Doctorate in Clinical Psychology: Main Research Portfolio

Cara Roberts-Collins

Doctorate in Clinical Psychology

University of Bath
Department of Psychology

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Main Project Abstract

Exploring the Prerequisite Skills for Cognitive Behavioural Therapy: Relationship to Emotion Awareness and Treatment Outcome for Young People with Autism Spectrum Disorders

Young people (YP) with Autism Spectrum Disorders (ASD) experience high levels of anxiety and depression. The NICE guidelines (2013) suggest adapted Cognitive Behaviour Therapy (CBT) for such difficulties. Research has identified prerequisites to engage in CBT, including the ability to understand thoughts, feelings and behaviours. In order to employ these skills, people need to have an awareness of their own emotions, and to be socialised to (or understand) the CBT model. However, there is no evidence to suggest whether prerequisite skills and emotion awareness are important factors in CBT outcome for YP with ASD. This study aimed to explore differences in emotion awareness between: 1) YP with ASD and controls; and 2) YP with ASD with and without prior experience of CBT; and 3) whether emotion awareness and cognitive competencies for CBT were related to treatment outcome.

Three groups of YP (aged 11-20 years old) took part in the study; those without ASD who had not had CBT (n=50), those with ASD who had not participated in CBT (n=23), and those with ASD who had taken part in CBT (n=27). All participants completed the Emotion Awareness Questionnaire (EAQ-30). A novel CBT skills task was developed and piloted by 14 YP with a diagnosis of ASD who had taken part in CBT. They also completed an interview about CBT and psychoeducation, and clinicians rated socialisation and therapeutic outcome. On the EAQ-30, those with ASD scored significantly lower than the control group on four subscales. Those with ASD who had attended CBT scored significantly lower on Differentiating Emotions and higher on Attending to Others’ Emotions. On the CBT task, participants could identify a greater number of feelings than thoughts or behaviours, and could link them together. Performance on the CBT task was not significantly related to outcome, socialisation, or psychoeducation. However, 85.7% reported a positive experience of CBT. This is the first study to examine the prerequisite skills for CBT and recognition of own emotions in adolescents with ASD. It highlights the importance of tailoring CBT and ensuring YP are taught about understanding their own emotions.
Service Improvement Project Abstract

Promoting Positive Coping and Self-management in Patients Undertaking Cardiac Catheterisation: Learning from Health Professionals

Pulmonary Arterial Hypertension (PAH) is a life limiting and debilitating condition associated with high levels of anxiety and depression. Cardiac catheterization (CATH) is a procedure used to diagnose PAH and to monitor treatment. Research suggests that the procedure can be anxiety provoking and stressful for patients, but no research to date has examined health professional’s perspectives and the key role they play in providing psychological support to patients. This study aimed to explore the way in which professionals understand and promote positive coping and self-management in patients undertaking CATH, their beliefs around the psychological impact of the procedure, and their confidence in providing such support. Based on this information, the study aimed to give recommendations for service improvement. Leventhal, Meyer and Narenz’s (1980) Self-Regulatory Model (SRM) of illness perceptions was used as a theoretical framework to design a semi-structured interview. Ten key health professionals from respiratory Pulmonary Hypertension and CATH teams were interviewed. This included Clinical Nurse Specialists and Consultant Physicians. Interviews were analysed qualitatively using thematic analysis (Braun & Clarke, 2006), resulting in four super-ordinate themes: (1) acknowledging individual differences; (2) a journey; (3) the patient/staff relationship; and (4) information and understanding. Professionals recognised the importance of gauging individuals’ previous experiences of illness and medical procedures, the practical and emotional journey experienced by both professionals and patients, the importance of developing a positive relationship with the patient, and ensuring openness and honesty about the procedure at each stage. Based on these findings specific recommendations were made to the service including the development of a patient leaflet, a patient ‘passport’, and a hospital based video. This research has important implications for increasing patient control, choice and positive coping for patients who find the CATH procedure more difficult to cope with.
Critical Review of the Literature Abstract

The experience of stigma for older adults with a diagnosis of HIV in the United Kingdom: a meta-synthesis

