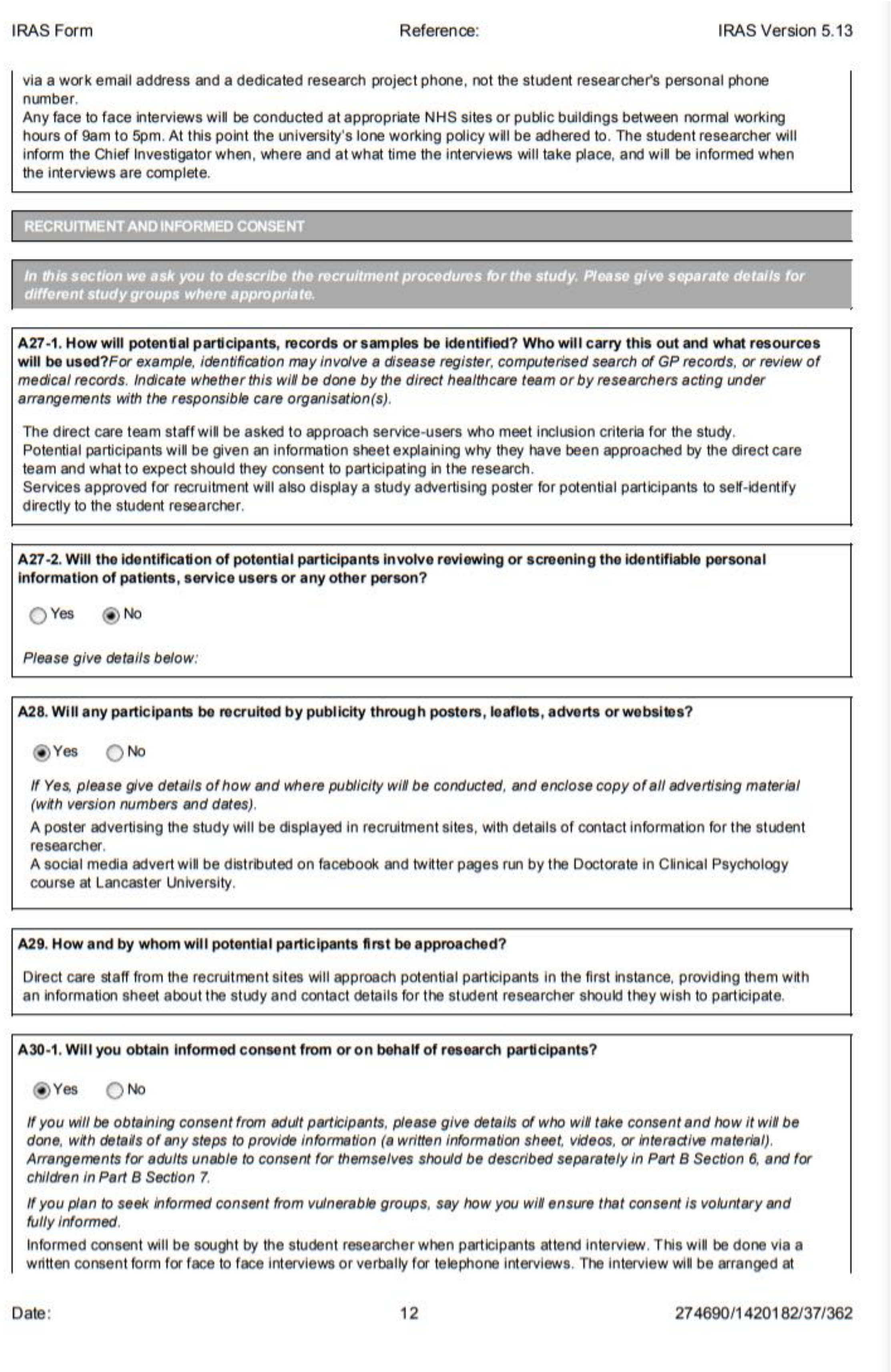
Issues to be dealt with in the same way as described in the previous question (A22).

**A24. What is the potential for benefit to research participants?**

There is no direct benefits to taking part. However it is hoped that this research may give participants the opportunity for their opinions and experiences to be heard.

**A26. What are the potential risks for the researchers themselves?** *(if any)*

For recruitment purposes potential participants will need to be able to contact the student researcher, this will be done



via a work email address and a dedicated research project phone, not the student researcher's personal phone number.
Any face to face interviews will be conducted at appropriate NHS sites or public buildings between normal working hours of 9am to 5pm. At this point the university's lone working policy will be adhered to. The student researcher will inform the Chief Investigator when, where and at what time the interviews will take place, and will be informed when the interviews are complete.

RECRUITMENT AND INFORMED CONSENT

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?***For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

The direct care team staff will be asked to approach service-users who meet inclusion criteria for the study.
Potential participants will be given an information sheet explaining why they have been approached by the direct care team and what to expect should they consent to participating in the research.
Services approved for recruitment will also display a study advertising poster for potential participants to self-identify directly to the student researcher.

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

○ Yes ● No

*Please give details below:*

**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?**

● Yes ○ No

*If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).*

A poster advertising the study will be displayed in recruitment sites, with details of contact information for the student researcher.
A social media advert will be distributed on facebook and twitter pages run by the Doctorate in Clinical Psychology course at Lancaster University.

**A29. How and by whom will potential participants first be approached?**

Direct care staff from the recruitment sites will approach potential participants in the first instance, providing them with an information sheet about the study and contact details for the student researcher should they wish to participate.

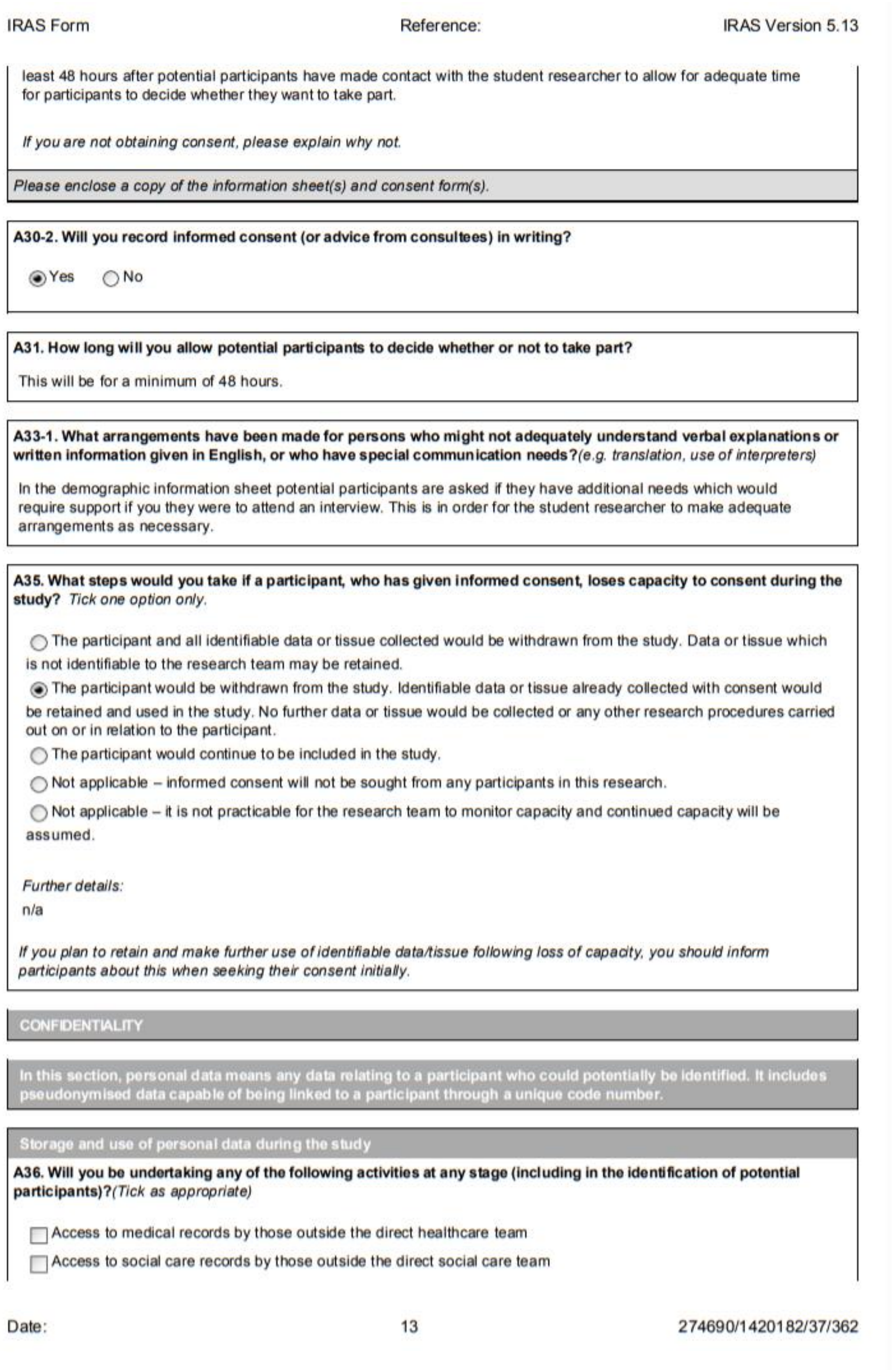
**A30-1. Will you obtain informed consent from or on behalf of research participants?**

● Yes ○ No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

Informed consent will be sought by the student researcher when participants attend interview. This will be done via a written consent form for face to face interviews or verbally for telephone interviews. The interview will be arranged at



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least 48 hours after potential participants have made contact with the student researcher to allow for adequate time for participants to decide whether they want to take part.

*If you are not obtaining consent, please explain why not.*

*Please enclose a copy of the information sheet(s) and consent form(s).*

**A30-2. Will you record informed consent (or advice from consultees) in writing?**

● Yes ○ No

**A31. How long will you allow potential participants to decide whether or not to take part?**

This will be for a minimum of 48 hours.

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?***(e.g. translation, use of interpreters)*

In the demographic information sheet potential participants are asked if they have additional needs which would require support if you they were to attend an interview. This is in order for the student researcher to make adequate arrangements as necessary.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study?** *Tick one option only.*

○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

● The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

n/a

*If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.*

## CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

### Storage and use of personal data during the study

**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?***(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team

☐ Access to social care records by those outside the direct social care team

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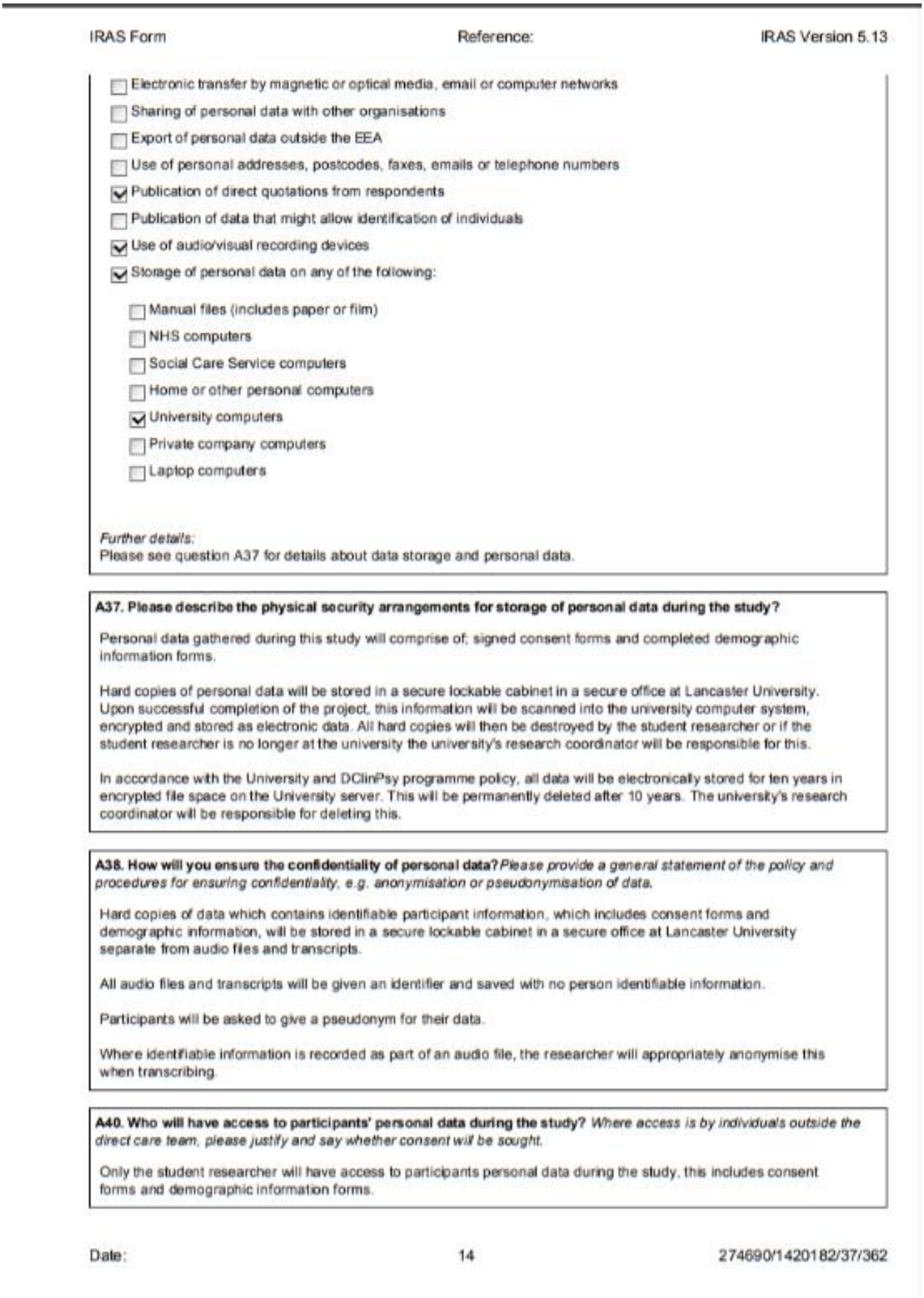


☐ Electronic transfer by magnetic or optical media, email or computer networks
☐ Sharing of personal data with other organisations
☐ Export of personal data outside the EEA
☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers
☑ Publication of direct quotations from respondents
☐ Publication of data that might allow identification of individuals
☑ Use of audio/visual recording devices
☑ Storage of personal data on any of the following:

  ☐ Manual files (includes paper or film)
  ☐ NHS computers
  ☐ Social Care Service computers
  ☐ Home or other personal computers
  ☑ University computers
  ☐ Private company computers
  ☐ Laptop computers

*Further details:*
Please see question A37 for details about data storage and personal data.

