# FIGHTING THE INVISIBLE ENEMY: BEING A PARENT OF A CHILD WHO HAS BEEN GIVEN A DIAGNOSIS OF PERVASIVE REFUSAL SYNDROME

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#### **ABSTRACT**

Pervasive Refusal Syndrome was introduced to the child and adolescent psychiatric literature by Lask, Britten, Kroll, Magagna and Tranter in 1991. It is not a formal diagnosis classified within the DSM-V (APA, 2013) or ICD-10 (WHO, 1994). However, it is employed clinically as a descriptive label to denote a specific constellation of symptoms. It is understood to be characterised by a profound and pervasive refusal across different domains: eating, drinking, speech, mobilisation, and personal care (Lask et al., 1991). It is reported to be accompanied with an active rejection of help, social withdrawal and school refusal (Lask et al., 1991; Thompson & Nunn, 1997).

A literature review highlighted that perspectives on PRS are predominantly based on expert professional opinion; the experiences and perspectives of children and their families are underrepresented. This exploratory study aimed to address this gap in the literature by examining how parents made sense of their child being given a diagnosis of PRS and what it was like to experience their child being unwell. Furthermore it aimed to explore how parents experienced and negotiated the treatment process.

Semi-structured interviews were conducted with eight participants. The data generated from the interviews was analysed using Interpretative Phenomenological Analysis. Three superordinate themes were identified and represented: parents' perspectives and experiences of PRS and its treatment; parents' experiences of and relationships with professionals; and the personal "journey" that parents experienced. The findings suggested that parents' experiences and meaning making processes were delineated by stages, which reflected the trajectory of their child's difficulties. It seemed each stage brought new experiences, understandings and challenges.

This study has provided a novel contribution to the literature and has offered new insights into the diagnosis from the perspective of a parent. The implications for clinical practice and recommendations for future research are outlined.

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#### **CHAPTER 1: INTRODUCTION**

#### 1. Overview

Pervasive Refusal Syndrome (PRS) was introduced to the child and adolescent psychiatric literature by Lask, Britten, Kroll, Magagna and Tranter in 1991. It is not a formal diagnosis classified within the Diagnostic and Statistical Manual (DSM-V) (APA, 2013) or International Classification of Diseases (ICD-10) (WHO, 1994). However, it is employed clinically as a descriptive label to denote a specific constellation of 'symptoms'. It is understood to be characterised by a profound and pervasive refusal across different domains: eating, drinking, speech, mobilisation, and personal care (Lask et al., 1991). Furthermore, it is believed to be accompanied with an active rejection of help, social withdrawal and school refusal (Lask et al., 1991; Lask, 2004; Thompson & Nunn, 1997). Due to the severity of the presentation it is considered to be potentially life threatening. Formalised treatment guidelines or management protocols do not currently exist and there is a minimal evidence base to draw upon when treating children and young people.

PRS' aetiology, diagnostic specificity and nomenclature has been debated within the literature since its inception. Indeed, further to a recent re-conceptualisation a renaming has been proposed: Pervasive Arousal Withdrawal Syndrome (PAWS) (Nunn, Lask & Owen, 2013). Moreover, the literature is primarily comprised of detailed case studies presented from professionals' perspectives. There are limited accounts of the children, young people and parents' perspectives and experiences of PRS and its treatment. In an attempt to address this gap in the literature, this exploratory study aimed to understand what it was like for parents to experience their child being unwell and how they made sense of the diagnosis. Furthermore it aimed to explore how parents experienced and negotiated the treatment process.

This chapter provides a review of the existing literature on PRS and outlines: the diagnostic criterion and its epidemiology; the differential diagnoses; the various

conceptualisations; and its treatment. The national health context is discussed and the family context is considered. The rationale for the present study and an outline of the research questions are presented.

#### 1.1 Literature Search Criteria

Relevant literature was identified by searching four electronic databases through EBSCO: Academic Search Complete; Child and Adolescent Studies; CINAHL Plus; and PsycINFO. An additional electronic database, SCOPUS, was also employed. These were considered to be the most suitable search providers available. The specific terms used for these searches were 'Pervasive Refusal Syndrome' and 'Pervasive Arousal Withdrawal Syndrome'. Due to the rarity of the diagnosis it was expected that the search would generate a limited number of articles. As such, no parameters were applied and the inclusion specification was not stringent. Articles from outside of the United Kingdom (UK) were included. However, only those published in English were accepted. Articles were selected on the basis that the keywords from the search terms were present in the title or abstract. A summary of the search results can be found in Table 1.

Table 1: Summary of literature search results

Search Term	Search	Total Number	Number of
	Engine	of Results	Relevant Articles
Pervasive Refusal Syndrome	EBSCO	48	35
(PRS)	SCOPUS	41	28*
Pervasive Arousal Withdrawal	EBSCO	2	2**
Syndrome (PAWS)	SCOPUS	8	2**

<sup>\*</sup>This search yielded 3 unique results.

Further searches were completed by reviewing the citations made within the literature. Consequently, additional book chapters and articles were obtained. After completing an initial review of this literature further searches for papers were completed on the most cited differential diagnoses. These were used as search term prefixes against the words: 'child'; 'children'; 'adolescent'; 'young

<sup>\*\*</sup>A search for PAWS did not yield any unique results.

people'; and 'parent'. National health policy documents were reviewed to contextualise the literature.

# 1.2 Defining and Situating PRS

The clinical presentations encountered by paediatric physical and mental health professionals comprise inherent complexities which derive from the interplay of biological, developmental, psychological, social, and environmental factors (Carr, 2006; Eminson, 2007). Given this intersectionality, a tentative approach to diagnosis and a comprehensive assessment is imperative to ensure that a broad investigation can be undertaken. A multidisciplinary diagnostic approach, involving a child and adolescent paediatrician and psychiatrist, has been advised when assessing a clinical presentation believed to be PRS (Jaspers, Hanssen, van der Valk, Hanekom, van Well & Schieveld, 2009; Lask, 2004; Lee et al., 2013; Nunn, Thompson, Moore, English, Burke & Byrne, 1998). The diagnostic criterion for PRS and its epidemiology will be discussed.

# 1.2.1 Diagnostic Criterion

The current diagnostic criteria, proposed by Thompson and Nunn (1997), stipulate that a child or young person must meet the following:

- 1. Clear food refusal and weight loss
- 2. Social withdrawal and school refusal
- 3. Partial or complete refusal in two or more of the following domains: mobilisation, speech, attention to personal care.
- 4. Active and angry resistance to acts of help and encouragement
- 5. No organic condition to account for the severity of the degree of the symptoms
- 6. No other psychiatric disorder that could better account for the symptoms

The specificity of the diagnosis has received continued consideration within the literature. This has been in response to an increased number of cases reported and subsequent re-conceptualisations. As such, alternative broader criterion

have been proposed (Jaspers et al., 2009). Jaspers et al. (2009) suggested that criterion 1 should be subsumed by criterion 3 as refusal was reported to be seen across all domains. They also proposed the inclusion of another criterion: "the endangered state of the patient requires hospitalisation" (Jaspers, 2009, p. 648). A more detailed account of the theoretical considerations underpinning these proposed revisions will be discussed shortly. Furthermore, the reification of PRS will be discussed.

# 1.2.2 Epidemiology

The incidence and prevalence of PRS is not known (Jaspers et al., 2009). This perhaps reflects the lack of consensus with regards to its status as a clinically distinct psychiatric entity and may suggest that differential diagnoses are being ascribed. A critical review of the literature, completed in 2009 by Jaspers et al., identified 24 published cases of PRS. It was documented that children and young people aged predominantly between 7 years old and 15 years old received the diagnosis of PRS (Jaspers et al., 2009), however the youngest child to receive the diagnosis was 4 years old (Taylor, Dossestor, Kilham & Bernard, 2000). Of the 24 cases reported, 75% were female (Jaspers et al., 2009). The current literature review identified 57 reported cases of PRS. The previous findings were replicated, i.e. 75% of the cases reported were female and the same age range was reflected. It seemed of note that, with the exception of one, all cases were reported in Europe and Australia. This seemed to indicate that PRS is a culture bound concept, which reflects the notion that expressions of psychological distress should be situated and understood within a historical, cultural and societal context (Patel, 2003). A detailed summary of the findings from the current literature review can be found in Appendix A. Only one case of PRS was reported in an adult (Riaz & Nawab, 2014). This case was excluded from the summary as the diagnosis was considered retrospectively.

#### 1.3 Differential Diagnoses

PRS is considered to have many forms of expression and as such can appear to share similarities with other clinical presentations. It has been reported that the

most common differential diagnoses considered are: depression (54%); somatoform disorder (42%); anxiety disorder (29%); eating disorder (17%); chronic fatigue syndrome (4%); factitious disorder (4%); catatonia (4%) and selective mutism (4%) (Jaspers et al., 2009). It has been argued that although aspects of children and young people's experiences could be recognised as these presentations, their overall experiences differ significantly and therefore fail to meet the full diagnostic criteria (Eminson, 2007; Nunn et al., 2013; Thompson & Nunn, 1997). Furthermore, it has been claimed that PRS has distinguishing features: a pervasive refusal across different domains (Lask, 2004) and an active resistance to and rejection of any form of help (Jaspers et al., 2009). Each of the differential diagnoses will be discussed in the context of the proposed similarities and differences to PRS.

# 1.3.1 Depression and Anxiety

It has been suggested that children and young people present with experiences that are analogous with the clinical features classified as depression, e.g. apathy, loss of appetite, lack of self-care and lack of interest (Thompson & Nunn, 1997; Von Folsach & Montgomery, 2006). However, it has been claimed that psychomotor slowing and sleep disturbances are not observed and as such these children and young people's presentations fail to meet the diagnostic criteria (Lask, 2004). Furthermore, Von Folsach and Montgomery (2006) postulate that the determined refusal and the variability children and young people display in their mood and interactions depending on their social context, do not fit with a diagnosis of depression. Similarly, it has been argued that although anxiety appears to be present (e.g. separation anxiety from parents and school refusal) the diagnosis of anxiety could not fully account for the range and intensity of experiences across domains (Jaspers et al., 2009; Lask, 2004).

# 1.3.2 Somatoform Disorder and Chronic Fatigue Syndrome

It has been claimed that the clinical features of PRS share commonalities with Conversion Disorder and Somatisation Disorder (Lask, 2004; Thompson & Nunn, 1997). Conversion Disorder is characterised by localised motor or sensory

impairment of a specific system without an organic cause (Garralda, 1992). Nunn et al. (2013) state that the global impairment observed in children and young people, alongside the active motor resistance often displayed during refusal of treatment, does not fit within the clinical features of Conversion Disorder. Likewise, Somatisation Disorder is often considered given the presence of multiple physical symptoms that are affecting several systems (Thompson & Nunn, 1997). However, it has been argued that this is not applicable as help seeking behaviour is not evident and refusal is prominent (Lask, 2004). Similarly, Chronic Fatigue Syndrome has been disregarded on the same premise as the pervasive impairment and refusal, alongside the angry and active rejection of help, are not clinical features (Nunn et al., 2013).

# 1.3.3 Eating Disorder

Diagnoses such as anorexia nervosa or atypical eating disorder are often considered as children and young people present with weight loss due to refusal of food (Khan & Chowdhury, 2011). However, Thompson and Nunn (1997) contend that the refusal of food is not based on the motivation to lose weight as one might find within an eating disorder. Concerns relating to body shape and weight are rare and compensatory behaviours associated with eating disorders have not been observed (Nunn et al., 2013). Moreover, the refusal is not exclusive to food and as such is claimed to be distinct to an eating disorder (Thompson & Nunn, 1997).

#### 1.3.4 Factitious Disorder

Thompson and Nunn (1997) suggest that children and young people may appear to present with a factitious disorder as they are "actively refusing in a conscious way to care for themselves" which results in them requiring medical attention (p. 162). However, in contrast to the help seeking and care eliciting which is prominent in factitious illness these children and young people present with refusal of help and care (Nunn et al, 2013). Similarly, external incentives connected to adopting an 'ill role' have not been observed and as such, the

possibility of malingering dismissed (Jaspers et al., 2009; Lask, 2004; Thompson & Nunn, 1997).

# 1.3.5 Catatonia

It has been argued that the mutism, social withdrawal and immobility that children and young people present with could be understood as a catatonic disorder (Fink & Carlson, 1995). However, it has been suggested that the nature of these presentations would fail to fulfil the diagnostic criteria (Nunn et al., 2013) based on the following assertions: the seeming unresponsiveness is indeed a purposive response as it denotes a refusal to engage with others (Thompson & Nunn, 1997); mutism is regarded to be selective; social withdrawal is seen as a form of refusal opposed to a response to unusual beliefs, hearing voices, or hypervigilance (Lask, 2004); movement is observed in children and young people during their sleep and in their response to physical caregiving, which suggests no psychomotor slowing or increased motor tone (Lask, 2004).

# 1.3.6 Selective Mutism

It has been reported that children and young people are selective with regards to whom they speak to and interact with, e.g. speaking with peers but refusing to talk with parents or professionals (Thompson & Nunn, 1997), or electing to speak to a preferred member of staff over others (Lee et al., 2013; Van der Walt & Baron, 2006). However, it is believed that the diagnosis does not provide a sufficient account for the pervasive deterioration and refusal across other domains (Nunn et al., 2013).

# 1.4 Aetiological Conceptualisations

The aetiology of PRS is unknown. However, as the number of reported cases has increased and the literature on this concept has grown, a variety of conceptualisations have been offered. These will be outlined and discussed in chronological order in order to track the conceptual development of PRS and

contextualise its current position within the literature. An overview of the aetiological factors reported in the case studies are summarised in Appendix A.

# 1.4.1 A Post-Traumatic Stress Response

In their seminal paper, Lask et al. (1991) proposed that PRS could be understood in the context of Post-Traumatic Stress Disorder (PTSD). They hypothesised that children and young people were responding to an intense fear and that their presentation served to help them escape an intolerable situation as a final resort (Lask et al., 1991). They raised the possibility that such a trauma response was based on experiences of sexual abuse. From the four female cases presented within their paper, one had disclosed sexual abuse and it was suspected in another two cases (Lask et al., 1991). They drew on research completed by Kiser et al. (1988) which examined children's responses to sexual abuse in the context of a PTSD diagnosis and found three overarching presentations: avoidance, reexperiencing and autonomic arousal. Lask et al. (1991) proposed that PRS could be understood within the avoidance presentation as it was characterised by restricted affect, withdrawal, loss of interest, reluctance to talk, aggression and avoidance (Kiser et al., 1988). In light of these findings, a two stage aetiological process in PRS was tentatively suggested: 1) the traumatic experience of sexual abuse; 2) fear "induced by either a violent family member, threats, or the likely consequences of disclosure" (Lask et al., 1991, p. 869). This served as a working hypothesis for the cause and development of PRS.

In 1998 McGowan and Green provided support for this conceptualisation based on a single case history of an 11 year old female. They reported that in contrast to Lask et al. (1991), the child had disclosed sexual abuse and physical intimidation in the absence of confounding factors (e.g. severe family dysfunction and social deprivation). As such, they suggested that their case illustrated that an experience of sexual abuse was sufficient to cause the onset of PRS. Indeed, they reported that once the disclosure had been made an immediate and full recovery followed. Thus providing further support for this conceptualisation.

# 1.4.2 The Attributional Reformulation and Learned Helplessness Theory

Nunn and Thompson (1996) offered an alternative theoretical paradigm, learned helplessness and hopelessness, which aimed to conceptualise the aetiology, range of experiences and treatment of PRS. Nunn and Thompson's (1996) formulation was based upon the cognitive theory of learned helplessness (Seligman, 1975) and attributional reformulation theory (Abramson, Seligman & Teasdale, 1978). The learned helplessness model is underpinned by the notion that helplessness develops in response to a perceived absence of control over an outcome of a situation. However, there is variability in the degree of helplessness experienced by people when presented with uncontrollability. It has been suggested that the impact of helplessness is mediated by one's attributions of causality on three levels and depends on whether an individual: personalises the cause ("it's my fault"); stabilises the cause ("things will never be the same again now that this has happened"); and globalises the cause ("my entire life is ruined because of this") (Abramson et al., 1978). Peterson, Maier and Seligman (1993) state that the learned helplessness model is only applicable if the following criterion are met: an experience of uncontrollability; a perception, explanation and expectation of uncontrollability; and observable consequences in behaviour to uncontrollability (most commonly passivity or activity).

Nunn and Thompson (1996) employed this model in an attempt to formulate the cause and development of PRS. They proposed that low mood, separation anxiety and social withdrawal developed in response to the perceived uncontrollability of negative future events and the belief that "responses are futile" (Nunn & Thompson, 1996, p. 123). From the child or young person's perspective, events which could be perceived as negative and uncontrollable included: family relocation, transitions (e.g. change in school), severe illness, loss of family members, parental conflict, or parental mental health issues (Nunn & Thompson, 1996). Given that abuse was not prominent in the case series upon which they based their conceptualisation, Nunn and Thompson (1996) cautiously hypothesised that abuse, as a form of unescapable trauma, could be regarded as an example of an uncontrollable event.

Nunn and Thompson (1996) suggested that parental helplessness and hopelessness may be occurring concurrently to the perceived uncontrollable events. They proposed that parental helplessness and hopelessness could be acquired by the child/young person vicariously, resulting in a personal and vicarious loss of hope, i.e. the child/young person becomes concerned with regards to their own future and the future of their family members. Indeed, Nunn and Thompson (1996) suggest that this process could be bi-directional as the parent and child/young person observe each other struggle with events over which they perceive they have no control.

# 1.4.3 Loss of the Child's Internal Parental Figure

Magagna (2004) provided a psychodynamic conceptualisation of PRS by considering the internal worlds of children and young people, in addition to their external situations. She suggested that families had "weakened psychic structures" which were too fragile to contain their child's intense feelings of love, anger, hate and fear (p. 217). She claimed that families often displayed denial of psychologically painful experiences and aggression on a daily basis. As a result, the child's feelings were denied and became unconsciously directed towards their internal family figures in order to protect the relationship with their parents (Magagna, 2004). She claimed that this subsequently led to the destruction of the child' own psychic structure as it caused damage to the internal parental figures which gave rise to feelings of guilt and depression. It is the lack of an inner psychic structure, which Magagna (2004) claims leads to a retreat from the external world, i.e. the child feels unable to deal with the emotional stimuli from internal and external sources.

#### 1.4.4 Depressive Devitalisation: "Lethal" Mothering

In 2005 Bodegard reported on a life threatening pervasive loss of function with no organic cause in five asylum seeking children in Sweden. He noted that four of the five children demonstrated a "stuporous withdrawal and total lack of purposive behaviour", which he regarded as a "depressive devitalisation" (p. 343). He proposed that depressive devitalisation was analogous to PRS,

however the refusal was characterised by passivity opposed to an active refusal. Given the similarities in pervasive loss of function, social withdrawal, and refusal of treatment, Von Folsach and Montgomery (2006) proposed that PRS and depressive devitalisation could be regarded as subgroups of an overarching refusal "syndrome" (p. 471).

Bodegard (2005a) offered a psychodynamic interpretation of how the devitalisation developed and located the cause within the interaction between the mother-child dyad. He referred to this as "lethal" mothering (p. 344). Bodegard's (2005a) interpretation was based on his observation that both the mother and child appeared to "silently reject" medical reports that there was no underlying organic cause for the child's experiences (p.344). Furthermore, he noted a "striking quality of resistance" towards treatment (Bodegard, 2005a, p. 344). Bodegard (2005a) suggested that a 'folie a deux' had been created between the mother and child, whereby both imagined that the child was gravely ill. He proposed that this fantasy resulted from the mother projecting her need for consolation and care (originating from her own traumatic experiences in her country of origin) onto her child. Through projective identification (Klein, 1952) the child identifies with the mother's helplessness and hopelessness and assumes this position. Bodegard (2005a) suggested that through this unconscious process the dyad are able to survive together in their current uncertain life circumstances (seeking asylum). Indeed, he noted that once the families had been granted permanent residency, the mothers became more hopeful and were able to respond to their child and their new circumstances differently, which in turn resulted in an improvement in their child's presentation.

# 1.4.5 A Refusal-Withdrawal-Regression Spectrum

Jaspers et al. (2009) introduced the concept of a refusal-withdrawal-regression (RWR) spectrum upon which the various behaviours observed in PRS could be understood. They argued that a child or young person could oscillate on this spectrum depending on their context and the underlying psychological processes taking place at any given time. Furthermore, they proposed that refusal (unwillingness to do something), withdrawal (retreat from reality or ceasing to

participate), and regression (returning to a state of earlier development) had a resistance in common: a shared rejection of action (passive and/or active) (Jaspers et al., 2009). Jans, Ball, Preiss, Haberhausen, Warnke and Renner (2011) supported the notion of a spectrum and suggested that the diagnostic criterion should be adapted to reflect the continuum of active refusal to passive resistance they observed in their case series of three young people. Further support was claimed by a case series published by Forslund and Johansson (2013), who reported that the refusal pattern varied amongst the five cases.

# 1.4.6 A Neurobiological Model

A neurobiological model is the most recent conceptualisation offered within the literature. Nunn et al. (2013) propose that a child's sympathetic nervous system can be activated to such an extreme that it causes an activation of the same extremity in the parasympathetic nervous system. They suggest that such a response can be triggered by the culmination of the child's individual "sensitivity" and the severity of stressor (Nunn et al., 2013, p. 169). They claim that sympathetic hyper arousal accounts for the anxiety and resistance to help and the parasympathetic hyper arousal accounts for the withdrawal, fatigue and dissociation, hence why there is variability in observed behaviours. (Nunn et al., 2013). Nunn et al. (2013) argue that the refusal reported in children is better understood as a "combination of extreme anxiety, avoidance and behaviour paralysis" (p. 169). A renaming has been proposed based on this model: Pervasive Arousal Withdrawal Syndrome (PAWS). Bodegard (2013b) claimed support for this conceptualisation and argued that PAWS should be regarded as a "complex PTSD" (p. 181). This has not been the first query with regards to a neurobiological cause. Wright and Beverley (2011) tentatively hypothesised that autoimmune antibodies produced after a viral infection may have contributed to symptoms which could fit within a PRS diagnosis.

#### 1.4.7 The Construct of PRS

The conceptualisations outlined intend to provide explanatory accounts of how children and young people come to experience a range of 'symptoms' believed to

be PRS. However, they have been devised on the assumption that PRS exists as a clinically distinct entity. Indeed, there is a lack of empirical support for PRS as a valid and reliable construct despite its reification by a number of professionals. Although cases of PRS have been reported there is little information regarding the presentation of the 'symptoms', how the 'symptoms' develop, or its prevalence. This has significant implications for treatment as clinicians may differ in their understanding of what the 'symptoms' are and thus how to treat them.

# 1.5 Treatment and Recovery

There are no existing evidence based guidelines for the treatment of PRS (Jan et al., 2011). However, Nunn et al. (1998) have proposed a comprehensive management plan which advocates a multidisciplinary approach to treatment based on the biopsychosocial model (Engel, 1980). They recommend treatment consists of: nursing, physiotherapy, family therapy, individual therapy and a therapeutic ward milieu (Nunn et al., 1998). Additionally, music therapy is reported to be helpful due to its application of non-verbal interventions (Van der Walt & Baron, 2006). Medication is not used to treat PRS. Jaspers et al. (2009) claim that medication is only effective in treating comorbid presentations such as anxiety and depression.

Historically children and young people have been treated on inpatient psychiatric wards however more recently there have been reports of successful treatment on general paediatric wards (Edwards & Done, 2004; Lee et al., 2013; McNicholas, Prior & Bates, 2012; Taylor et al., 2000), an acute paediatric ward (Van der Walt & Baron, 2006) and at home (Wright & Beverley, 2011). On average it has been claimed that the average duration of treatment is 12 to 13 months (Jaspers et al., 2009).

In their review, Jaspers et al. (2009) found that 67% of young people made a full recovery, 25% made a partial recovery and 4% had periods of time without difficulties but continued to relapse. Guirguis, Reid, Rao, Grahame and Kaplan (2011) completed a follow up study with four young people in the UK and assessed long term outcome based on activities of daily living. Each case had

been followed up between 3 and 16 years post discharge. They found that two of the young people had made a full recovery, one had been diagnosed with anorexia and the fourth person declined to be interviewed (Guirguis et al., 2011). Forslund and Johansson (2013) conducted a follow up study of five young people diagnosed in Sweden. They used the Global Assessment of Functioning Scale and self-rated questionnaires to measure improvement. They found that all young people had recovered 1 to 8 years post discharge (Forslund & Johansson, 2013). Whilst these studies provide some information with regards to recovery and prognosis their utility is limited due to the lack of standardised measures and small sample.

#### 1.6 National Health Context

Child and adolescent mental health services (CAMHS) in the UK are based upon a four tiered hierarchical model (Health Advisory Service, 1995). Psychiatric inpatient care is a specialist Tier 4 service. The CAMHS Tier 4 Steering Group (2014) reported that Tier 4 service provision is not evenly distributed across the UK and inconsistencies exist in the development of care pathways. Many children and young people are placed outside of their geographical locality, often some distance away from home, and may not always have a smooth journey through the pathway to receive the care that they need. Indeed, only a few Tier 4 services are known to have specialist beds available for presentations believed to be PRS (McNicholas & Nicholson, 2014). Furthermore, as PRS is not a formal diagnosis a care pathway has not been developed. As such, the services and settings within which children and young people are treated can vary, for example: on psychiatric inpatient wards (Guirguis et al., 2011; Lask, 2004); paediatric wards (Edwards & Done, 2004; Lee et al., 2013); and as an outpatient at home (Wright & Beverley, 2011). This invariably will have an impact on the treatment offered and the experiences of children, young people and their families.

#### 1.7 PRS: Parents and Families

Thus far consideration has been given to the diagnosis, its various conceptualisations and its treatment. However, it is also important to consider the child and young person within the context of their family. Indeed, many of the conceptualisations implicate the role of parents in the development of PRS (Bodegard, 2005; Lask et al., 1991; Magagna, 2004; Thompson & Nunn, 1996) and it has been referred to as a "family psychiatric illness" (Bodegard, 2005, p. 349). Furthermore, it has been intimated that PRS can occur as a result of traumatic experiences, one of which could be sexual abuse. Such assertions will inevitably have implications for the ways in which families are regarded in clinical practice and how PRS is treated. Moreover, it will shape how parents experience and understand their child's distress and will inform their attitude towards and experience of professionals and the treatment approach.

Parents' involvement in treatment has been advocated as it is believed to reduce anxiety and distress within the family, which in turn can prevent the child from prematurely being removed from treatment (Jaspers et al., 2009; Lask, 2004). Nunn et al. (1998) suggest that withdrawal from treatment is common and claims it reflects the parents' struggle to "accept" the diagnosis of PRS (p. 246). They outlined "specific behaviour problems in the family" which could pose an obstacle to treatment (Nunn et al., 1998, p. 246). They suggest that parents may deny or minimise issues and can fail to adhere to the treatment plan due to "enmeshment" in the family (p. 246). These assertions are reflected in the conceptualisations outlined previously, e.g. familial denial of psychologically painful experiences (Magagna, 2004) and maladaptive co-dependency resulting from "lethal" mothering (Bodegard, 2005). It could be argued that the current literature pathologises families by locating the problem within them. Indeed, although limited perspectives from parents exist within the literature, those that have been shared suggest that the narration of PRS' causes had an impact on their experiences as a parent.

Having read an article by Lask (2004), a father spoke of how he felt professionals were suspicious of whether he had sexually abused his eight year old daughter

(Lee et al., 2013). He spoke of how it had taken a few months for professionals to "genuinely accept" this was not the case (Lee et al., 2013, p. 169). Anon (2001) spoke of how she felt "observed" by professionals when she interacted with her eight year old son which resulted in "slightly forced" conversations (p. 462). Despite these initial experiences both parents spoke of how they had been invited to be actively involved in treatment, which in their view helped them to support their children (Anon, 2001; Lee et al., 2013). Indeed, two young people emphasised the importance of their parent's role during their inpatient treatment when asked about their views on the contributory factors to their recovery (Forslund & Johansson, 2013). Forslund and Johansson (2013) also reported that three young people believed it was important to involve parents in treatment and have mutual communication between parents and professionals. These findings highlight the fundamental role that parents have in their children's recovery.

In their accounts, the mother and father describe the emotional impact their child's difficulties had on them (Anon, 2001; Lee et al., 2013). They also spoke of the ways in which they had to readjust their usual parenting style and learn how to relate to their child differently. They also referred to the impact their child's difficulties had on their family, e.g. learning how to help support other siblings and trying to maintain work and school commitments. Their accounts suggest that being a parent of child who has been diagnosed with PRS can result in many personal and systemic challenges.

#### 1.8 The Current Study

The literature review highlighted that the majority of published work on PRS consisted of professional commentary based on a dominant psychiatric narrative. The perspectives of children, young people and their parents were underrepresented. The literature was also found to be limited to case studies with no research into PRS. This is a significant omission.

As previously discussed, the inclusion of parents in the treatment approach is regarded to be imperative (Nunn et al., 1998). Indeed, Forslund and Johansson's

(2013) study highlighted that young people viewed their parents as having a significant role in their recovery. As parents have a fundamental role in supporting their children throughout treatment and recovery it is important to gain their understanding and experiences of their child's difficulties.