The number of older adults with a diagnosis of HIV has grown significantly in recent years. Research suggests that people living with HIV experience high levels of HIV-related stigma and discrimination (National Aids Trust, 2013). However, how ageing and HIV related stigma connect has only recently been examined. This review aimed to synthesise the stigma literature on the population of older adults with a diagnosis of HIV in the United Kingdom. Electronic databases were searched for published papers, resulting in five studies that met the inclusion criteria. Key data was extracted from these papers and synthesised using qualitative thematic analysis (Braun & Clarke, 2006). Five main themes were identified as important for older adults with a diagnosis of HIV: 1) the HIV community; 2) the impact of HIV; 3) discrimination, judgement and managing disclosure; 4) age; and 5) the future. These themes are similar to those identified for the younger population of people with HIV; however it is proposed that these themes could be more pertinent for older adults who may also experience ageism and generally have higher levels of isolation, loneliness and health concerns. A conceptual model of perceived stigma for older adults with HIV is developed, implications for clinicians working with older adults and people with HIV are discussed and key gaps in the literature are identified for future research.
Critical Review of the Literature - The Experience of Stigma for Older Adults with a Diagnosis of HIV in the United Kingdom: a Meta-Synthesis

Cara Roberts-Collins (email: c.roberts-collins@bath.ac.uk)

Word count (excluding tables, figures and references): 7403

December 2015

Internal supervisor: Dr Catherine Butler

Target journal: AIDS Care, impact factor 2.095. This journal publishes work focussing on the psychological and socio-medical aspects of AIDS/HIV, including reviews and qualitative research (see Appendix 1 for the Instructions to Authors).
Introduction

“… I feel I am the one who has been left to turn the light out at the end of the party.”
(Single gay white British male, aged 61, diagnosed for 12 years)

Ageing with HIV

The number of people living with HIV (PLWH) aged 65 plus “has grown tenfold in the past 10 years” (Gebo & Justice, 2009). Public Health England report that in the United Kingdom (UK) one in six HIV positive people is now over 55 years of age (Skingsley et al., 2015). In 2014, 48% of people receiving care for HIV in the UK were aged 45 and over, compared to 25% in the last 10 years (Skingsley et al., 2015). Additionally, new diagnoses in the UK have nearly doubled among older adults, from 16% of all new cases in 2005 to 30% in 2014 (Skingsley et al., 2015) (see Figure 1). This includes increases in newly diagnosed heterosexual men and women aged 50 plus, from 1 in 14 in 2004 to 1 in 5 in 2013 (Yin et al., 2014).

This significant rise in diagnosis is thought to be due to continued transmission in addition to improved survival rates as a result of increasing success of antiretroviral therapy (ART) (Skingsley et al., 2015). A person newly diagnosed now could be expected to live until 73 years old, whereas in the 1990’s, life expectancy was around 60 years old (The Lancet, 2008). Elford et al (2008b) suggest the distinction of two groups of older HIV positive men based on time of diagnosis: those who were diagnosed with HIV under the age of 50 years old who have aged with the virus, and those who are newly diagnosed since turning 50 years old.

Service providers are expecting a ‘grey wave’ of HIV that will lead to increasing demand on services (British HIV Association (BHIVA), 2009). Given these significant increases in the number of older adults with HIV, Public Health England highlight the need for the development of integrated care pathways to treat the comorbidities within the ageing population (Beer, James, & Summer, 2014; Skingsley et al., 2015).

Despite this significant increase in diagnoses of HIV, nearly 58% of older adults are diagnosed late, compared to 39% of working age adults (Yin et al., 2014). A late diagnosis is defined as after the time at which ART should begin (CD4 count <350 cells/mm³ within three months of diagnosis) (Yin et al., 2014). Older people are also more likely to present late, are excluded from educational programmes, and are not considered for testing by health workers (Age International, 2014). Routine HIV screening normally offered by sexual health and HIV clinics in the UK is not routinely accessed by older people (Kohli et al., 2006). Due to this factor, and the common belief that older people are not sexually active, educational programs are targeted at the younger generation.
However, the older generation are more likely to be widowed, divorced or separated, meaning they may engage in sexual relationships and potentially have unprotected sex, therefore increasing the risk of HIV acquisition (Kohli et al., 2006). Additionally, surveys suggest that older people have lower awareness of how HIV is transmitted (National Aids Trust (NAT), 2014). People over the age of 75 years old also show less sympathy and support for people with HIV, particularly those who are infected through unprotected sex (NAT, 2014).