**A37. Please describe the physical security arrangements for storage of personal data during the study?**

Personal data gathered during this study will comprise of; signed consent forms and completed demographic information forms.

Hard copies of personal data will be stored in a secure lockable cabinet in a secure office at Lancaster University. Upon successful completion of the project, this information will be scanned into the university computer system, encrypted and stored as electronic data. All hard copies will then be destroyed by the student researcher or if the student researcher is no longer at the university the university's research coordinator will be responsible for this.

In accordance with the University and DClinPsy programme policy, all data will be electronically stored for ten years in encrypted file space on the University server. This will be permanently deleted after 10 years. The university's research coordinator will be responsible for deleting this.

**A38. How will you ensure the confidentiality of personal data?** *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Hard copies of data which contains identifiable participant information, which includes consent forms and demographic information, will be stored in a secure lockable cabinet in a secure office at Lancaster University separate from audio files and transcripts.

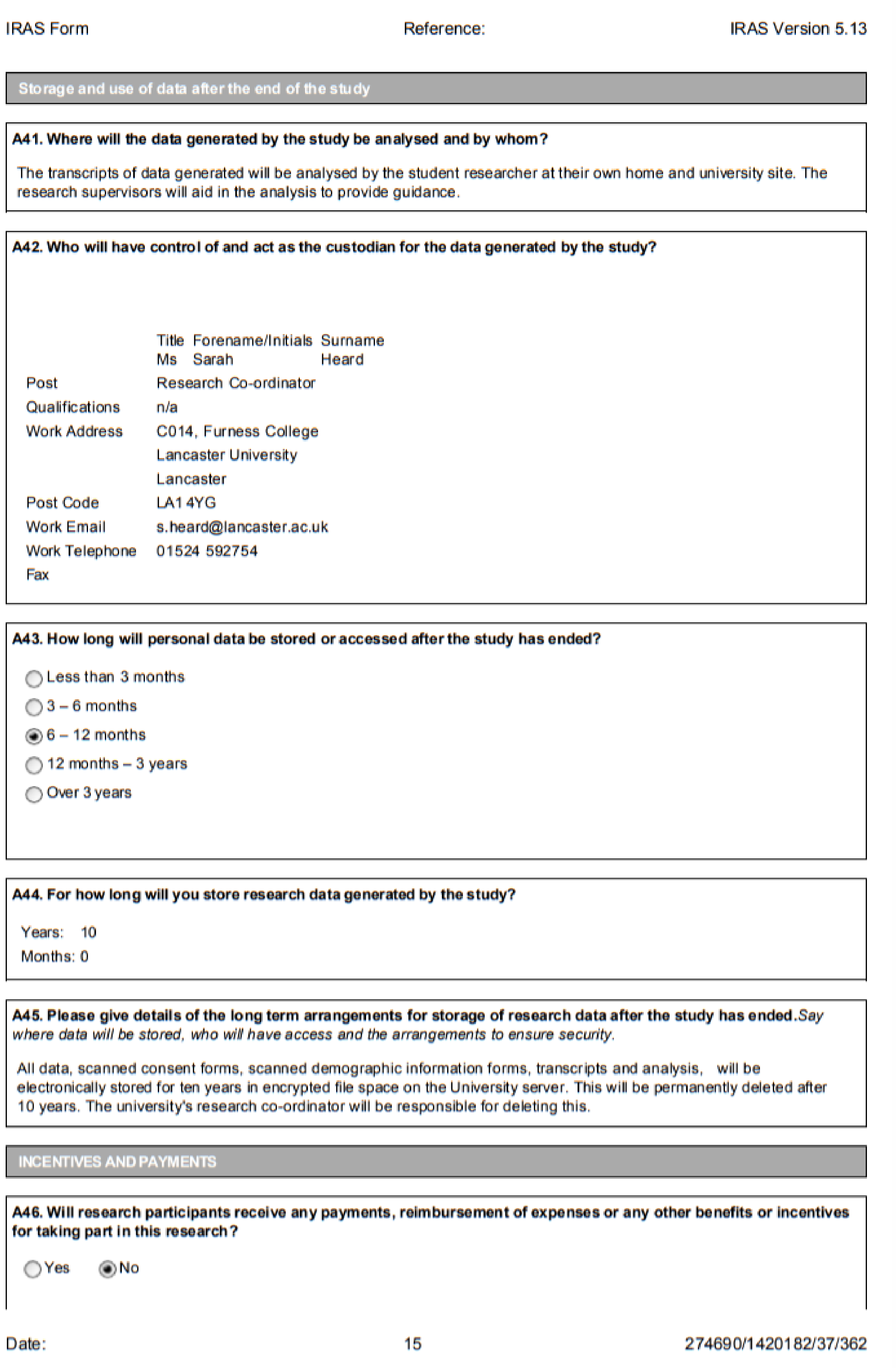
All audio files and transcripts will be given an identifier and saved with no person identifiable information.

Participants will be asked to give a pseudonym for their data.

Where identifiable information is recorded as part of an audio file, the researcher will appropriately anonymise this when transcribing.

**A40. Who will have access to participants' personal data during the study?** *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Only the student researcher will have access to participants personal data during the study, this includes consent forms and demographic information forms.



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## Storage and use of data after the end of the study

**A41. Where will the data generated by the study be analysed and by whom?**

The transcripts of data generated will be analysed by the student researcher at their own home and university site. The research supervisors will aid in the analysis to provide guidance.

**A42. Who will have control of and act as the custodian for the data generated by the study?**

| | Title | Forename/Initials | Surname |
|---|---|---|---|
| | Ms | Sarah | Heard |
| Post | Research Co-ordinator | | |
| Qualifications | n/a | | |
| Work Address | C014, Furness College<br>Lancaster University<br>Lancaster | | |
| Post Code | LA1 4YG | | |
| Work Email | s.heard@lancaster.ac.uk | | |
| Work Telephone | 01524 592754 | | |
| Fax | | | |

**A43. How long will personal data be stored or accessed after the study has ended?**

- ○ Less than 3 months
- ○ 3 – 6 months
- ● 6 – 12 months
- ○ 12 months – 3 years
- ○ Over 3 years

**A44. For how long will you store research data generated by the study?**

Years: 10
Months: 0

**A45. Please give details of the long term arrangements for storage of research data after the study has ended.** *Say where data will be stored, who will have access and the arrangements to ensure security.*

All data, scanned consent forms, scanned demographic information forms, transcripts and analysis, will be electronically stored for ten years in encrypted file space on the University server. This will be permanently deleted after 10 years. The university's research co-ordinator will be responsible for deleting this.

## INCENTIVES AND PAYMENTS

**A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

○ Yes ● No

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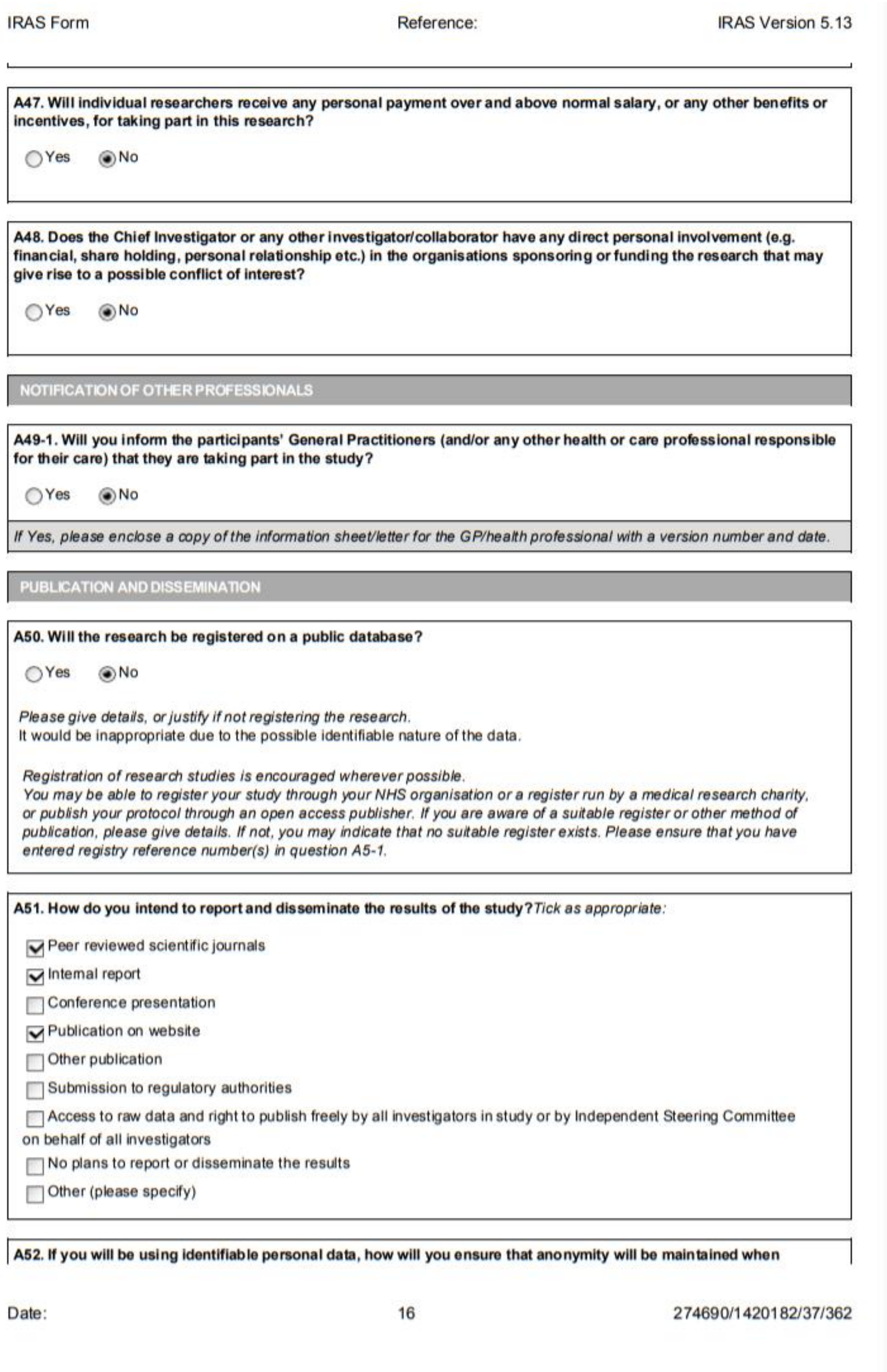

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**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?**

○ Yes ● No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

○ Yes ● No

NOTIFICATION OF OTHER PROFESSIONALS

**A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?**

○ Yes ● No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*

PUBLICATION AND DISSEMINATION

**A50. Will the research be registered on a public database?**

○ Yes ● No

*Please give details, or justify if not registering the research.*
It would be inappropriate due to the possible identifiable nature of the data.

*Registration of research studies is encouraged wherever possible.*
*You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

**A51. How do you intend to report and disseminate the results of the study?** *Tick as appropriate:*

☑ Peer reviewed scientific journals
☑ Internal report
☐ Conference presentation
☑ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
☐ No plans to report or disseminate the results
☐ Other (please specify)

**A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when**

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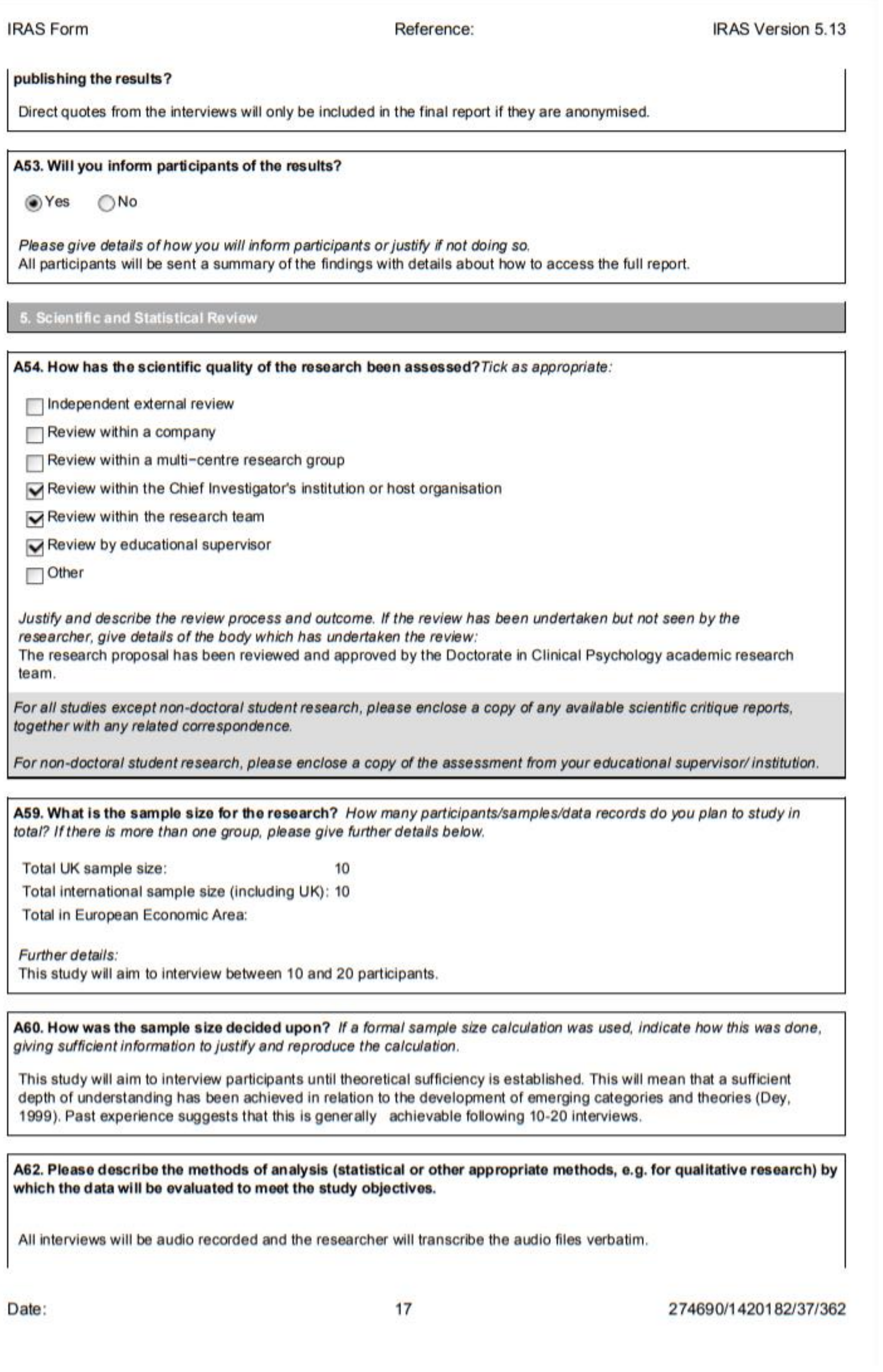

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**publishing the results?**

Direct quotes from the interviews will only be included in the final report if they are anonymised.