This study was designed to address the gap in the literature, aiming to provide an insight into parents' understanding and experiences of their child's difficulties, the diagnosis of PRS and the treatment their child received. The following research questions were devised:

- What is it like to be a parent of a child who has been given a diagnosis of PRS?
- How do parents make sense of the diagnosis and their child's experiences?
- How did parents experience the treatment their child received and what are their perspectives on the treatment?

It is hoped that addressing these questions will enhance understanding about the nature and cause of the 'symptoms' and what aspects of treatment were helpful. It is hoped that gaining this knowledge from the parents' perspective will provide novel insights which can inform clinical practice and help clinicians improve support for children and their families.

As previously discussed, PRS is not a diagnosis classified within the DSM-V (APA, 2013) or ICD-10 (WHO, 1994) and currently lacks empirical support for its validity and reliability as a clinical construct. However, it continues to be used clinically and is talked about with children and their families. As a result it could be argued that the diagnosis is considered to be 'real' to those receiving it. In light of this it seems particularly pertinent to conduct research in this area as gaining more knowledge may help to support or challenge this construct. This study assumes that PRS is a clinical entity based on its use in practice, but acknowledges its limitations.

#### **CHAPTER 2: METHODOLOGY AND METHOD**

#### 2. Overview

This chapter outlines the methodology (i.e. the general approach taken to study the research topic including its philosophical and theoretical commitments) and the method used (i.e. the specific technique employed) (Silverman, 1993). The rationale for the chosen methodology is addressed in the first instance and discusses: the adoption of a qualitative approach; the study's epistemological position; the methodologies that were considered; and why Interpretative Phenomenological Analysis (IPA) was selected. A detailed description of IPA and its theoretical underpinnings is provided. Lastly the method is described and outlines the process of: ethical approval; recruitment and selection of participants; data collection; and data analysis.

# 2.1 Rationale for Adopting a Qualitative Approach

This exploratory study aimed to understand how parents made sense of their child being given a diagnosis of PRS and what it was like to experience their child being unwell. Furthermore it aimed to explore how parents experienced and negotiated the treatment process and attributed meaning to their experiences. The methodological approach was selected on how best it could serve these aims and address the questions being asked.

Qualitative research seeks to understand how people make sense of the world and experience particular events. It is concerned with meaning and the "quality and texture of experience" (Willig, 2008, p. 8). Such an approach provides scope to gain rich, contextualised, personal accounts, which can elucidate unexpected insights and new understandings (Willig, 2001). It has been acknowledged that qualitative approaches allow for an in-depth exploration where little is known about a topic (Howitt, 2010; Willig, 2008). Indeed Barker, Pistrang and Elliot (2002) recommend qualitative methodologies for exploratory orientated research into phenomenon not previously studied.

The objectives of quantitative approaches differ in the sense that they aim to: test hypotheses; identify causal relationships; and predict outcomes from which generalisations can be made at a population level (Barker et al., 2002). Yardley and Marks (2004) comment on this distinction and note its relevance when conducting clinical and health psychology research. They state that qualitative methods are more suited within this field when the focus is on "subjective meanings and their socio-cultural context" and argue that this is because "these are not causes or mechanisms which can be scientifically proven, but malleable, negotiable interpretations which people offer themselves and others to make sense of their feelings and actions" (Yardley & Marks, 2004, p. 5).

In light of these distinctions a qualitative approach was chosen for its congruence with the aims of this study.

# 2.2 Ontological and Epistemological Position

Qualitative methodologies, whilst sharing common concerns, hold varying assumptions and utilise a range of research methods (Willig & Stainton-Rogers, 2008). These sets of assumptions, beliefs and practices are characterised by ontological (what is there to know?), epistemological (what is it possible to know and how?), and methodological (the approach taken to gain knowledge about what it is believed can be known) differences in their approach to research and contribution to knowledge (Proctor, 1998; Welford, Murphy & Casey, 2011). It is important to clarify these interrelated questions as the ontological and epistemological position of the research determines the assumptions that are made about the relationship between the data gathered and the world (Harper, 2012; Willig 2008). Establishing these positions from the outset ensures consistency between the study's claim to knowledge and the methodology and method employed (Willig, 2008).

Ontological and epistemological positions are best understood as positions along a continuum (Welford et al., 2011) ranging from naïve realism to radical relativism (Madill, Jordan & Shirley, 2000). Naïve realism assumes the existence of an

objective true reality which can be accessed and observed without distortion (Willig, 2008). Whilst radical relativism asserts that no such true world outside our ideas exists as our realities are entirely constructed through discursive resources and social, cultural and historical paradigms (Gergen, 1998). Pocock (2015) states it would be impossible to synthesise these extreme positions in clinical practice and research, however proposes that rapprochement is possible between the moderate positions. The ontological and epistemological positions of this study will be now discussed.

This study approached the world from a critical realist ontological position. Critical realism (Bhaskar, 1977) holds that real entities exist independent of an individual's conceptualisation (Fade, 2004). However such entities can only be partially accessed and indirectly understood through language (Nightingale & Cromby, 1999). Critical realism claims that an individual's beliefs and expectations have an impact on what they perceive (Bunge, 1993), resulting in subjectivity in knowledge production. As such, data produced in this study was regarded as representations of an underlying reality that exists for participants without focusing on whether this was a true or false account.

This study assumed a contextual constructionist epistemological position. Contextual constructionism holds that knowledge production and meaning making is context bound (historically, culturally, socially) and therefore local, provisional and situation dependent in a continuously changing reality (Jaeger & Rosnow, 1988). Pidgeon and Henwood (1997) propose that knowledge production is influenced by "the participants' own understandings, the researchers' interpretations and the cultural meaning systems which inform both participants' and researchers' interpretations" (p. 250). In this sense knowledge production in research is co-created (Larkin, Watts & Clifton, 2006). From this position "knowledge, while validated with reference to the world, remains relative and incomplete" (Jaeger & Rosnow, 1988, p. 67). Thus the data produced in this study and its findings is influenced by the way that the data was gathered and analysed (Madill et al., 2000).

# 2.3 Selecting an Appropriate Methodology and Method

From the range of qualitative methodologies which could have been used, four were identified for consideration based on their suitability to meet the research aims and align with the ontological and epistemological position of the study. An overview of each methodology will be provided and the rationale for selecting Interpretive Phenomenological Analysis (IPA) (Smith, 1996) will be discussed.

Grounded Theory (GT) (Charmaz, 2006; Glaser & Strauss, 1967) was considered due to its concerns with meaning making. Its objective is to develop theory on the processes of a social phenomenon, which is achieved through the use of a large heterogeneous sample and a bottom up approach which ensures that the theory of the phenomena is grounded in the data (McLeod, 2001). Given its aims, GT was not suitable as this study aimed to research a small homogenous group (parents whose child had received a diagnosis of PRS) to understand how they made sense of their experiences rather than build a theoretical account.

Discourse Analysis (DA) (Potter & Wetherell, 1987) was considered for its interest in language. DA is underpinned by the idea that language is used to construct experiences and social realities. It examines the linguistic resources that people use to construct accounts of experiences. This study had a different focus on linguistics and aimed to use parents' language to understand how they made sense of their experiences and discover what meaning they held, opposed to how they constructed their experiences.

Thematic Analysis (TA) (Braun & Clarke, 2006) is not regarded as a methodology as such but an atheoretical method which seeks to find patterns within the data and give in-depth descriptions of the dominant themes. It lends itself to epistemological flexibility and can thus approach data in numerous ways. A phenomenological TA could have been employed to explore what it is like to be a parent of a child who has received a diagnosis of PRS. However IPA as a methodology and method allowed for a more nuanced, detailed analysis due to its idiographic focus and use of hermeneutics to understand how people make

sense of their experiences (Smith, Flower & Larkin, 2009). This will be expanded upon in more detail in the following section.

The central concerns of IPA are: the detailed examination of lived experience; how people make sense of their everyday experiences within their personal and social realities; and the meanings they attribute to those experiences (Eatough & Smith, 2008). These met the study's aim to explore individuals' subjective lived experiences of being a parent of a child who has been given a diagnosis of PRS. Smith and Eatough's (2007) assertion that IPA is well suited to researching topics in clinical and health psychology, where it is important to discern how people view and understand significant events in their lives, also contributed to the decision to select IPA as a methodology and method. Indeed the creativity and freedom that IPA allows (Willig, 2001) can be useful in researching unusual groups (Pringle et al., 2011) and groups that are difficult to reach in healthcare settings (Biggerstaff & Thompson, 2008). Given the rarity of the PRS diagnosis and the difficulty of gaining the perspectives and experiences of parents, IPA seemed well justified over the other methodologies. A more detailed description of IPA and its theoretical and philosophical underpinnings will now be discussed.

# 2.4 Interpretative Phenomenological Analysis (IPA)

IPA is concerned with meaning and process: it aims to explore a particular person's experience within a particular context (Larkin et al., 2006). It focuses on the meaning of an experience (e.g. an event, object, process, relationship) to a given person and its significance for that person (Larkin & Thompson, 2012). IPA is an inductive, experiential approach (Smith, 2004) informed by the philosophical underpinnings of phenomenology, hermeneutics and idiography (Smith et al., 2009).

# 2.4.1 Phenomenology

Founded by Edmund Husserl (1913), phenomenology is a philosophical movement concerned with the study of experience. It comprises many variations

of thought which have implications for the way in which phenomenological ideas are integrated into research methodologies and methods (Giorgi & Giorgi, 2008). Husserl was interested in exploring experience in the way that it occurs and in its own terms by examining that which is experienced in the consciousness of a person (Smith et al., 2009). He regarded intentionality as the key feature of consciousness, i.e. one's consciousness is always being directed towards something (Langdridge, 2007). This relational process implies that all perceptions have meaning and experience does not happen in a vacuum. Indeed, Husserl (1927) discussed the notion that one could step outside of one's 'natural attitude' (everyday taken for granted assumptions and interpretations) and adopt a 'phenomenological attitude' (a reflexive move of turning inward) in order to understand things as one experiences them. He suggested this could be achieved through 'bracketing off' (put temporarily to one side) taken for granted understandings and knowledge in order to see the key features of the phenomenon (the 'reduction').

Heidegger's contributions marked a move away from consciousness to being, i.e. the person and the world are mutually constitutive (Larkin & Thompson, 2012). Heidegger (1927) argued that it was not possible to make the reduction as one's observations are always made from one's own position and thus the closest one can get to experience is through a hermeneutic lens: interpretation.

Merleau-Ponty (1945) and Sartre (1943) expanded upon Heidegger's work by introducing the focus on existence itself (Langdridge, 2007). In contrast to Heidegger's focus on the worldliness of existence, Merleau-Ponty (1945) emphasised the embodied nature of our existence, i.e. the lived body that engages with the world. Sartre (1943) discussed the notion of a person's worldliness in the context of personal and social relationships, i.e. one's perception of the world is shaped by the presence of others and the projects they are engaged in (Smith et al., 2009).

IPA draws on these contributions and understands experience as a lived process to which meaning is attributed from the unique perspective of that person's

embodied and situated relationship to the world (Smith et al., 2009). However our attempts to understand these experiences are interpretative.

# 2.4.2 Hermeneutics

Hermeneutics is the theory of interpretation and views "the knower and the known as fundamentally interrelated and assumes that any interpretation necessarily involves an essential circularity of understanding – a hermeneutic circle" (Tappan, 1997, p. 651). This is an integral concept in IPA as it highlights the dynamic relationship between the part and the whole and the inability to understand one without the other (Smith, 2007). It is also significant as the IPA researcher engages in a double hermeneutic, i.e. they make an interpretation of a participant making sense of (interpreting) their experiences (Smith & Osborn, 2003). This implicates the researcher in the work and highlights the need for reflexivity (Caelli, 2001). This will be discussed shortly.

# 2.4.3 Idiography

Idiography is concerned with the study of the particular in contrast to nomothetic approaches which study what is shared amongst a group or population (Willig, 2008). It aligns with the stance of a person in context which holds that multiple perspectives can be held about the same phenomenon (Barker et al., 2002). Thus idiography is interested in a particular person's experience at a particular point in time. Idiography is reflected in the sampling method and data analysis when conducting IPA.

# 2.5 Reflexivity

Drawing on hermeneutic theory helps to demonstrate the role of the researcher in the co-construction of sense making and knowledge production with a participant (Larkin et al., 2006). As such, reflexivity is central to conducting an IPA. Finlay and Gough (2003) suggest that reflexivity entails a "critical self-reflection of the ways in which the researcher's social background, assumptions, positioning and behaviour impact on the research process" (p. 9). However, Willig (2008) states

that reflexivity entails more than just acknowledging biases or assumptions. She discusses the possibility that certain insights and understandings may only be actualised by one's responses to the context of the research and the data gathered (Willig, 2008). Thus it is important to consider these from the outset and throughout the research process. For this study a reflexive journal was kept through each stage of the research process (Appendix B).

# 2.5.1 Personal Statement

Completing a reflexive journal at the research design stage encouraged me to consider how my position may have informed, guided and shaped the stages and processes involved in the research. I considered my personal, social and professional contexts. In addition to my beliefs, assumptions and knowledge about the topic area. Those that seemed most pertinent are shared.

My interest in PRS developed from my professional experiences of working in a range of CAMHS and children's social care settings prior to training. I was most aware of the intersectionality of the personal and professional during my work in these contexts. Bearing witness to the emotional distress of children and their families and seeing the impact this had on their lives, was an issue that I continued to grapple with in supervision. At times I felt helpless in the system and repeatedly returned to consider my "relationship to help" (Reder & Fredman, 1996). Identifying this from the outset enabled me to prepare for the interviews, i.e. I considered how I could minimise personal bias in order not to collude with, encourage or elucidate expected or congruent responses from participants. Reflecting on my position in this way influenced the questions I posed to participants and the language I used to construct them. I also became aware of how my responses (verbal and non-verbal) could potentially be regarded as affirmations of implied agreement (e.g. through nodding my head). I was mindful that I might have found some topic areas difficult to hear in the interviews and consequently monitored whether I was closing down or avoiding conversations.

Contemplating these issues made me reflect on the duality of my identity as a researcher and trainee clinical psychologist. I reflected on my personal response

to seeing others in emotional distress and my natural propensity to respond therapeutically. I was aware that the purpose of the interview was distinctly different to a therapeutic session and was mindful not to make therapeutic responses or attempts as this would have been unethical (Coyle, 1998). I made use of the reflexive journal and conversations within supervision to explore my responses, thereby 'bracketing' these feelings and experiences before conducting subsequent interviews.

Whilst reading the existing literature on PRS I was struck by the terminology and language used. In my opinion the language implied blame, judgement and pathologised the experiences of children and their families. I was also interested in how PRS as a descriptive label was presented as a diagnosis in the literature despite being a contested category. It was important to acknowledge and reflect on these ideas as I was mindful not to impose these or be led by these ideas during the interviews and analysis.

I was aware that my position as a white British female in my early thirties could impact on the way in which participants interacted with me and what they chose to share. In my professional roles it had been my experience that parents were often curious about my relationship status and whether I had children. I understood this as them trying to situate me as a person but also them seeking out whether I had the experience to relate to and understand their experiences. I wondered whether this would be an issue during the interviews and if so how this might open up or close down conversations. I was also mindful that participants might view me as an expert and position me as having superior knowledge or authority on the topic. I was aware that being positioned in such a way might reflect the relationships that participants experienced with health professionals over the course of their experiences or perhaps in other contexts. I considered how a perceived power imbalance might prevent participants from discussing aspects of their experiences, for example they might omit details where they felt they had been at fault or lacked understanding for fear of being judged, or perhaps may have felt less able to reveal aspects of conflict with experts in their accounts. It seemed important to hold these possibilities in mind during the interviews and to consider what attempts could be made to minimise a potential

power imbalance. I reflected on the ways in which the opening and structure of the interview could empower participants: through emphasising the importance of their experiences and perspectives; noting that there was no right or wrong answers; encouraging them to provide feedback within the interview; and providing them with an opportunity to withdraw from the interview at any time.

### 2.6 Ethical Approval

This research was registered at the University of East London (UEL) (Appendix C). Ethical approval was sought and granted from three ethics committees: UEL Research Ethics Committee (Appendix D); Great Ormond Street Hospital for Children NHS Foundation Trust Clinical Research Adoptions Committee (CRAC) (Appendix E); and the London-Bromley NRES Committee (Appendix F). During the ethics process a separate quantitative study researching the same population at Great Ormond Street Hospital was approved by CRAC. This study was added to my NRES and UEL application as a substantial amendment and was granted ethical approval by both committees (Appendix G & H). Once ethical approval had been granted for both studies it was approved by the affiliated Research and Development Team at the University College London Institute of Child Health (Appendix I).

#### 2.7 Method

#### 2.7.1 Participants

#### 2.7.1.1 Sampling Method

Following IPA's theoretical tenets, a purposive sampling method was employed with the intention to gain a homogenous sample of participants for whom the research questions were significant and meaningful (Smith & Eatough, 2007). This was so that participants were able to give an in depth account of the phenomenon being researched. Furthermore, homogeneity would allow for a detailed examination of variability within the group by analysing convergences

and divergences (Smith et al., 2009). The study sample was already closely defined due to the rarity of PRS being diagnosed.

#### 2.7.1.2 Inclusion and Exclusion Criterion

Participants were selected on the basis that they were a parent of a child who had been given a formal diagnosis of PRS in the past. Participants were required to speak a good level of English and thus would be excluded if they required the use of an interpreter. This exclusion criterion was formed on the basis that qualitative research relies heavily on language and that the meaning and richness of the data could be lost through translation (Temple & Young, 2004). Indeed Smith and Osborn (2003) note that using an interpreter would provide an additional layer of interpretation over the double hermeneutic already in place.

#### 2.7.1.3 Recruitment Strategy

This study was a joint venture with two Clinical Psychologists from the Mildred Creak Unit (MCU) at Great Ormond Street Hospital: a specialist psychiatric inpatient ward for children and young people. The venture consisted of two qualitative research projects which aimed to explore the views and experiences of the diagnosis of PRS: 1) from the child/young person's perspective; and 2) from the parent's perspective. A pool of participants had already been identified from a clinical audit which found that fifteen children and young people had been assessed and treated for the diagnosis of PRS at the MCU between 2003 and 2013 (McNicholas & Nicholson, 2014). In addition one of the Clinical Psychologists was in contact with a parent they had met at a conference who met the inclusion criteria (whose child had been treated elsewhere in the UK) and had expressed interest in participating in the research.

Initially the two projects were combined for the processes of gaining ethical approval and recruitment. This was based on the rationale that both studies were intended to run concurrently and would be accessing the same clinical population through the MCU. In addition, it provided a contingency plan in the event that there were difficulties with recruiting, i.e. it would provide the flexibility to change

the focus of the study from the parents' experiences to that of the children/young people or the family should little interest be shown.

#### 2.7.1.4 Recruitment Procedure

Participant information sheets (PIS) and consent forms were devised to provide potential participants with an overview of the purpose of the study. This included a clear description of what participation would involve and details of people they could contact if they wanted to ask questions or clarify information.

Parents were contacted in the first instance for the following reasons: the research topic was sensitive and potentially upsetting; it might have been a long period of time since the MCUs involvement given the 10 year period identified; and some children/young people were still aged under 16 years old. Thus parents were given discretion to pass on the information about the study to their child.

An invitation letter was sent to parents by the MCU Consultant Psychiatrist and Clinical Psychologists (Appendix J). A PIS (Appendix K) and consent form (Appendix L) for the parents accompanied their letter. An invitation for their child to take part was also enclosed. The information they received depended on the age of their child:

- Parents of children under 16 years old
  - A PIS about what their child's participation would involve (Appendix M)
     and consent form (Appendix N)
  - An unsealed envelope addressed to the child containing: a PIS
     (Appendix O) and consent form (Appendix P)
- Parents of young people aged over 16 years old
  - An unsealed envelope addressed to the young person containing: an invitation letter (Appendix Q); PIS (Appendix R); consent form (Appendix S); and a stamp addressed envelope

Parents and young people aged over 16 years old were invited to complete an opt out form and return it in the pre-paid stamped addressed envelope to the MCU team within ten working days. It was made clear in the invitation letter that if the opt out slip had not been received it would be assumed that they consented to be contacted by me to discuss the study and their potential involvement. There was also the opportunity to opt in and provide a preferred method of contact. Throughout the recruitment process I was available to discuss and answer any questions that were raised. People were also given the option to liaise with the clinical or academic supervisors if they preferred.

The Clinical Psychologist's contact was sent an invitation letter (Appendix T), PIS (Appendix K) and consent form (Appendix L) via email. An invitation letter (Appendix U), PIS (Appendix R) and consent form (Appendix S) for their child (aged over 16 years old) was also enclosed in the email.

### 2.7.1.5 Recruitment Response

Recruitment took place from November 2014 to February 2015. In total thirteen parents were contacted as two of the children/young people identified in the case file review were still actively receiving treatment (McNicholas & Nicholson, 2014). Seven parents were recruited from this method: two returned the opt in slip; four made contact with me via email; and one person was recruited from a telephone call. One young person expressed interest in participating through their parent. The Clinical Psychologist's contact agreed to take part via email.

In total eight parents and one young person were recruited. Careful consideration was given as to whether the young person should be included within this study. Their contribution would have provided a unique perspective and novel insight into their lived experience of PRS and its treatment. However a decision to exclude them was made based on the rationale that the inclusion of their account would jeopardise the integrity of the data, i.e. the participant sample would no longer be homogenous as the phenomena they were invited to talk about was considerably different (the experience of being a parent of a child given the diagnosis versus a young person talking about being diagnosed). The young

person was still able to provide their perspective and the data will be presented in a case study separate to this piece of research. Given this omission, a request to change the title of the study was granted (Appendix X).

## 2.7.1.6 Participant Demographics: Situating the Sample

In order to situate the sample pertinent information about the participants that took part can be found in Table 2. Pseudonyms have been used to ensure anonymity. The participants were all biological parents of the child that had been given the diagnosis of PRS. All of the parents that took part were in heterosexual relationships and were married: two couples took part in the study. At the time of the study, of the six children/young people given the diagnosis, one young person was experiencing mental health difficulties.

**Table 2: Participant information and essential details** 

Participant	Gender	Relationship	Gender of	Age of	Interview
		to the child	child	child at	location
				onset	
Bridget	F	Mother	F	13	NHS premises
Tim	М	Father	M	10	Workplace
George	М	Father	F	13	Home
Fahra	F	Mother	M	11	Home
Helena	F	Mother	F	13	Home
Laura	F	Mother	M	10	GOSH
Carla	F	Mother	F	12	GOSH
Susie	F	Mother	F	8	Home

#### 2.7.2 Ethical Considerations

#### 2.7.2.1 Informed Consent

A PIS was sent to participants when they were invited to take part. This afforded people the opportunity to consider the information and discuss it with family and friends. It was also given to them at the interview and was discussed thoroughly

before the interview took place. Participants were advised that they could withdraw at any time up until the end of February 2015 and that they did not have to provide a reason.

### 2.7.2.2 Confidentiality

Issues of confidentiality and how these would be addressed were outlined in the PIS and discussed in person at the interview. Participants were informed that the content of the interviews would remain confidential unless the interviewer had serious concerns about their safety and/or the safety of others. It was made clear that where possible this would be discussed with them before confidentiality was broken.

During the transcription process I anonymised the data by changing names and removing any identifiable information. The audio files and transcripts were password protected and stored securely on encrypted devices. Consent forms are stored separately to the audio files and transcripts. Access to the data is restricted to the clinical supervisors, university supervisor, thesis examiners and myself. On the recommendation of the London-Bromley NRES Committee audio files and transcripts will be destroyed after five years in accordance to the Data Protection Act (1998).

### 2.7.2.3 Participant Wellbeing

Due to the sensitivity of the topic being researched measures and procedures were put in place to ensure that participants felt comfortable and were supported if issues arose.

Prior to the interview commencing participants were informed that they could share as much or as little as they wanted and could decline to answer questions. Participants were informed that they could stop the interview at any time, take a break or re-schedule if they wished. Participants were invited to share their ideas on how best they could let me know if they were becoming upset and wanted to

stop the interview or take a break. Seven participants said they felt able to let me know verbally whilst one person felt more comfortable using a gesture.

A post interview de-brief was conducted with participants in which their experiences of the interview and how they were feeling were discussed. This also provided an opportunity for sources of support to be discussed if necessary. As participants were recruited from across the UK they were encouraged to seek support from their GP in the first instance in order to be linked in with local services. A GP letter was devised outlining the nature of the study and what participation involved (Appendix Y). This was not a requirement for participation. Three parents opted for a letter to be sent out of courtesy. The parent (whose child was experiencing mental health difficulties) asked for their GP to be informed as they were considering seeking therapeutic support in the future. In the event that an immediate psychiatric review was believed to be required the participant would have been supported to access the local Accident and Emergency Department.

# 2.7.3 Data Collection

Interviews are regarded as the most suitable method of data collection for IPA studies due to their ability to invite and facilitate first person accounts, thoughts and feelings about the phenomenon being researched (Smith et al., 2009). A semi-structured approach to interviewing was employed. This enabled the interview to follow a general guide which reflected the research questions, whilst providing a flexible and adaptive interviewing technique that allowed participants to lead the interview (Eatough & Smith, 2008) and be the experiential expert (Smith & Osborn, 2003).

#### 2.7.3.1 Interview Schedule

Smith et al. (2009) state that the aim of an interview schedule is to "facilitate a comfortable interaction" which will enable a participant to talk more openly, reflectively and analytically as the rapport builds (p. 57). To help build this rapport from the outset a brief informal opening was given before the interview (Kvale & Brinkmann, 2009). Willig (2008) notes that as IPA is concerned with accessing

the life world of the participant the questions posed should be non-directive and open-ended. Smith et al.'s (2009) guide for formulating questions informed the schedule. Prompts and probes were included as follow up questions to gain more detail. I memorised the schedule and used it flexibly so that exploration of new avenues could be followed in a way that did not disrupt the natural flow of the conversation. An interview protocol comprising the opening and interview schedule was devised (Appendix Z).

#### 2.7.3.2 Conducting the Interviews

Interview locations were chosen on the participant's preference and their ability to provide privacy (see Table 2). The interview protocol was followed as previously discussed. Audio of the interviews was recorded digitally for the purposes of transcription. The duration of interviews varied from 60 to 140 minutes, however on average interviews lasted approximately 75 minutes.

One participant requested to be interviewed by one of the Clinical Psychologists supervising the research as they were not comfortable being interviewed by someone outside of the MCU team. This request was granted on the basis that: it would be unethical to decline as they were eager to participate; the parent was not known to either of the Clinical Psychologists; the interview protocol and schedule could be replicated easily; and the interview transcription could be verified and added to by the Clinical Psychologist to ensure it captured the non-verbal communication and experience.

#### 2.7.4 Data Analysis

IPA is not prescriptive in its approach to conducting data analysis. A number of flexible guidelines exist which researchers are encouraged to adapt and develop to match their own way of working (Smith, Jarman & Osborn, 1999). However, what underpins all IPA analytic methods is the analytic focus on the participants' attempts to make sense of their experiences (Smith et al., 2009). I was guided by the framework of analysis outlined by Smith et al. (2009) as it encompassed the principles, processes, and strategies customarily used by IPA researchers.

#### 2.7.4.1 Interview Transcription

Interviews were transcribed following Smith et al.'s (2009) guidance. A semantic record of the interview was created by transcribing the interview verbatim. Prosodic features of the interview were noted, however not to the detail that would be required for other methods, for example Conversation Analysis (Jefferson, 2004). A transcription system was devised to ensure consistency amongst transcripts (Appendix AA). Pseudonyms were selected for each participant and identifiable information such as dates and locations were removed to uphold confidentiality. The process of transcription is regarded as a form of interpretative activity in itself (Smith et al., 2009) as one begins to engage with the participant's account at a detailed level. Following Smith and Eatough's (2007) guidance I made use of the reflexive journal to capture my initial thoughts, feelings and points of potential significance.

## 2.7.4.2 Method of Analysis

### Step 1: Reading and re-reading

The aim of this stage was to immerse myself in the world of the participant to ensure that they became the focus of analysis. Through repeated readings of the transcript and listening to the audio recording of the interview I was able to 'actively engage' with the data. Approaching the data in this way allowed me to develop a sense of the overall structure of the interview. It also helped me to develop a responsiveness to sections which appeared rich and detailed, or held paradoxes and inconsistencies. In order to remain focused on the data and be open to new insights my first impressions were documented within the reflexive journal in an attempt to 'bracket' them, whilst also creating the opportunity for me to return to these at a later stage of analysis if required.

### Step 2: Initial noting

A detailed and comprehensive set of notes were made on the data. This involved examining the semantic content and language used on an exploratory level. This was achieved by engaging in a close line by line review of the experiential claims, concerns and understandings made by the participant (Larkin et al., 2006). Exploratory commentary focused on three domains: descriptive comments; linguistic comments; and conceptual comments. Annotated notes were made on the transcripts in the right hand margin next to the text (Appendix BB).