**A53. Will you inform participants of the results?**

● Yes ○ No

*Please give details of how you will inform participants or justify if not doing so.*
All participants will be sent a summary of the findings with details about how to access the full report.

**5. Scientific and Statistical Review**

**A54. How has the scientific quality of the research been assessed?** *Tick as appropriate:*

☐ Independent external review
☐ Review within a company
☐ Review within a multi−centre research group
☑ Review within the Chief Investigator's institution or host organisation
☑ Review within the research team
☑ Review by educational supervisor
☐ Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*
The research proposal has been reviewed and approved by the Doctorate in Clinical Psychology academic research team.

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.*

**A59. What is the sample size for the research?** *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 10
Total international sample size (including UK): 10
Total in European Economic Area:

*Further details:*
This study will aim to interview between 10 and 20 participants.

**A60. How was the sample size decided upon?** *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

This study will aim to interview participants until theoretical sufficiency is established. This will mean that a sufficient depth of understanding has been achieved in relation to the development of emerging categories and theories (Dey, 1999). Past experience suggests that this is generally achievable following 10-20 interviews.

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

All interviews will be audio recorded and the researcher will transcribe the audio files verbatim.

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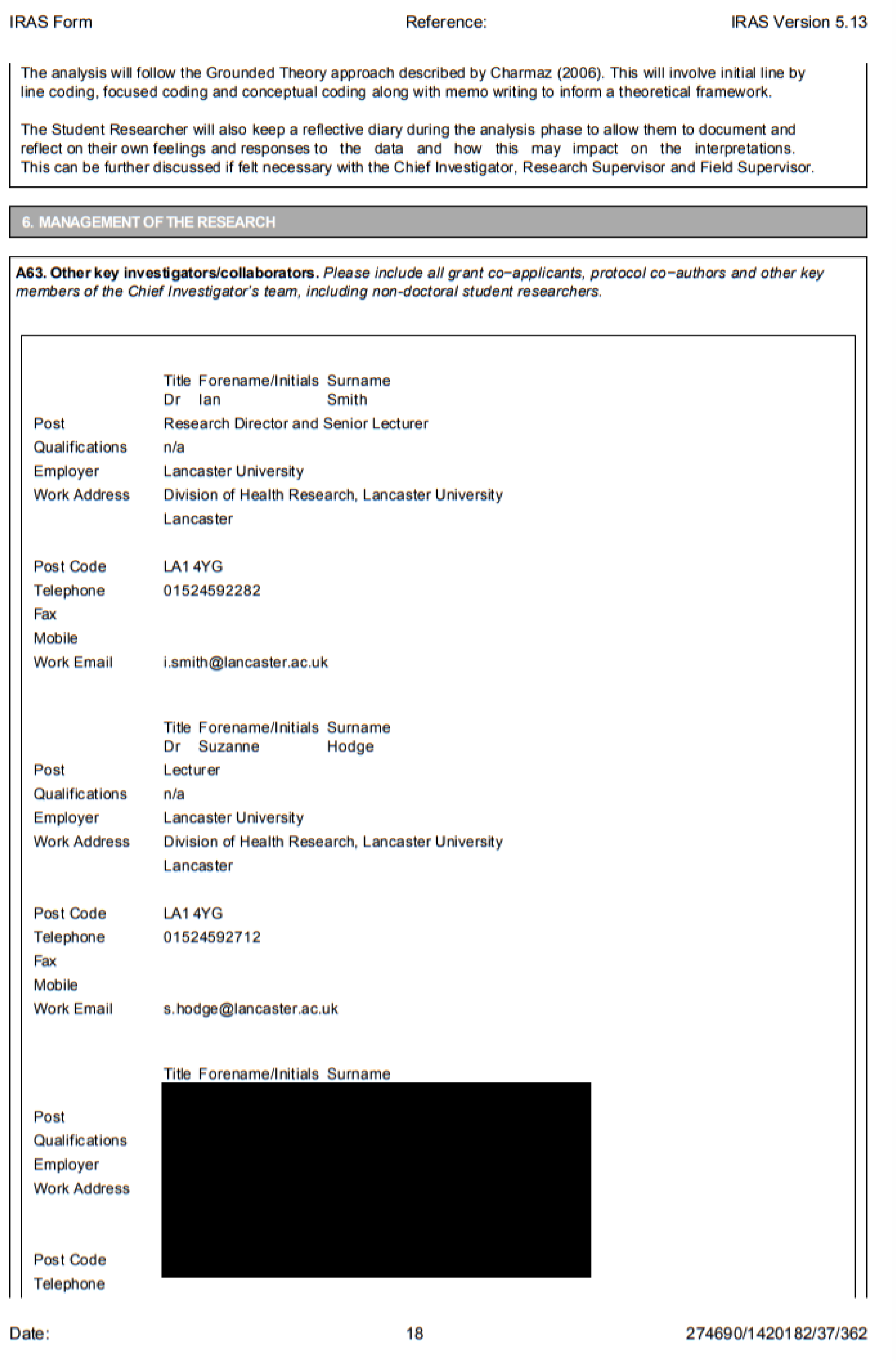


The analysis will follow the Grounded Theory approach described by Charmaz (2006). This will involve initial line by line coding, focused coding and conceptual coding along with memo writing to inform a theoretical framework.

The Student Researcher will also keep a reflective diary during the analysis phase to allow them to document and reflect on their own feelings and responses to the data and how this may impact on the interpretations. This can be further discussed if felt necessary with the Chief Investigator, Research Supervisor and Field Supervisor.

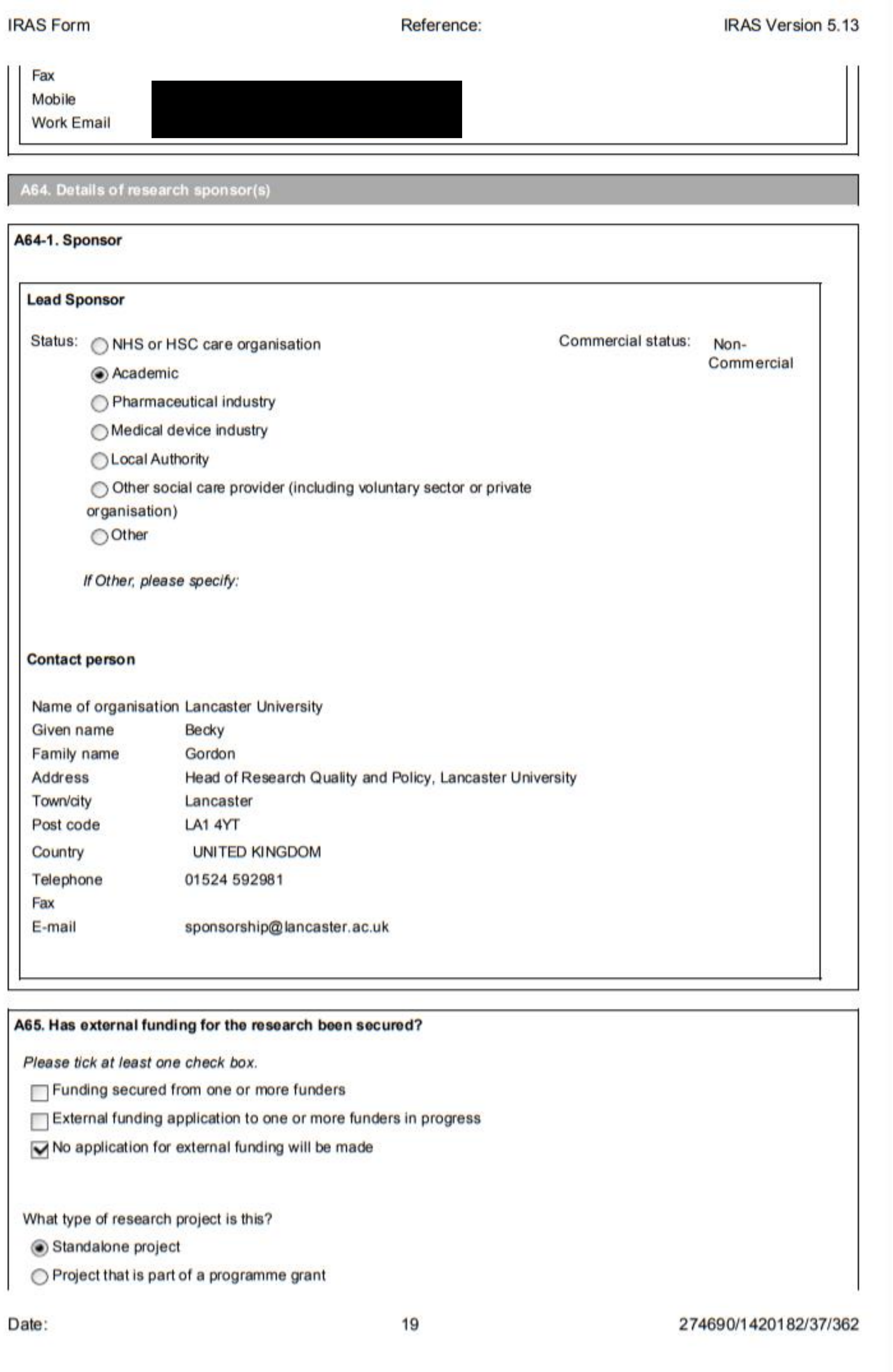
## 6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators.** *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

| | | | |
|---|---|---|---|
| | Title | Forename/Initials | Surname |
| | Dr | Ian | Smith |
| Post | Research Director and Senior Lecturer | | |
| Qualifications | n/a | | |
| Employer | Lancaster University | | |
| Work Address | Division of Health Research, Lancaster University<br>Lancaster | | |
| Post Code | LA1 4YG | | |
| Telephone | 01524592282 | | |
| Fax | | | |
| Mobile | | | |
| Work Email | i.smith@lancaster.ac.uk | | |

| | | | |
|---|---|---|---|
| | Title | Forename/Initials | Surname |
| | Dr | Suzanne | Hodge |
| Post | Lecturer | | |
| Qualifications | n/a | | |
| Employer | Lancaster University | | |
| Work Address | Division of Health Research, Lancaster University<br>Lancaster | | |
| Post Code | LA1 4YG | | |
| Telephone | 01524592712 | | |
| Fax | | | |
| Mobile | | | |
| Work Email | s.hodge@lancaster.ac.uk | | |

| | | | |
|---|---|---|---|
| | Title | Forename/Initials | Surname |
| | [redacted] | | |
| Post | | | |
| Qualifications | | | |
| Employer | | | |
| Work Address | | | |
| Post Code | | | |
| Telephone | | | |



| | |
|---|---|
| Fax | |
| Mobile | [redacted] |
| Work Email | |

**A64. Details of research sponsor(s)**

**A64-1. Sponsor**

**Lead Sponsor**

Status:
○ NHS or HSC care organisation
● Academic
○ Pharmaceutical industry
○ Medical device industry
○ Local Authority
○ Other social care provider (including voluntary sector or private organisation)
○ Other

*If Other, please specify:*

Commercial status: Non-Commercial

**Contact person**

| | |
|---|---|
| Name of organisation | Lancaster University |
| Given name | Becky |
| Family name | Gordon |
| Address | Head of Research Quality and Policy, Lancaster University |
| Town/city | Lancaster |
| Post code | LA1 4YT |
| Country | UNITED KINGDOM |
| Telephone | 01524 592981 |
| Fax | |
| E-mail | sponsorship@lancaster.ac.uk |

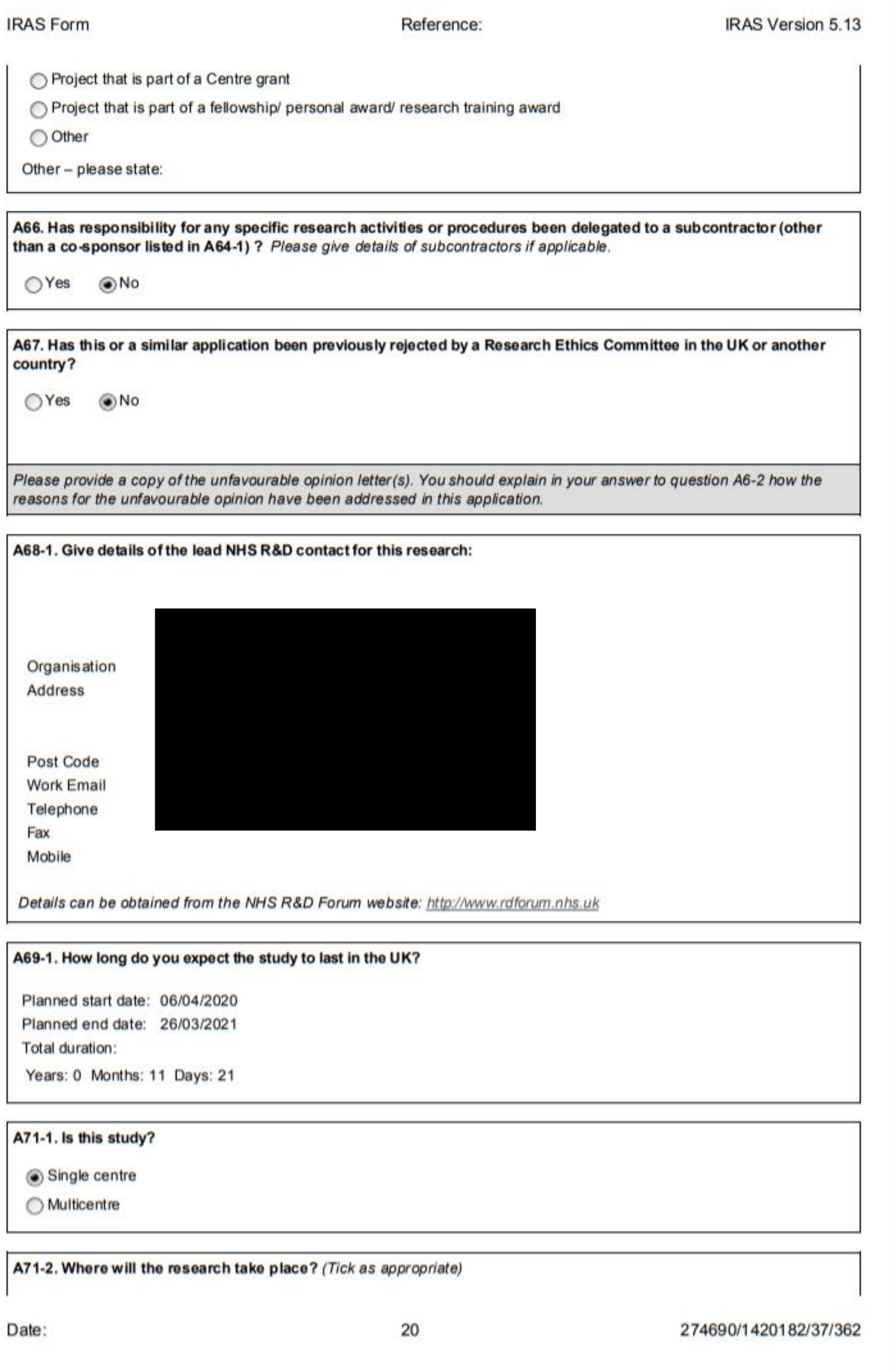
**A65. Has external funding for the research been secured?**

*Please tick at least one check box.*

☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

● Standalone project
○ Project that is part of a programme grant



○ Project that is part of a Centre grant
○ Project that is part of a fellowship/ personal award/ research training award
○ Other

Other – please state:

**A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ?** *Please give details of subcontractors if applicable.*

○ Yes ● No

**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?**

○ Yes ● No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

**A68-1. Give details of the lead NHS R&D contact for this research:**

Organisation
Address

Post Code
Work Email
Telephone
Fax
Mobile

[redacted]

*Details can be obtained from the NHS R&D Forum website:* http://www.rdforum.nhs.uk

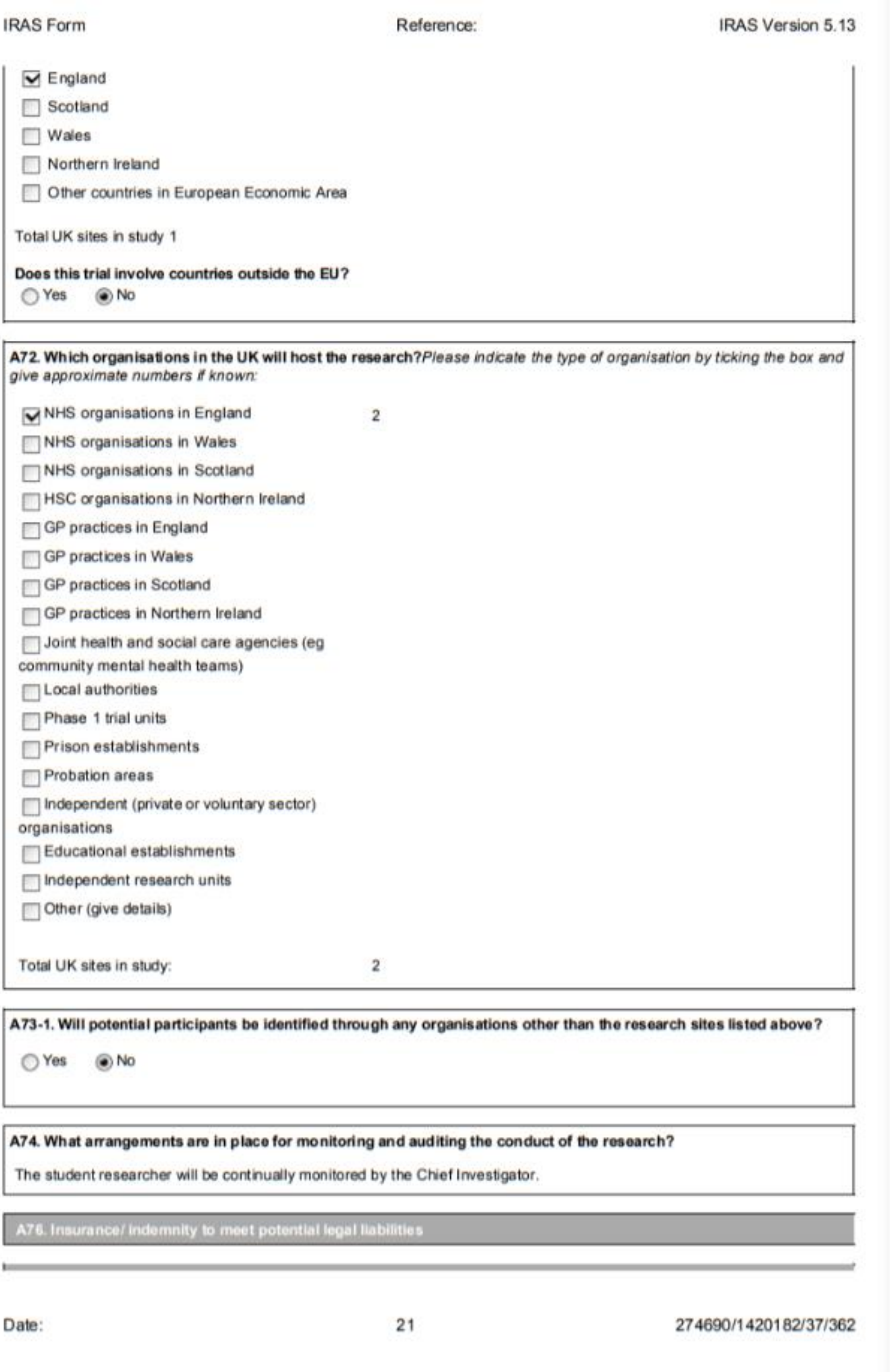
**A69-1. How long do you expect the study to last in the UK?**

Planned start date: 06/04/2020
Planned end date: 26/03/2021
Total duration:
Years: 0 Months: 11 Days: 21

**A71-1. Is this study?**

● Single centre
○ Multicentre

**A71-2. Where will the research take place?** *(Tick as appropriate)*



☑ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 1

**Does this trial involve countries outside the EU?**
○ Yes ● No

**A72. Which organisations in the UK will host the research?** *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

| | |
|---|---|
| ☑ NHS organisations in England | 2 |
| ☐ NHS organisations in Wales | |
| ☐ NHS organisations in Scotland | |
| ☐ HSC organisations in Northern Ireland | |
| ☐ GP practices in England | |
| ☐ GP practices in Wales | |
| ☐ GP practices in Scotland | |
| ☐ GP practices in Northern Ireland | |
| ☐ Joint health and social care agencies (eg community mental health teams) | |
| ☐ Local authorities | |
| ☐ Phase 1 trial units | |
| ☐ Prison establishments | |
| ☐ Probation areas | |
| ☐ Independent (private or voluntary sector) organisations | |
| ☐ Educational establishments | |
| ☐ Independent research units | |
| ☐ Other (give details) | |
| Total UK sites in study: | 2 |

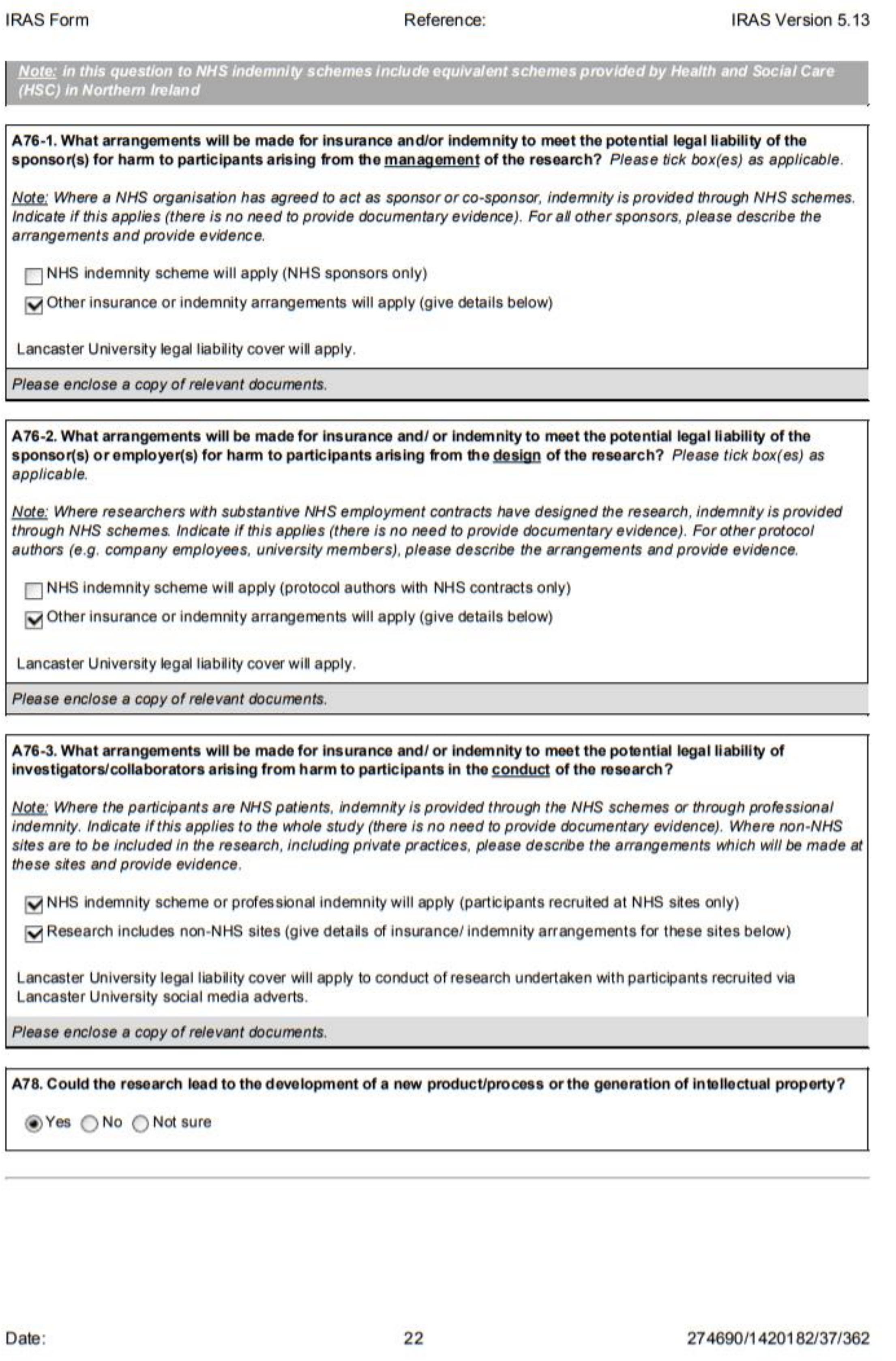
**A73-1. Will potential participants be identified through any organisations other than the research sites listed above?**

○ Yes ● No

**A74. What arrangements are in place for monitoring and auditing the conduct of the research?**

The student researcher will be continually monitored by the Chief Investigator.

**A76. Insurance/ indemnity to meet potential legal liabilities**



*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research?** *Please tick box(es) as applicable.*

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply.

*Please enclose a copy of relevant documents.*

**A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research?** *Please tick box(es) as applicable.*

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply.