### Step 3: Developing initial themes

This stage involved transforming the exploratory notes into specific themes. The aim was to produce themes which captured the 'psychological quality' (Smith et al., 2009) inherent in the initial notes and within the participant's original words. This was achieved by mapping the interrelationships, connections and patterns between exploratory notes and making links to psychological concepts to attain a higher level of abstraction. Themes reflected the participant's own words and my interpretations to ensure that the connection between the two was not lost. Themes were noted in the left hand margin on the transcripts (Appendix BB).

#### Step 4: Searching for connections amongst themes

The purpose of this stage was to develop superordinate themes. This was achieved by exploring how initial themes fit together by searching for patterns and connections. I drew on the following four methods: abstraction (putting like with like and developing an overarching title to encapsulate the new cluster of themes); polarisation (searching for oppositional relationships); contextualisation (searching for key life events); subsumption (elevating a theme as it brought together a series of related initial themes). This process was completed on an excel spreadsheet. Initial themes were typed into each cell chronologically in the order that they appeared in the transcript alongside key phrases or words. Initial themes were then grouped together based on my interpretations using the methods previously outlined. This was an iterative and dynamic process which

involved returning to the original transcript to ensure that my interpretations and subsequent themes were grounded in the data itself. Through this process some themes were disregarded due to the lack of evidence to support them. Two summary tables were produced to summarise the development of superordinate and subordinate themes for each participant (Appendix CC).

#### Step 5: Moving to the next case

Steps 1-4 were systematically repeated for each of the transcripts. In an attempt to approach each transcript on its own terms and thus be analysed on its individuality, ideas or themes generated from previous analyses were 'bracketed' as much as possible so that there were opportunities for new insights to be gleaned.

### Step 6: Looking for patterns across cases

The purpose of this stage was to complete a group analysis. I employed the use of a paper system and wrote down all of the themes that had been produced from each individual analysis. I used different coloured paper so that each participant and their respective transcript was easily identifiable. I compared and contrasted themes across participants and looked for connections between each participant's summary tables. This process required an interpretative focus and entailed revision and reconfiguration of themes. The final superordinate and subordinate themes, alongside extracts from each transcript to support each theme, were collated on a pin board (Appendix DD).

### **CHAPTER 3: ANALYSIS**

#### 3. Overview

This exploratory study aimed to understand what it was like for parents to experience their child being unwell and how they made sense of the diagnosis of PRS. Furthermore it aimed to explore how parents experienced and negotiated the treatment process. The data generated from the interviews was analysed using Interpretative Phenomenological Analysis (IPA). This chapter presents the main findings, these are outlined in Table 3. Each superordinate theme and its subordinate themes will be outlined and discussed in turn. Extracts<sup>1</sup> from the interview transcripts will be presented to illustrate themes. The themes are considered to be interwoven and as such are not entirely separate to each other.

Table 3: Superordinate themes and subordinate themes

Superordinate Themes	Subordinate Themes		
	The "invisible enemy" takes hold		
The Vitality of PRS and the	<ul> <li>Negotiating the release of the hostage</li> </ul>		
Power of its Departure	<ul> <li>Nurturing and assimilating the child</li> </ul>		
	<ul> <li>"Everything and nothing": the utility of PRS as a</li> </ul>		
	diagnostic label		
	"Foxtrot Oscar": finding a voice in the system		
"Them and Us": Fostering	"The lurking thing"		
Trust and Building Bridges	<ul> <li>"Everybody protects their interests": balancing</li> </ul>		
	power to "come alongside"		
	"It did knock the stuffing out of me"		
A Book in the Library of Life	Strengths and vulnerabilities in the "survival bubble"		
	Personal and relational growth		

The analytic interpretation derived from the data represents one of many possible interpretations. As the previous chapter outlined, a contextual constructionist

<sup>&</sup>lt;sup>1</sup> Extracts are referenced with an identifier which provides details of the page and line numbers of the text as it appears in the transcript.

epistemological position acknowledges that a researcher's personal and cultural perspectives will influence their reading and interpretation of the data (Madill et al., 2000). My knowledge of psychological theory and experience of working within health and social care settings was drawn upon in the analysis to help understand participants' experiences.

### 3.1 The Vitality of PRS and the Power of its Departure

Parents' perspectives and experiences of PRS and its treatment are comprised within this superordinate theme: the early stages of PRS; the approach to treatment and recovery; and their views on the utility of the diagnostic label.

#### 3.1.1 The "invisible enemy" takes hold

In their accounts, all of the parents depicted PRS as an active, dynamic illness which developed in strength as it gained momentum and enveloped their child. All parents talked about PRS as if it were a separate entity to their child. Parents' use of language and the manner in which they spoke about their child's experiences seemed to reflect "externalising conversations" that take place in narrative therapy (Morgan, 2000, p. 17). Such conversations aim to locate the problem outside of the person so that "the problem, not the person, is the problem" (White & Epston, 1990, p. 40). Externalising PRS appeared to enable parents to remain connected to their child despite them seeming unrecognisable or "lost" (Laura, p9: 226). For some parents externalising PRS also seemed to help them withstand and tolerate their child's rejection and anger towards them. For these parents it seemed the child began to hold dual identities: the "real" and the "not real" child.

All of the parents spoke of how PRS "manifested itself" (Carla, p19: 622) through benign physical symptoms before going on "to do other things" (Carla, p1: 06). Reflecting on this stage of the illness, Susie spoke of how her daughter seemed suddenly lifeless and appeared to suggest that it was difficult to hold onto the recognisable parts of her daughter as the illness became omnipresent.

It was just like, it was you know ... just like someone had pulled her plug out. She just had no energy at all (p1: 22-23).

I just felt like every aspect of her was slipping through my fingers (p2: 39-40).

Similarly, Laura gave an emotional account of how her son had become "very shut down" (p1: 08) and stopped eating and drinking.

... he really wasn't taking anything in and he was just, he was just disappearing. Um ...physically and mentally [voice breaks and begins to cry] ... (p2: 56-57).

All parents spoke of this sense of their child "slipping" or "disappearing" away as the illness took hold. Once in its grip parents spoke of how they saw a marked change in their child. Susie spoke of how her daughter came to embody an animalistic "thing" as the illness progressed and gained strength.

You're not dealing with a normal healthy child you know you're dealing with this err ... [sighs] sort of err ... I don't want to say animal like but it gets that basic. You've got this thing growling at you in the bed and that's what you're dealing with you know (p14: 437-442).

Susie seemed to intimate that the arrival of this "thing" required her to change the way she related to her daughter. Reflecting on her earlier experiences, Helena spoke of how she came to reconcile the difference she saw in her daughter in the absence of any medical explanation.

... I was fighting this invisible enemy. I knew that this was not Zoe and this thing was taking hold of Zoe. And I thought, I got stronger, I thought 'I'm not going to let this, I know I can get Zoe back' (p5: 159-162).

I'm not going to let it take my daughter away. I don't know what it is. And I know Zoe is there and I know she can see me there. And I know she can hear me and she knows that I won't give in (p6: 168-171).

Personifying the illness as the "invisible enemy" seemed to enable Helena to make the illness visible (psychologically) and separate it from her daughter. It seemed that her reference to the illness' "invisibility" not only intimated that the cause could not be seen, but perhaps implied that it was hard to defend against because of this. Conceptualising the illness as an "enemy" that was against her and her daughter, perhaps enabled Helena to "fight" and take action against it as it did not involve fighting her daughter. It also appeared to enable Helena and her daughter to maintain their connection, which in turn seemed to fuel Helena's strength to keep "fighting" on her behalf. This was an experience which was reflected amongst all parents' accounts.

Carla spoke of having to play "funny games with it [the illness]" (p9: 272). Helena seemed to provide an example of how she found herself "playing" with the illness:

H: So it was like you were walking on egg shells, but walking on a double level of egg shells because you couldn't talk normally. Erm sometimes on egg shells you know you can avoid a few things but this was like everything you did as well. Everything was like 'Recognise I'm not well.' But you didn't want to feed it [the illness] either, so there was that level.

I: What do you mean by you didn't want to feed it?

H: We [her and her husband] didn't want to succumb to it too much either. We didn't want to be completely un-normal about things. We wanted to have a normality as much as possible as it should be like that. Otherwise this thing would take total control and she'd be in control of it and not to come out of it. So you had to find that balance (p10: 318-329).

Helena's use of the idiom "walking on eggshells" implied the careful and deliberate manner in which she had to interact with her daughter. The "double level of egg shells" appeared to intimate the precariousness of interactions and the extent to which all communication, verbal and non-verbal, was potentially upsetting. Helena seemed to be suggesting that any form of "normality" posed a threat to the illness as it signified a dismissal of its existence. For Helena this seemed to raise the dilemma of whether to collude with the illness (by overtly focusing on it) or to challenge it (by talking and acting "normally"), both of which had the seemingly unfavourable outcome of the illness holding power and control; a double bind. It appeared that through considered, tactical manoeuvres Helena was able to "play" along with the illness and achieve this balance in order to ensure the illness did not have "total control". This experience was reflected amongst all of the parents' accounts.

### 3.1.2 Negotiating the release of the hostage

Reflecting on their knowledge and experience of PRS, all parents highlighted the importance of respecting the child and the illness itself. Parents spoke of having to learn how to relate to and interact with the illness, as well as their child. It seemed that by attending to these relationships simultaneously, parents facilitated a process whereby their child began to feel psychologically and emotionally safe enough to "find a way out of themselves" (Laura, p10: 326) and "come out of their shell" (Susie, p19: 614). Parents spoke of ways in which they created opportunities for their child to test out what it might be like to "carry on like normal" (Fahra, p6: 182) as if the illness was not there. In this sense parents appeared to provide their children with "an out" (Carla, p13: 398) and an opportunity to "start over" (Carla, p13: 399). This seemed to reflect the notion of "preferred stories" in narrative therapy (White & Epston, 1990), i.e. parents created opportunities for "preferred stories" to develop which allowed their children to explore and live out "new self-images, new possibilities for relationships and new futures" (Freedman & Combs, 1996, p. 16). All parents referred to this as an ongoing process of negotiation which had to be approached with sensitivity and tentativeness. All parents also regarded this process as a

significant contributory factor to their child reaching the "brink" (Susie, p24: 791) of recovery.

Carla recalled how a comment, made by a Consultant Psychiatrist, resonated with her and helped her to understand how her daughter might be able to feel less stuck in the illness.

He said "The thing is we've got to lead Candice out of this with dignity." And that's stuck ... that's stuck with me for lots of things. Even when kids do something wrong. Like my youngest son if he's done something and he's really on the back foot about it that phrase really ... lead ... don't keep saying to him "Oh you shouldn't have done it." Just give him, give him an out. Almost like a hostage situation. Allow them to come out start over (p12-13: 394-400).

Carla intimated that children may perhaps feel like they have done something "wrong" and as such may be hesitant to come out of the illness due to feeling ashamed or perhaps for fear of punishment. She seemed to imply that akin to a "hostage situation" it was important to reduce the child's fear of ramifications by communicating to the child that they would be able to "start over" with their family.

Bridget shared an analogy that she found helped her and others to understand what psychological processes were taking place for her daughter.

A little bit like The Lion, The Witch and The Wardrobe analogy, in as much as there's an absolutely horrendous thunderstorm out there. You're absolutely ... deep deep scared. So you will grab Snoopy and the things, and some ear muffs and some duvets and some water and, just locking herself away in the wardrobe. And then, logically you know that the thunderstorms not going to last forever, but it might rumble in the distance for a few, you know, for a few miles but you couldn't hear it but it

wouldn't be above you, so you opened this door. 'Oh no there's another rumble!' so you go back in again (p30: 965-973).

Bridget implied that she understood that her daughter had psychologically retreated in response to a perceived threat or danger. She intimated that her daughter knew that she could not remain withdrawn forever and as a result would test out reconnecting with the world. Reconnection was made difficult as the perceived threat and danger seemed to be looming and as such felt too much of a risk to take. Susie referred to this stage of the illness and said that despite an appearance of no improvement "there is probably a lot going on in the mind that is healing and sorting itself out" (p20: 629-630). Indeed Bridget seemed to extend her analogy to make sense of how, once her daughter felt more able to reconnect, she was posed with the prospect of being widely praised and perhaps felt as though this was too overwhelming.

So that's the analogy that we used but then after a while it became sort of like, 'Well I know I've got to come out of the wardrobe. Come on, let's get real here. But hang on a minute. If I come out of the wardrobe that is going to be good. People will be pleased with me and I'm not safe enough to be praised so I'll just go back in.' (p30-31: 990-993).

Tim provided an insight into how he enabled his son to regain a sense of self, agency and mastery in a way that felt safe for his son.

T: We would literally meet on another planet. So in the game he was a very active Jedi [laughs] jumping around and chatting with other people in the game. Because you know it's one of these things where you make online friends. You know you work together and you kill baddies and huge monsters and all that kind of stuff and you explore the planets. And erm ... in a funny sort of way in the game he was very able because children are better at these things instead of old adults like me [laughs]. So he was almost leading me around and sort of

helping him. And it was a weird contrast sort of him lying on the mat you know not being able to sit, even walk, but in the game he was jumping around and slaughtering the monsters [laughs] with his light saber in the game you know. So it was kind of odd to see this very able person in a virtual world.

I: What was your character?

T: [Laughs] I've always been a healer! I was always the dog, or the healer or whatever. He was the kind of out there fighter or whatever you know. So erm obviously we made a good team [laughs]! (p22-23: 726-741).

It appeared that the virtual world mirrored the therapeutic space, i.e. it provided an opportunity for Tim's son to safely explore aspects of himself and test these out relationally with others. Furthermore it seemed that Tim's presence in the game enabled his son to explore unimpeded which appeared akin to a secure attachment exploration. The virtual world also allowed Tim and his son to communicate and maintain their relationship. The game seemed to also provide an opportunity for Tim's son to fulfil a developmental task of forming friendships and gaining an identity separate to his family. It seemed that the content of the game perhaps reflected in some ways the process that was taking place in the real world: fighting the huge monster (PRS) and trying to find a way out of the illness together, as a "good team".

#### 3.1.3 Nurturing and assimilating the child: the recovery

I always say that it's not that it happened but it's the recovery. You just think 'Blimey!' Because when we start recovering, and I say we because it was like that, it was like 'Woah!' (Carla, p18: 578-580).

All of the parents referred to the power of their child's recovery and spoke of how they also saw themselves recovering as part of this process. There seemed to be a shared perspective that it was their child's "choice" and "decision" to recover. Parents regarded time, patience, routine and structure as the fundamental factors that contributed to their child's recovery. This subordinate theme encapsulates the process that took place during the recovery.

Bridget spoke of how her daughter made an animation of a duck during the months she was starting to improve. She described a "slow and laborious" (p26: 854) process in which each of the duck's limbs had to be moved and photographed before it could become a complete animation, this seemed to reflect the slow and gradual recovery process that all parents described. Susie spoke of how her daughter had found it useful to use individual therapy as a place to "slip back into and explore" (p30: 958) the illness whilst she began to participate in the ward community. It seemed that holding onto the illness in this way provided her daughter with a sense of safety, i.e. she could re-retreat into it if she needed to.

All of the parents spoke of the importance of facilitating their child's connection to life outside of the illness and the hospital through maintaining contact with friends and family. Carla spoke of how she helped her daughter stay connected to her family.

I started bringing a photo album of this dog bear thing she's got. We always take a picture of him, when he's like on holiday or up a tree. So I thought 'cause she'd gone down the route of hating herself and all that I just did it from the dog's perspective. You know "Hi! I'm Henry. I live in X and this is the forest I go in". There was one picture with a bit of her in and I said "By the way that's Candice" ... but yeah then we had this nice book that was the focus but she wasn't in it (p16: 512-518).

It seemed this imaginative approach allowed Candice to feel included and connected to her family at a distance that she felt comfortable with. Fahra spoke of treating her son "like normal" and not "like he's got problems" (p5: 160). She

believed that this helped her son to start to show improvements. Recalling the first time that her son had spoken to her in two years she said:

This is my golden time to be honest. Two years your son he's not hear his voice (*sic*) ... I was not crying but I was like frozen like with happiness ... And then I didn't say "Oh! You talked today!" I just pretended to be normal (p6: 176-178).

All of the parents referred to such "golden moments" and for many were described as "winning the lottery". Susie spoke of how these moments came "thick and fast" (p19: 625) as her daughter's recovery gained in momentum. She spoke of the first time her daughter was affectionate towards her since becoming unwell.

The first time she actually kissed me again. I remember that very vividly ... Because you know all signs of affection sort of go as well ... you just think 'That's so amazing! It's just so great to have her back again' you know? (p25-26: 824-828).

For George these "little moments" (Helena, p17: 551) signified progress. Speaking of his response to these he said:

Our daughter was gradually coming back to us so ... I could use plenty of adjectives but you know [laughs] ... I felt like we were father and daughter again you know? Not two strangers together (p16: 522-525).

With the exception of Fahra, all of the parents spoke of the concerns and challenges that their child's transition home raised. Helena referred to this as a "daunting" (p25: 820) time for the child and the parents. Susie believed that a gradual managed move home was useful.

It is a difficult thing to have your child back um ... although she was, I'd say she was 90% well there was still that 10% to go.

Erm and also it was us, it sounds awful because I think anybody looking in from the outside would say "Well of course you're glad to have your child back and of course it should all be rosy and it should be perfect". But it's not in reality because you've got used to not having that child there and managing that child who is still recovering. Your other child had got used to not having that child around (p32: 1039-1046).

Susie seemed to provide an honest account of how the recovery continued through her child's transition back home. She implied that her family underwent a process of adjustment as they learned how to be with each other as a family again. It appeared that Susie acknowledged that this was perhaps not the experience one would expect.

In her account, Helena reported that her daughter experienced difficulties within her friendship group once she returned home. She spoke of how these difficulties resulted in her daughter taking an overdose and believed that had the appropriate professional support structures been in place her daughter may have felt better supported.

Laura spoke of how she had anticipated a relapse and had been "expecting certain triggers points" (p5: 135).

And so you know when he got his first girlfriend ... and that finished I was thinking 'Oh God! Here we go!' And the first flu he had after it that frightened the daylights out of me because he hadn't eaten for a few days and I thought 'Oh God! Here we go!' But he was alright, he was perfectly fine. But you know I was very anxious the first few ... well a year or so I suppose (p5: 136-141).

It seemed that parents believed that the transition home, with all the challenges it posed, tested the psychological and emotional resilience of the child: something that had been nurtured over the course of treatment.

## 3.1.4 "Everything and nothing": the utility of PRS as a diagnostic label

All of the parents spoke of the utility of PRS as a diagnostic label. Its wording seemed to accurately describe the behaviours parents were observing in their children and as such brought relief as it signified that professionals understood what was happening for their child and could therefore begin to treat them accordingly. This knowledge enabled parents to acquire more information about its "form" (Carla, p19: 621) and learn what to expect with regards to its trajectory and treatment. However, parents described a sense of ambivalence as the diagnosis also gave rise to feelings of "utter horror" (Bridget, p7: 231) and disbelief that their child was experiencing mental health difficulties. For many parents this required a conceptual shift from believing that their child's experiences were a result of an organic cause, to coming to understand them as an expression of psychological distress. It seemed the diagnosis provided a useful framework upon which parents could begin to make sense of their child's experiences, however it still posed the conundrum of the cause: an issue that all parents reflected on in their accounts. In this sense it seemed the label of PRS was "everything and nothing" (Carla, p18: 567).

Reflecting on the treatment her son received prior to the diagnosis, Fahra said that professionals "helped the wrong way" and made "it [the illness] upside down" (p20: 648). This appeared to be a shared view amongst all of the parents who reported that professionals' early attempts to intervene were met with further decline and deterioration. Indeed Laura believed that her son would have died without the diagnosis and the resultant recognition that he needed a specific approach to treatment.

Without that diagnosis and without that help he would have gone off the edge, without any question he would have gone off that edge (p11: 341-343).

Tim reflected on the "culture of treating labels" (p19: 612) and spoke of how people become "completely stuffed" (p19: 613) if they don't fit within one. Indeed this seemed to reflect Laura's assertion that her son would have died without the

diagnosis as the professionals lacked understanding and clarity on what they were treating. However, in their accounts four parents acknowledged that, given its rarity, professionals might not have encountered their child's presentation and the diagnosis of PRS previously. Reflecting on its rarity led many parents to share how they had come to view and understand the diagnosis and its origins. These appeared to be retrospective understandings.

Helena shared her observation that PRS appeared to develop during "teenage and pre-teenage" (p15: 467) stages of development. Two parents shared similar observations. Carla spoke of how PRS "almost feels like a teenage disease ... because you can see traits of it within other teenagers" (p19: 609-610) and believed it was an expression of "working out who they are as teenagers but to the power of twenty five million" (p18: 562-563). It seemed that perhaps Carla was drawing on a dominant cultural and societal discourse that adolescence involves a process of identity formation and is comprised of developmental stages, within which there are tasks that a young person must achieve and master before moving on to adulthood. In this sense parents appeared to intimate that PRS was a result of a struggle and/or failure to achieve developmental tasks.

Susie spoke of how it seemed as though "these children are a particular mould" (p38:1230) and intimated that they shared inherent personal attributes.

I think that these children, you can help them with their environment and the way that you are with them, but I think they are born a certain way. I think they are born with these um personal characteristics and traits and you know you just have to help them manage these personality traits they have I think. I mean she is very very sensitive, she takes things, you know she feels things very very very deeply (p38: 1243-1248).

Susie seemed to intimate that her daughter's "personality traits" might have predisposed her to experience mental health difficulties. Indeed five other parents referred to such innate "characteristics" and suggested that emotional sensitivity and fear of rejection and failure were shared commonalities amongst children

who had been given a diagnosis of PRS. Perhaps these "personal characteristics and traits" contributed to their child's struggle to negotiate the developmental tasks adolescence posed. Certainly all of the parents talked of losses (friendships, familial illness and bereavement, transition) that their child had experienced prior to becoming unwell. It seemed possible that perhaps parents were suggesting that their child's experiences were a result of attempting to process and adapt to these changes.

Three of the parents referred to the terminology used within the label itself. They were all in agreement that the inclusion of "refusal" was appropriate as it accurately depicted the nature of the presentation. This seemed interesting as all of the parents, with the exception of Fahra, used "refusal" and "withdrawal" interchangeably in their accounts. Perhaps this reflects the notion that these concepts can be understood as being on a spectrum (Jans et al., 2011; Jasper et al., 2009). Carla and Tim referred to the label itself as "irrelevant" and believed it was "just a few words tacked together to explain a much bigger thing" (Carla, p19: 601-602). In contrast Bridget spoke of the importance of terminology given that labels can stick with people over their life span. She shared her distaste and anger at the proposed renaming of PRS to Pervasive Arousal Withdrawal Syndrome (PAWS). In her opinion "arousal", despite being a "very medical term" (p37: 1208), had "negative sexual connotations" (p37: 1211) for the general public which she believed would have implications for people who "live in the real world [not in the academic medical world]" (p39: 1256). Bridget seemed to highlight how diagnostic labels can result in stigmatisation in contexts outside the health domain and perhaps indicates a need to consult people about how they would like to refer to the difficulties they are experiencing.

#### 3.2 "Them and Us": Fostering Trust and Building Bridges

This superordinate theme followed parents' relationships with professionals as their child moved through the NHS care pathway. It focused on parents' experiences of not being heard and finding a voice in the system, their experience of feeling under scrutiny by professionals, and their experiences of working through the power imbalance with professionals in order to achieve a

trusting, collaborative working relationship. This seemed to be a significant process for all of the parents.

### 3.2.1 "Foxtrot Oscar<sup>2</sup>": finding a voice in the system

With the exception of Susie, all of the parents shared experiences of not being listened to by health professionals when they tried to seek help for their child. They spoke of feeling dismissed, frustrated and angry as a result of professionals' failure to listen and take action. Parents spoke of needing to assert themselves within the system to be heard. Some parents found allies within the system who advocated on their behalf so that their child could gain access to the care that they needed. All of the parents spoke of the emotional intensity of this time, as in addition to the pressure of the "head bashing" (Helena, p7: 201) they had grave concerns about their child.

Our local GPs were utterly useless and positively obstructive. Erm ... in that that they refused to acknowledge that there was anything wrong with him at all ... You know taking no interest whatsoever. So erm there was indeed always hostility you know you felt you couldn't go to them and say "My child's ill" because you were made to feel it was your fault (Tim, p3: 80-83).

Tim seemed to intimate that in addition to feeling dismissed and blamed by GPs he also felt as though they were in opposition to him. Perhaps Tim's feeling of being opposed derived from his view that the GPs were obstructing his son from accessing other services despite his repeated request for help. Certainly GPs are often regarded as the gatekeepers for other services within the NHS. Later in his account Tim reflected on his use of the word "hostility".

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<sup>&</sup>lt;sup>2</sup> Foxtrot Oscar is a colloquial euphemism for "fuck off". It derives from the phonetic alphabet where Foxtrot is used to denote the letter F and Oscar the letter O. I have borrowed George's phrase for the title as it seemed to encapsulate the strength of hostility and dismissiveness parents experienced from professionals.

I probably became hostile towards them [laughs] when they didn't help or sort of didn't even acknowledge or say "Oh yes he doesn't seem very well does he?" Erm ... I think the lack of care and concern err ... a basic humanity ... if someone comes, some parent comes to you and says "Look my child isn't very well" you should at least listen to them and believe them (p19: 619-623).

Tim seemed to imply that his concerns were dismissed as he was not believed, this consequently engendered negative feelings towards the GPs. Many parents referred to not being believed and expressed their bewilderment given the severity of the visible physical decline in their child's health. George spoke of how he felt he was "virtually told to Foxtrot Oscar" (p18: 567) by a local hospital Doctor when he pleaded with him to help. George referred to his encounters with this particular Doctor throughout his account. Speaking of the anger he felt with regards to the Doctor's attitude he said:

The thrust of my anger was towards this Doctor who just turned up ... I mean at that stage we were erm ... on the edge you know because we just thought 'We're going to lose Sammy. No-one seems to be doing anything. Nobody cares.' Erm ... yeah when he said "Yeah she's making it up" I just thought 'What the hell are you [whispers] fucking talking about?' (p3: 87-94).

George's anger seemed to reflect the growing hostility that Tim spoke of. The intensity of the hostility seemed to derive from an acute sense of fear and helplessness as they observed their children physically deteriorating. Fahra described not being listened to as "the worst possible experience" (p8: 258) and spoke of how she felt professionals were using their "power" to silence her.

F: When something you want to but no-one can listen to you (*sic*). That's why I think, that what I say to you, that sometimes the professional use their power.

I: Did you at any point feel like you had power?

F: Erm ... I had a power for, fight for ... still err protect my children (p8: 260-264).

Fahra seemed to intimate that she could "fight" to protect her children and in this sense she had power. Many parents spoke of the ways in which they gained power by asserting themselves through the process. Carla described how she "got into work mode" (p1: 31-32) which enabled her to be successfully heard and responded to. Perhaps her ways of interacting in "work mode" and "parent mode" differed. She seemed to resourcefully identify that perhaps she was more likely to be heard if she emulated a professional manner and used language that would perhaps qualify and elevate her position. Laura spoke of the importance of conviction and tenacity when negotiating with professionals and said that she and her husband "pushed really hard" (p17: 538) on matters they deemed important. In desperation Helena threatened professionals with sharing her story with the media. This threat served its purpose and professionals took action to get her daughter seen by specialist services.

Parents' power was also strengthened by finding allies in the system. These ranged from administrators to doctors. George spoke of the "determination" shown by one Doctor as she "jumped through the hoops" to get specialist help (p5: 158). Similarly Carla spoke of a nursing officer who bypassed the usual administrative procedures to get her daughter an appointment at a local hospital. Laura spoke of how she found an ally in her son's physiotherapist and asked her to advocate on her behalf by passing on a written note to the consultant prior to the ward round.

I knew I only had fifteen minutes with this consultant um and I knew in that time I couldn't get across all of the things that he [her son] wasn't able to do and how much he'd shut down. And I said to the physio "Can you give this to the consultant so he reads it before I even get in the room" (p13: 420-423).

It seemed that professionals were able to bring about action through their working knowledge of the system and their position within it. Thus recruiting allies and penetrating the system in this way allowed parents to gain a voice and be heard. The act of joining also seemed to validate parents' experiences.

# 3.2.2 "The lurking thing"

There's a kind of lurking thing when a child's in severe distress that, you know it's probably even more in the press now than it was ten years ago, but you know there is a kind of thought 'Oh child abuse' [sighs heavily] (Tim, p14: 447-450).

Tim's reference to the "lurking thing" seemed to encapsulate the way in which the question of abuse arises when a child experiences severe emotional and psychological distress. He seemed to intimate that the question of abuse is not overtly spoken about but is a factor people consider and query as the cause. Seven parents spoke of how they experienced the "lurking thing", to a varying degree, in their encounters with professionals.

Laura intimated that it was difficult to be at ease with her son as she became heightened to professionals' observations of her.

I think I was quite self-conscious at first because I was very much aware that everyone was watching us. And I thought you know every time we left they'd [staff] sit down and write about us and how we were with him [her son] and all of that. I found that really hard (p8: 247-250).

In his account George spoke of how he felt an "aspersion" (p8: 235) was cast when doctors began to ask questions about his relationship with his daughter.

It was bloody intrusive. I thought "What the bloody hell are you asking me this for? What's that got to do with it?" Erm you

know what about the fact she won't communicate, won't um ... she's refusing to eat, she's withdrawing you know? Plus the fact that you know "We used to watch 'EastEnders' together, or watch 'Local Hero', or to take a walk through the park to Waitrose, or did I shout at her, or did I hit her?" I don't think I actually said did I hit her but they were steering things towards the physical ... um violence, but there wasn't. So yeah I couldn't understand it (p8: 240-249)

George's anger is evident in this extract. It seemed that he was unsure of the purpose of the questioning but had a sense that the conversation was being "steered" to question whether he was physically violent towards his daughter. He also seemed to intimate that the questions required him to share parts of his life which he considered to be private, as a result he experienced this as an intrusion. Helena seemed to feel as though professionals were out to expose her in some way through seeking contradictions or evidence of wrong doing (through "cross examination").

It's obviously soul destroying when you're sitting there feeling like you're being cross examined and you're feeling guilty whereas you weren't. And it was also very humiliating I suppose in a way being cross examined in that way 'cause that's how it felt (p11: 338-341).

I don't think they [professionals] purposively made you feel guilty but the way the questions were coming across ... It was like they were questioning us and what we did and how we did things and whatever. And I suppose it makes you feel like well if you're asking those questions do you not trust us? Um but I suppose they have to. So it's a double edged sword isn't it really? And um it wore you down because you felt you were on the guard the whole time (p11: 347-353).

Helena's reference to the "double edged sword" seemed to reflect the way in which she understood that professionals had to ask questions to find out about a child and their context, but how this seemed to be to the detriment of maintaining a good relationship with the parent. It can also be gleaned from Helena and Laura's experiences that parents are presented with a form of double bind, i.e. as a result of feeling observed parents develop a heightened sense of personal awareness and anticipate critical appraisal from others, which inevitability impacts on the way they behave and relate (become "on guard"), which in turn may be perceived or interpreted negatively by professionals.

Fahra spoke of how her son was placed under a child protection investigation after professionals questioned the closeness of their relationship.

It was very difficult for me because my son was facing very difficult situation because he was sick I was worried sick and they [health and social care professionals] gave me more pressure for me and better that they help me (*sic*). That is the worst of my life. Worse than my son. I was worried that he was sick or that he was diagnosis, worse that I was worried the professional people how they attack me (*sic*). They treat me like a ... something like that. But it's not good for, to fuss and to ... judge for the person (*sic*). (p21: 676-683).

Fahra seemed to provide an insight into the effects of bringing the "lurking thing" out of the shadows. It seemed that the child protection investigation felt like a personal attack and perhaps implied that she was at fault or harmful to her son in some way. She felt as though professionals placed additional "pressure" on her and intimates that their efforts would have been better placed helping her. It appeared that the "lurking thing" had come to overshadow her son's illness, i.e. it became the main focus for professionals and perhaps Fahra. No concerns were raised by the child protection investigation and Fahra spoke of how this outcome resulted in professionals apologising. This experience seemed to have a significant impact on the way she viewed professionals: this will be expanded on in the following section.

## 3.2.3 "Everybody protects their interests": balancing power to "come alongside"

All of the parents made reference to the way in which they and professionals had to find a way to come together in order to work collaboratively. It seemed this process involved building trust and required both parties to devolve a degree of power to each other so that they could be united in their approach. Parents respected the knowledge, experience and skills of the professionals but impressed the importance of sharing and drawing upon their own knowledge and experience of their child.

Carla spoke of having to "let go" (p21: 692) of her daughter to enable her to get the help she needed.

You've got to realise that they are just not going to get better with you. I'm their mum. I'm not their nurse. I'm not their chiropractor. I'm not their play therapist you know? It's awful and you've got to sort of put your hands up to that. I'm actually going to be shit at this (p22: 692-696).

Carla implied that she had to accept that she was not able to help her daughter alone. Bridget and Laura echoed this experience, which perhaps reflects their engagement in a process of adjustment to and acceptance of the effects of the illness, not only on their child but perhaps on them and their families. All the parents spoke of feeling reassured by professionals' knowledge and experience and believed that this enabled them to place trust in them. Susie spoke of the nature of her relationship with the Consultant Psychiatrist and how she found this helpful.

He led. He was a very strong um sort of leader sort of thing and that's, I think that's what you need as a parent. You don't need somebody that's trying to manage your situation to be wishy washy with you. Because Dr X was strong it enabled us

[her and her husband] to be strong and we were able to be strong for her [her daughter] then (p33: 1084-1089).

Susie implied that she benefited from being led with clear direction. It seemed that perhaps the Consultant Psychiatrist provided "containment" (Casement, 1985) for Susie, i.e. to some degree he held the responsibility, distress and concern which enabled Susie to cope and remain "strong" for her daughter.

All parents talked about the importance of bi-directional communication during the treatment process. Understanding the rationale which underpinned the approach to treatment seemed to be particularly pertinent for parents. George said that he initially disagreed with professionals being firm with his daughter and didn't understand its purpose.

I often felt like staff didn't know what they were doing. We'd [he and his wife] often say ... and then one of the nurses would turn around and say full stop to Sammy "You've got to do this" and I thought 'No! Why are you doing that?' I s'pose because I didn't understand the treatment and how it would work (p12: 367-371).

Obviously they did explain to me that they were, they had [laughs], Sammy wasn't the first young person that they'd treated and they knew what they were doing (p12: 383-385).

George seemed to intimate that he and his wife accommodated his daughter whilst in contrast nurses directly challenged. Seven parents spoke of having to resist intervening: they believed that their child would not manage or feared that they would "kick off". In this respect Susie felt that her daughter benefited from being "separated" from her.

Had I been with her the whole time I probably would have been stopping them saying "She can't do that. She is not able to do that" you know? Whereas because I wasn't there they were

able to you know say to her "Right we are doing that now". And okay she kicked off, but mum wasn't there to protect her or you know, she had to do it. You know so she got her independence back that way (p27-28: 887-893).

It seemed that this extract connected to Susie's belief that a parent required "strong leadership", i.e. given their emotional distance professionals had the capacity to assume a role which perhaps felt uncomfortable for a parent to take up.

Throughout her account Fahra spoke of the power she felt professionals had through their expert position. She believed that a parent should be consulted with and listened to, given their expert knowledge and experience of their child. This was a sentiment shared amongst all parents. Fahra believed that professionals sometimes had difficulty listening to parents as they became focused on "fixing the case" (p25: 793) and viewed no improvement as a professional "failure", which to them was "the end of the world" (p25: 796). Fahra spoke of how she believed professionals "protect their interests" (p9: 291) when no improvement was seen in order to conceal their failure.

If after three months it [treatment] doesn't work ... then you're a professional, you have power and what do you do? Then you do writing a report (*sic*). That is very important. Then you write a report to say there is no improvement, maybe he's got a problem, a psychological problem blah blah [speech speeded up]. Because if you give them a report then you're not feeling like a failure for a professional (*sic*) (p7: 218-223).

Fahra implied that professionals attributed no improvement to her son's "problem" rather than perhaps accepting that their interventions had not resulted in the outcome they had hoped for. It seemed that she was suggesting her son had become pathologised by professionals as a result.

Bridget shared an experience which seemed to reflect Fahra's notion of professionals protecting their interests. Bridget's daughter turned sixteen during her stay on an inpatient unit. For her clinical team this raised an issue with regards to her consent to treatment (as she presented with angry resistance) and as such informed Bridget that they would be placing her on a Mental Health Act (1983, 2007) section. Bridget said she was told this was because it would be "an awful lot easier and tidier" (p33: 1071). Bridget spoke of how this was contested within the staff team as despite her daughter's presentation she did communicate and consent to treatment in her own way. The proceedings took place and the section was not agreed. This seemed to have significance as it highlighted the issues of treating a person who presents with angry resistance or withdrawal.

### 3.3 A Book in the Library of Life

It's almost like the illness is a book on a bookshelf ... and the books are all different stages of our life (Susie, p40: 1290).

All of the parents referred to their own personal "story" or "journey" throughout their accounts. This superordinate theme portrayed the parents' personal stories: the emotional, psychological and physical impact of parents' experiences; the sources of support parents found helpful and the ways in which they coped; and the personal and relational growth they experienced as a result of their experiences.

#### 3.3.1 "It did knock the stuffing out of me"

Reflecting on the personal impact of his experiences, Tim said "It did knock the stuffing out of me" (p22: 719). This phrase seemed to capture the emotional, psychological and physical impact that all parents reported during their experiences.

Reflecting on her earlier experiences, Carla described feeling "really all at sea" (p6: 193) intimating that she experienced a confusing myriad of emotions. Susie powerfully described how she experienced the intensity of emotions physically.

I just felt as though someone had just caught hold of my stomach and was twisting it. And I just felt the whole time that this fear was growing in me and I just felt like um ... I was losing her but nobody seemed to be doing anything about it (p4: 47-50).

Susie seemed to be referring to the physical effects of anxiety when she describes her "stomach twisting". Helena appeared to suggest that as the illness progressed she had to disconnect and supress her emotions in order to cope.

I suppose I closed down in a funny sort of way. I shut down. That was the only way. I shut things off because that ... I trained myself through all those months of being ill at that time, you sort of shut your emotions off a bit (p8-9: 264-267).

George spoke of "not really thinking straight" (p5: 146) whilst Carla talked about "not firing on all cylinders" (p14: 435). Both phrases seemed to suggest a sense of preoccupation or disorientation which prevented them from having clarity of thought. This seemed to be an experience reflected in many of the parents' accounts.

Susie spoke of how her daughter sought physical and emotional proximity to her in the early stages of the illness. When asked what this was like for her Susie said:

Ahh [sighs heavily] ... Suffocating. Absolutely suffocating [sighs]. Because ... you know ... it's a really strange feeling because you ... love that child ... you have that unconditional love for that child, but also felt completely suffocated by her. You know the fact that she just wanted me and wouldn't let anybody else in. And it was almost like we had become one, you know? We should be two independent people and yet we were just like one being, it was really strange (p5:156-162).

It appeared that Susie was describing a loss of self and perhaps agency through the process of "becoming one". It appeared that this was an unpleasant experience for Susie which perhaps created negative feelings and thoughts towards her daughter. Reconciling these feelings with the "unconditional love" she had for her daughter seemed difficult. This experience was also shared by Laura.

George described the routine he and his wife maintained to balance work commitments with visiting their daughter.

Physically it was very wearing. You know going up to the hospital to see Sammy and then going to work, coming back. Remember that this went on, for a year this went on, we were going to work, leaving work, you know going to the hospital ... um um leaving about 8 o'clock, 7 o'clock, by the time you get back from there you're shattered! Doing this day in day out, 24 hours a day, 7 days a week. We took it in shifts sometimes to go down there but we were exhausted (p12-13: 395-400).

George seemed to intimate that maintaining this routine took great physical exertion. He appeared to imply that there was no reprieve and the routine was all consuming: an experience described by all of the parents.

Whilst reflecting on our conversations during the debrief Tim seemed to intimate that he had experienced low mood as a result of his experiences.

I think it did affect us especially me ... erm ... I don't know if I'd say I got depressed but [exhales] ... (p21: 669-670).

Bridget spoke of how she experienced emotional difficulties after her daughter had recovered.

I had a bout of difficulty in XXXX and I was sort of diagnosed with a sort of post traumaticy stress type thing (*sic*). And because I've had to keep strong for so long I think personally I never really particularly recovered from that (p36: 1176-1179).

Bridget implied that she had a significant emotional response to her experiences after her daughter had recovered. Perhaps the sustained emotional and psychological distress she experienced over the course of her daughter's illness had been a form of "trauma". Although this response was not replicated in other parents' accounts it seemed that all parents felt as though they had been through a traumatic experience.

## 3.3.2 Strengths and vulnerabilities in the "survival bubble"

Everybody is not the same. Not every parent deals with it in the same way. Illness is a very private thing and people do handle it in different ways (Susie, p20: 655-657).

Susie thoughtfully made reference to the individuality of coping styles. Indeed all parents spoke about coping yet there was variation amongst the ways in which they coped and what support they found helpful. However a notion of "surviving" was referred to by all of the parents.

Tim spoke of having to "switch into a different mode" (p10: 327) where "you just do what needs to be done" (p22: 716). In his account he comes to understand this as a "sort of survival thing you know with what I could cope with" (p21: 676-677) and referred to it as a "survival mode" (p21: 681). Tim appeared to be suggesting that it was difficult to cope with anything other than the basic things that needed to be done. Through his reference to "survival" he seemed to intimate that this "mode" was imperative for him to stay alive, perhaps psychologically and physically. Helena spoke of how she saw herself "surviving".

You were in a bubble. I think through the whole thing you became more and more isolated and you were in a survival bubble. (p5: 156-159).

Helena's description conjured an image of a bubble which provided her with complete protection. She seemed to intimate that the more isolated she became from others the greater protection she felt from the bubble. It is possible that the membrane of the bubble represented a boundary which performed the function of protection but perhaps also served to keep others at a distance. Given the composition of a bubble there is an inherent fragility as it can be easily burst. Indeed later in her account Helena seemed to describe how she received a puncture to her bubble through a comment made by a friend.

She said "She's so ill". I just thought 'Oh God!' It's like someone had just syringed the energy out of me and I had to go out of the room. I almost collapsed on the stairs but I got down and then I just cried [becomes tearful]. Um ... you just hold it together ... like you do [laughs]. You just keep going (p6: 188-192).

Helena's vivid description intimates that the prick of the syringe (her friend's comment) deflated her bubble and resulted in an overwhelming sense of emotion. She seemed to suggest that despite this she was able to recover and "keep going". Similarly Laura spoke of the way in which her "survival" was threatened by a comment made by a friend.

You just sort of get on with it and its only when you see it through others people's eyes that you [begins to cry] see how [voice breaks] how bad it was ... Erm and I remember the, we have a friend who's a GP and he came in and was [voice breaks whilst crying] ... he was so shocked. And I, and I, you just get used to it, you just get used to it. Used to the way he [her son] is, especially when you're living with it all the time.

And seeing his face really brought home just how bad it was (p3-4: 98-104).

From parents' accounts it seemed that their ability to "survive" was mediated by personal resources and external sources of support. Throughout her account Fahra described herself as a "positive" and "patient" mum and referred to the "strong feeling" she had that her son would return to his life, despite professionals' doubts. When asked how she managed these conflicting views, Fahra seemed to intimate that this "strong feeling" was strengthened by her faith:

I'm a religious person and I believe in God as well. Then I always know that everything, one day everything will be okay (p12: 380-382).

Bridget also spoke of the strength she gained from her faith and from the support of the church community. Although spoke of how her faith was being tested since her daughter's recent relapse.

Susie spoke of how her friends and family gave her opportunities to talk to her "heart's content" (p20: 649) and said it felt as though she was "unburdening" (p21: 662) herself. Bridget echoed this need to talk it through with others and said she "would talk to anybody that would listen" (p27: 884). However unlike Susie she found that friends were not always receptive.

One friend criticised me and said "You realise you are boring people by talking so much about Lucy?" I was mortified.

Because it was what I needed to cope, was talking (p27: 880-882).

George talked about the "pointlessness" of talking to anyone outside of the "inner circle" because they didn't understand (p9: 276). He spoke of forming friendships with other parents whose children were being looked after on the inpatient ward and suggested that these relationships were more supportive than his existing friendships because they could relate to his experiences.

When you talk to someone who does understand, who does empathise it's sort of a huge release you know. Not only mentally but physically but you just feel a sort of [clears throat]. Sometimes you'd be talking to somebody and you'd come away and think 'Oh for God's sake what's the point!' And when you feel mentally tired and you're physically tired then you think 'Ah! Why do I even bother?' But then when you talked to Lizzy's parents we'd often laugh about it ... ... black humour I suppose (p14: 477-484).

The "release" George spoke of seemed to intimate letting go of physical tension as he could effortlessly share his experiences without becoming physically exhausted from the frustration of trying to be understood. It seemed that their shared understanding allowed them to relax and comfortably use black humour with each other, which perhaps provided another outlet to relieve the emotional tension.

Six parents spoke of the formal therapeutic support they received. Susie and Bridget both accessed individual therapy from a Clinical Psychologist in the teams treating their children. For Susie, ongoing therapy created an opportunity to talk openly and safely about her concerns and feelings without feeling constrained.

It was such a safe place because you could say anything. I mean obviously with Paul [her husband] and Amy [her youngest daughter] and even with family and friends, there's certain things that maybe you can't say because you don't want to hurt them, or complicate the situation or that you don't want them to worry about you too much, whereas with the therapist I could just say anything and knew that was a safe place (p22: 678-683).

There seemed to be a range of experiences and views on the nature and utility of family therapy. Four of the six parents said that they had not found it helpful as they had felt judged and blamed. Bridget felt that she was "quietened down" (p22: 720) in family therapy. When asked what that experience was like, she said:

Very very demoralising, um very patronising in front of my children. I was sitting there asking for help and I was being shot down (p22: 722-724).

In contrast Susie spoke of how significant family therapy sessions were for her martial relationship and her family's functioning.

I found out things about Paul [her husband] that I perhaps didn't know or wasn't fully aware of and I think he found out things about me. And you know ... what was working for him, how he was getting through it and things like that. How I was getting through it. So it helped us when we were away from the unit to actually function as a family (p22: 703-708).

Susie seemed to be suggesting that family therapy helped her and her husband gain a greater knowledge and understanding of each other. She implied that this ongoing process allowed them to support each other successfully which in turn enabled them to continue functioning as a family unit.

## 3.3.3 Personal and relational growth

All of the parents, with the exception of Tim, spoke of the ways in which their experiences had resulted in personal and relational growth. Susie seemed to note the unexpectedness of these gains.

I wouldn't wish it on my worst enemy believe me, but so many positive things came out of it. It's really strange isn't it? (p43: 1389-1390)

Throughout her account Laura referred to her experience as a "journey" and spoke of how it altered her "whole perspective on life and what was important" (p4: 106). She powerfully described how contemplating her son's mortality made her question her values and the purpose of life.

Well anyway with a week of pushing him in the wheelchair with his head under the blanket and I pushed him past the morgue thinking 'Is he going to end up in there?' So it was such an intense time. And I remember the first time we came out and left the hospital and saw the daffodils [begins to cry] and seeing that actually there was normal life [voice breaks] ... out there. And it just made you think that all these trivial things that people are talking about. I mean our peers at the time were talking about getting their children into schools and house prices and all this. And you just think 'For God's sake! That's so unimportant.' It was just sort of ... so that was the real sort of enlightening that you know life is just about health really. And mental health (p6: 170-179).

Conveying the juxtaposition of the morgue and the daffodils seemed to represent the way in which life went on for others in the outside world, yet her world had stopped as she engaged in the daily struggle of trying to keep her son alive.

Laura appeared to intimate that through this struggle she came to understand that good health was of the upmost importance in life.

Re-evaluating what was important in life was a sentiment echoed by Susie. She talked about learning from her experiences and spoke of how she had been left feeling "almost invincible" (p36: 1184) once her daughter had recovered. She seemed to acknowledge that she was not infallible, but had become equipped with knowledge and skills that would help her "tackle" (p36: 1185) future challenges. Fahra reflected this sense of personal growth and spoke of becoming "stronger".

I been like more stronger (*sic*). Because if I'm face that three year difficult situation and I am going to surviving (*sic*). Thank God I'm still healthy, I'm not depressed myself. I'm not being stressed myself and I've survived that situation. And I think yeah it was a very difficult experience and then I will be more experienced (p16: 510-514).

Fahra seemed to be implying that perhaps it was not certain that she would emerge physically and emotionally intact from her experiences and intimated that God had given her strength to survive.

Susie extended this notion of growth to the relationships within her family and said "we learned so much about each other through it" (p40: 1394). She spoke of how she believed this had impacted on their family unit.

I just feel like we [she and her family] have learnt so much through this illness and we got through the PRS that whatever happens to us now we'll manage it, whatever that may be. So it just sort of leaves you with that feeling that whatever happens we could cope. We will all pull together and we will cope you know? Which is a good place to be (p40: 1306-1310).

Susie seemed to suggest a newfound sense of cohesion within her family that had been fostered through their new knowledge of each other. This cohesion seemed to be important for Susie and perhaps indicates that she felt this was pivotal to them surviving any difficulties in the future.

It seemed that learning about each other was made possible by communication. Indeed all parents made reference to the importance of communicating throughout their accounts. George reflected on the value of this for him.

I suppose in one way it's shown me how important it is to ... communicate. How much I relied on Annie [his wife] as well to

help get me through it. Um and ... very important that we kept together as a family (p17: 531-534).

George seemed to be conveying that he had learnt that communicating within his relationship had allowed it to be a great source of support. Perhaps maintaining communication had enabled his wife to become attune to his needs and therefore better placed to provide support that he would find helpful: a process that Susie had made reference to in the previous section.

Helena spoke of how her marital relationship had become stronger as a result of going through the experience together. She said they were "pleased that something good had come out of it" (p21: 669). Helena shared how this strength was recognised and named by outreach aftercare professionals who came to visit them at their home before their daughter was discharged.

What came across quite strongly was the amount of parents that actually split up. They said that we've actually done the opposite. And they said that they were so proud of us because it had made us so much stronger (p21: 668-674).

Helena seemed to be surprised by the number of relationship breakdowns. It seemed she had not considered that her own relationship may have ended. When asked how it felt to hear the professionals say they were proud, Helena said:

Oh it was amazing! It was amazing. It was lovely. They were so positive. We had been surrounded for so long, for three years, with negativity it was so nice to get something positive (p21: 684-686).

Whilst recalling this moment Helena became animated in her speech and facial expressions. It seemed that perhaps this was the first positive comment Helena and her husband had received from professionals since their daughter had become unwell. It appeared that Helena perceived this as praise for doing

something well which perhaps was something she had longed for earlier in the process.

In her account Bridget referred to her and her husband as a "good team" and said that their relationship had become stronger whilst their daughter was unwell. However she spoke of how their relationship hit "rock bottom" (p14: 433) after her daughter recovered and wider support stopped (from professionals and the church).

It was like [gasps] "Shit! What did we just go through? Oh my goodness!" And that was hard. And probably we came quite close to splitting up at that point. Um but I went and got some counselling and it made me sort of take a step back. And we went for a really lovely weekend away and had a good chat and you know had a really good rekindling time away. Erm we talked a lot and we were very aware that we were talking an awful lot (p14: 437-442).

Bridget appeared to imply that the impact of trying to process their experiences contributed to the relationship breakdown. Being apart from their family to reconnect as a martial couple seemed to enable Bridget and her husband to nurture their relationship and rebuild that aspect of their lives. Bridget's emphasis on how much they talked during this time seemed to highlight the importance of communication in this "rekindling" process.

It seemed important to acknowledge this experience as Bridget helpfully shared that personal and relational growth does not come without challenges. She also reflected an experience that resonated for all of the parents: psychological processing was not concurrent to their experiences. Perhaps this can be attributed to the "survival mode" of coping which entailed being present in the 'here and now' to get through each day and subsumed any form of reflection.

#### **CHAPTER 4: DISCUSSION**

#### 4. Overview

This chapter provides a discussion of the findings and attends to issues regarding their validity and utility. A summary of the findings are provided and discussed within the context of the research questions. In light of these discussions, the implications and recommendations for clinical practice and future research are outlined. A critical review of the research is undertaken and considers: quality and validity; methodological limitations; and reflexivity. The chapter concludes with an overview of the research.

# 4.1 Summary of Findings

The findings suggested that parents' experiences and meaning making processes were delineated by stages, which reflected the trajectory of their child's difficulties. It seemed each stage brought new experiences, understandings and challenges.

The theme 'Vitality of PRS and the Power of its Departure' represented: how parents experienced and came to understand their child's difficulties; the ways in which they contemplated if and what function PRS served for their child; and how this informed their understanding of the diagnosis, approach to treatment and their child's recovery. The findings suggest that this was a dynamic and recursive process as they responded to the different aspects of difficulty their child presented with over time.

The findings suggested that these processes took place within the context of parents striving to negotiate the system to get their child the care they needed, whilst trying to develop relationships with professionals. The theme 'Them and Us: Fostering Trust and Building Bridges" represented the relationship development between parents and professionals as their children moved through the care pathway. The findings suggested that parents felt dismissed by

professionals and in response resourcefully found ways to be heard within the system. Parents' spoke of feeling judged and blamed for their child's difficulties, which they believed was underpinned by professionals' assumptions that they had harmed their child in some way. The findings suggested that collaborative relationships were able to develop but these were characterised by rupture and repair as challenges arose over the longitudinal course of treatment.

Parents referred to the "personal journey" they took alongside their child. These journeys were encapsulated within the theme 'A Book in the Library of Life'. The findings suggested that parents' experiences had a significant negative impact on them emotionally, psychologically and physically. Parents spoke of coping by engaging in a "survival mode" which enabled them to sustain the strength required to support their children and family. However, the findings suggested that parents could still feel vulnerable in this mode and drew on forms of support to bolster their survival. Personal and relational growth was found to have taken place as a result of parents' experiences. Parents reported re-evaluating their values and what was important in life, which led to a change in perspective. Parents also spoke of how their experiences had led them to have a deeper understanding of their partner and their functioning as a family, resulting in enhanced relationships.

## 4.2 Addressing the Research Questions

# 4.2.1 What is it like to be a parent of a child who has been given a diagnosis of PRS?

The findings highlighted that there were two prominent aspects of parents' experiences that ran concurrently: the personal impact and their role as a parent within the therapeutic relationship with professionals. Once their child had recovered, parents reported personal and relational growth. It seemed this growth reflected an ongoing process whereby their experience of being a parent of a child diagnosed with PRS continued to impact on their lives.

# A Book in the Library of Life

Parents described the negative impact their experiences had on them personally. The length of time between their children becoming unwell and their discharge from hospital was approximately 2 to 3 years. The impact of parents' experiences were protracted as each stage of their child's difficulties brought new challenges and concerns. These experiences replicate those discussed by parents in the literature (Anon, 2001; Lee et al., 2013). The findings intimated that parents felt as though they were in a perpetual state of distress. Parents responded to this in different ways: some spoke of becoming "numb" by "shutting off" emotions to cope, whilst for others this was expressed outwardly through anger or seeking support from many sources to alleviate the distress. The findings suggested that this reflected the individuality of parents and the nature of external resources available to them.

Parents spoke of how their lives became orientated to helping their child survive the day. They reported that this required them to assume a "survival mode" of existence. The findings suggest that although this was an adaptive coping strategy, it subsumed any time for reflection or psychological processing as its focus was on the here and now. Two parents suggested that this had contributed to the development of their own mental health issues after their children had recovered. One parent intimated that he felt low in mood and lacked interest and pleasure in the pursuits he had once enjoyed. This experience replicated the account given by one father in the literature who reported he had received ongoing support from a psychologist for low mood once his daughter returned home (Lee et al., 2013). Indeed, one parent reported that she received a diagnosis of PTSD approximately two years after her daughter had recovered. Many of the parents intimated that their experiences were traumatic. It may be helpful to consider parents' experiences within the context of a trauma framework, e.g. Ehlers and Clark's (2000) model. This is further supported by the findings that parents' experiences resulted in personal and relational growth. This seemed to reflect the notion of posttraumatic growth, where positive change occurs after adverse life experiences (Tedeschi & Calhoun, 1995) as there is an

intrinsic need to engage in emotional processing and assimilate experiences (Joseph & Linley, 2005).

# "Them and Us": Fostering Trust and Building Bridges

Parents placed prominence on relational issues with professionals. Rupture and repair was found to be a notable feature of their relationships. Parents reported that they often felt not listened to and dismissed. The findings highlighted the tenacity with which parents strived to be heard and drew upon personal and external resources to achieve this. Parents were found to resourcefully seek and utilise allies within the system in order to bring about action and have their voice heard. The findings suggest that parents felt validated by professionals advocating for them and indicate that this facilitated the building of mutual trust. Parents reported that a significant cause of relationship breakdown was the query of abuse from professionals, expressed either explicitly or implicitly. The findings suggest that parents felt scrutinised, judged and blamed for their child's distress. The findings also highlighted that parents could understand why this was necessary retrospectively, however at the time it was felt to be accusatory. The findings suggest that working through this rupture was the most difficult for parents, perhaps as it felt like a "personal attack". The findings highlighted that a collaborative, trusting relationship could be achieved through devolving power to each other. For some parents this involved a process of adjustment to and acceptance of the impact of the child's difficulties and that they were not able to help them alone. The findings suggested that parents were not always aware of the rationale behind the treatment approach which led to disagreements and mistrust in professionals as parents were unsure of the purpose. The findings intimated that parents had to seek such clarification whereas it would have been helpful for it to be shared from the outset.

# 4.2.2 How do parents make sense of the diagnosis and their child's experiences?

Parents were found to 'externalise' (White & Epston, 1990) their child's difficulties and named them PRS. Externalising PRS was found to influence the way in

which parents approached their child's difficulties and experiences and came to understand the diagnosis of PRS and its treatment.