*Please enclose a copy of relevant documents.*

**A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?**

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

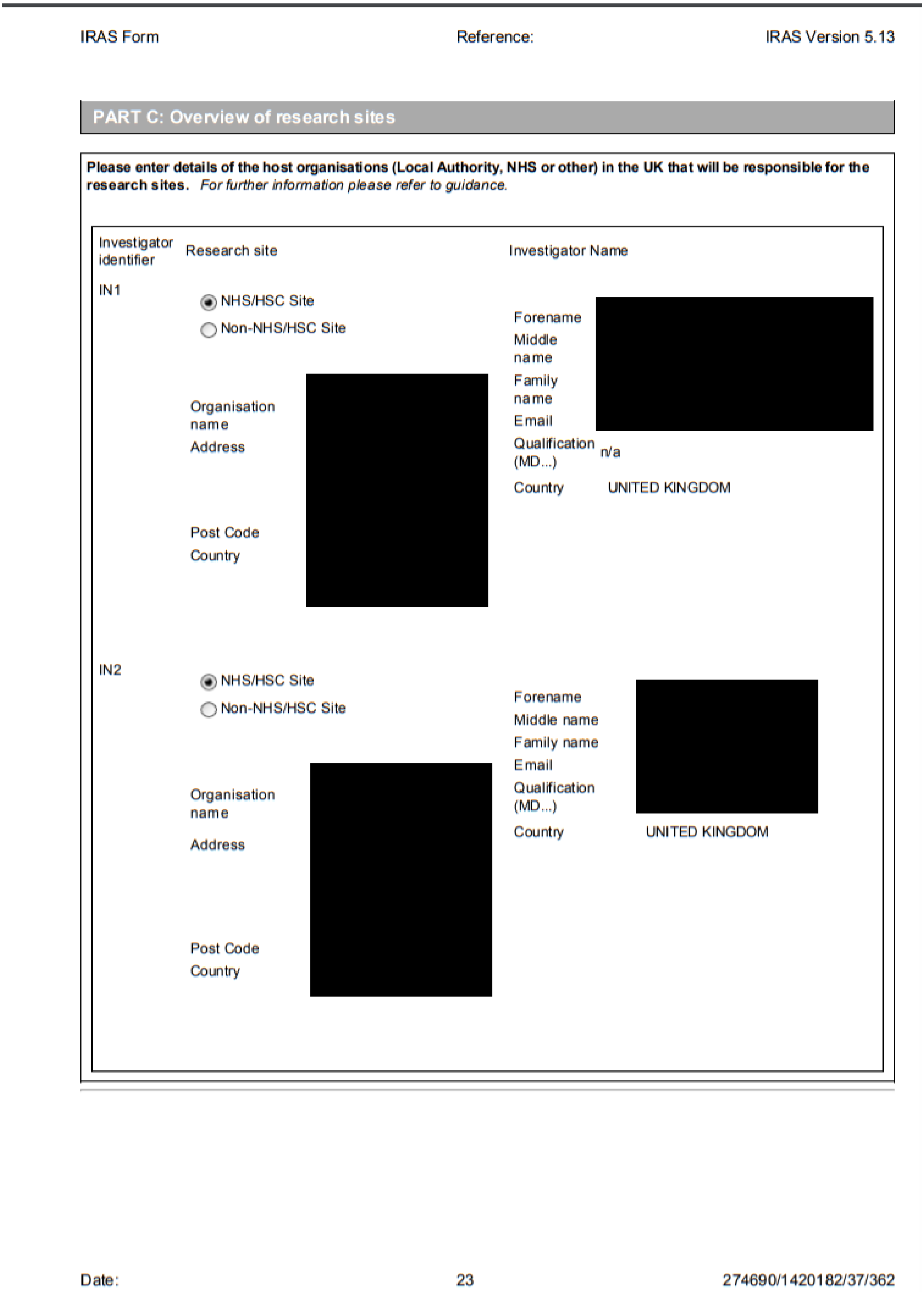
☑ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply to conduct of research undertaken with participants recruited via Lancaster University social media adverts.

*Please enclose a copy of relevant documents.*

**A78. Could the research lead to the development of a new product/process or the generation of intellectual property?**

● Yes ○ No ○ Not sure



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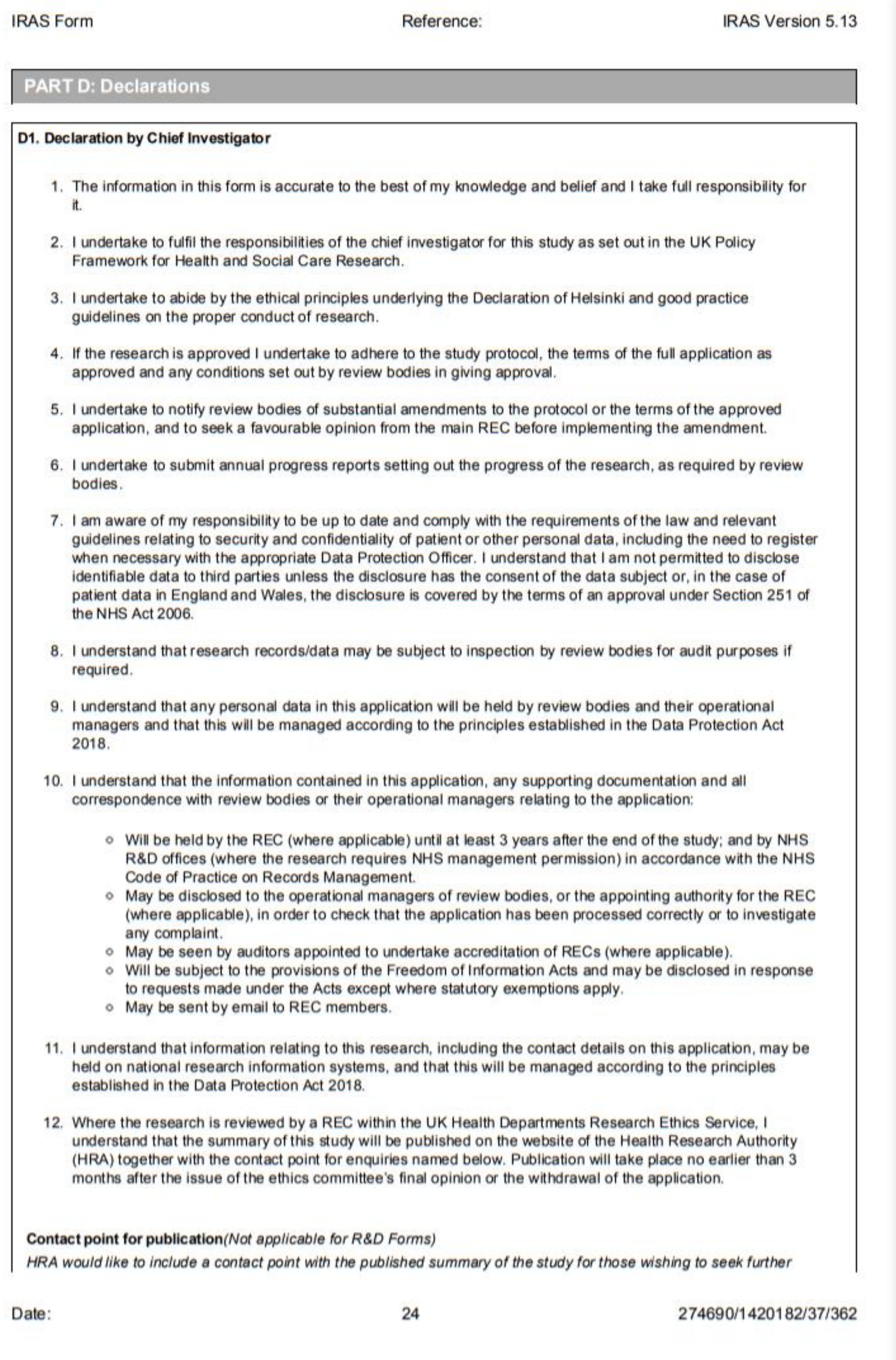
## PART C: Overview of research sites

**Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites.** *For further information please refer to guidance.*

| Investigator identifier | Research site | Investigator Name |
|---|---|---|
| IN1 | ● NHS/HSC Site<br>○ Non-NHS/HSC Site<br>Organisation name<br>Address<br>Post Code<br>Country<br>[redacted] | Forename<br>Middle name<br>Family name<br>Email<br>[redacted]<br>Qualification (MD...) n/a<br>Country UNITED KINGDOM |
| IN2 | ● NHS/HSC Site<br>○ Non-NHS/HSC Site<br>Organisation name<br>Address<br>Post Code<br>Country<br>[redacted] | Forename<br>Middle name<br>Family name<br>Email<br>Qualification (MD...)<br>[redacted]<br>Country UNITED KINGDOM |

Date: 23 274690/1420182/37/362



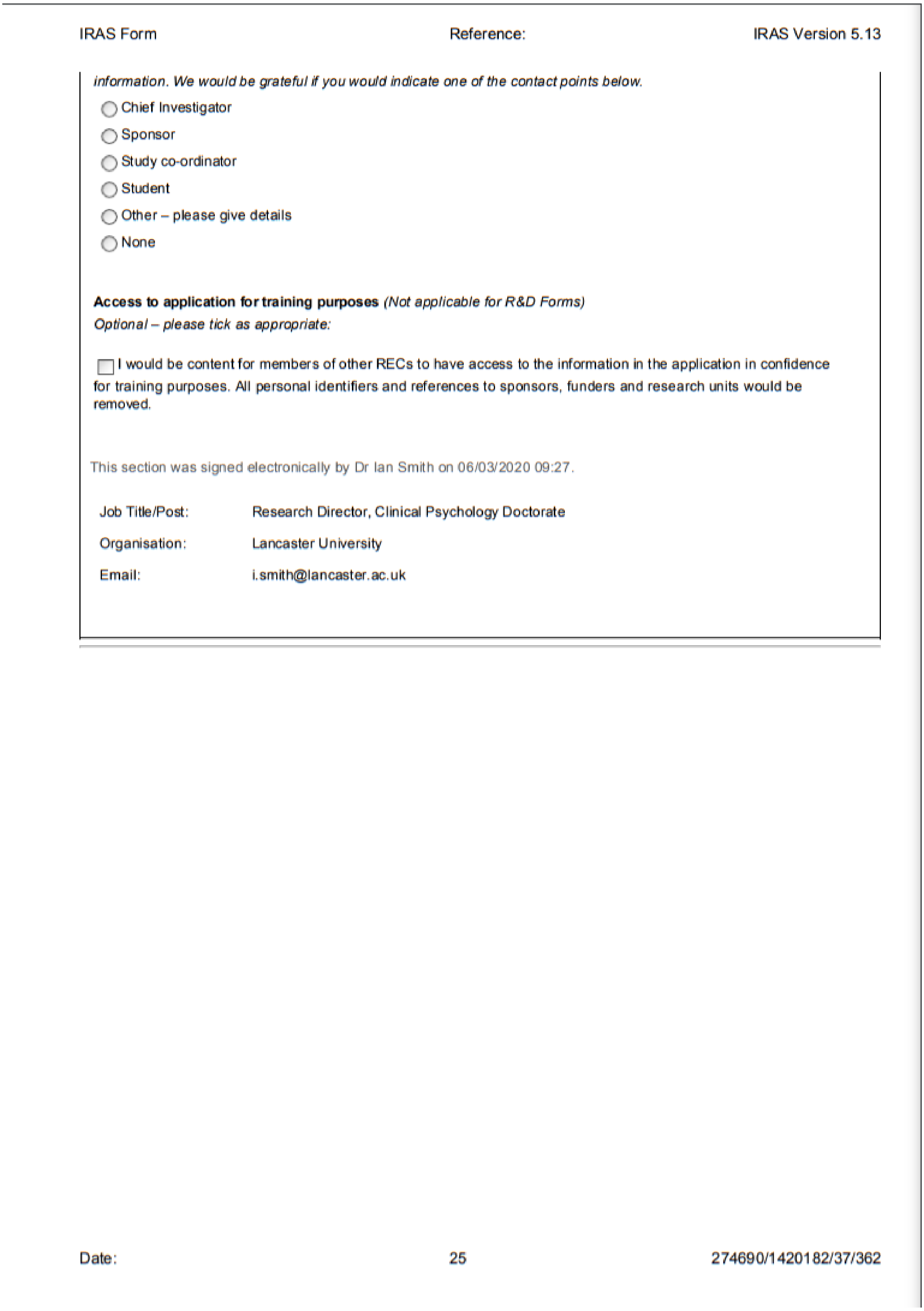
## PART D: Declarations

**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to fulfil the responsibilities of the chief investigator for this study as set out in the UK Policy Framework for Health and Social Care Research.
3. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
4. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
5. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
6. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
7. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
8. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
9. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 2018.
10. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.
11. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 2018.
12. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the Health Research Authority (HRA) together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after the issue of the ethics committee's final opinion or the withdrawal of the application.

**Contact point for publication***(Not applicable for R&D Forms)*

*HRA would like to include a contact point with the published summary of the study for those wishing to seek further*



*information. We would be grateful if you would indicate one of the contact points below.*

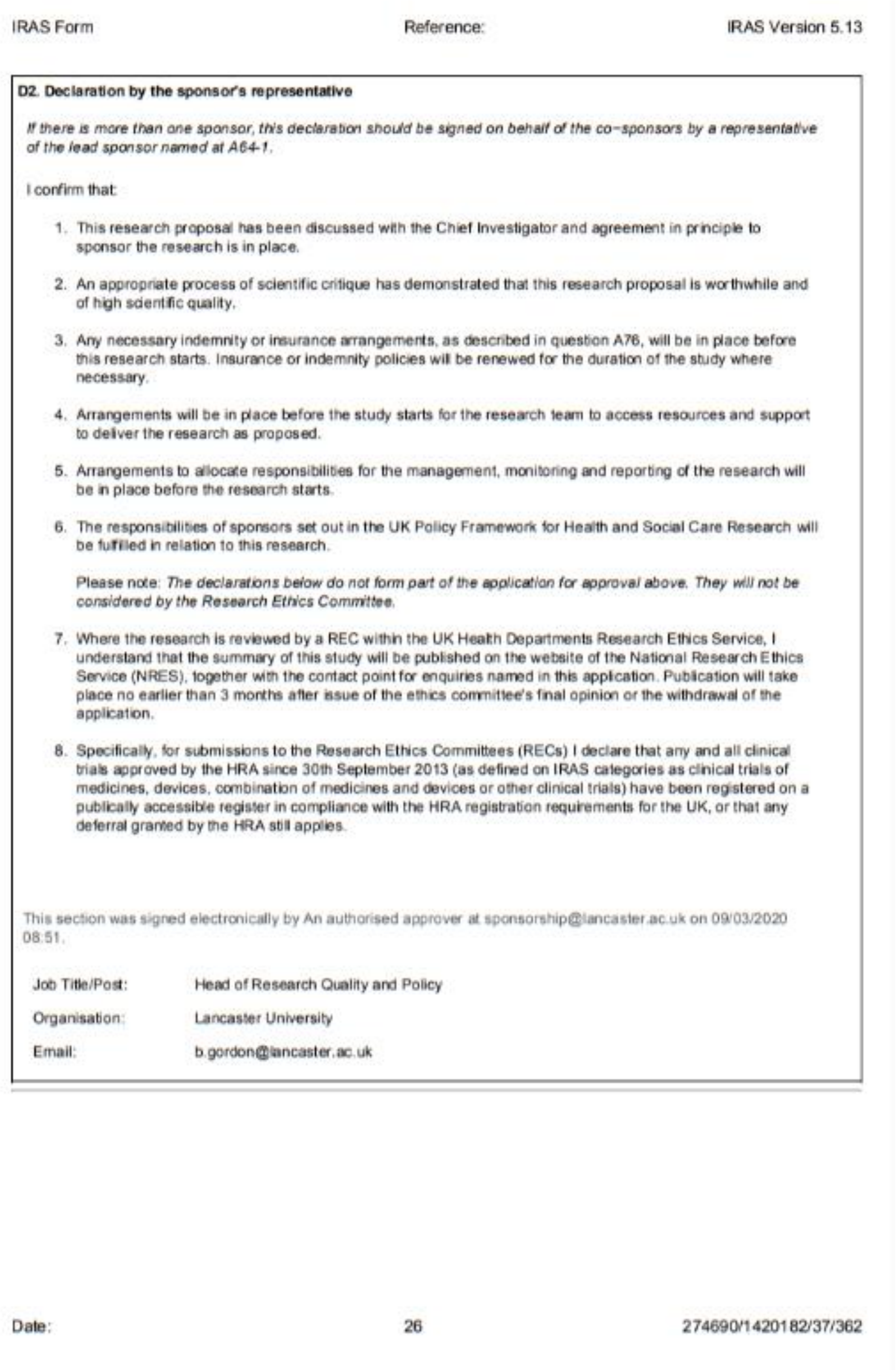
○ Chief Investigator
○ Sponsor
○ Study co-ordinator
○ Student
○ Other – please give details
○ None

**Access to application for training purposes** *(Not applicable for R&D Forms)*
*Optional – please tick as appropriate:*

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Dr Ian Smith on 06/03/2020 09:27.

| | |
|---|---|
| Job Title/Post: | Research Director, Clinical Psychology Doctorate |
| Organisation: | Lancaster University |
| Email: | i.smith@lancaster.ac.uk |



**D2. Declaration by the sponsor's representative**

*If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.*

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The responsibilities of sponsors set out in the UK Policy Framework for Health and Social Care Research will be fulfilled in relation to this research.

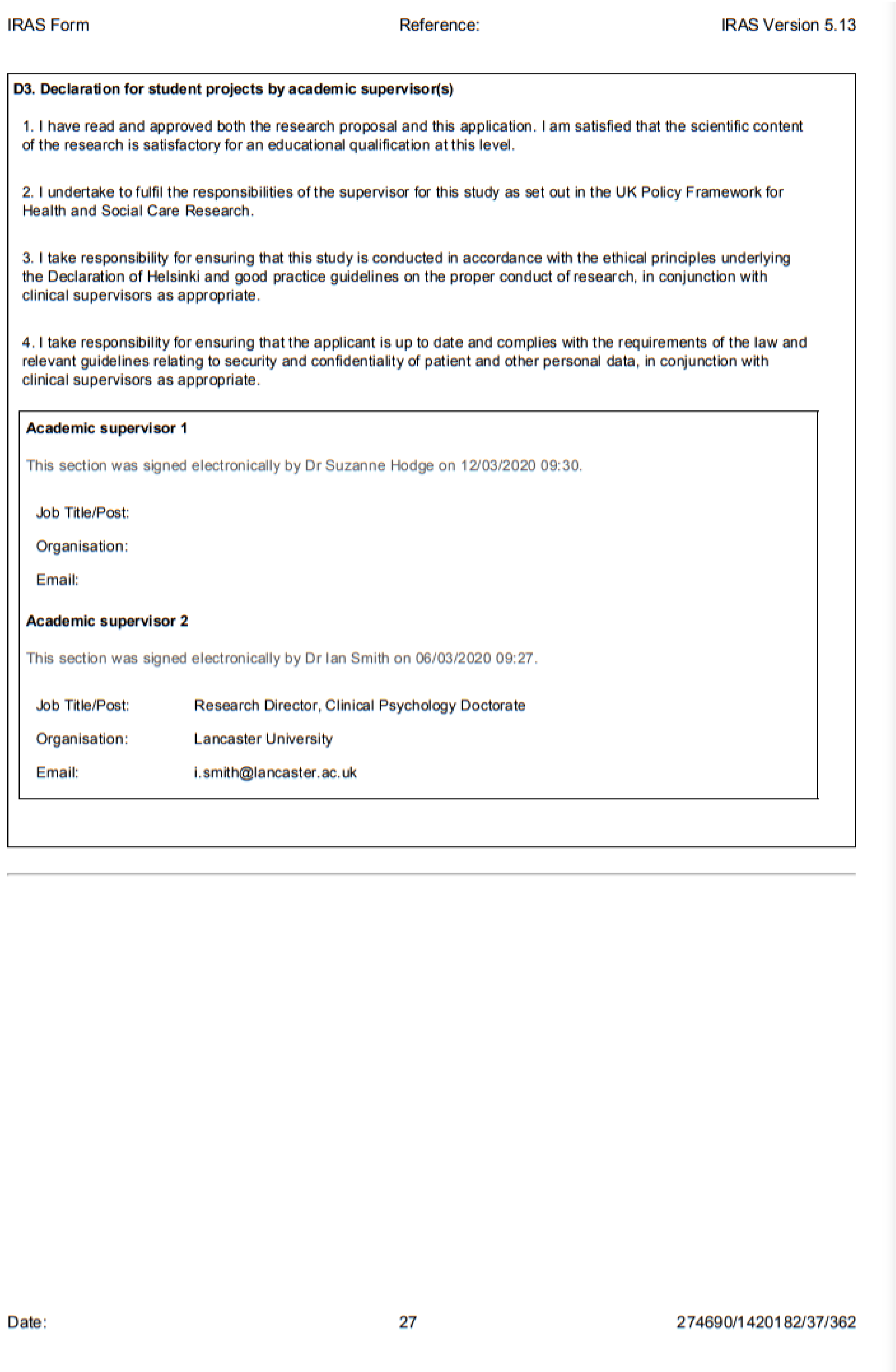
   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at sponsorship@lancaster.ac.uk on 09/03/2020 08:51.

| | |
|---|---|
| Job Title/Post: | Head of Research Quality and Policy |
| Organisation: | Lancaster University |
| Email: | b.gordon@lancaster.ac.uk |



**D3. Declaration for student projects by academic supervisor(s)**

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the UK Policy Framework for Health and Social Care Research.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

**Academic supervisor 1**

This section was signed electronically by Dr Suzanne Hodge on 12/03/2020 09:30.

Job Title/Post:
Organisation:
Email:

**Academic supervisor 2**

This section was signed electronically by Dr Ian Smith on 06/03/2020 09:27.

Job Title/Post: Research Director, Clinical Psychology Doctorate
Organisation: Lancaster University
Email: i.smith@lancaster.ac.uk

## Appendix 4-A: Research Protocol

**Version 1.1 - 20/02/20**

### Using grounded theory to investigate service-user perceptions about the relationship between receiving a personality disorder diagnosis and the effect on their psychological wellbeing.

**Name of applicant/supervisors/affiliations**

Chief Investigator:

Dr Ian Smith

Research Director and Senior Lecturer, Clinical Psychology, Division of Health Research, Lancaster University, Lancaster, LA1 4YG

Phone: 01524 592282

Email: i.smith@lancaster.ac.uk

-----------------------------------------------------------

Student Researcher:

Sophie Green

Trainee Clinical Psychologist, Lancaster University, Lancaster, LA1 4YG

Phone: 07508375665

Email: s.green9@lancaster.ac.uk

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Co-Investigator (Research Supervisor):

Dr Suzanne Hodge

Lecturer, Clinical Psychology, Division of Health Research, Lancaster University, Lancaster, LA1 4YG Phone: 01524 592712

Email: s.hodge@lancaster.ac.uk

----------------------------------------------------------

Co-Investigator (Field Supervisor):

Dr [redacted]

Clinical Lead [redacted]

Phone: [redacted]

Email: [redacted]nhs.uk

## Introduction

Personality disorders have been defined by the British Psychological Society (2006) as “a description of those enduring characteristics of a person that impair their well-being or social functioning”. The British Psychological Society’s report highlights that 30-40% of service-users accessing community mental health services and 40-50% of service-users in inpatient services meet criteria for a ‘personality disorder,’ however these figures vary significantly.

Previous research has focused on investigating service-users’ perceptions of being diagnosed with a personality disorder and there has been a variety of responses to this. The diagnosis has on the one hand been reported as containing and giving knowledge and control, but on the other as being simplistic and negative (Horn, Johnstone & Brooke, 2007). When questioned about the term ‘personality disorder’ some service users have reported that it is derogatory whereas for others it was the condition, rather than the label given to it, which was distressing (Stalker, Ferguson, & Barclay, 2005). For service users in inpatient settings the diagnosis was felt to trigger prejudice from staff and resulted in a lack of adequate care (Rogers, & Dunne, 2011).

The same discrepancies have been found in research which focuses on clinicians’ views on diagnosing personality disorders. For clinicians there are difficulties with communicating a diagnosis of personality disorder to an individual, with the major barriers being cited as the clinician being unsure about the validity of the diagnosis, concern regarding the stigma associated with the diagnosis of personality disorders and the consequent harm this label might cause to a service-user (Lequesne, & Hersh, 2004). Research has shown that because of these factors clinicians may withhold a diagnosis of personality disorder from an individual (Sisti, Segal, Siegel, Johnson & Gunderson, 2016).

Diagnostic frameworks cluster personality disorders into different types. The focus of this study is on Borderline Personality Disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013), and Emotionally Unstable Personality Disorder Borderline Type, as defined by the International Classification of Diseases, Tenth Edition (2016). The constructs of Borderline Personality Disorder (BPD) and Emotionally Unstable Personality Disorder (EUPD) are similar to each other and have been considered as equivalent diagnoses with both being used interchangeably in services in the UK (Bach & First, 2018; National Institute for Clinical Excellence, 2009). For the purposes of this research BPD and EUPD will be treated as equivalent diagnoses for the same presenting difficulties. This study is focusing on the BPD and EUPD diagnoses due research which has shown people with these diagnoses are more likely to complete suicide than the general population (Pompili, Girardi, Ruberto, & Tatarelli, 2005), access inpatient and outpatient mental health services more highly, have associated severe impairment and disproportionately high use of primary care services (Leichsenring, Leibing, Kruse, New, & Leweke, 2011; Morgan, & Zimmerman, 2002).

Although service-user and clinician views about the diagnosis of personality disorders have been increasingly researched, to date no research has looked specifically at service-users’ perceptions of the way in which a diagnosis of BDP and EUPD is communicated and the impact of this on service user wellbeing. The wellbeing of a service-user who has received a BPD or EUPD diagnosis is a key consideration for clinical psychologists. Furthermore, as previous research has shown that for individuals who discovered that a diagnosis of BPD had been withheld by a service provider all discontinued treatment with that same provider (Sulzer, Muenchow, Potvin, Harris & Gigot, 2016). This highlights the need and importance of research into the communication of these diagnoses.

This study aims to understand how the way in which a diagnosis of borderline personality disorder is communicated and the subsequent impact this might have on service-user wellbeing. This will look to explain why some people may have different experiences or responses and why certain approaches in delivering a diagnosis of borderline personality disorder may be more beneficial, or less detrimental, than other approaches.

*Research questions* –

What are participants' experiences of receiving a diagnosis of borderline personality disorder?

How does the perceived communication of a diagnosis of borderline personality disorder affect service-user wellbeing?

## Method

### Participants

Participants will be individuals who report having received a formal diagnosis of Borderline

Personality Disorder or Emotionally Unstable Personality Disorder in the last 5 years. This time frame has been chosen to allow for a clear enough memory of the communication of the diagnosis.

There are many debates about diagnosis of personality disorders in adolescents including the ethics, validity and usefulness of this (Levy et al., 1999; Miller, Muehlenkamp, & Jacobson, 2008) therefore this study will recruit participants aged 18 and above.

I will aim to interview between 10 and 20 participants, or until theoretical sufficiency is established. This will mean that a sufficient depth of understanding has been achieved in relation to the development of emerging categories and theories (Dey, 1999).

Potential participants will be recruited from NHS services in the North West of England and from third sector organisations.

Potential participants will be asked their age, gender, how they received their diagnosis and from whom in a demographic questionnaire (see Appendix A for the demographic questionnaire). This will ensure a broad range of experiences are reflected in the participants who are invited to interview and to enable theoretical sampling.

*Inclusion Criteria* –

Individuals with a formal diagnosis of borderline personality disorder or emotionally unstable personality disorder

Aged 18 and above

Have been informed of their diagnosis

Received their diagnosis in the last 5 years

Living in the UK

*Exclusion Criteria* –

Individuals still undergoing assessment for borderline personality disorder or emotionally unstable personality disorder

Individuals with an informal, retracted or queried diagnosis of borderline personality disorder or emotionally unstable personality disorder

### Design

This research will employ a qualitative design. Individual semi-structured interviews (see Appendix B for a sample topic guide) will be conducted with participants. This will allow for some degree of comparability between participants responses but also flexibility to pursue important topics for each participant.

Interviews will be transcribed verbatim by the Student Researcher. Due to the nature of the primary research question a constructivist Grounded Theory approach will be used (Charmaz, 2006). This method works by the assumption that there is not an underlying theory waiting to be discovered by research, rather that theory will be constructed through mapping perceptions of processes and researcher's interaction with the data.