# The Vitality of PRS and the Power of its Departure

PRS was narrated as an active illness that subsumed the child, who was rendered passive by its power. Parents spoke of the loss they experienced as PRS took hold and their child became unrecognisable to them. The findings suggested that externalising PRS helped parents to feel connected to their child and maintain 'continuing bonds' (Klass, Silverman & Nickman, 1996) during the period of perceived loss. It also enabled some parents to tolerate their child's rejection and anger towards them as this could be attributed to the volition of PRS, not their child. The findings suggested that children came to hold dual identities for their parents: the "real" and "not real" child. This seemed to reflect a form of splitting (Klein, 1952), i.e. all the perceived 'bad' aspects of the child's behaviour was attributed to PRS and the all the 'good' attributed to the child. It seemed to enable parents to take action against the problem as it was attributed to the "not real child" and thus did not represent them taking action against their "real child". This seemed particularly pertinent with regards to issues of consent in treatment. For example, many parents spoke of giving consent for their child to be fed through a naso-gastric tube, however this was met with angry resistance and distress by the child, which gave rise to feelings of guilt in the parents.

Relating to and interacting with the dual identities was reported to be central to maintaining relationships and enabling the child to feel heard and safe. However, the findings suggested that attending to these identities was difficult and posed a double bind for parents: whether to collude with the "not real" child and give PRS control and power, or act "normally" with the "real child" but risk this being interpreted as a dismissal of their difficulties, which would result in "regression". This seemed to replicate the experiences of professionals and parents (Anon, 2001; Jans et al., 2011; Lee et al., 2013; Nunn et al., 1998). The findings suggested that achieving this balance involved an ongoing process of negotiation, which had to be approached with sensitivity and tentativeness. It was found that through their engagement in this process, parents began to

contemplate the functionality of PRS for their child and considered ways in which they could help them live without it. The findings demonstrated the importance of creating opportunities for "preferred stories" (White & Epston, 1990) to develop, as these enabled children to live out new possibilities for the future and move forward in their recovery. This is consistent with the notion of enabling children to have an "out" and maintain self-esteem (Nourse, Ryan & McMenamin, 1999, p. 14).

PRS was understood as a psychological retreat in response to a perceived threat or danger for all of the parents. The perspectives on what constituted that threat or danger differed amongst parents, however there were common themes with regards to loss and change (e.g. friendship difficulties, illness, bereavement, transitions). These themes were identified within Nunn and Thompson's (1996) proposed formulation of learned helplessness as potential significant events that could result in the child and parent feeling helpless and hopeless about the future. However, parents were found to attribute the cause to a myriad of factors: internal and external. The belief that PRS is a "teenage disease" and that those vulnerable to developing it are children of a "particular mould" and "personality traits" was held by the majority of parents. They seemed to imply that their children were predisposed to developing PRS based on their personal attributes and that external events served as a trigger. Their perspectives also suggested that their child's difficulties coincided with a significant time in development, adolescence. The findings suggested that parents queried whether PRS had developed in response to their child struggling with identity formation and achieving developmental tasks.

The findings suggested that parents were ambivalent towards the utility of PRS as a diagnostic label. The diagnosis was believed to be helpful by parents, as it signified professionals understood what was happening for their child and that they could be treated. However, it also brought to the fore the notion that their child's experiences originated from emotional distress opposed to an organic cause. It was found that parents thought giving a name to their child's experiences was 'irrelevant' as what seemed more relevant was the cause, something the label of PRS could not offer. However, one parent did speak of the

stigmatisation that a label can evoke and believed that the PAWS label would be stigmatising due to the negative connotations associated with the word 'arousal'.

# 4.2.3 <u>How did parents experience the treatment their child received and what are</u> their perspectives on the treatment?

# Nurturing and Assimilating the Child

The findings highlighted that parents believed that it was their child's decision to recover. Time, patience, routine and structure were found to be the fundamental components parents believed helped their children to make the choice to move on from their difficulties. The findings suggested that the focus of the treatment and approach to care involved nurturing and assimilating the child in order to facilitate the strengthening of their psychological and emotional resilience. Parents spoke of how of the robustness of this was tested post discharge (e.g. transitioning home, returning to school, negotiating friendships and romantic relationships). Some young people were reported to struggle whilst others experienced no difficulties. Parents whose children had difficulties, reported a lack of ongoing support in the community post discharge. However, those young people who had no difficulties did not all access support that was offered. Perhaps young people who were offered support, regardless of whether they took this offer up, felt 'contained' (Casement, 1985) by services which provided them with a greater sense of support. Interestingly, parents did not speak at length about the treatment process itself, perhaps as they were not viewing it through a clinical lens. Instead, it seemed that the therapeutic relationship with professionals held more importance in their accounts.

# 4.3 Implications for Clinical Practice

The findings have provided a novel insight into how parents came to understand and conceptualise PRS. A notable feature of which was the myriad of factors that they believed contributed to the development of PRS. Perhaps using Carter and McGoldrick's (1990) model of the family life cycle to formulate the potential

stressors and events could help normalise families' experiences and understand the intersectionality of these factors.

Parents spoke of the inaccessibility of family therapy due to feeling blamed and judged. However, the ways in which parents spoke of PRS lends itself to narrative therapeutic interventions. Perhaps adopting a narrative model could build on the already naturally occurring externalising conversations and help the child and family to develop and strengthen preferred stories.

The findings highlighted that the "PRS journey" has a significant personal impact on parents. It may be useful to routinely offer individual psychological support as part of the treatment plan or provide opportunities to receive peer support through parent networks.

The findings indicate that the therapeutic relationship between parents and professionals is central to parents' experiences. Parents spoke of needing to feel heard, be informed of the treatment rationale and be included in decisions about the approach taken. This enabled parents to trust professionals and support the treatment. It may be useful to invite and include parents in MDT meetings as this could provide transparency with regards to the treatment approach and would provide a context within which queries could be raised and issues discussed. Indeed, this was a stance adopted by the treatment team described by Lee et al. (2013).

Providing support from a CAMHS community team post discharge was believed to be imperative for parents. Those young people who had not been offered this were reported to struggle. Ongoing support for parents and children in the community is recommended.

#### 4.4 Recommendations for Future Research

Employing IPA as a methodology enabled novel insights to be gleaned with regards to what it is like to be a parent of a child diagnosed with PRS. However, it is important to note that parents provided a retrospective account of their

experiences and it is likely that this impacted on the findings. It is possible that the findings related to personal and relational growth may not have been spoken of if parents had been interviewed at the time their child was unwell. Similarly, it is possible that parents may have spoken differently about how they understood and experienced their child's distress. One could hypothesise that due to the passage of time, the perspectives and experiences reported in this study may reflect accounts that have received a greater degree of psychological processing and reflection. A less processed account may reveal more about what it is like for parents at the time their child is receiving treatment for PRS. This would have greater applicability for clinical practice in the treatment setting and might also provide unexpected insights. It is possible that an ethnographic research method would be more appropriate in gathering this type of data, as the researcher could engage in the everyday experiences of a parent over the period their child was in hospital and in this respect could join with the parent to gain an "insider perspective" (Griffen & Bengry-Howell, 2008, p. 17).

Similarly, this research reflects a snapshot of parents' experiences and perspectives at the time their child was diagnosed and treated. Perhaps more insight could be gained into the diagnostic process if parents were interviewed about their experiences prior to their child receiving the diagnosis. This may be particularly pertinent given the potential differential diagnoses that are often considered.

# 4.5 Critical Review

Elliot, Fischer and Rennie (1999) state that the value of any scientific research method must be evaluated "in light of its ability to provide meaningful and useful answers to the questions that motivated the research" (p. 216). Based on this assertion an evaluation of the research will be completed and the following aspects will be considered: quality and validity; methodological limitations; and reflexivity.

# 4.5.1 Quality and Validity

Elliot et al.'s (1999) guidelines for assessing quality and validity in qualitative research were employed for the purpose of evaluating this study. They were selected on the rationale that the broad criterion are intended to be used flexibly and as such, can be applied to all qualitative research irrespective of its theoretical orientation (Smith et al., 2009). Each of the seven criteria outlined within the guidelines will be discussed and addressed in turn.

## Owning one's Perspective

Reflexivity has been demonstrated and documented throughout this study. The methodology chapter outlined the study's ontological and epistemological position. In addition, it acknowledged my personal and professional perspectives and considered how these may have influenced the research, my understanding of the phenomenon under investigation and my analytic interpretations. In an attempt to address these issues I endeavoured to make visible my values and assumptions by recording thoughts and reflections in a reflexive journal throughout the research process (Appendix B). Furthermore, consideration was given as to how these could be 'bracketed' to ensure that parents' accounts were not obscured and I was attuned to the parents' stories. Reflexivity will be discussed in more detail shortly.

#### Situating the Sample

I have contextualised the data within the methodology chapter by providing basic demographic details and background information on participants. Ethnicity was not reported as this would have compromised anonymity given the small purposive sample from GOSH. However, it is acknowledged that this omission may have occluded novel insights and understandings of how PRS may be understood and experienced through a cultural lens.

# Grounding in Examples

The analysis chapter provides direct quotes and extracts, which are accompanied by synthesised descriptions of participants' accounts and tentative interpretations. It is hoped that by presenting the data in this way readers are brought as close as possible to the experiences described by the participants (Popay, Rogers & Williams, 1998) and can clearly identify interpretations.

## Credibility Checks

This refers to the way in which the themes from the data have been checked for credibility. Each of the superordinate and subordinate themes were reviewed by my academic supervisor and two peers from an IPA group. Revisions were made based on these discussions, which were reviewed again before themes were finalised. Credibility checks were not completed to achieve a definitive account, but were employed to consider whether my interpretation was credible in light of the data set.

#### Coherence

This refers to the extent to which the interpretation of the data is coherent and integrated, whilst retaining the nuance and complexity of the data. It requires the understandings to fit together to form a "data based narrative" (Elliot et al., 1999, p. 223). Indeed, Yardley (2000) states that the quality of the narrative is integral to the value of the research. The analysis chapter is presented in a format which intends to allow the reader to parse the narrative in two ways: individual and group. I have attended to convergence and divergence within and across participants' accounts and have illustrated these within each theme.

# Accomplishing General vs Specific Research Tasks

This was an exploratory study which aimed to gain a specific understanding of what it was like to be a parent of a child diagnosed with PRS. Indeed, this study generated rich and novel insights into the specific parents that participated. It is

possible that these experiences are not only representative of this sample. It is likely that these findings have relevance for other parents whose children have received a diagnosis of PRS and perhaps parents whose children have received a rare diagnosis.

#### Resonating with the Reader

Elliot et al. (1999) suggest that the analysis should capture the importance and meaning of the phenomenon in such a way that it engenders interest in the reader and enables them to have a greater understanding of the area being studied. I attempted to bring the participants' experiences to life by attending to the language and metaphor they used in their accounts and hoped that in doing so it would provide an engaging, stimulating and informative read.

## 4.5.2 Methodological Limitations

# 4.5.2.1 Sample and Recruitment

A purposive homogenous sample was recruited. All of the participants were parents of a child that had been given a diagnosis of PRS. The sample recruited from GOSH was restricted to those children that had received the diagnosis between the years 2003 to 2013. Coincidentally, the child of the parent who was recruited informally was also diagnosed within this time period. Despite achieving homogeneity in this sense, there was variation as to the year each child was diagnosed. It is likely that this may have had an impact on the findings.

Firstly, professionals' understandings and conceptualisations of PRS changed and developed over this time as more cases were reported in the literature. It is possible that this could have had a significant impact on how PRS was thought about and talked about with parents. Furthermore, it may have impacted on clinical practice and professionals attitudes towards children and their families. In this respect parents accounts may also reflect something of the theoretical understandings and clinical practice of the time. Moreover, the financial and political climate changed within this time period, which had a significant impact on

health and social care services. It is possible that the obstructiveness and lack of concern parents experienced may have reflected a wider context of constraints on services and pressures on healthcare professionals. These issues seem particularly pertinent given that our understanding of PRS remains limited, the concept is not reified and the provision of care within health services continues to be reviewed.

All of the parents, with the exception of one, reported that their child had recovered from PRS and had not experienced any further mental health difficulties. Many of the parents spoke of PRS as if it were a closed book that had been shelved. This perspective may only be representative of parents whose children made a full recovery and continue to do well. Indeed, one parent reported that her daughter had recovered from PRS but some years later has begun to experience difficulties with eating. Interestingly, she viewed the book of PRS as being shelved but perhaps for many young people and their families there are further chapters to be written. Studying the perspectives and experiences of those parents whose children continue to experience difficulties may help broaden our knowledge on the challenges that children and their families encounter and may provide insight into what aspects of clinical practice could be improved.

Although not reported in this study for confidentiality purposes, participants' ages, ethnicity and socio-economic backgrounds differed. These are factors which will have impacted on their experiences and informed their perspectives. It would be useful to explore the intersectionality of these and their impact on parents' understandings and experiences.

Seven of the eight participants were recruited from GOSH. This enhanced homogeneity as the sample was largely comprised of parents whose children had received treatment at GOSH. However, this is likely to have had implications for the findings. GOSH is known as a centre of national and global excellence by professionals and the public and is regarded to offer the best treatment. This was a view reflected by parents in this study. They spoke of how they felt able to trust and devolve power to the professionals as they were reassured by their

knowledge and experience. It is difficult to ascertain whether this would be an experience shared by parents whose children were treated by local services. However, it is noteworthy that the parent whose child did not receive treatment at GOSH made reference to this issue during the post interview de-brief. She was curious about the treatment at GOSH and wondered whether her daughter would be experiencing ongoing difficulties with eating had she been treated at GOSH. Although this does not prevent the findings from being helpful, exploring the experiences and perspectives of parents whose children were treated in other settings may be of interest and could offer an alternative perspective and new understandings.

#### 4.5.2.2 Interviews

I conducted all of the interviews with the exception of one. As previously discussed, this parent was interviewed by my clinical supervisor because they felt uncomfortable being interviewed by someone outside of the clinical care team. This request was given careful consideration given that it had the potential to jeopardise the integrity of the data. The request was agreed on the rationale outlined in chapter 2 and on the basis that measures could be taken to ensure replicability in the interview and authenticity in the transcript. However, this inevitably had an implication for the findings.

As previously outlined, the knowledge produced in interviews is co-constructed between the researcher and participant (Larkin et al., 2006). Rapley (2001) argues that interviews are inherently social interactions and as such, the data gathered is dependent on the specific interactional context which is produced in and through the talk of both the researcher and participant. Although each of my interviews with participants was unique, the language I used and the interviewing style I adopted were authentic to me. It could be argued that introducing another interviewer could have significantly impacted on what was spoken of and what was not, as my supervisor's use of language and style is different to mine. In addition, her position within the clinical care team may have also contributed to what the participant felt able to discuss. Indeed, this parent was the only person who did not make reference to the "lurking thing". This may be because this

wasn't central to their experience, however it is important to consider that perhaps it is absent from their account because the context of the interview constrained some avenues of conversation.

# 4.5.3 Reflexivity

Throughout the research I have attempted to engage with the "reflexive dance" by oscillating between bracketing my pre-understandings and referring back to them as a source of potential insight (Finlay, 2008, p. 1). Keeping a reflexive journal throughout the research process helped me to: record decisions I made; follow the development of my observations, feelings and thoughts during the process; and illuminate how these impacted on my reading and analytic interpretations of the data.

I am curious to how my pre-understandings and preconceptions may have influenced the findings. The issues encapsulated within the "the lurking thing" were aspects I had expected. As these conversations occurred in interviews I was mindful of how I attended to these. However, during analysis it seemed that this was a pertinent aspect to parents' stories. I was struck by the findings related to personal and relational growth as I had not expected to find this. On reflection this was perhaps based on the assumption that parents' experiences would have resulted in the opposite effect. Indeed, perhaps this was an area which I could have pursued more as it may have gleaned more information about the sense making process and meanings parents attributed to their experiences.

#### 4.6 Conclusions

This exploratory study aimed to explore: how parents made sense of their child being given a diagnosis of PRS; what it was like to experience their child being unwell; and how parents experienced and negotiated the treatment process.

Semi-structured interviews were conducted with eight participants. The data was analysed using Interpretative Phenomenological Analysis. Three superordinate

themes were identified and represented: parents' perspectives and experiences of PRS and its treatment; parents' experiences of and relationships with professionals; and the personal "journey" that parents experienced. The findings suggested that parents' experiences and meaning making processes were delineated by stages, which reflected the trajectory of their child's difficulties. It seemed each stage brought new experiences, understandings and challenges. This study has offered new insights into the diagnosis from the perspective of a parent and provides a powerful account of their emotional journey. All of the parents chose to share their story to inform practice and provide support to other parents.

That's one thing I wanted to create ... be passionate and bring hope for some parents. Because when you enter into the PRS journey there are some days where there isn't even a pin prick of light (Bridget, p40: 1295-1297).

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**APPENDIX A: Summary of Cases Reported in the Literature** 

			Study Group	dno.					Reported Aetiological Factors			
Reference	Country of Study	No. of Cases	Age/ years	Gender	Setring Setting	Previous Child Mental Health Issues	Previous Severe Physical Health Issues	Parental Mental Health Issues	Traumatic/Significant Events	Family Stress	School	Viral Infection Prior to Onset
Lask et al. (1991)	UK	4	9-14	Females	Psychiatric Inpatient Unit	2/4 cases	None reported	1/4 cases	Sexual and physical abuse was disclosed by one child and it was suspected in two other cases. Witness to violence – 2/4 cases	Not reported	Not reported	None reported
Jacobs et al. (1995)	UK	-	10	Female	Psychiatric Inpatient Unit	Not reported	Not reported	Not reported	Death of younger sibling	1/1 case	Not reported	Not reported
Graham & Foreman (1995)		_	8	Female	Psychiatric Inpatient Unit	None reported	Not reported	Not reported	Family relocation	1/1 case	None reported	1/1 case
Nunn & Thompson (1996)*	Australia	<del>-</del>	15	Female	Psychiatric Inpatient Unit	None reported	1/1 cases	None reported	Multiple family bereavements and illness	1/1 case	None reported	1/1 case
Thompson & Nunn (1997)	Australia	2	10-15	6 Females 1 Male	Psychiatric Inpatient Unit - 6/7cases Outpatient -1/7 cases	3/7 cases	3/7 cases	3/7 cases	Family relocation – 2/7 cases Sexual abuse – 1/7 cases Multiple family bereavements & severe illness – 3/7 cases Change in school – 1/7 cases	3/7 cases	1/7 cases	5/7 cases
McGowan & Green (1998)	NΩ	1	11	Female	Psychiatric Inpatient Unit	Not reported	Not reported	Not reported	Sexual abuse	1/1 case	Not reported	Not reported
Taylor et al (2000)	Australia	_	4	Male	General Paediatric Ward	None reported	None reported	1/1 case	None reported	1/1 case	Not applicable	1/1 case
Anonymous (2001)	MU	1	8	Male	Psychiatric Inpatient Ward		All of th	ie above are	All of the above are not reported – this is a paper from a parents' perspective	parents' pers	pective	
Lask (2004)	NK	1	14	Female	Psychiatric Inpatient Unit	None reported		None reported	Serious leg injury			Not reported
Magagna (2004)	UK	_	17	Female	Psychiatric Inpatient Unit	None reported	Not reported	1/1 case	Loss of family member Family relocation	1/1 case	Not reported	Not reported
Edwards & Done (2004)	UK	1	11	Female	Paediatric Ward	None reported	None reported	Not reported	Family relocation Changed school	None reported	1/1 case	None reported
Bodegard (2005)**	Sweden	റ	7-10	3 Female 2 Male	Psychiatric Inpatient Unit	3/5 cases	1/5 cases	5/5 cases	Multiple instances of trauma experienced by all: witnessed violence ∨ sexual abuse, experienced racial abuse, bereavement & multiple losses, relocating to Sweden for asylum.	5/5 cases	Not reported	None reported
Van der Walt & Baron (2006)	Australia	~	11	Female	Acute Paediatric Inpatient Ward	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported

			Study Group	roup					Reported Aetiological Factors			
Reference	Country of Study	No. of Cases	Age/ years	Gender	Service Setting	Previous Child Mental Health Issues	Previous Severe Physical Health Issues	Parental Mental Health Issues	Traumatic/Significant Events	Family Stress	School Stress	Viral Infection Prior to Onset
Jaspers et al (2009)	Netherlands	<b>—</b>	11	Female	Psychiatric Inpatient Unit	1/1 case	None reported	None reported	Difficult relationship with school teacher Changed school	None reported	1/1 cases	Suspected but not confirmed
Jans et al (2011)	Germany	3	14-16	2 Female 1 Male	Psychiatric Inpatient Unit	1	None reported	Not reported	Family relocations – 2	3/3 cases	1/3 cases	None reported
Wright & Beverley (2011)	NY N	_	14	Male	Cared for at home with MDT input	None reported	Not reported	Not reported	None reported	1/1 case	None reported	1/1 case
Guirguis et al (2011)	Ϋ́	4	12	3 Female 1 Male	Psychiatric Inpatient Unit	Not reported	Not reported	1/4 cases	Suspected sexual abuse – 1/4 cases Family history of psychiatric illness – 3/4 cases	Not reported	Not reported	Not reported
Findlay et al (2011)	Canada	<b>~</b>	10	Female	Not known	Not reported	1/1 case	Not reported	Prolonged hospitalisation in ITU severe medical illness	Not reported	Not reported	Not reported
McNicholas et al (2012)	Ireland	<del>-</del>	<del>-</del>	Female	Paediatric Ward	None reported	None reported	None reported	None reported	Not reported	Not reported	1/1 case
Lee et al (2013)	Y Y	<b>~</b>	8	Female	Paediatric Ward	None reported	None reported	None reported	Bereavement – loss of mother due to cancer	1/1 case	None reported	None reported
Forslund &Johansson (2013)	Sweden	2	7-17	3 Females 2 Males	Psychiatric Inpatient Ward	2/5 cases	Not reported	4/5 cases	All held asylum seeking status Witnessed sexual violence -3/5 cases Experienced physical abuse – 2/5 cases	Not reported	Not reported	Not reported
McNicholas & Nicholson (2014)	UK	15	10-15	11 Female 4 Male	Psychiatric Inpatient Unit	Not reported	5/15 cases	Not reported	Not reported	9/15 cases	9/15 cases	12/15 cases

\*Please note that the case described by Nunn and Thompson (1996) is also included within the 7 cases they present in Thompson and Nunn (1997)
\*\* Bodegard reported that these cases "resembled" PRS but believed their presentation reflected a "depressive devitalisation".

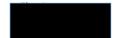
A hand written reflexive journal was kept throughout the research process. The following entry was made after my fifth interview, with Laura.

Incredibly emotional interview. The way in which Laura spoke and the language she used in her account was both moving and powerful. At points I felt quite tearful myself. There was an emotional intensity in the quality and nature of the interview that I had not experienced in previous interviews. I also noticed that I was struggling to have my own thoughts whilst she was giving her account. I was initially worried about this as I was mindful that I needed to hold the research questions in mind, however as the interview progressed I became more at ease with this and have since become curious about what it signifies or represents. Drawing from psychoanalytic concepts of transference and counter- transference, I wonder whether my experience perhaps maps on to a theme in Laura's account of feeling consumed by her son's ill health and the paralysis she felt in being able to help or understand. Conducting the interview at GOSH seemed to significantly shape the nature and content of the interview. So far Laura has been the only participant that has chosen to be interviewed at GOSH. When we exchanged emails she had mentioned that it would be the first time that she was returning to GOSH since her son's discharge some time ago. When I met her at reception she made a comment about the familiar smell of the hospital and recalled the 'rabbit warren' like layout of the corridors. Perhaps the interview in this context brought back memories that may not have been foregrounded for Laura if we had met at another location. Despite the length of time since her son's discharge it seemed Laura's experiences remained very much unresolved. Perhaps her choice to be interviewed at GOSH reflected this, i.e. it was an opportunity to process her experiences as she told her story. It has made me consider participants' motivation to take part. I have been struck by the comment that many parents have made, that our interview has been the first time that someone has asked them about their experiences opposed to the focus being on their child. It seems that perhaps in this sense the interview may have performed a similar function for Laura, although this was not explicitly mentioned. Continue to consider context and its potential role in shaping the interview prior to the next scheduled interview at GOSH.

### **APPENDIX C: Research Registration Letter**



Emma Smith



9 May 2014

Student Number: 1236172

Dear Emma,

### Registration as a Candidate for the University's Research Degree

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee, has registered you for the degree of Professional Doctorate.

Title of Professional Doctorate: Professional Doctorate in Clinical Psychology

**Director of Studies:** Claire Higgins

Supervisor/s: Jenny Jim and Neil Rees

**Registered Thesis Title:** Pervasive Refusal Syndrome (PRS): Exploring families' views on the label of PRS and their experiences

**Expected completion:** According to your actual date of registration, which is **1 October 2013**, the registration period is as follows:

Minimum 18 months maximum 48 months (4 years), according to a full time mode of study.

Your thesis is therefore due to be submitted between:

1 April 2015 - 1 October 2017

I wish you all the best with your intended research degree programme. Please contact me if you have any further queries regarding to this matter.

Yours sincerely,

Dr James J Walsh

James T Walsh

School Research Degrees Leader Direct line: 020 8223 4471 Email: j.j.walsh@uel.ac.uk

Cc: Claire Higgins, Jenny Jim, Neil Rees

### SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



## School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937 e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology







### APPENDIX E: Ethical Approval from GOSH





Joint Research and Development Office Division of Research and Innovation

Dr Jenny Nicholson Psychosocial Services Great Ormond Street Hospital

13<sup>th</sup> June 2014

Dear Jenny

Title: Pervasive Refusal Syndrome (PRS): Perspectives of Parents' and

Childrens' Views (About the Diagnosis and their Experiences)

R&D Ref: 14BS05

Funding: Clinical Own Account Decision: Scientific Approval

Further to your re-application, I am writing to inform you that the Clinical Research Adoptions Committee (CRAC) reviewed your application and has no objections to the conduct of this project at GOSH.

The CRAC Reviewer had the following comments on your proposal, which they felt may be of help to you in general and in particular when making the application to an Ethics Committee for its opinion:

- 1. It is important that the initial contact with the 14 families is made NOT by the student researcher but by the PI or 2nd applicant (i.e. GOSH staff). As these are ex-patients, being contacted by a trainee from UEL might cause distress about possible lack of confidentiality.
- 2. B6 not known if those recruited via the parent contact, especially the young people, are 'healthy' volunteers. Please clarify.
- 3. The info sheets could do with a little tidying up. I would avoid terms like 'my' research study and 'I am interested in'. Also as some of the patients will have been treated 10 years ago I would suggest your son/daughter rather than your child. In relation to mention of supervisor, I think it should say name of PI not just UEL supervisor. There are some discrepancies between info sheets and protocol, e.g. it might be important to make clear that the trainee who has done the pre-interview discussion might not be the person conducting the interview. Finally there might be financial costs for participants depending where/how they choose to be interviewed. Please review your information sheets again as some typos were found in the sheets as well.

Joint Research and Development Office Division of Research and Innovation UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH Tel: 020 7905 2700 Fax: 020 7905 2201 www.gosh.nhs.uk

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Joint Research and Development Office
Division of Research and Innovation
You will shortly be contacted by the R&D department regarding R&D approval. Once all the documents have been received by them you will receive an R&D approval email and you can commence your project.

Regards

Professor John Anderson

Chair

Clinical Research Adoption Committee

Joint Research and Development Office Division of Research and Innovation UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH Tel: 020 7905 2700 Fax: 020 7905 2201 www.gosh.nhs.uk

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### **APPENDIX F: Ethical Approval from NRES (NHS)**



### **NRES Committee London - Bromley**

Level 3, Block B Whitefriars Lewins Mead Bristol BS1 2NT

Telephone: 0117 342 1387

21 October 2014

Ms Emma Smith School of Psychology The University of East London Stratford Campus, Water Lane, London E15 4LZ

Dear Ms Smith

Study title: Pervasive Refusal Syndrome (PRS): Perspectives of

Parents' and Childrens' Views (About the Diagnosis and

their Experiences)

REC reference: 14/LO/1651 IRAS project ID: 160511

Thank you for your letter of the 20<sup>th</sup> of October 2014, 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.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mr Mark Dawson, nrescommittee.london-bromley@nhs.net.

### 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 favourable opinion is subject to the following conditions being met prior to the start of the

study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <a href="http://www.rdforum.nhs.uk">http://www.rdforum.nhs.uk</a>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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 approvals from host organisations

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (<a href="mailto:catherineblewett@nhs.net">catherineblewett@nhs.net</a>), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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).

### Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Approved documents

The final list of documents reviewed and approved by the Con	nmittee is as	follows:
Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEL Professional Indemnity Certificate 2014-2015]	Version 1.0	01 August 2014
GP/consultant information sheets or letters [GP Letter]	version 1.0	03 October 2014
Interview schedules or topic guides for participants [Interview schedule - parents and guardians]	Version 1.0	10 March 2014
Interview schedules or topic guides for participants [Interview schedule - child/young person]	Version 1.0	10 March 2014
Letters of invitation to participant [Word of Mouth Covering Letter parents with children over 16]	version 2.0	03 October 2014
Letters of invitation to participant [Word of Mouth Covering Letter parents with children under 16]	version 2.0	03 October 2014
Letters of invitation to participant [GOSH Letter to parents with children over 16]	version 2.0	03 October 2014
Letters of invitation to participant [GOSH Letter to participants]	version 2.0	03 October 2014
Letters of invitation to participant [GOSH Covering Letter to young beople over 16]	version 1.0	03 October 2014
Letters of invitation to participant [Word of Mouth Covering Letter young people over 16]	version 1.0	03 October 2014
Other [Word of Mouth Covering Letter]	1.0	26 August 2014
Other [UEL Employers Liability Insuarnce Certificate 2014-2015]	Version 1.0	01 August 2014
Other [Interview Schedule - parent/guardian - Version 1.0]	1.0	26 August 2014
Other [UEL Ethical Approval]	Version 1.0	04 April 2014
Other [CLAIRE HIGGINS CV 2014]	1.0	26 August 2014
Other [CRAC ethical approval]	Version 1.0	13 June 2014
Other [Letter - Response to REC board re- decision of provisional opinion]	Version 1.0	12 October 2014
Participant consent form [Assent form for young people aged 16+]	version 4.0	03 October 2014
Participant consent form [Assent form for young people under 16]	version 4.0	03 October 2014
Participant consent form [Assent forms for parents and guardians]	version 4.0	03 October 2014
Participant consent form [Assent forms for parents and guardians under 16s]	version 4.0	03 October 2014
Participant information sheet (PIS) [Information sheet for young adults over 16s]	version 4.0	03 October 2014
Participant information sheet (PIS) [Information sheet for young beople under 16]	version 4.0	03 October 2014
Participant information sheet (PIS) [Information sheet for parents and guardians]	version 4.0	03 October 2014
Participant information sheet (PIS) [Information sheet for parents and guardians of under 16]	version 4.0	03 October 2014
REC Application Form [REC_Form_17102014]		17 October 2014
Research protocol or project proposal [Research Protocol]	version 4.0	03 October 2014
Summary CV for Chief Investigator (CI) [EMMA SMITH CV 2014]	1.0	26 August 2014
Summary CV for student [EMMA SMITH CV 2014]	1.0	26 August 2014
Summary CV for supervisor (student research) [JENNY JIM CV	1.0	26 August 2014

2014]

### 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.

### 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

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

### **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 Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

### 14/LO/1651

Please quote this number on all correspondence

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

Yours sincerely



### Ms Carol Jones Chair

Email:nrescommittee.london-bromley@nhs.net

Enclosures: "After ethical review – guidance for

researchers" [SL-AR2]

Copy to: Professor Neville Punchard

Dr Thomas Lewis, Research Management and Governance Officer

Division of Research & Innovation

### **APPENDIX G: NRES Substantial Amendment Favourable Opinion**



### **NRES Committee London - Bromley**

Level 3, Block B Whitefriars Lewins Mead Bristol BS1 2NT Tel: 01173 421383

27 October 2014

Ms Emma Smith School of Psychology The University of East London Stratford Campus, Water Lane, London E15 4LZ

Dear Ms Smith

Study title: Pervasive Refusal Syndrome (PRS): Perspectives of

Parents' and Childrens' Views (About the Diagnosis and

their Experiences)

REC reference: 14/LO/1651

Amendment number: Amendment 1 20.10.14

Amendment date: 22 October 2014

IRAS project ID: 160511

The above amendment was reviewed by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
GP/consultant information sheets or letters	2	20 October 2014
Notice of Substantial Amendment (non-CTIMP)	Amendment 1 20.10.14	22 October 2014
Other [GOSH covering letter for young people over 16]	2	20 October 2014
Other [Word of Mouth Covering Letter (parents with children over 16)]	3	20 October 2014
Other [Word of Mouth Covering Letter (young people over 16)]	2	20 October 2014
Other [Word of Mouth Covering Letter (parents with children under 16)]	3	20 October 2014
Other [GOSH covering letter for parents with children under 16]	3	20 October 2014
Other [GOSH covering letter for parents with children over 16]	3	20 October 2014
Participant consent form [Assent form for parents]	5	20 October 2014

A Research Ethics Committee established by the Health Research Authority

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Health	Research	Aut	ho	rity

Participant consent form [Assent form for parents of under 16s]	5	20 October 2014
Participant consent form [Assent form for young people under 16]	5	20 October 2014
Participant consent form [Assent form for young adults]	5	20 October 2014
Participant information sheet (PIS) [Parents of under 16s]	5	20 October 2014
Participant information sheet (PIS) [Parents]	5	20 October 2014
Participant information sheet (PIS) [Young Adults]	5	20 October 2014
Participant information sheet (PIS) [Parents]	5	20 October 2014
Participant information sheet (PIS) [Young people under 16]	5	20 October 2014
Research protocol or project proposal	5	20 October 2014
Validated questionnaire [DAWBA English Youth]		
Validated questionnaire [DAWBA English Parent]		

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### 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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

14/LO/1651: Please quote this number on all correspondence

Yours sincerely

Ms Carol Jones Chair

E-mail: nrescommittee.london-bromley@nhs.net

Enclosures: List of names and professions of members who took part in the

review

Copy to: Dr Thomas Lewis, Research Management and Governance Officer

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### **NRES Committee London - Bromley**

### Attendance at Sub-Committee of the REC meeting in correspondence

### **Committee Members:**

Name	Profession	Present	Notes
Dr Jo Brooke	Senior Lecturer and Nurse Consultant in Dementia	Yes	
Ms Carol Jones (Chair)	Management Consultant	Yes	

### Also in attendance:

Name	Position (or reason for attending)
Miss Lauren Allen	REC Manager

### **APPENDIX H: UEL Ethical Approval of Amendments**

### UNIVERSITY OF EAST LONDON School of Psychology

### REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

### FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Mark Finn (Chair of the School Research Ethics Committee).

### HOW TO COMPLETE & SUBMIT THE REQUEST

- 1. Complete the request form electronically and accurately.
- 2. Type your name in the 'student's signature' section (page 2).
- When submitting this request form, ensure that all necessary documents are attached (see below).
- Using your UEL email address, email the completed request form along with associated documents to: Dr Mark Finn at m.finn@uel.ac.uk
- Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
- Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

### REQUIRED DOCUMENTS

- A copy of your previously approved ethics application with proposed amendments(s) <u>added as tracked changes</u>.
- Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
- 3. A copy of the approval of your initial ethics application.

Name of applicant: Emma Smith

Programme of study: Professional Doctorate in Clinical Psychology

Title of research: Pervasive Refusal Syndrome (PRS): Parents' perspectives and

children views (about the diagnosis and their care)

Name of supervisor: Dr Jenny Jim and Dr Claire Higgins

### Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Only face to face interviews will be	Given the infancy of this research and the
conducted. The offer to conduct telephone	possibility that it might be the first time
and skype interviews has been removed	since treatment that children/young
from all paperwork.	adults/parents/guardians may be talking
	about their experiences, NHS ethics had
	concerns about the safety of doing this over
	the telephone and skype. This was a
	condition of the favourable opinion.
	NIII di cala cala
Participants can take up the offer for the	NHS ethics suggested this with the rationale
researcher to notify their GP of their	that participants should be given the
participation in the study. This is optional	opportunity for their GP to be informed
not a requirement for taking part.	should they require any future support as a
	result of talking about their experiences in
	the interview. This was a condition of the
	favourable opinion.
Including in my paperwork, information	Great Ormond Street Hospital's ethics board
about an additional study that Great	(CRAC) and NHS Ethics believed that the
Ormond Street Hospital is completing with	study was so closely linked that it should
this population and inviting them to take	'piggy back' this study. This has been
	submitted as an amendment to my study and
part.	has been given a favourable opinion.
	nas occii given a favourable opinion.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and	✓	
agree to them?		

Student's signature (please type your name): Emma Smith

Date: 27<sup>th</sup> October 2014

то в	E COMPLETED BY REVIE	WER
Amendment(s) approved	YES	

### Comments

Amendments approved on the basis of NHS approval of its required amendments

Reviewer: M Finn

Date: 29/10/14

### **APPENDIX I: UCL ICH R&D Approval**



## Great Ormond Street NHS Hospital for Children

**NHS Foundation Trust** 

Joint Research and Development Office
Division of Research and Innovation

Direct Line: 020 7905 2698

Email: R&DGovernance@gosh.nhs.uk

31/10/2014

Dr Jane McNicholas

Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH)

Dear Dr Jane McNicholas,

Project Title Pervasive Refusal Syndrome (PRS): Perspectives of parents and children

views (about the diagnosis and their experiences)

Protocol version 5

Protocol date 20<sup>th</sup> October 2014 REC Reference 14/LO/1651 R&D Reference 14BS05

Sponsor University of East London

Chief Investigator (CI) Miss Emma Smith

### Notification of Great Ormond Street Hospital NHS Permission.

The research approval process for the above named study has been completed successfully. I am pleased to issue approval, on behalf of Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), for the above study to proceed.

All research carried out within this Trust must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd edition, Department of Health (DH)).

This approval is issued on the basis of the project documentation submitted to date. The approval may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The conditions for host site approval are as follows:

- The Principal Investigator (PI) must ensure compliance with protocol and advise the Joint R&D
  Office of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework (RGF), the PI is obliged to report any Serious Adverse Events (SAEs) to the Sponsor and the Joint R&D Office in line with the study protocol and Sponsor requirements. Adverse Incidents (AEs) must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.
- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI is responsible for the set up and maintenance of the Investigator Site File (ISF) generated to store all documentation relating to this project.

Joint Research and Development Office
Division of Research and Innovation
UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH
Tel: 020 7905 2700 Fax: 020 7905 2201
www.gosh.nhs.uk

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Page 1 of 2

Non-CTIMP Approval Letter v2.1



**NHS Foundation Trust** 

Joint Research and Development Office Division of Research and Innovation

- The PI must ensure that all named staff are compliant with the Data Protection Act (DPA) 1998, Human Tissue Act (HTA) 2005, Mental Capacity Act (MCA) 2005 and all other applicable statutory guidance and legislation.
- The PI must allow monitoring and auditing by the Sponsor and the Joint R&D Office.
- The PI must report any cases of suspected research misconduct and fraud to the Joint R&D Office
- The PI must provide an annual report to the Joint R&D Office for all research involving NHS
  patients, staff and/or resources. The PI must notify the Joint R&D Office of any presentations of
  such research at scientific or professional meetings, or on the event of papers being published
  and any direct or indirect impacts on patient care.

Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the Joint R&D Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,

**Dr Thomas Lewis** 

Research Management and Governance Officer Joint Research and Development Office

Joint Research and Development Office
Division of Research and Innovation
UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH
Tel: 020 7905 2700 Fax: 020 7905 2201
www.gosh.nhs.uk

Page 2 of 2

Non-CTIMP Approval Letter v2.1

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### APPENDIX J (Part 1): GOSH covering letter for parents of young people aged under 16



Department of Child and Adolescent Mental Health Great Ormond Street Hospital for Children NHS Foundation Trust Great Ormond Street London WC1N 3JH

NAME(S) OF PARENT(S) ADDRESS DATE

Dear X,

I am writing to invite you to take part in a piece of research that is being undertaken by Great Ormond Street Hospital and the University of East London.

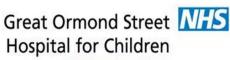
The study will be exploring the perspectives of parents/guardians and children about the diagnosis of Pervasive Refusal Syndrome and their experiences. All parents/guardians of children who received this diagnosis and were treated on the Mildred Creak Unit between 2003 and 2013 are being invited to participate. It is hoped that this study will help professionals have a better understanding of what it is like to be given this diagnosis, be treated for the symptoms and what the journey to recovery is like. It will also help inform future interventions and care packages offered to children and their families.

Parents/guardians and children are also invited to complete the Development and Well Being Assessment (DAWBA) which is an online package of questionnaires which looks at common emotional, behavioural and hyperactivity disorders. The purpose of this part of the research is to help determine the long term psychological impact a diagnosis of Pervasive Refusal Syndrome has to help further inform future interventions and care packages.

Please find enclosed a pack which contains an information sheet and consent form which provides a detailed overview of the study and what participation would involve. An unsealed envelope is also included with this letter; this contains an information sheet and consent form for your son/daughter. You can share this with him/her at your discretion. You can participate in the study without your son/daughter participating. Similarly, your son/daughter can participate in the study without your participation, although your consent for this is still required.

If you do not want you and your son/daughter to participate in this study please complete and return the form below within 10 working days. If we do not receive this form Emma Smith, Lead Researcher, will contact you.

GOSH Covering Letter to Participants (parents with children under 16) – Version 3.0 – $20^{th}$  October 2014



**NHS Foundation Trust** 

Thank you for taking time to read this letter and the information enclosed. I wish you and your family the best for the future.

Yours Sincerely,

Dr Jon Goldin Consultant Child and Adolescent Psychiatrist Mildred Creak Unit

Dr Jane McNicholas Dr Jenny Nicholson Clinical Psychologist Clinical Psychologist Mildred Creak Unit Mildred Creak Unit

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l add

(Continued)

2014

GOSH Covering Letter to Participants (parents with children under 16) – Version 3.0 –20<sup>th</sup> October



**NHS Foundation Trust** 

Department of Child and Adolescent Mental Health Great Ormond Street Hospital for Children NHS Foundation Trust Great Ormond Street London WC1N 3JH

NAME(S) OF PARENT(S) ADDRESS DATE

Dear X,

I am writing to invite you to take part in a piece of research that is being undertaken by Great Ormond Street Hospital and the University of East London.

The study will be exploring the perspectives of parents/guardians and children about the diagnosis of Pervasive Refusal Syndrome and their experiences. All parents/guardians of children who received this diagnosis and were treated on the Mildred Creak Unit between 2003 and 2013 are being invited to participate. It is hoped that this study will help professionals have a better understanding of what it is like to be given this diagnosis, be treated for the symptoms and what the journey to recovery is like. It will also help inform future interventions and care packages offered to children and their families.

Parents/guardians and children are also invited to complete the Development and Well Being Assessment (DAWBA) which is an online package of questionnaires which looks at common emotional, behavioural and hyperactivity disorders. The purpose of this part of the research is to help determine the long term psychological impact a diagnosis of Pervasive Refusal Syndrome has to help further inform future interventions and care packages.

Please find enclosed a pack which contains an information sheet and consent form which provides a detailed overview of the study and what participation would involve. An unsealed envelope is also included with this letter; this contains an information sheet and consent form for your son/daughter. Please can you pass this on to your son/daughter so they are able to decide whether they would like to take part. You can participate in the study without your son/daughter participating. Similarly, your son/daughter can participate in the study without your participation.

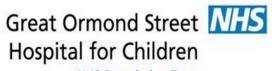
If you do not want to participate in this study please complete and return the form below within 10 working days. If we do not receive this form Emma Smith, Lead Researcher, will contact you.

GOSH Covering Letter to Participants (parents with children over 16) – Version 3.0 –20th October 2014



Thank you for taking time to read this letter and the information enclosed. I wish you and your family

the best for the future.		
Yours Sincerely,		
Dr Jon Goldin Consultant Child and Adolescent Psychiatrist Mildred Creak Unit		
Dr Jane McNicholas Clinical Psychologist Mildred Creak Unit	Dr Jenny Nicholson Clinical Psychologist Mildred Creak Unit	
Please tear and return in the self-addressed pre-paid envelope		
Title of Research: Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences).		
Name:		
Please tick and initial one of the following:		
I would <b>not like</b> to participate in this study and do not want to be contacted		
*I would <b>like to find out more</b> about this study and agree to be contacted		
*I would <b>like to participate</b> in this study and agree to be contacted		
*If you have agreed to be contacted please provide a contact number or email address below:		
GOSH Covering Letter to Participants (parents with children over 16) – Version 3.0 –20th October 2014		





**NHS Foundation Trust** 

#### INFORMATION SHEET FOR PARENTS/GUARDIANS

### **UNIVERSITY OF EAST LONDON**

School of Psychology Stratford Campus Water Lane London E15 4LZ

**Title of Research:** Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences).

Name of Researcher: Emma Smith, Trainee Clinical Psychologist

Email address: <u>u1236172@uel.ac.uk</u>
Contact Number:

Invitation to take part

You are invited to take part in a research study. In order to help you decide whether you would like to take part, it is important that you understand why the research is being done and what taking part would involve. I, or my supervisors, will be able to meet with you in person or have a telephone conversation to go through this letter and answer any questions you may have.

### What is the purpose of the study?

The research is being conducted under the supervision of Dr Jenny Jim and Dr Claire Higgins as part of a Professional Doctorate in Clinical Psychology that I am completing at the University of East London. It is also being supervised by Dr Jane McNicholas and Dr Jenny Nicholson at Great Ormond Street Hospital.

This study aims to find out about the personal views and experiences of children/young people who have been given a diagnosis of Pervasive Refusal Syndrome and their parents/guardians' views and experiences.

At present little is known about children and parents/guardians experience of being given the diagnosis, and their experiences of the treatment of the symptoms and the journey to recovery. This research aims to address this gap.

A secondary aim of the study is to assess the current mental health functioning of children who have previously been given a diagnosis of Pervasive Refusal Syndrome. This will be achieved using an online measure called the Development and Well Being Assessment (DAWBA).

Version 5.0:20th October 2014



**NHS Foundation Trust** 

### Why have I been invited?

The study is interested in parents/guardians' views of Pervasive Refusal Syndrome as a diagnosis, their experience of their son/daughter being given this diagnosis and their experiences of caring for a child living with the symptoms. It is also interested in parents/guardians' opinions about their son/daughter's care.

### Do I have to take part?

It is your decision as to whether you participate in the study or not. You are free to choose not to participate in this study and should not feel under any pressure to do so.

If you decide to take part in the study, it is important that you know that you are free to withdraw from the interview at any time and will not be asked to give a reason. You are also free to withdraw your data from the study up until February 2015. After this date the data will be analysed and written up for examination purposes and possible publication.

### What will happen if I agree to take part?

If you wish to take part please return the opt in form or contact me, Emma Smith, via email or telephone.

Prior to the interview you will be asked to read and sign an assent form. Given the nature of the study your GP can be informed of your participation should you wish, however this is not a requirement for taking part. This is included on the assent form.

Once assent has been given, you will then be asked to take part in a one to one interview. You will be interviewed by me, Jane McNicholas or Jenny Nicholson. The interview will last up to an hour and will take place at a date, time and location which is convenient to you. The interview will be digitally audio recorded and transcribed (typed into text). I will complete the transcribing for all interviews and all information that might identify you and your son/daughter/family (e.g. names and places) will be changed for confidentiality purposes.

The interview will ask questions about how you made sense of your son/daughter's experiences, what it was like when your son/daughter received the diagnosis of Pervasive Refusal Syndrome, what your thoughts are on the diagnosis and what you thought about the care they received. There is no right or wrong answer as the study is interested in hearing about personal views and experiences.

Following the interview you will be given the option to complete the DAWBA (Development and Well Being Assessment) with reference to your son/daughter. The DAWBA is a package of interviews, questionnaires and rating techniques designed to assess for the presence of common and less common emotional, behavioural, and hyperactivity disorders. The DAWBA takes between 30 and 50 minutes to complete and can be completed at a time(s) that is convenient for you. Please note that completion of the DAWBA is an optional part of the research.

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After the questionnaires have been completed you will be given the opportunity to discuss the process via telephone with the researcher (Jane McNicholas or Jenny Nicholson) and ask any further questions. The researcher will access the DAWBA outcomes using a secure username and password. Through this log in process the researcher will be aware of when the DAWBA has been completed by you.

If the questionnaires have raised issues for you or your son/daughter a discussion about contacting your/their GP or current local healthcare team will be had and support will be provided to access this.

#### What are the possible disadvantages of taking part?

The study is not designed to cause you any harm, discomfort or distress. However, the interview will ask you questions about the time your son/daughter became unwell, was diagnosed with Pervasive Refusal Syndrome and had to receive treatment. It is possible that remembering this period of time may cause you to be upset. Before starting the interview the interviewer will have a conversation with you about how you might let them know if you are feeling upset. They will remind you that you can end the interview at any time. They will check in with you at the end of the interview to see how you are feeling.

I am a Trainee Clinical Psychologist with previous experience of working with adults in a mental health setting, as are Jane McNicholas and Jenny Nicholson. As such, we are able to safely respond to these issues should they arise, and will discuss you seeking extra support from your GP if needed as a result of taking part in this study.

You can also contact the Great Ormond Street Hospital Patient Advice and Liaison Service (PALS). PALS is a free and confidential service which helps patients, parents and carers with any information, concerns, or problems that they have about their NHS care/service. Further information can be found through the following link:

http://www.gosh.nhs.uk/parents-and-visitors/clinical-support-services/pals/

### Will there be any financial costs to taking part?

You will not be paid for taking part in this study. Depending on where you choose to be interviewed there may be travel costs. However, these can be reimbursed if original receipts are brought to the interview. Otherwise, there will be no financial costs to you as a result of taking part in this study.

### What are the possible benefits of taking part?

It cannot be promised that the study will help you or your son/daughter personally, but the information gathered from this study will hopefully help to give mental health practitioners an understanding of a parent/guardians' perspective on the diagnostic label of Pervasive Refusal Syndrome and their views on their son/daughter's experiences. Alongside this, information surrounding parents/guardians' opinions and experiences of the care their son/daughter and family received may help to inform future interventions and care packages offered to children and their families

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### If I take part in the study will my information be kept confidential?

Your participation will be kept confidential. Your personal details will be saved separately to the individual transcripts of interviews and information generated by DAWBA responses. Any information about you or your son/daughter (including names and locations) will be removed from what you said in the transcript. The transcript will be saved as a password protected document and will be saved on a password protected computer, USB and external hard drive. All devices have encryption software installed. The audio recording will also be saved in the same way. The audio recording and transcript will be destroyed after 5 years. Only I, supervisors of this study and examiners will have access to the audio-recording and anonymised transcripts from the interviews. The DAWBA outcomes will be added to a secure, anonymous database at Great Ormond Street Hospital.

If you say something that makes the interviewer worry that there is a risk of harm to you, your son/daughter or to others, it may be necessary to break confidentiality to tell other professionals in order to ensure your safety and/or the safety of others. Where possible they will always try to share this with you first.

### What will happen to the results of the study?

The results of the study will be written up and submitted as a research project as part of a Doctorate in Clinical Psychology. The results may also be published in a research paper. If this is the case, you will not be identified in any report/publication. Quotes and extracts of things you have said may be used in the final research paper however this will be anonymised. You can request a summary of what was found once the study has ended.

### Has the study been given ethical approval?

The research has obtained ethical approval from the Research Ethics Committee from the University of East London, London – Bromley NRES Committee and Great Ormond Street Hospital.

### What if I have a question or there is a problem?

If you have any questions or worries about the study, you can contact me or a member of the supervisory team. We will do our best to answer your questions.

The supervisory team's contact details are:

Dr Jenny Jim: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4411 or email j.jim@uel.ac.uk

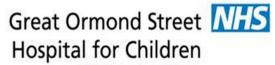
Dr. Claire Higgins: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4174 or email c.higgins@uel.ac.uk

Dr Jane McNicholas: Department of Child and Adolescent Mental Health Service, Great Ormond Street

Hospital, Great Ormond Street, London, WC1N 3JH 0207 829 8679 or email <a href="mailto:Jane.McNicholas@gosh.nhs.uk">Jane.McNicholas@gosh.nhs.uk</a>

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Dr Jenny Nicholson: Department of Child and Adolescent Mental Health Service, Great Ormond Street Hospital, Great Ormond Street, London, WC1N 3JH

### **Contact for further information**

If you would like to take part in the study or have any questions please contact me on:

E-mail: u1236172@uel.ac.uk Telephone:

Thank you for taking the time to read this information sheet. Please retain this information sheet in case you want to refer to it in the future.

Emma Smith Trainee Clinical Psychologist

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**NHS Foundation Trust** 

### ASSENT FORM FOR PARENTS/GUARDIANS

**Title of Research:** Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences).

Name of Researcher: Emma Smith, Trainee Clinical Psychologist Please tick and initial the box 1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had any questions I asked answered satisfactorily. 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. 3. I understand that completion of the DAWBA is a secondary aim of the study and is optional. 4. I understand that any information that I give will be confidential and will only be used anonymously in any written work or publications. 5. I agree to the interview being audio recorded for the purpose of transcription by the researcher. I understand that the recording will be deleted once its purpose has been completed. 6. I understand that relevant sections of the data collected during the study. may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. 7. I agree for to take part in the above study. 8. I would like my GP to be informed of my participation in this study. [Please note that this is not a requirement to take part in this study] ..... Name of Parent/Guardian Date Signature Name of Researcher Signature Version 5.0:20th October 2014

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### APPENDIX M: Parent Information Sheet for Young People Aged Under 16





**NHS Foundation Trust** 

### INFORMATION SHEET FOR PARENTS/GUARDIANS OF UNDER 16s

### **UNIVERSITY OF EAST LONDON**

School of Psychology Stratford Campus Water Lane London E15 4LZ

Title of Research: Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences).

Name of Researcher: Emma Smith, Trainee Clinical Psychologist

Email address: u1236172@uel.ac.uk

Contact Number:

### Invitation to take part

Your son/daughter is invited to take part in a research study. In order to help you decide whether you would be comfortable allowing your son/daughter to take part, it is important for you to understand why the research is being done and what taking part would involve for you and your son/daughter. I, or a member of the supervisory team, is able to meet or have a telephone conversation with you and your son/daughter to go through this letter and answer any questions you may have.

Enclosed with this letter is an unsealed envelope containing a copy of this information to give to your son/daughter at your discretion. Consent will be required from yourself and your son/daughter to allow him/her to take part. Only one parent or guardian needs to consent to a young person taking part, though where possible it would be best for everyone to agree together.

### What is the purpose of the study?

The research is being conducted under the supervision of Dr Jenny Jim and Dr Claire Higgins as part of a Professional Doctorate in Clinical Psychology that I am completing at the University of East London. It is also being supervised by Dr Jane McNicholas and Dr Jenny Nicholson at Great Ormond Street Hospital.

This study aims to find out about the personal views and experiences of children/young people who have been given a diagnosis of Pervasive Refusal Syndrome and their parents' views and experiences.

At present little is known about children's and parents' experience of being given a diagnosis, and also their experiences of treatment of the symptoms and the journey to recovery. This research aims to address this gap.

A secondary aim of the study is to assess the current mental health functioning of children who have previously been given a diagnosis of Pervasive Refusal Syndrome. This will be achieved using an online measure called the Development and Well Being Assessment (DAWBA).

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### Why has my son/daughter been invited?

The study is interested in young people's views of Pervasive Refusal Syndrome as a diagnosis, their experience of being given this diagnosis and their experiences of living with the symptoms of Pervasive Refusal Syndrome. It is also interested in young people's opinions about their care during their illness.

### Does my son/daughter have to take part?

It is your decision as to whether your son/daughter takes part in the study or not. Your son/daughter is free to choose not to participate in this study and should not feel under any pressure to do so. You are also under no obligation to agree to your son/daughter taking part, even if they would like to do so themselves. In addition your son/daughter is under no obligation to complete the on-line assessment (DAWBA) even if he/she chooses to take part in the main study.

If you and your son/daughter decide that he/she will take part in the study, it is important that you both know that your son/daughter is free to withdraw from the interview at any time and will not be asked to give a reason. You are also both free to withdraw your data from the study up until February 2015. After this date the data will be analysed and written up for examination purposes and possible publication.

### What will happen if my son/daughter and I agree that they can take part?

If your son/daughter wishes to take part and you are in agreement to this please return the opt in form or contact me, Emma Smith, via email or telephone.

Prior to the interview you and your son/daughter will be asked to read and sign an assent form. Given the nature of the study your son/daughter's GP can be informed of their participation should you wish, however this is not a requirement for taking part. This is included on the assent form.

Once consent has been given, your son/daughter will then be asked to take part in a one to one interview. They will be interviewed by me, Jane McNicholas or Jenny Nicholason. The interview will last up to an hour and will take place at a date, time and location which is convenient to you and your son/daughter. The interview will be digitally audio-recorded and transcribed (typed into text). I will be transcribing all of the interviews and all information that might identify your son/daughter (e.g. names and places) will be changed to ensure confidentiality.

The interview will ask questions about how your son/daughter made sense of their experiences, what it was like being given a diagnosis of Pervasive Refusal Syndrome, what their thoughts are on the diagnosis and what they thought about the care they received. There is no right or wrong answer as the study is interested in hearing about young people's personal views and experiences.

Following the interview your son/daughter will be given the option of completing the DAWBA (Development and Well Being Assessment). The DAWBA is an online package of interviews, questionnaires and rating techniques designed to assess for the presence of common and less common emotional, behavioural, and hyperactivity disorders. The DAWBA takes between 30 and 50 minutes to

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complete and can be completed at a time(s) that is convenient for your son/daughter. <u>Please note that completion of the DAWBA is an optional part of the research.</u>

After the questionnaires have been completed your son/daughter will be given the opportunity to discuss the process via telephone with the researcher (Jane McNicholas or Jenny Nicholson) and ask any further questions. The researcher will access the DAWBA outcomes using a secure username and password. Through this log in process the researcher will be aware of when the DAWBA has been completed.