### Materials

Participants will be provided with an information sheet (see Appendix C for the information sheet), a demographic questionnaire (Appendix A) and a consent form (see Appendix D for the consent form).

The researcher will have access to a semi-structured interview schedule, audio recorder and transcription equipment (foot pedal).

## Procedure

### Recruitment

Approval has been gained from two NHS services to recruit for the study. At present the following services have given approval; [redacted] NHS Foundation, [redacted] and [redacted] NHS Foundation Trust, [redacted].

The researcher will also use social media to ensure that the sample of participants in not limited to those currently accessing NHS services. The study has approval to be advertised on twitter and Facebook (see Appendix E for a sample social media advert) by Lancaster University's Doctorate in Clinical Psychology programme.

The researcher will attend relevant management meetings to discuss the study with the above identified services. Staff members will be provided with the information sheet, demographic questionnaire and consent form. Staff members will be requested to hand these out to eligible service-users. Services will also be asked to advertise the study using a poster (see Appendix F for a sample study poster) in an accessible area of their service.

Potential participants who are interested in taking part or who would like more information will then be able to use the information sheet or poster to contact the researcher via email or phone. At this time potential participants will be asked to complete a pre-interview demographic questionnaire. Potential participants' responses to the demographic questionnaires will be considered in line with theoretical sampling as the study progresses to ensure that a wide range of experiences are included in the study. A suitable time for the interview will then be arranged where the researcher will go through the participant information sheet, obtain informed consent and conduct the semistructured interview.

Information sheets, consent forms, demographic questionnaires and advertising posters have been screened by experts by experience to ensure they are appropriate.

### Data Collection

Once recruited, participants will be asked to attend an initial interview session which is expected to last approximately 1 hour.

Approximately the first ten minutes of the interview will account for introductions, discussions about confidentiality and anonymity and its limits and participants will be reminded of their right to withdraw. It will also be made explicit that participants do not have to answer any of the questions if they feel this may cause them distress. Participants will be offered the opportunity to ask any further questions regarding the research before taking part. Informed consent will be sought at this time.

Due to the nature of grounded theory the findings from earlier interviews may be used to adapt and focus questions used in later interviews.

Participants may also be invited for a second follow up interview to expand on answers and check developing theory (Charmaz, 2006).

If during the interview participants become distressed they will be offered the opportunity to have a break, rearrange or discontinue the interview should they prefer.

At the end of the interviews, participants will again be given the opportunity to ask questions and will be debriefed. All participants will be reminded of the helplines and available opportunities for support if they wish to seek this.

### Analysis

All interviews will be audio recorded and the student researcher will transcribe the audio files verbatim.

The analysis will follow the Grounded Theory approach described by Charmaz (2006). This will involve initial line by line coding, focused coding and conceptual coding along with memo writing to inform a theoretical framework.

The Student Researcher will also keep a reflective diary during the analysis phase to allow them to document and reflect on their own feelings and responses to the data and how this may impact on the interpretations. This can be further discussed if felt necessary with the Chief Investigator, Research Supervisor and Field Supervisor.

## Practical issues (e.g., costs/logistics)

### Data Management and Storage

All interview recordings will be transferred to a password protected file space on the Student

Researcher’s secure university server as soon as possible after interview. Following this the Student Researcher will delete the audio file from the recording device used in the interview. The transcripts of the interviews will also be stored in a password protected file space on the Student Researcher’s secure university server.

Hard copies of data which contains identifiable participant information will be stored in a secure lockable cabinet in a secure office with only the Student Researcher having access to this. Upon successful completion of the project, this information will be scanned into the university computer system, encrypted and stored as electronic data. All hard copies will then be destroyed by the Student Researcher.

Only the Student Researcher, Chief Investigator and Research Supervisor will have access to these files. This is in order to provide the Student Researcher with guidance on the interview and analysis process. The Field Supervisor will not have direct access to any participant data, but they may have access to appropriately anonymised excerpts of transcribed interviews.

In accordance with the University and DClinPsy programme policy, all data will be electronically stored for ten years in encrypted file space on the University server. This will be permanently deleted after 10 years. The research co-ordinator will be responsible for deleting this.

## Ethical concerns

### Risk to Participants

No risks are associated with participants taking part in this study. However, it may be that some participants find the discussion of their experiences distressing. If participants become distressed during the interview, the researcher will firstly offer to pause or stop the interview. If a participant becomes increasingly distressed during the interview the researcher will remind them of their right to withdraw from the study or ask if they would like a break. There is information incorporated into the participant information sheet in the event that participants choose to seek further support following their participation in the study.

Participants may withdraw from the study at any time. However, the removal of their data will be limited to two weeks following their participation at interview. After this, it may not be possible to remove individual data as analysis may be started and the data pooled.

All participants will be told the boundaries of confidentiality and anonymity at the beginning of the interview. This includes that all discussions will be confidential unless there is a disclosure to suggest the participant or another person may be at risk of harm. This will then be discussed with the participant and relevant safeguarding procedure will be followed.

### Risk to Researchers

It will be necessary for participants to have the Student Researcher's email address for recruitment purposes. In the interest of risk of participants having access to personal contact details, the Student Researcher's university email will be used. A specific research project phone will be used for recruitment purposes, not the Student Researcher's personal phone number.

Data collection will be conducted via telephone call and face to face interview. Face to face interviews may be offered if the geographical location permits and will be booked at appropriate NHS sites. At this point the university's lone working policy will be adhered to. The Student Researcher will inform the Chief Investigator when, where and at what time the interviews will take place, and will be informed when the interviews are complete.

## Timescale

Submit ethics proposal – February 2020

Data collection – April to August 2020

Data analysis – April to August 2020

Submit thesis – March 2021

Submit for publication – August 2021

**References**

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Rogers, B., & Dunne, E. (2011). 'They told me I had this personality disorder… All of a sudden I was wasting their time': Personality disorder and the inpatient experience. *Journal of Mental Health*, *20*(3), 226-233.

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## Appendix 4-B: Participant Information Sheet

### Participant Information Sheet

Version 1.2
30.04.2020
IRAS ID - 274690

***Investigating the way in which people were given a diagnosis of personality disorder and the perceived effects of this communication on wellbeing.***

My name is Sophie Green and I am conducting this research as a student in the Doctorate in Clinical Psychology at Lancaster University, Lancaster, United Kingdom. This sheet will give you some details about my project, please read this information carefully and take time to think about if you would like to take part. If you have any questions about the study please contact me via the details below.

**What is the study about?**

The purpose of this study is to investigate the way in which people were given a diagnosis of borderline personality disorder (BPD) or emotionally unstable personality disorder (EUPD) and how this communication may have affected their wellbeing.

**Why have I been approached?**

You have been given this information sheet because you are a person who has received a diagnosis of BPD or EUPD.

**Do I have to take part?**

No. It’s completely up to you to decide whether or not you take part. If you decide that you do not wish to take part, this will not have any negative impact on any current services or support that you are accessing.

**What will I be asked to do if I take part?**

- If you decide you would like to take part, I will phone you to gather some basic demographic details. This will help me make sure that I talk to people with a wide range of experiences. If you are chosen to take part you will be asked to attend an interview with me which will last about 1 hour. I can give you more information about what to expect prior to the day of the interview.
- In this interview I will ask you about your experiences of receiving a diagnosis of borderline personality disorder and how this has effected your wellbeing.
- The interview will take place at a time and place which is convenient for you such as an NHS site, via telephone or a neutral but private place.
- I may ask you to attend a second interview gather further information as the study progresses.

- The interviews will be audio recorded and then written up by me.

**Will my data be identifiable?**

- The data collected for this study will be kept in an encrypted secure university location and only the researchers conducting this study will have access to it.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study.
- All your personal data will be confidential and will be kept separately from your interview responses.
- There are some limits to confidentiality: if what you say in the interview made me think that you, or someone else, is at significant risk of getting hurt, then I may have to speak to a member of staff or someone else about this to stop anyone getting hurt. If possible, I would tell you if I have to do this.

**What if I change my mind?**

You can choose to leave the study at any time. You can also ask for your data to be taken out, for up to two weeks after the interview. Deciding to withdraw from the study will have no negative impact on any current services or support that you are accessing.

**What will happen to the results?**

The results will be written up as a research project and may be published in an academic or professional journal. Results may also be presented at conferences.

A summary of the findings can be sent to you, and to other people taking part in the study and staff. If you would like a copy of the results, please ask me.

**Are there any risks?**

There are no risks anticipated with participating in this study. However, if you experience any distress during the interview you can pause, use strategies to help you manage any emotional distress or withdraw at any time. There are also some details of organisations/helplines that might be useful at the end of this sheet.

**Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part. However it is hoped that this research may give you the opportunity for your opinions and experiences to be heard and this could provide valuable information about how services can better support individuals with similar experiences to yourself.

**Who has reviewed the project?**

This study has NHS ethical approval from the South Central – Oxford B Research Ethics Committee and has also been approved by the NHS Health Research Authority

**Who is involved in the project?**

Sophie Green (Student Researcher) Trainee Clinical Psychologist, Lancaster University

Dr Ian Smith (Chief Investigator) Research Director and Senior Lecturer, Clinical Psychology, Division of Health Research, Lancaster University

Dr Suzanne Hodge (Research Supervisor) Lecturer, Clinical Psychology, Division of Health Research, Lancaster University

Dr [redacted] (Field Supervisor) Clinical Lead, [redacted] [redacted] NHS Foundation Trust

**Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bill Sellwood, Programme Director of the Doctorate in Clinical Psychology

Faculty of Health and Medicine

Lancaster University

Tel: +44 (0)1524 593998

Email: b.sellwood@lancaster.ac.uk

Or

Professor Roger Pickup Associate Dean for Research

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YG

Tel: +44 (0)1524 593746

Email: r.pickup@lancaster.ac.uk

**Resources in the event of distress**

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

- *Your GP*
- *Any mental health services that you are currently accessing*
- *The Samaritans if you feel you need to talk to someone using their 24 hour helpline: 116 123 or website www.samaritans.org*
- *You can contact Mind on the following number (Monday to Friday, 9am to 6pm): 0300 123 3393, or by email on: info@mind.org.uk or by text message on: 86463*
- *You can leave a message with SANE on the following number 07984 967 708 and someone will call you back as soon as practicable, or by email on: support@sane.org.uk*

Thank you for taking the time to read this information sheet.

If you have read this information and would like to take part in the research please contact Sophie Green at:

**s.green9@lancaster.ac.uk or on 07508375665**

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

## Appendix 4-C: Consent Form

### Consent Form

Version 1.3
07.08.2020
IRAS ID - 274690

***Investigating the way in which people were given a diagnosis of personality disorder and the perceived effects of this communication on wellbeing.***

We are asking if you would like to take part in a research project which will look at the way in which people received a diagnosis of borderline personality disorder or emotionally unstable personality disorder and how this communication may have affected their wellbeing.

Before you consent to participating in the study we ask that you read the participant information sheet and add your initials to each box below if you agree. If you have any questions or queries before signing the consent form please speak to a member of the research team.

Please initial

1. I confirm that I have read the participant information sheet (V1.2 30.04.2020) and fully understand what is expected of me within this study. ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined. ☐
5. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research team, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
7. I understand that up to two weeks after the interview I can withdraw my data without needing to give reason. ☐

8. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project. ☐

9. I understand that anonymised verbatim (word-for-word) quotes will be used when the study is written up and published. ☐

10. I understand that the researcher will discuss data with their research supervisor and field supervisor as needed. ☐

11. I understand that any information I give will remain anonymous and my identity will be kept confidential unless there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with others in order to avoid harm. ☐

12. I understand that any information I give will only be accessed by the research team directly involved in this study. ☐

13. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

14. I understand that this form will be stored securely at Lancaster University and I have been given a copy of this form for my own records. ☐

15. I consent to take part in the above study. ☐

**Name of Participant__________________ Signature____________________ Date ___________**

**Name of Researcher __________________Signature ____________________Date___________**

## Appendix 4-D: Sample Topic Guide

### Sample Interview Topic Guide

Version 1.1
20.02.2020
IRAS ID - 274690

***Using grounded theory to investigate the way in which people were given a diagnosis of personality disorder and the perceived effects of this communication on wellbeing.***

**Introduction:**

Today we are going to talk about your experiences of receiving a personality disorder diagnosis. This will be in a vaguely chronological order, before, during, after.

Is there anything important for me to know about you before we begin? E.g. things that might affect the interview, things you don't want to talk about?

How do you refer to/how would you like me to refer to your diagnosis?

**Before diagnosis:**

Are you able to tell me about your circumstances before receiving a diagnosis of borderline personality disorder/emotionally unstable personality disorder?

What contact did you have with services at this point in time?

How would you describe your wellbeing at this time?

**During diagnosis:**

Are you able tell me about your experience of receiving a diagnosis of borderline personality disorder/emotionally unstable personality disorder?

What prior knowledge/understanding of BPD did you have?

What were your thoughts/feelings at this time?

What were the more positive aspects of this experience?

What were the more negative aspects of this experience?

What was more helpful about this experience?

What was less helpful about this experience?

What was it about XXX that was helpful/unhelpful?

Can you describe the follow up after diagnosis?

How did you respond?

What was your reasoning for doing XXX?

**After diagnosis:**

How did receiving a diagnosis of BPD impact on your wellbeing?

Was there any positive impact on you?

Was there any negative impact on you?

What contact did you have with services following the diagnosis?

How do you view your diagnosis now?

How do you view your wellbeing now?

**Ending:**

Is there anything else you would like to add?

Is there anything you would like to ask me?

## Appendix 4-E: Advertising Materials

### Social Media Advert

Have you been diagnosed with Borderline Personality Disorder or Emotionally Unstable Personality Disorder in the last 5 years?
Aged 18 and over and living in the UK?
Would you like to take part in research about how the communication of this diagnosis may have effected your wellbeing?

Please contact Sophie if you would like to take part. Thank you!

Doctorate in Clinical Psychology | Lancaster University

**We are recruiting research participants!**

**Have you received a diagnosis of borderline personality disorder or emotionally unstable personality disorder in the last 5 years?**

**Then we want to hear from you!**

**We are interested in talking to people about how they received a BPD or EUPD diagnosis and the effect of this on their wellbeing**

**My name is Sophie Green and I am a Trainee Clinical Psychologist at Lancaster University conducting research as part of my training**

**Get in touch…**

**Call or text**
**07508375665**

**Email**
**s.green9@lancaster.ac.uk**

**Scan to email**
**me now!**

### Advertising Poster

## We are recruiting research participants!

## Have you received a diagnosis of borderline personality disorder or emotionally unstable personality disorder in the last 5 years?

## Then we want to hear from you!

**We are interested in talking to people about how they received a BPD or EUPD diagnosis and the effect of this on their wellbeing**

**My name is Sophie Green and I am a Trainee Clinical Psychologist at Lancaster University conducting research as part of my training**

**Get in touch…**

☎ **Call or text**
**07508375665**

✉ **Email**
**s.green9@lancaster.ac.uk**

**Scan to email me now!**

Sophie Green
s.green9@lancaster.ac.uk
07508375665

Sophie Green
s.green9@lancaster.ac.uk
07508375665

Sophie Green
s.green9@lancaster.ac.uk
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s.green9@lancaster.ac.uk
07508375665

Sophie Green
s.green9@lancaster.ac.uk
07508375665

## Appendix 4-F: REC Favourable Opinion Letter

NHS
Health Research Authority
[redacted]

[redacted]

**Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval**

03 June 2020

Dr Ian Smith
Division of Health Research, Lancaster University
Lancaster
LA1 4YG

Dear Dr Smith

| | |
|---|---|
| **Study title:** | **Using grounded theory to investigate service-user perceptions about the relationship between receiving a personality disorder diagnosis and the effect on their psychological wellbeing.** |
| **REC reference:** | **20/SC/0165** |
| **Protocol number:** | **N/A** |
| **IRAS project ID:** | **274690** |

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, ‘clinical trials’ are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee ( see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-rese arch-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilit ies/

You should notify the REC of the registration details.  We will audit these as part of the annual progress reporting process.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**After ethical review: Reporting requirements**

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

**Ethical review of research sites**

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Copies of advertisement materials for research participants [Advertising Materials] | 1.1 | 20 February 2020 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employers Liability and Public Liability Insurance] | 1.1 | 20 February 2020 |
| Interview schedules or topic guides for participants [Sample Topic Guide] | 1.1 | 20 February 2020 |
| IRAS Application Form [IRAS_Form_13032020] | | 13 March 2020 |
| IRAS Checklist XML [Checklist_13032020] | | 13 March 2020 |
| IRAS Checklist XML [Checklist_30032020] | | 30 March 2020 |
| IRAS Checklist XML [Checklist_18052020] | | 18 May 2020 |
| Non-validated questionnaire [Demographic Questionnaire] | 1.2 | 30 April 2020 |
| Other [Professional Negligence Insurance] | 1.1 | 20 February 2020 |
| Other [Confirmation Agreement Email [redacted]] | 1.1 | 10 January 2020 |
| Other [[redacted] thesis contract] | 1.1 | 15 October 2019 |
| Participant consent form [Consent Form] | 1.2 | 30 April 2020 |
| Participant information sheet (PIS) [Participant Information Sheet] | 1.2 | 30 April 2020 |

| | | |
|---|---|---|
| Research protocol or project proposal [Thesis Research Protocol] | 1.1 | 20 February 2020 |
| Summary CV for Chief Investigator (CI) [Chief Investigator CV] | 1.1 | 14 February 2020 |
| Summary CV for student [CV for student researcher] | 1.1 | 30 March 2020 |
| Summary CV for supervisor (student research) [CV for Suzanne Hodge academic supervisor] | 1.1 | 30 March 2020 |

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

**IRAS project ID: 274690    Please quote this number on all correspondence**

With the Committee’s best wishes for the success of this project.

Yours sincerely

[redacted]

[redacted]

Email: [redacted]

*Enclosures:* “After ethical review – guidance for researchers” *[SL-AR2]*

*Copy to:* Mrs Becky Gordon

## Appendix 4-G: HRA Approval Letter

Dr Ian Smith
Division of Health Research, Lancaster University

Lancaster
LA1 4YG

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

04 June 2020

Dear Dr Smith

### HRA and Health and Care

| | |
|---|---|
| **Study title:** | **Using grounded theory to investigate service-user perceptions about the relationship between receiving a personality disorder diagnosis and the effect on their psychological wellbeing.** |
| **IRAS project ID:** | **274690** |
| **Protocol number:** | **N/A** |
| **REC reference:** | **20/SC/0165** |
| **Sponsor** | **Lancaster University** |

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

**What are my notification responsibilities during the study?**

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **274690**. Please quote this on all correspondence.

Yours sincerely,
Hayley Henderson
Approvals Manager

Email: approvals@hra.nhs.uk
*Copy to: Mrs Becky Gordon, Sponsor Contact*

**List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

| *Document* | *Version* | *Date* |
|---|---|---|
| Copies of advertisement materials for research participants [Advertising Materials] | 1.1 | 20 February 2020 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employers Liability and Public Liability Insurance] | 1.1 | 20 February 2020 |
| Interview schedules or topic guides for participants [Sample Topic Guide] | 1.1 | 20 February 2020 |
| IRAS Application Form [IRAS_Form_13032020] |  | 13 March 2020 |
| Non-validated questionnaire [Demographic Questionnaire] | 1.2 | 30 April 2020 |
| Organisation Information Document [[redacted] OID] | 1.3 | 07 May 2020 |
| Organisation Information Document [[redacted] OID] | 1.3 | 07 May 2020 |
| Other [Professional Negligence Insurance] | 1.1 | 20 February 2020 |
| Other [Confirmation Agreement Email [redacted]] | 1.1 | 10 January 2020 |
| Other [[redacted] thesis contract] | 1.1 | 15 October 2019 |
| Participant consent form [Consent Form] | 1.2 | 30 April 2020 |
| Participant information sheet (PIS) [Participant Information Sheet] | 1.2 | 30 April 2020 |
| Research protocol or project proposal [Thesis Research Protocol] | 1.1 | 20 February 2020 |
| Schedule of Events or SoECAT [Schedule of Events] | 1.1 | 28 February 2020 |
| Summary CV for Chief Investigator (CI) [Chief Investigator CV] | 1.1 | 14 February 2020 |
| Summary CV for student [CV for student researcher] | 1.1 | 30 March 2020 |
| Summary CV for supervisor (student research) [CV for Suzanne Hodge academic supervisor] | 1.1 | 30 March 2020 |

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

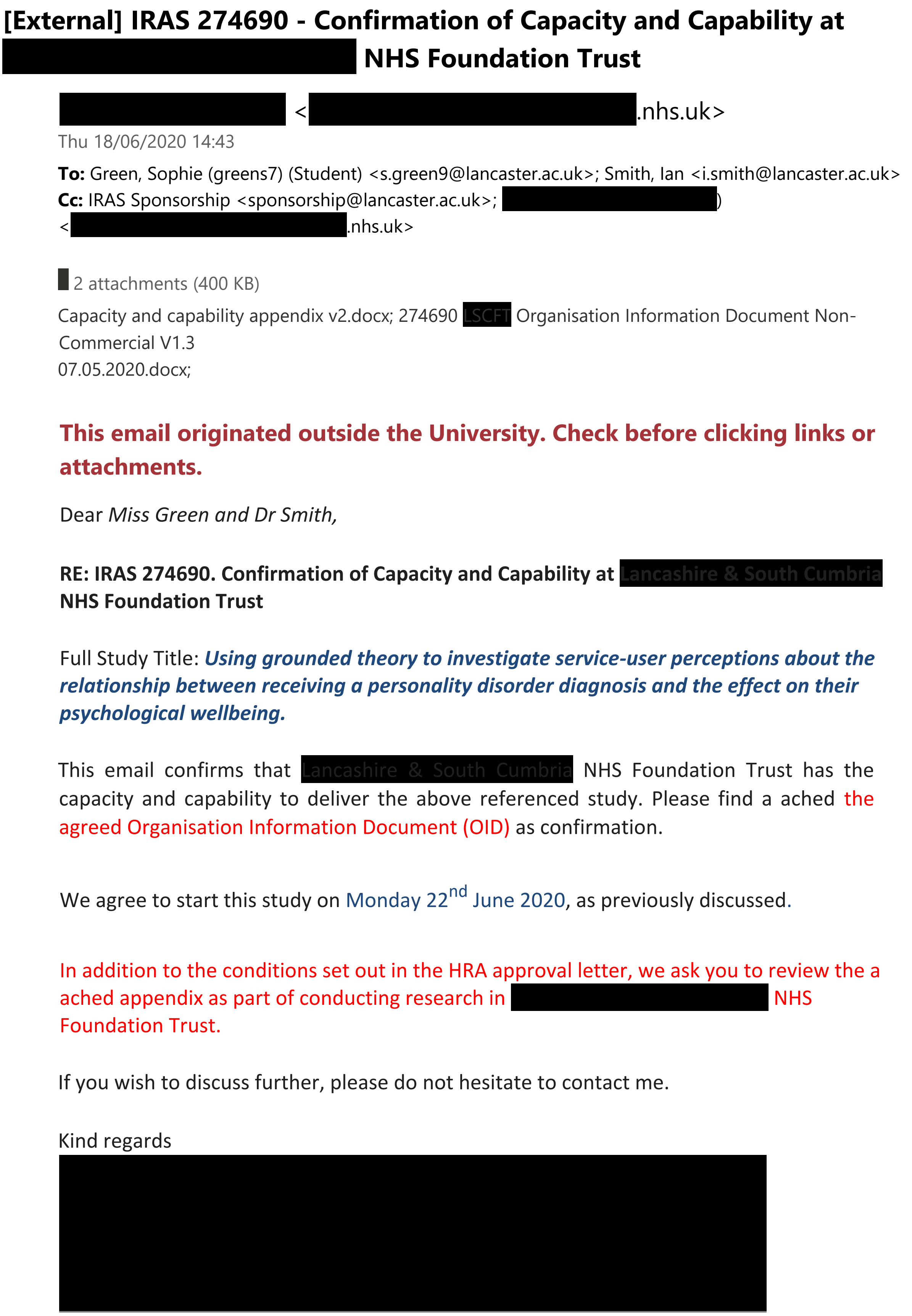
| **Types of participating NHS organisation** | **Expectations related to confirmation of capacity and capability** | **Agreement to be used** | **Funding arrangements** | **Oversight expectations** | **HR Good Practice Resource Pack expectations** |
|---|---|---|---|---|---|
| All sites will perform the same research activities therefore there is only one site type. | Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study. | An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used. | No study funding will be provided to sites asper the Organisational Information Document. | A Local Collaborator should be appointed at study sites. | No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in the IRAS form (except for administration of questionnaires or surveys), would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | employed) or an NHS to NHS confirmation of pre engagement - checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members only administering questionnaires or surveys, a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate. |

### Other information to aid study set-up and delivery

| *This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.* |
|---|
| The applicant has indicated they do not intend to apply for inclusion on the NIHRCRN Portfolio. |

## Appendix 4-H Capacity and Capability Confirmations



### [External] IRAS 274690 - Confirmation of Capacity and Capability at [redacted] NHS Foundation Trust

[redacted] <[redacted].nhs.uk>
Thu 18/06/2020 14:43

**To:** Green, Sophie (greens7) (Student) <s.green9@lancaster.ac.uk>; Smith, Ian <i.smith@lancaster.ac.uk>
**Cc:** IRAS Sponsorship <sponsorship@lancaster.ac.uk>; [redacted])
<[redacted].nhs.uk>

2 attachments (400 KB)

Capacity and capability appendix v2.docx; 274690 [redacted] Organisation Information Document Non-Commercial V1.3
07.05.2020.docx;

**This email originated outside the University. Check before clicking links or attachments.**

Dear *Miss Green and Dr Smith,*

**RE: IRAS 274690. Confirmation of Capacity and Capability at [redacted] NHS Foundation Trust**

Full Study Title: ***Using grounded theory to investigate service-user perceptions about the relationship between receiving a personality disorder diagnosis and the effect on their psychological wellbeing.***

This email confirms that [redacted] NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find a ached the agreed Organisation Information Document (OID) as confirmation.

We agree to start this study on Monday 22nd June 2020, as previously discussed.

In addition to the conditions set out in the HRA approval letter, we ask you to review the a ached appendix as part of conducting research in [redacted] NHS Foundation Trust.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards
[redacted]

[redacted]
[redacted].nhs.uk
[redacted]

---

## [External] [redacted] Confirmation of Capacity & Capability

**From:** [redacted].nhs.uk>
**Sent:** 21 September 2020 12:21
**To:** Green, Sophie (greens7) (Student) <s.green9@lancaster.ac.uk>
**Cc:** [redacted].nhs.uk>; IRAS Sponsorship <sponsorship@lancaster.ac.uk>
**Subject:** [External] [redacted] Confirmation of Capacity & Capability

**This email originated outside the University. Check before clicking links or attachments.**

Dear Sophie

Re: Using grounded theory to investigate service-user perceptions about the relationship between receiving a personality disorder diagnosis and the effect on their psychological wellbeing. IRAS Ref: 274690 [redacted]

On behalf of [redacted] NHS Foundation Trust I am pleased to confirm Capacity and Capability for the above research to commence at our site. Please take the me to read the specific conditions of this approval. In particular, please read the guidance explaining how to report your recruitment activity. Further guidance can also be viewed on our website: https://www.[redacted]

The target date for the first participant to be recruited by is 21/10/2020. Please can you notify us at [redacted].nhs.uk when this has been achieved, or if you are having any difficulty recruiting the first participant.

If Sponsor Greenlight is not required for your project, you may now commence recruitment once your Letter of Access has been issued.

Best wishes
[redacted]