If the questionnaires have raised issues for your son/daughter a discussion about contacting their GP or current local healthcare team will be had and support will be provided to access this.

### What are the possible disadvantages of taking part?

The study is not designed to cause your son/daughter any harm, discomfort or distress. However, the interview will ask your son/daughter questions about the time in their life when they became unwell, were diagnosed with Pervasive Refusal Syndrome and had to receive treatment. It is possible that remembering this period of time in their life may cause them to be upset. Before starting the interview the interviewer will have a conversation with your son/daughter about how he/she might let them know if he/she are feeling upset and will tell him/her that they can end the interview at any time. The interviewer will check in with your son/daughter at the end of the interview to see how he/she is feeling.

I am a Trainee Clinical Psychologist with previous experience of working with children and young people in a mental health setting. Jane McNicholas and Jenny Nicholson are Clinical Psychologists who work at Great Ormond Street Hospital within a mental health setting. Given our experience, we are able to safely respond to these issues should they arise, and will inform you if they believe your son/daughter would benefit from extra support from your GP if needed as a result of taking part in this study.

You and your son/daughter can also contact the Great Ormond Street Hospital Patient Advice and Liaison Service (PALS). PALS is a free and confidential service which helps patients, parents and carers with any information, concerns, or problems that they have about their NHS care/service. Further information can be found through the following link:

http://www.gosh.nhs.uk/parents-and-visitors/clinical-support-services/pals/

### Will there be any financial costs to taking part?

Your son/daughter will not be paid for taking part in this study. Depending on where you and your son/daughter choose to be interviewed there may be travel costs. However, these can be reimbursed if original receipts are brought to the interview. There will be no other financial costs to your son/daughter or yourself as a result of taking part in this study.

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### What are the possible benefits of taking part?

It cannot be promised that the study will help your son/daughter personally, but the information gathered from this study will hopefully help to give mental health practitioners an understanding of what it is like for a child/young person to be given a diagnosis of Pervasive Refusal Syndrome and what it is like to live with the symptoms. Alongside this, the information about children/young people's experiences of the care they received may help to inform future interventions and care packages offered to children and their families.

### If my son/daughter takes part in the study will their information be kept confidential?

Your son/daughter's participation will be kept confidential. You and your son/daughter's personal details will be saved separately to the individual transcripts of interviews and information generated by DAWBA responses. Any information about you or your son/daughter (including names and locations) will be removed from what your son/daughter has said in the transcript. The transcript will be saved as a password protected document and will be saved on a password protected computer, USB and external hard drive. All devices have encryption software installed. The audio recording will also be saved in the same way. The audio recording and transcript will be destroyed after 5 years. Only I, supervisors of this study and examiners will have access to the audio-recording and anonymised transcript from the interview. The DAWBA outcomes will be added to a secure, anonymous database at Great Ormond Street Hospital.

If your son/daughter says something that makes the interviewer worry that there is a risk of harm to your son/daughter or to others, it may be necessary to break confidentiality to tell other professionals in order to ensure your son/daughter's safety and/or the safety of others. Where possible the interviewer would always try to share this with you and your son/daughter first.

### What will happen to the results of the study?

The results of the study will be written up and submitted as a research project as part of the Doctorate in Clinical Psychology. The results may also be published in a research paper. If this is the case, your son/daughter will not be identified in any report/publication. Quotes and extracts of things your son/daughter has said may be used in the final research paper however this will be anonymised. You and your son/daughter can request a summary of the main findings once the study has ended.

### Has the study been given ethical approval?

The research has obtained ethical approval from the Research Ethics Committee from the University of East London, London - Bromley NRES Committee, and Great Ormond Street Hospital.

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### **NHS Foundation Trust**

### What if I have a question or there is a problem?

If you have any questions or concerns about any aspect of this study, you can contact me or a member of the supervisory team. We will do our best to answer your questions. The supervisory team's contact details are:

Dr Jenny Jim: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4411 or email j.jim@uel.ac.uk

Dr. Claire Higgins: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4174 or email c.higgins@uel.ac.uk

Dr Jane McNicholas: Department of Child and Adolescent Mental Health Service, Great Ormond Street

Hospital, Great Ormond Street, London, WC1N 3JH 0207 405 9200 or email Jane.McNicholas@gosh.nhs.uk

Dr Jenny Nicholson: Department of Child and Adolescent Mental Health Service, Great Ormond Street

Hospital, Great Ormond Street, London, WC1N 3JH

### **Contact for further information**

If your son/daughter would like to take part in the study and you agree, or if you have any questions please contact me on:

E-mail: u1236172@uel.ac.uk Telephone:

Thank you for taking the time to read this information sheet. Please retain this information sheet in case you want to refer to it in the future.

Emma Smith Trainee Clinical Psychologist

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**NHS Foundation Trust ASSENT FORM FOR PARENTS/GUARDIANS OF UNDER 16s** Title of Research: Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences). Name of Researcher: Emma Smith, Trainee Clinical Psychologist Please tick and initial the box 1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had any questions I asked answered satisfactorily. 2. I understand that my son/daughter's participation is voluntary and that he/she are free to withdraw at any time, without giving any reason. 3. I understand that completion of the DAWBA is a secondary aim of the study and is optional. 4. I understand that any information that my son/daughter and I give will be confidential and will only be used anonymously in any written work or 5. I agree to the interview being audio recorded for the purpose of transcription by the researcher. I understand that the recording will be deleted once its purpose has been completed. 6. I understand that relevant sections of the data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my son/daughters records. 7. I agree for my son/daughter, ..... to take part in the above study. 8. I would like my son/daughter's GP to be informed of their participation in this study. [Please note that this is not a requirement to take part in this study] Name of Parent/Guardian Date Signature Name of Researcher Date Signature Version 5.0:20th October 2014

### APPENDIX O: Participant Information Sheet for Young People Aged Under 16





**NHS Foundation Trust** 

### **INFORMATION SHEET FOR YOUNG PEOPLE (UNDER 16s)**

### **UNIVERSITY OF EAST LONDON**

School of Psychology Stratford Campus Water Lane London E15 4LZ

**Title of Research:** Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences).

Name of Researcher: Emma Smith, Trainee Clinical Psychologist

Email address: u1236172@uel.ac.uk

Contact Number:

### Invitation to take part

You are being invited to take part in a research study. In order to help you decide whether you would be comfortable taking part, it is important for you to understand why the research is being done and what taking part would involve. I, or one of my supervisors, is able to meet or have a telephone conversation with you and your parents/guardians to go through this letter and answer any questions you may have.

Your parents/guardians also have a copy of this information. In order for you to take part assent will be required from yourself and your parents/guardians. Only one parent or guardian needs to assent to you taking part, though where possible it would be best for everyone to agree together.

### What is the purpose of the study?

The research is being conducted under the supervision of Dr Jenny Jim and Dr Claire Higgins as part of a Professional Doctorate in Clinical Psychology that I am completing at the University of East London. It is also being supervised by Dr Jane McNicholas and Dr Jenny Nicholson at Great Ormond Street Hospital.

This study aims to find out about the personal views and experiences of children/young people who have been given a diagnosis of Pervasive Refusal Syndrome and their parents' views and experiences.

At present little is known about children and parents' experience of being given a diagnosis, and their experiences of treatment and the journey to recovery. It is hoped that young people will be able to help professionals have a better understanding.

A secondary aim of the study is to assess the current mental health functioning of children who have previously been given a diagnosis of Pervasive Refusal Syndrome. This will be achieved using an online measure called the Development and Well Being Assessment (DAWBA).

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**NHS Foundation Trust** 

### Why have I been invited?

The study is interested in young people's views of the diagnosis of Pervasive Refusal Syndrome, their experience of being given this diagnosis and their experiences of living with the symptoms. It is also interested in young people's opinions about the care they received.

### Do I have to take part?

No, it is up to you to decide whether you would like to take part or not. I, or one of my supervisors, will describe the study and go through this information sheet with you either in person or over the telephone. You can ask us any questions or share any worries that you might have about taking part. We will do our best to answer them. Your parents/guardians will also have an information sheet and you can discuss it with them. If you decide that you would like to take part a parent/guardian also needs to give their permission. If you both agree then the person who does the interview will ask you both to sign an assent (consent) form, a document which means that you both agree and give permission to be part of the study. If you decide you do not want to take part that is OK, you will not be asked to give a reason, and nothing will happen to you or your parents/guardians.

### What will happen if I agree to take part?

If you wish to take part and your parents/guardians are in agreement to this please ask them to return the opt in form or contact me, Emma Smith, via email or telephone.

Prior to the interview you and your parents/guardians will be asked to read and sign an assent form. Given the nature of the study we can let your GP know that you are taking part in the study if you wish, however you do not have to agree to this to take part. This is included on the assent form.

Once assent is given, you will then be asked to take part in a one to one interview. You will be interviewed by me, Jane McNicholas or Jenny Nicholson. The interview will last up to an hour and will take place at a date, time and location which is convenient to you and your parents/guardians. The interview will be digitally audio recorded and transcribed (typed into text). I will be transcribing all of the interviews and all information that might identify you (e.g. names and places) will be changed to ensure confidentiality.

The interview will ask questions about your experiences of Pervasive Refusal Syndrome, what you think about the diagnosis and what you thought about the care you received. There is no right or wrong answer as the study is interested in hearing about young people's personal views and experiences.

Following the interview you will be given the option of completing the DAWBA (Development and Well Being Assessment). The DAWBA is a package of interviews, questionnaires and rating techniques designed to assess for the presence of common and less common emotional, behavioural, and hyperactivity disorders. The DAWBA takes between 30 and 50 minutes to complete and can be completed at a time(s) that is convenient for you. Please note that completion of the DAWBA is an optional part of the research.

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After the questionnaires have been completed you will be given the opportunity to discuss the process via telephone with the researcher (Jane McNicholas or Jenny Nicholson) and ask any further questions. The researcher will access the DAWBA outcomes using a secure username and password. Through this log in process the researcher will be aware of when the DAWBA has been completed by you.

If the questionnaires have raised issues for you a discussion about contacting your GP or current local healthcare team will be had and support will be provided to access this.

#### Is there anything to be worried about if I take part?

The study is not designed to cause you any harm, discomfort or distress. However, the interview will ask you questions about the time in your life when you were diagnosed with Pervasive Refusal Syndrome and had to receive treatment. It is possible that remembering this period of time may cause you to be upset. Before starting the interview the interviewer will have a conversation with you about how you might let them know if you are feeling upset. The interviewer will also remind you that you can stop the interview at any time. The interviewer will ask you how you are feeling during the interview and after the interview to check that you are OK.

I am a Trainee Clinical Psychologist with previous experience of working with children and young people. Jane McNicholas and Jenny Nicholson are Clinical Psychologists who work at Great Ormond Street Hospital with children and young people. Due to our work with children and young people we can safely talk to anyone feeling upset and can speak to your parents/guardians about asking your GP for help if further support is needed as a result of taking part in this study.

### Will there be any financial costs to taking part?

You will not be paid for taking part in this study. Depending on where you and your parent/guardian choose to be interviewed there may be travel costs. However, we can pay you back if original receipts are brought to the interview. Otherwise, there will be no financial costs to you or your parents/guardians as a result of taking part in this study.

### What are the possible benefits of taking part?

It cannot be promised that the study will help you personally, but the information collected from this study will hopefully help mental health workers have a better understanding of what it is like for a young person to be given a diagnosis of Pervasive Refusal Syndrome and what it is like to live with the symptoms.

### If I take part in the study will my information be kept private and confidential?

Your involvement in the study will be kept confidential. Your personal details will be saved separately to the answers you give in the interviews and information generated by DAWBA responses. Any information about you or your family (including names and locations) will be removed from the descriptions of what you said. Your answers to the interviews will be saved as a password protected document and will be saved on a password protected computer, USB and external hard drive. All Version 5.0:20th October 2014



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devices have encryption software installed. The audio recording will also be saved in the same way. The audio recording and transcript will be destroyed after 5 years. Only I, supervisors of this study, and examiners will have access to the audio-recording and responses from the interviews. The DAWBA outcomes will be added to a secure, anonymous database at Great Ormond Street Hospital.

If you say something that makes the interviewer worry that there is a risk of harm to you or to others, it may be necessary for them to break confidentiality. This means that the interviewer will need to tell other professionals and your parents/guardians to make sure you are safe and/or others are safe. The interviewer would always try to share this with you first.

### What will happen to the results of the study?

The results of the study will be written up as a research project for the course in Clinical Psychology, and will be submitted for an exam. The project might also be published in a journal. Small sections of things you have said may be used in the final research paper however none of your personal details will be used. You and your parent/guardian can ask to get a summary of what was found after the study has ended.

## Has the study been reviewed and approved?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure the research is safe and fair. This study has been reviewed and approved by the Research Ethics Committee from the University of East London, London - Bromley NRES Committee and Great Ormond Street Hospital.

### What if I have a question or there is a problem?

If you have any questions or worries about the study, you can contact me or one of the study's supervisors. We will do our best to answer your questions.

The supervisory team's contact details are:

Dr Jenny Jim: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4411 or email j.jim@uel.ac.uk

Dr. Claire Higgins: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4174 or email <a href="mailto:c.higgins@uel.ac.uk">c.higgins@uel.ac.uk</a>

Dr Jane McNicholas: Department of Child and Adolescent Mental Health Service, Great Ormond Street

Hospital, Great Ormond Street, London, WC1N 3JH 0207 405 9200 or email <u>Jane.McNicholas@gosh.nhs.uk</u>

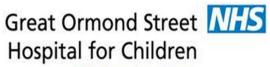
Dr Jenny Nicholson: Department of Child and Adolescent Mental Health Service, Great Ormond Street

Hospital, Great Ormond Street, London, WC1N 3JH

### Contact for further information

If you would like to take part in the study and your parent/guardian agrees, please ask your parents/guardians to return the opt in form or contact me on:

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**NHS Foundation Trust** 

E-mail: u1236172@uel.ac.uk Telephone:

Thank you for taking the time to read this information sheet. Please keep hold of this information sheet in case you want to look at it again in the future.

Emma Smith Trainee Clinical Psychologist

Version 5.0:20th October 2014





**NHS Foundation Trust** 

# ASSENT FORM FOR YOUNG PEOPLE (UNDER 16)

**Title of Research:** Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences).

			Pleas	se tick and initia
				the box
1.		about the informat	nation sheet for the study. I have had ion, ask questions and have had any	
2.	I understand that tak at any time, without		ary and that I am free to stop taking part	
3.	I understand that coland is optional.	mpletion of the DA	AWBA is a secondary aim of the study	
4.			I give will be kept confidential and will ten work or publications.	
5.			corded and typed up by Emma Smith. I deleted once the study has ended.	
6.	may be looked at by	individuals from revant to my taking	the data collected during the study, regulatory authorities or from the NHS grant in this research. I give permission or my records.	
7.	I agree to take part i	n the study.		
8.	I would like my GP to that this is not a requ		n taking part in this study. [Please note part in this study]	
	ame	Date	Signature	
ame of Parent/Guardian		Date	Signature	
ame of Researcher		 Date	Signature	

### **APPENDIX Q: Invitation Letter to Young People Aged Over 16**



Department of Child and Adolescent Mental Health Great Ormond Street Hospital for Children NHS Foundation Trust Great Ormond Street London WC1N 3JH

NAME ADDRESS DATE

Dear X,

I am writing to invite you to take part in a piece of research that is being undertaken by Great Ormond Street Hospital and the University of East London.

The study will be exploring the perspectives of young people and their parents/guardians about the diagnosis of Pervasive Refusal Syndrome and their experiences. All young people who received this diagnosis and were treated on the Mildred Creak Unit between 2003 and 2013 are being invited to participate. Their parents/guardians are being invited to participate too. It is hoped that this study will help professionals have a better understanding of what it is like to be given this diagnosis, be treated for the symptoms and what the journey to recovery is like. It will also help inform future interventions and care packages offered to children, young people and their families.

Parents/guardians and children are also invited to complete the Development and Well Being Assessment (DAWBA) which is an online package of questionnaires which looks at common emotional, behavioural and hyperactivity disorders. The purpose of this part of the research is to help determine the long term psychological impact a diagnosis of Pervasive Refusal Syndrome has to help further inform future interventions and care packages.

Please find enclosed a pack which contains an information sheet and consent form which provides a detailed overview of the study and what participation would involve. You can participate in the study without your parent/guardian participating. Similarly, your parent/guardian can participate in the study without your participation.

If you do not want to participate in this study please complete and return the form below within 10 working days. If we do not receive this form Emma Smith, Lead Researcher, will contact you.

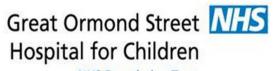
GOSH Covering Letter to Participants (young people over 16) – Version 2.0 –20<sup>th</sup> October 2014



Thank you for taking time to read this letter and the information enclosed. I wish you and your family the best for the future.

Yours Sincerely,		
Dr Jon Goldin Consultant Child and Adolescent Mildred Creak Unit	Psychiatrist	
Dr Jane McNicholas Clinical Psychologist Mildred Creak Unit	Dr Jenny Nicholson Clinical Psychologist Mildred Creak Unit	
Title of Research: Pervasive Refu	ddressed pre-paid envelope usal Syndrome (PRS): Perspectives of parents	
Name:	. ,	
Please tick and initial one of the t	ollowing:	
I would <b>not like</b> to participate in this	s study and do not want to be contacted	
*I would <b>like to find out more</b> abou	ut this study and agree to be contacted	
*I would <b>like to participate</b> in this s	tudy and agree to be contacted	
*If you have agreed to be contacted	please provide a contact number or email add	dress below:
GOSH Covering Letter to Participan	ts (young people over 16) – Version 2.0 – 20 <sup>th</sup> Oct	ohor 2014

### APPENDIX R: Participant Information Sheet for Young People Aged Over 16





# **NHS Foundation Trust**

### **INFORMATION SHEET FOR YOUNG PEOPLE (AGED 16+)**

### **UNIVERSITY OF EAST LONDON**

School of Psychology Stratford Campus Water Lane London E15 4LZ

Title of Research: Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views

(about the diagnosis and their experiences).

Name of Researcher: Emma Smith, Trainee Clinical Psychologist

Email address: u1236172@uel.ac.uk

**Contact Number:** 

### Invitation to take part

You are invited to take part in a research study. In order to help you decide whether you would be comfortable taking part, it is important you understand why the research is being done and what taking part would involve. I, or one of my supervisors, is able to meet or have a telephone conversation with you to go through this letter and answer any questions you may have.

### What is the purpose of the study?

The research is being conducted under the supervision of Dr Jenny Jim and Dr Claire Higgins as part of a Professional Doctorate in Clinical Psychology that I am completing at the University of East London. It is also being supervised by Dr Jane McNicholas and Dr Jenny Nicholson at Great Ormond Street Hospital

This study aims to find out about the personal views and experiences of young people/young adults who have been given a diagnosis of Pervasive Refusal Syndrome and their parents' views and experiences.

At present little is known about children and parents' experience of being given a diagnosis, and their experience of treatment of the symptoms and the journey to recovery. It is hoped that young people will be able to help professionals have a better understanding.

A secondary aim of the study is to assess the current mental health functioning of children who have previously been given a diagnosis of Pervasive Refusal Syndrome. This will be achieved using an online measure called the Development and Well Being Assessment (DAWBA).

Version 5.0:20th October 2014



**NHS Foundation Trust** 

### Why have I been invited?

The study is interested in getting young people/young adult's views of the diagnosis of Pervasive Refusal Syndrome, their experience of being given this diagnosis and their experiences of living with the symptoms. It is also interested in young people/young adult's opinions about their care during their illness.

### Do I have to take part?

No, it is up to you to decide whether you would like to take part or not. I or one of my supervisors will describe the study and go through this information sheet with you either in person or over the telephone. You can ask us any questions or share any worries that you might have about taking part. We will do our best to answer them. If you decide to take part we will ask you to sign an assent (consent) form. There will be no consequences if you choose not to take part.

If you agree to take part in the study, it is important that you know that you are free to withdraw from the interview at any time and will not be asked to give a reason. You are also free to withdraw your data from the study up until February 2015. After this date the data will be analysed and written up for examination purposes and possible publication.

### What will happen if I agree to take part?

If you wish to take part please contact me, Emma Smith, via the opt in form, email or telephone.

Prior to the interview you will be asked to read and sign an assent form. Given the nature of the study we can let your GP know that you are taking part in the study if you wish, however you do not have to agree to this to take part. This is included on the assent form.

You will then be asked to take part in a one to one interview. You will be interviewed by me, Jane McNicholas or Jenny Nicholson. The interview will last up to an hour and will take place at a date, time and location which is convenient to you. The interview will be digitally audio recorded and transcribed (typed into text). I will be transcribing all interviews and all information that might identify you (e.g. names and places) will be changed to ensure confidentiality.

The interview will ask questions about your experiences of Pervasive Refusal Syndrome, what you think about the diagnosis and what you thought about the care you received. There is no right or wrong answer as the study is interested in hearing about young people's personal views and experiences.

Following the interview you will be given the option of completing the DAWBA (Development and Well Being Assessment). The DAWBA is a package of interviews, questionnaires and rating techniques designed to assess for the presence of common and less common emotional, behavioural, and hyperactivity disorders. The DAWBA takes between 30 and 50 minutes to complete and can be completed at a time(s) that is convenient for you. Please note that completion of the DAWBA is an optional part of the research.

Version 5.0:20th October 2014



**NHS Foundation Trust** 

After the questionnaires have been completed you will be given the opportunity to discuss the process via telephone with the researcher (Jane McNicholas or Jenny Nicholson) and ask any further questions. The researcher will access the DAWBA outcomes using a secure username and password. Through this log in process the researcher will be aware of when the DAWBA has been completed by you.

If the questionnaires have raised issues for you a discussion about contacting your GP or current local healthcare team will be had and support will be provided to access this.

### Is there anything to be worried about if I take part?

The study is not designed to cause you any harm, discomfort or distress. However, the interview will ask you questions about the time in your life when you were diagnosed with Pervasive Refusal Syndrome and had to receive treatment. It is possible that remembering this period of time may cause you to be upset. Before starting the interview the interviewer will have a conversation with you about how you might let them know if you are feeling upset. The interviewer will also remind you that you can stop the interview at any time. They will ask you how you are feeling during the interview and after the interview to check that you are OK.

I am a Trainee Clinical Psychologist with previous experience of working with children, young people and adults in a mental health setting. Jane McNicholas and Jenny Nicholson have the same experience and are Clinical Psychologists who work at Great Ormond Street Hospital with children and young people. Given our experience, we can safely reply to anyone feeling upset and can speak to your parents/guardians if you would like us to about seeking help from your GP if further help is needed as a result of taking part in this study.

You can also contact the Great Ormond Street Hospital Patient Advice and Liaison Service (PALS). PALS is a free and confidential service which helps patients, parents and carers with any information, concerns, or problems that they have about their NHS care/service. Further information can be found through the following link:

http://www.gosh.nhs.uk/parents-and-visitors/clinical-support-services/pals/

### Will there be any financial costs to taking part?

You will not be paid for taking part in this study. Depending on where you choose to be interviewed there may be travel costs. However, these can be reimbursed if original receipts are brought to the interview. Otherwise, there will be no financial costs to as a result of taking part in this study.

### What are the possible benefits of taking part?

It cannot be promised that the study will help you personally, but the information collected from this study will hopefully help mental health workers have a better understanding of what it is like for a child/young person to be given a diagnosis of Pervasive Refusal Syndrome and what it is like to live with the symptoms.

Version 5.0:20th October 2014



**NHS Foundation Trust** 

### If I take part in the study will my information be kept private and confidential?

Your participation in the study will be kept confidential. Your personal details will be saved separately to the individual answers you give in the interviews and information generated by DAWBA responses. Any information about you or your family (including names and locations) will be removed from the individual descriptions of what you said. Your individual answers to the interviews will be saved as a password protected document and will be saved on a password protected computer, USB and external hard drive. All devices have encryption software installed. The audio recording will also be saved in the same way. The audio recording and transcript will be destroyed after 5 years. Only I, supervisors of this study and examiners will have access to the audio-recording and responses from the interviews. The DAWBA outcomes will be added to a secure, anonymous database at Great Ormond Street Hospital.

If you say something that makes the interviewer worry that there is a risk of harm to you or to others, it may be necessary for them to break confidentiality. This means that they will need to tell other professionals and where applicable your parents/guardians to make sure you are safe and/or others are safe. The interviewer will always try to share this with you first.

### What will happen to the results of the study?

The results of the study will be written up as a research project the course in Clinical Psychology, and will be submitted for an exam. It is also hoped the study will be published in a journal. Quotes and extracts of things you have said may be used in the final research paper however none of your personal details will be used. You can request a summary of what was found once the study has ended.

### Has the study been reviewed and approved?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure the research is safe and fair. This study has been reviewed and approved by the Research Ethics Committee from the University of East London, London – Bromley NRES Committee and Great Ormond Street Hospital.

### What if I have a question or there is a problem?

If you have any questions or worries about the study, you can contact me or a member of the supervisory team. We will do our best to answer your questions.

The supervisory team's contact details are:

Dr Jenny Jim: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4411 or email j.jim@uel.ac.uk

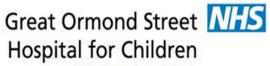
Dr. Claire Higgins: School of Psychology, University of East London, Water Lane, London E15 4LZ

0208 223 4174 or email c.higgins@uel.ac.uk

Dr Jane McNicholas: Department of Child and Adolescent Mental Health Service, Great Ormond Street

Hospital, Great Ormond Street, London, WC1N 3JH 0207 405 9200 or email <u>Jane.McNicholas@gosh.nhs.uk</u>

Version 5.0:20th October 2014





## **NHS Foundation Trust**

Dr Jenny Nicholson: Department of Child and Adolescent Mental Health Service, Great Ormond Street Hospital, Great Ormond Street, London, WC1N 3JH

### **Contact for further information**

If you would like to take part in the study please contact me on:

E-mail: u1236172@uel.ac.uk Telephone:

Thank you for taking the time to read this information sheet. Please keep hold of this information sheet in case you want to look at it again in the future.

Emma Smith Trainee Clinical Psychologist

Version 5.0:20th October 2014





**NHS Foundation Trust** 

# ASSENT FORM FOR YOUNG PEOPLE (AGED 16+)

**Title of Research:** Pervasive Refusal Syndrome (PRS): Perspectives of parents and children

	views (an	out the diagnosis at	nd their experiences).	
Name	of Researcher: Emma	a Smith, Trainee Cli	nical Psychologist	
			Pleas	e tick and initial
				the box
1.		ut the information, ask	neet for the study. I have had any	
2.	I understand that taking at any time, without giving		that I am free to stop taking part	
3.	I understand that compleand is optional.	etion of the DAWBA is	s a secondary aim of the study	
4.	I understand that any intonly be used anonymou	formation that I give w sly in any written worl	vill be kept confidential and will cor publications.	
5.	I agree to the interview I understand that the rec	peing audio recorded cording will be deleted	and typed up by the researcher.  I once the study has ended.	
6.	may be looked at by ind	ividuals from regulato nt to my taking part in	a collected during the study, ry authorities or from the NHS this research. I give permission cords.	
7.	I agree to take part in th	e study.		
8.	I would like my GP to be that this is not a requirer		part in this study. [Please note is study]	
Your Na	ame	Date	Signature	
	of Researcher	Date	Signature	
Version	5.0:20th October 2014			



Department of Child and Adolescent Mental Health Great Ormond Street Hospital for Children NHS Foundation Trust Great Ormond Street London WC1N 3JH

November 2014

Dear X.

I am writing to invite you to take part in a piece of research that is being undertaken by Great Ormond Street Hospital and the University of East London.

The study will be exploring the perspectives of parents/guardians and children about the diagnosis of Pervasive Refusal Syndrome and their experiences. It is hoped that this study will help professionals have a better understanding of what it is like to be given this diagnosis, be treated for the symptoms and what the journey to recovery is like. It will also help inform future interventions and care packages offered to children and their families.

Parents/guardians and children are also invited to complete the Development and Well Being Assessment (DAWBA) which is an online package of questionnaires which looks at common emotional, behavioural and hyperactivity disorders. The purpose of this part of the research is to help determine the long term psychological impact a diagnosis of Pervasive Refusal Syndrome has to help further inform future interventions and care packages.

Please find enclosed a pack which contains an information sheet and consent form which provides a detailed overview of the study and what participation would involve. An unsealed envelope is also included with this letter; this contains an information sheet and consent form for your son/daughter. Please can you pass this on to your son/daughter so they are able to decide whether they would like to take part. You can participate in the study without your son/daughter participating. Similarly, your son/daughter can participate in the study without your participation.

Thank you for taking time to read this letter and the information enclosed. I wish you and your family the best for the future.

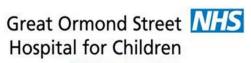
Word of Mouth Covering Letter to Participants (parents with children over 16) – Version  $3.0-20^{\rm th}$  October 2014



Yours Sincerely,

Emma Smith Trainee Clinical Psychologist
Please tear and return in the self-addressed pre-paid envelope   ≥
Title of Research: Pervasive Refusal Syndrome (PRS): Perspectives of parents and children views (about the diagnosis and their experiences).
Name:
Please tick and initial one of the following:
I would <b>not like</b> to participate in this study and do not want to be contacted
*I would like to find out more about this study and agree to be contacted
*I would like to participate in this study and agree to be contacted
*If you have agreed to be contacted <b>please provide a contact number or email address</b> below:
Word of Mouth Covering Letter to Participants (parents with children over 16) – Version $3.0-20^{\rm th}$ October 2014

### APPENDIX U: Word of Mouth Covering Letter for Young People Aged Over 16



**NHS Foundation Trust** 

Department of Child and Adolescent Mental Health Great Ormond Street Hospital for Children NHS Foundation Trust Great Ormond Street London WC1N 3JH

November 2014

Dear X,

I am writing to invite you to take part in a piece of research that is being undertaken by Great Ormond Street Hospital and the University of East London.

The study will be exploring the perspectives of children/young people and their parents/guardians about the diagnosis of Pervasive Refusal Syndrome and their experiences. It is hoped that this study will help professionals have a better understanding of what it is like to be given this diagnosis, be treated for the symptoms and what the journey to recovery is like. It will also help inform future interventions and care packages offered to children and their families.

Parents/guardians and children/young people are also invited to complete the Development and Well Being Assessment (DAWBA) which is an online package of questionnaires which looks at common emotional, behavioural and hyperactivity disorders. The purpose of this part of the research is to help determine the long term psychological impact a diagnosis of Pervasive Refusal Syndrome has to help further inform future interventions and care packages.

Please find enclosed a pack which contains an information sheet and consent form which provides a detailed overview of the study and what participation would involve. You can participate in the study without your parent/guardian participating. Similarly, your parent/guardian can participate in the study without your participation.

Thank you for taking time to read this letter and the information enclosed. I wish you and your family the best for the future.

Yours Sincerely,

Word of Mouth Covering Letter to Participants (young people over 16) – Version  $2.0-20^{\rm th}$  October 2014



### **Emma Smith** Trainee Clinical Psychologist

ase tear and return in the self-addressed pre-paid envelope
e of Research: Pervasive Refusal Syndrome (PRS): Perspectives of parents and dren views (about the diagnosis and their experiences).
ne:
ase tick and initial one of the following:
ould <b>not like</b> to participate in this study and do not want to be contacted
ould <b>like to find out more</b> about this study and agree to be contacted
ould <b>like to participate</b> in this study and agree to be contacted
ou have agreed to be contacted <b>please provide a contact number or email address</b> w:
d of Mouth Covering Letter to Participants (young people over 16) – Version 2.0 – 20 <sup>th</sup> October
4

# **APPENDIX X: Confirmation of Change of Thesis Title**



Emma Smith



Date: 27th March 2015

Student number: 1236172

Dear Emma Smith

### Notification of a Change of Thesis Title:

I am pleased to inform you that the School Research Degree Sub-Committee has approved the change of thesis title. Both the old and new thesis titles are set out below:

Old thesis title: Pervasive Refusal Syndrome (PRS): Prospective of parents and children views (about diagnosis and their experiences

New thesis title: Fighting the invisible enemy: being a parent of a child who has been given a diagnosis of Pervasive Refusal Syndrome

Your registration period remains unchanged. Please contact me if you have any further queries with regards to this matter.

Yours sincerely,

Dr Kenneth Gannon

School Research Degrees Leader Direct line: 020 8223 4576 Email: k.n.gannon@uel.ac.uk

### **APPENDIX Y: GP Letter - Notification of Participation**



Department of Child and Adolescent Mental Health Great Ormond Street Hospital for Children NHS Foundation Trust Great Ormond Street London WC1N 3JH

GP NAME GP SURGERY ADDRESS DATE

Dear Dr X,

RE: NAME OF PARTICIPANT
DATE OF BIRTH
ADDRESS
NHS no. (If known by participant)

I am writing to inform you that **NAME OF PARTICIPANT** has agreed to participate in a piece of research being undertaken by Great Ormond Street Hospital and the University of East London. The study aims to explore the perspectives of children/young people and their parents/guardians about the diagnosis of Pervasive Refusal Syndrome and their experiences. It is hoped that this study will help professionals have a better understanding of what it is like to be given this diagnosis, be treated for the symptoms and what the journey to recovery is like. It will also help inform future interventions and care packages offered to children and their families.

Participation involved **NAME OF PARTICIPANT** taking part in a one to one interview in which questions surrounded how he/she made sense of their /their son/daughter's experiences, what it was like when they/their son/daughter received the diagnosis of Pervasive Refusal Syndrome, their thoughts on the diagnosis and what they thought about the care they/their son/daughter received. **NAME OF PARTICIPANT** also agreed to complete the Development and Well Being Assessment (DAWBA) online, at his/her convenience following the interview.

Given the sensitive nature of this research topic it is possible that remembering this period of time may be upsetting. In the event that **NAME OF PARTICIPANT** should require extra support as a result of taking part in this study, I have advised them to make contact with you in the first instance.

Yours Sincerely,

Emma Smith Trainee Clinical Psychologist University of East London Dr Jane McNicholas Clinical Psychologist Mildred Creak Unit Dr Jenny Nicholson Clinical Psychologist Mildred Creak Unit

Letter to GP advising of study participation – Version 2.0 – 20th October 2014

### **INTERVIEW PROTOCOL**

#### Prior to the interview

#### Checklist:

 Read through the information sheet with the participant and discuss any questions and/or concerns.

Remind the participant of:

- o Anonymity all names will be changed and identifiable information anonymised.
- They can withdraw from the study at any time prior to February 2015 and without giving a reason.
- Audio recording and transcripts will be deleted after five years post completion.
- A summary of the findings can be sent post completion if they would like.
- Read through the consent form with the participant and discuss any questions and/or concerns before they sign.

Ensure that:

- o The check box is ticked and initialled
- The contact details of their GP are obtained, should they want their GP to be advised of their participation

#### Opening:

When setting up the interview inform the participant of the following:

- The interview will last for approximately an hour but, if towards the end of the hour, it seems the interview could last a little longer this is okay. We can see how we get on.
- They are welcome to take breaks e.g. comfort breaks or if they become upset during the conversation.
- The interview is set up a little like a one sided chat. They will be asked some questions to
  open up conversation but as this is a chance to hear about their views and experiences
  so you shall mostly be listening. Explain that you may follow up on things by asking
  questions that seem silly or obvious, but you need to ask these to ensure that you are not
  assuming meaning and to make sure that you have fully understood.
- They are free to share as little or as much as they feel comfortable with. There are no right or wrong answers. If there are questions that they do not want to answer that is okay and encourage them to let you know. Emphasise that they can take their time.
- Acknowledge that given the nature of the conversation sensitive issues may come up.
  - Discuss how the participant might let you know that they want to end the conversation or stop the interview (e.g. perhaps through a use of a word or gesture).
  - Advise the participant that should they feel like they need future support after the
    interview that they can contact their GP, GOSH PALS (details of which on the
    information sheet) etc. Remind the participant that there will be a debrief at the
    end of the interview to check in on how they are feeling.
- Ask the participant if it is okay to take notes. Explain that it can be helpful to make notes
  during the interview to remind you of important things that they have said that you think it
  might be useful to return to or to clarify.
- Finally, acknowledge that it's a lot of information to take in and ask them whether they have any questions or concerns. Ask if they are happy to begin the interview.

Interview protocol: Version 1.0 December 2014 (Interview Schedule Version 3.0: 8<sup>th</sup> December 2014)

### Interview Schedule

- Can you tell me about how your son/daughter came to be diagnosed with Pervasive Refusal Syndrome (PRS)?
- 2. Going back to when your son/daughter was first diagnosed with PRS, do you remember what that experience was like for you as a parent?

PROMPTS: Can you remember what thoughts were running through your head?

How did you feel?

What were the stages involved in getting the diagnosis?

3. How was it decided what treatment and care your son/daughter would receive? PROMPTS: How did you feel about that decision?

What were your thoughts about the treatment/support offered?

4. What was it like to go through the treatment process with your son/daughter?

PROMPTS: What, if anything, made this easier?

What, if anything, made this more difficult?

How did you feel?

5. Did you discuss your experiences and/or the diagnosis with anyone?

(E.g. partner/friends/family/son or daughter's school?)

PROMPTS: If yes, what were your reasons for choosing to discuss it with them? How was it to talk with them?

If no, what were your reasons for choosing not to discuss it with them?

6. What impact, if any, do you think your son/daughter's experiences have had on you? PROMPTS: If had an impact, how? Why?

If not had an impact, why do you think this is?

- 7. Do you have any ideas about why your son/daughter started to have these experiences?
- 8. What do you think about the diagnosis now?
- 9. Is there anything important that we have not spoken about that you would like to mention?

\*NOTE: At the end of the interview let the participant know that you will move onto de-briefing to talk about their experience of the interview and how they are feeling. Give participants an option to decide whether they would like to turn the tape off or have it remain on during the de-brief, explain the rationale that often conversations may continue whilst de-briefing which is why you are asking.

Interview protocol: Version 1.0 December 2014 (Interview Schedule Version 3.0: 8<sup>th</sup> December 2014)

### Post Interview

### De-briefing:

- Ask the participant how they found the interview.
  - Was there anything that came up unexpectedly or perhaps were there things they were expecting to talk about but didn't come up?
- Ask the participant how they are feeling.
  - o Discuss forms of support available and take appropriate action if necessary
- Explain what will happen next with regards to data and results: a summary will be available after examination (late summer).
- Encourage the participant to make contact with you or members of the supervisory team should they have any questions or concerns with regards to their involvement.
- Thank them for sharing their story with you.

Interview protocol: Version 1.0 December 2014 (Interview Schedule Version 3.0: 8<sup>th</sup> December 2014)

# **APPENDIX AA: Transcription System**

# **Transcription System** 1: Interviewer F: Initial denoting the participant's name (pseudonym) and used to indicate when they are speaking Interruption or overlap in conversation [ ] Indicates nonverbal activity (e.g. crying, a gesture, or movement) ( ) Indicates inaudible utterance or muffled sound A short pause (5 seconds or less) Indicates a long pause (6 seconds or more) XXXX Indicates anonymised information (e.g. dates, locations, and names). Punctuation Employed to aid reading

**APPENDIX BB: Example of an Annotated Transcript (Page 1)** 

Emergent Themes	Transcript [Carla]	Exploratory Coding
physical lithurs	Okay so can you tell me how it was that your daughter came to be     diagnosed with Pervasive Refusal Syndrome?     C: My daughter got ill physically ill in about the February post half term	child became physically ill
Illness active and in control Profitusive illness	unition years of time years ago how and mushly to presented like a cold um and she's had allergies so we thought maybe it's that, but it went on. And it started to do other things. So where it was a cold initially to became, it became pains, and then it became erm it became just sort of like, she'd sort of feel like she was in bad pain and it was a cold and a courb, And it could have been we sort of	Phreise suggests illness in codes and active. Physical poin
Seehing medical help	thought "Is it pneumonia or is there something else going on?" So we went to the Doctors and of course it was just a GP so he said its just, it's just a cold, it's a virus blah blah blah. And then she didn't go to school because she didn't feel well enough to go to school. And	restring help from 6P ness got in the way of school .
Stages of iduces	we thought it was a chest infection so we'd been getting antibiotics. It and things like that. But then it got to the stage, if I'm sort of remembering correctly, where she thought she couldn't breathe and 17 that kind of thing. She was up in the night. Erm and she was getting that we took her to erm the Doctors again, so we were	Medication modern medication intermedication interior stages
Sections medical halp	to-ing and fro-ing to the Doctors. But <u>one time they did actually lea</u> an ambulance and she went to hospital and they checked her over because of this cough and all everything. Because they were concerned about that. But then she came home again. Then we were I said well I'd like her to see the chest physician at our local	Continuosly seeking medical help suggests that Dis June, missing the such of the whole but a die occion teached professionals concerned, and Dr - hospital - home partien administration Cavidening and one mes, seeking varied help.
Obstacle to gaining access	24 hospital that runs the sort of asthma clinic because she's seen her 25 when she was small like all kids do when they've got you know. 26 'But of course we didn't have an open appointment still because we 27 were no longer on medication.	Sarcasm indicating the bureaucrous
Personal enuchanal impact Need to Kinus What's gring an		Euphosis on feeling desperate Need to know couse / find an explanation To more official perhaps? focused on good?
		1

APPENDIX BB: Example of an Annotated Transcript (Page 7)

	Emergent Themes		Transcript [Carla]	Exploratory Coding
All S	Anthavolence to Specialist trup	199 200 201 202 203 ::	was there it existed for me as like [exhales] when we get to that point fleedssured Splicialist belo was evaluable. A but just thought "No" for now, do you see what I mean? I felt regal a but just thought "No" for now, do you see what I mean? I felt comforted by seeing it but I didn't want this, didn't want it. So what he physe were told Can Just? happened is that we were told Can Just? A how, Sure sure, Yep.	ciolist help was available is obidunt want thougs to progress
ું કુ. જુ.	Obstaces to access			505H avoidable, issues with
C#	Feching	212 213 214 215 215 217 217	an eating disorder, it mimicked it and I had it explained to me at some point but it wasn't about that and so then I just thought "Well we've got to come here." And so I actually said "Don't worry about that we'll Pushing to get that funding." So he said "In the mean time you'll have to go and get that funding." So he said "In the mean time you'll have to go to your local general hospital and they will take care of feeding and everything." And I didn't know what he meant and the time. I just Not knowing what he would be like a [Laughs]	pushing to get furting to others Gost. We'll = perfectls posting for it. Moving what was meant by tenu feelig.
-	family Support.	219 220 221 222	roast dinner or something, I dunno. So anyway then we were going to the hospital due to needs the hospital due to needs. The hospital, then we were effectively living at the hospital. So when his of hospital due to the we got there, you know it was, we carried her, My Dad carried her. Support from her own forther in and we got to the. You know what it's like when you get to the desk	d hespital due-to needs.
Ö	Obstacle of Accounced	223 224 225 226	and they're like "Yes." You know and they want to give you you're colour and everything and you're sort of up again! So I said "We are Up agains and everything and you're sort of up again! So I said "We are Up agains appeared." Oh right well we'll ring the ward. Well go and wait over Us yours there." And I said "Well she's going to need a wheelchair because she's	phan steff: their agendic
Professi Kuna	Professionals madelining	227 228 229 230 231	not walking." And like "Ooh." So it was all like that and all that like um farhage furshouted weeking another obstruct.  "Argh!" And then um a brilliant male nurse sort of come over and he treathered.  "Cause that was another indication he went "Oh hi Candice! Right do heart the clue, invight, whooled of hear things you want a drink? I'm having a drink." Drink but didn't really drink it was another like "Oh yeah" so it was like okay yeah. And um they ferrops reculation of the approach.	aright, wholed of how things in the ward.

APPENDIX BB: Example of an Annotated Transcript (Page 13)

Emergent Themes		Transcript [Carla] Exploratory Coding	
Illness having cooped	397 398 399 400	he's done something and he's really on the back foot about it that phrase welfagles: clauded is being held in really lead don't keep saying to him "Oh you shouldn't have done it"  Just give him, give him an out. Almost like a hostage situation allow them the come out, start over. And um … that was, that was tough.  Because I thought the day of this assessment would be the day we were	id uiving es oner.
Emchacol impact	403 404 405	allowed to come you know but they said no you're only going for the assessment. And when they said that I thought I was going to collapse. In pact of finaling out dampter world. And it would be another week before we could come here. And but NOT be colouristical increasing the when we did come there, we came up and going back was hard, because	ter conta
N6 dube	406 407 408 409 410	we had to go back to the general hospital but we had a week to site to out. Octoberate, parkent watching But what I remember about then was there was a certain smell of my aughter then but it was the feed. That's just how they smell for a long time. Outside of survey of survey of survey so out know it felt different. And then we came here and they did the change of short of the change is one outstanding amount of people, well a big amount.	meed on distrib
Recovery	411 412 413 414 415	to me but [begins to cry] I think I get upset not because that it was frightening or anything like that but it's just sort of the power of the recovery fectually were proverful, harder the that's the thing that's almost harder to <u>rationalise</u> than the actual illness if the control of the provest that makes sense. So you can, so you can Because she came in, then things suchedly, without observe cause?	color to ss.
	416 417 418 420 421 422 423	there's a kitchen, there's a you know? And you know the truth of it is that you'get quite sort of pacified by the fact that there's other ill children and other desperate parents. Because there were a couple of people who said we saw you on the first day. But I can't remember what they looked like but that would be totally in keeping with not really looking at anyone. But um leaving her was hard. Because of all the weird places you go out, I mean we hadn't been to lunch together for ages but we ended up out to lunch in blooky Carluccios' and we, the plan was to come back. But she was so	dere to
Shuthere in Averthern	424 425 426 427 428	distressed when we left her that we couldn't back because I thought it would be too upsetting so we went home. But the thing that worked for us was that the thing that worked for us was that then was structure. Like when I was at the other place I was there constantly, shuchive was happen to a solution was gone ended and all this. But when it by backence. We have not come on this day it was, like the days that you didn't was like oh you can only come on this day it was, like the days that you didn't	heine
Coping	429	come were just like space you could just like be in and you knew she was safe. Space from illuers, clause ter, lart also perhaps space to re-convect with whilst humans often family 13 convect the work of was some save perhaps.	ene, ter, c, gave

# APPENDIX BB: Example of an Annotated Transcript (Page 19)

	<b>Emergent Themes</b>		Transcript [Carla]
	Illness is on condred	595 596 597	that anything is beyond your control, but that was. And I think a lot of parents lillwiss beyond their corders.  must experience that. Because I was thinking we were alright, I thought we were doing alright but no. So you have to be a bit more receptive and that Se. Gen / Resplice to indeed they things
	prothetegical insport	598	kind of thing. But yeah I'm not born again or anything about it but I'm Oreal F of year see them  Has because were understanding of other people's problems.  Year Year What do wit think about the diagnosts now, PRS?
	Dicaposis as	601 602 603 604	n a much bigg nce of bits of it someone has
		606 607 608	C: Not to the stage where you're so in manic mode or whatever but I just think have executed of his policy.  I don't know I just think I'm not saying that we could have helped Candice (guidan't have helped on our own. I don't believe that for one minute. She had to be helped not by olders.
	Cause ferplanation	609 610 611	us because it felt quite manipulative. That's why it almost feels like a teenage "free of the seed of
	Descriptive olx	613 614 615 616 617 618	the funny thing is whenever I see, I knew I was getting alright about it because the funny thing is whenever I see, I knew I was getting alright about it because the funny thing is whenever I see, I knew I was getting alright about I because the performance what is it? Oh I can't remember what it's called but I read it and it didn't frighten me. And I just thought "Oh yeah that's what you have to pay for for the radio" And then I thought "Oh I thought of that first rather than the radio" and then I thought of that was, that was like thought of not being able to do anything!" So that was, that was like thought of the control
	Explanation franc professional helpful. Working to lawn who	619 620 621 622 623 624 625	a breakthrough for me in the dentist. But the other thing is the way that it was explained to us in that the way that it would recede in the way that it so the control of the form if you like. All the I retended the shape the start happening. All the way that to look out for the form, how it all manifested itself then we did know what to look out for the follow, how it all manifested itself then we did know what to look out for when things did start happening. And I found that comforting but it was control of the way back she stopped walking and that was likebut that was
	Recovery or journey	626	okay and <u>you get to the point where you're able to say well that is okay</u> . So you're being officed to the grant part of the process of the p
- 1			

# APPENDIX CC: Example of a Single Case Analysis - Carla

Subordinate Theme	Emerging Themes (plus key words/phrases)	Page & Line Numbers
Support	Family and friends being part of it	p11, 338
	brother in law	p2, 60
	Paid carers to provide practical support	p4, 107
	dad (grandfather)	p7, 221
	Support from partner worked as a team	p6, 172: p12,336
	Lack of support - no one was helping me or doing anything	p9, 267
	nurses provided emotional support : they had a bit more time for you	p9-10, 293-300: p8, 262
	best friend	p11,360
	parents (grandparents)	p14,437-438: p15, 475-476
	Support from teacher: I couldn't have functioned without the teacher, he became like my husband	p22, 701-702
	Seeking support from staff after discharge - I think that was more for me not her.	p20, 637-638
Intrapsychic Impact	Emotional impact - for me it was really really painful	p18, 577
	I was getting pretty desperate at this stage to know what was going on	p1,29-30
	I'm going to get sad but its not because I'm sad it was just an overwhelming feeling	p4, 110-111
	It was so awful to hear [] it was distressing for me	p5, 152-156
	Regulating emotions: I had to sort of keep a lid on it I think because it was really distressing	p6,178-179
	Horror: Easter was horrific	p6, 179
	I felt really all at sea	p6,193
	Change in thinking: once I got in that mind set	p9, 275
	Identifies emotionally with other parents: other desperate parents	p13,418
	Impact on ability to function/think: I wasn't firing on all cylinders	p14,435
	Angry at myself	p14,435
	Ability to tolerate the reality of situation: Hearing something that's factual and bare and raw [] Argh!	p15, 487-489
	Personal growth: I'm more understanding of other people's problems	p17, 530, 555-557 p19,598- 599
Distress in the family	parental distress: my mum and dad sort of internalised it	p11,350
	sibling distress	p5, 156-158
Coping	Structure and routine: 'rhyme and reason'	p3, 83-84: p13, 425 - 429
	Carrying on	p6, 179 - 181
	Time away/Space 'to be' in	p13, 429
Changing roles	Parent as carer	p8-9, 264-268
	Parent as enforcer	p3, 78-79, 85-87
	Parent as part of a team with family/friends: 'we started taking on the job sort of role'	p14, 436-438
	Parent as enemy: 'that she would try to defy us'	p16, 506

Being frank and forceful to make things happen p1-2,31-42:  Influence of professional on gaining access to services: I think he must have strong armed our local hospital to take us.  Searching for answers  Seeking medical advice p1, 11, 18-2  Wanting to know what's wrong p1, 30:  Questioning cause: hormonal component, parents to blame, good genetic mix up p1, 593-594  Open to multiplicity of causes p18, 566-56  Trying to understand: she's found solace in this illness: language she was saying had to be almost interpreted that's how I read it, its almost like a p19, 609-61	: p3, 91-94 4 25 118, 568-574, 67 p5, 154-156: p17,
Influence of professional on gaining access to services: I think he must have strong armed our local hospital to take us.  Searching for answers  Seeking medical advice  Wanting to know what's wrong  Questioning cause: hormonal component, parents to blame, good genetic mix up  Open to multiplicity of causes  Trying to understand: she's found solace in this illness: language she was saying had to be almost interpreted that's how I read it, its almost like a  p8, 233-234  p1, 11, 18-2  p1, 30:  p17, 539: p  p18, 566-56  p18, 566-56  p19, 61-67: p  p2, 61-67: p  p19, 609-61	25 018, 568-574, 67 p5, 154-156: p17,
services: I think he must have strong armed our local hospital to take us.  Searching for answers  Seeking medical advice  Wanting to know what's wrong  Questioning cause: hormonal component, parents to blame, good genetic mix up  Open to multiplicity of causes  Trying to understand: she's found solace in this illness: language she was saying had to be almost interpreted that's how I read it, its almost like a  p1, 11, 18-2  p17, 539: p  593-594  p18, 566-56  p2, 61-67: p  535-542	25 018, 568-574, 67 p5, 154-156: p17,
Wanting to know what's wrong p1, 30:  Questioning cause: hormonal component, parents to blame, good genetic mix up 593-594  Open to multiplicity of causes p18, 566-56  Trying to understand: she's found solace in this illness: language she was saying had to be almost interpreted that's how I read it, its almost like a p19, 609-61	67 p5, 154-156: p17,
Questioning cause: hormonal component, parents to blame, good genetic mix up 593-594  Open to multiplicity of causes p18, 566-56  Trying to understand: she's found solace in this illness: language she was saying had to be almost interpreted that's how I read it, its almost like a p19, 609-61	67 p5, 154-156: p17,
to blame, good genetic mix up  Open to multiplicity of causes  Trying to understand: she's found solace in this illness: language she was saying had to be almost interpreted that's how I read it, its almost like a  p18, 566-56  p2, 61-67: p 535-542  p19, 609-61	67 p5, 154-156: p17,
Trying to understand: she's found solace in this illness: language she was saying had to be almost interpreted that's how I read it, its almost like a p19, 609-61	p5, 154-156: p17,
illness: language she was saying had to be almost interpreted that's how I read it, its almost like a p19, 609-61	
p15,005 01	10
teenage disease	
Ambivalence towards knowledge of PRS  Specialist support as an indication of severity: I felt comforted by seeing it but I didn't want this, didn't want it	<u> </u>
Decision not to look up information P10-11, 330	0-335
Reassurance seeking: I remembered the word yes [that child would get better] and long recovery	4
Responsibility given to others to read information and feedback only positive aspects: its like giving someone a film and saying has it got a happy ending?: I couldn't read it [] but in my head I was curious [] just tell me bits.	78: p15, 464-470
Wanting to know: I wanted to grab hold of them p12, 386-38 and ask them loads of questions	88
Knowledge of what to look out for was comforting p19, 619-62	24
Small digestible amounts of information made it alright: 'I was getting clues', 'it was like people were	6
feeding me what was going to be alright'  Impact of NG Tube  No expectations: I didn't know what it would be like [Laughs]: it never crossed my mind, it was a surprise	3, 243, 257
Procedure distressing for child p8, 240-248	8
Emotional impact: quite shocking, really upset p8, 249-252	2
NG tube marking a stage of severity: we're in this whole new world of feeding	3
Physical consequences: certain smell of my daughter, but it was the feed []it felt different.	09
Vitality of PRS  Illness active and in control: 'it started to do other things': you just don't think that anything it beyond your control, but that was'  p1,06: p18,	, 594-596
Need to challenge not collude with illness: ' you p5, 164-165 sort of needed her to be challenged but not in a cruel way'	5
funny game you have to play with it': like a hostage situation allow them to come out and start	8: p13, 399-400
over.  Inevitability of moving through stages of illness p19, 620-62	23: p1, 06-18
Utility of PRS diagnosis  Irrelevance of diagnostic label: 'it's just a few words tacked together to explain a much bigger complex thing': 'it was just a description of what it did'	

Subordinate Theme	Emerging Themes (plus key words/phrases)	Page & Line Numbers
	Did not want label to form part of child's identity	p20, 629-632
	Diagnosis signified professional knowledge and informed treatment: you thought someone knows what's going on here	p4, 116-120: p1, 327-328
Recovery	Maintaining bonds and connections to life: 'what we had to do was bring her life here and that's what we did': it was still hub-bubby and busy around her	p16,518-525: p11, 354-355: p5, 132-134
	Recovery as a journey: 'long route': 'road to recovery but its not straight'	p2, 57: p19-20, 627-628
	Role of other children/peers: That peer thing can't be underestimated I don't think.	p6, 168: p22,713-715, 718- 719
	Glimpses of the features of recovery: 'I sort of had another flash that would be part of it': 'bursts of light [] I thought actually that makes sense in the non-sense'	p10, 320-321: p6, 170-171
	Recovery more powerful than illness: harder to rationalise than the illness: you think blimey!	p13, 412-414: p18, 577-578
	Recovery as a process: 'you'd start getting little snippets' : a rebirth	p16, 497-499: p17,552-554
	Recovering together: 'when we started recovering and I say we because it was like that'	p18,578-579
Managing others	Telling others: parents, family, best friend: 'told	
	school much as needed to [] didn't want them blabbing on: only told people that needed to know	p5, 138-139: p11, 338-349, 359-360
	Impact of telling: people really interrogate you or	p5, 141-145: p9, 288-292
	[] don't get involved', 'on a hunt' to know : GOSH as the 'magic word [] they just think oh fuck and they deal with you differently	
	The witnessing other: 'really aware of people	p3, 87-91: p9,278-279
	watching us': 'everyone around you thinks you've got the most compromised child': she came in like a baby [] that's what he saw in his professional capacity: 'we were like the novelty act'	p12, 390-394: p8, 235
Building the therapeutic relationship	Trust in approach: I subscribed sort of signed up to it immediately [] complete utter faith [] completely immerse ourselves in it	p14, 449-460
	Sense of safety: 'I felt safe there (hospital) : you knew she was safe	p3, 72-73: p13, 429
	Collaborative endeavour between parent and team:	
	'this is what we're going to do' : 'we're going to lead Candice out of this with dignity'	p4, 124-125: p12, 394-395: p16, 503-507
	Professionals as knowledgeable and experts: 'I'm	p22, 694-697
	their Mum, not their nurse, their chiropractor, play therapist [] I'm actually going to be shit at this	p2, 55-56: p11,333-335
	Professionals modelling approach: 'that was another indication'	p4. 112-113: p7, 228-231

# APPENDIX CC: Example of a Single Case Analysis - Carla

Superordinate Themes	Subordinate Themes
Individual Impact	Intrapsychic
	Changing roles
Services and Treatment	Negotiating Services
	Building the therapeutic relationship
	Recovery
Knowledge	Searching for answers
	Ambivalence towards knowledge of PRS
	Vitality of PRS
	Utility of the diagnosis of PRS
Personal and external resources	Coping
	Support
Difficult Aspects	Distress in family
	Impact of NG Tube
	Managing others

**APPENDIX DD: Final Superordinate and Subordinate Themes** 