**HIV and Stigma**

Evidence suggests that one in three PLWH has experienced HIV-related discrimination at some time in their lives, and 69% of people feel that there is still a great deal of stigma in the UK around HIV (NAT, 2013). “Stigma” refers to “a trait (infection with the HIV virus, in this case) and being known to possess that trait” and is often linked to negative social views (Goffman, 1963). In the 50plus Survey 66% of older PLWH stated that social stigma and discrimination was their top concern (Power, Bell, & Freemantle, 2010).

A conceptual model of perceived stigma has been developed for people with HIV (Berger, Ferrans, & Lashley, 2001) (see Figure 2). This model was originally developed to guide the generation of items for the HIV Stigma Scale. It includes: precursors to HIV, perceived stigma of having HIV, and possible responses to this stigmatisation. There is no specific model available for older PLWH; it is hypothesised that an adapted model may be applicable to older PLWH.

*Figure 1. HIV care by age group from 2005 to 2014 reported by Public Health England (Skingsley et al., 2015).*
Figure 2. Conceptual model of perceived stigma in HIV (Berger et al., 2001).

Intersectionality
Concerns around rejection are major stressors for PLWH (Berger et al., 2001). On top of this, HIV can exacerbate health inequality within populations who are already vulnerable and stigmatised and are potentially at a greater risk of mental health problems (e.g. gay, black African) (Petrak & Miller, 2002). However, until recently, how aging and HIV related stigma connect has not been examined exclusively.

Research suggests that older PLWH are disadvantaged in a number of additional ways to younger PLWH, from social care and housing problems, poorer health, and significant financial issues compared to their peers (Power et al., 2010). For example, men who were older and had been diagnosed for longer were considered to be at the “lowest rung of a contemporary Gay social hierarchy” which “resented and rejected those who were classed as ‘dependent on the state’” (Dodds, 2006, p.447). Older PLWH also have weaker social support systems which increases their levels of isolation, anxiety and
Being an older gay man with HIV therefore brings together a number of issues including ageism, racism, homophobia and HIV-related stigma, and thus increases mental health challenges (Gorman & Nelson, 2004). Additionally, the impact of the long-term physical and psychological burden of HIV significantly increases thoughts of suicide, particularly for heterosexual non-UK born men (Sherr et al., 2008). It is proposed that the intersection of HIV and being older brings increased discrimination; similar to that experienced by men who have sex with men (MSM) who experience discrimination based on both sexual and HIV status (NAT, 2013). Older groups of people with HIV are predominantly made up of gay males at present, although this is likely to change in the future (Sherr et al., 2009) to include more heterosexuals and Africans living in the UK.

Current guidelines and services
The British Psychological Society (BPS), BHIVA and the Medical Foundation for AIDS and Sexual Health (MedFASH) (2011) identify that services providing psychological support for PLWH need to recognise the impact of the stigma associated with HIV. However, NAT (2010) reports that the psychological needs of PLWH have not been served well by the current guidance from the National Institute for Health and Care Excellence (NICE) and needs to be improved to focus on older adults.

Within current clinical practice, Clinical Psychologists work with individuals who are finding it difficult to adjust to their diagnosis of HIV and/or the medication, worries around disclosure, and responses to stigma (Brown, Macintyre, & Truillo, 2003). Clinicians working in general HIV services may not have experiences of working with older adults with potentially unique difficulties. Similarly, older adult clinicians may not have experience of working with HIV. It is therefore expected that this review will be useful for clinicians working within both areas to expand their awareness of the issues of stigma specific to older adults with HIV.

Purpose of the review
Existing reviews in this area have predominantly examined research in the United States (US) (e.g. Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011), have a medical focus (e.g. Martin, Fain, & Klotz, 2008) and a very wide scope across both physical and psychological functioning (e.g. Chambers et al., 2013; Paparini, 2009). The current review will therefore examine the literature specific to aging with HIV in the UK. It will focus on psychological well-being, including stigma, discrimination, quality of life, coping, and social support.
Although this review will focus on age, it is important to note intersectional factors in that issues of age, race, gender and sexuality cannot be separated (i.e. the intersecting impact of racism, sexism, and ageism) and will be included in the analysis where relevant. This is in line with recent HIV report recommendations: The SHIBAH (Sexual Health Issues affecting Black Africans living with HIV) report examined the emerging difficulties of women approaching the menopause with HIV, and recommended further research into the interactions between gender, ageing, HIV and sexual health (Chinouya, Ssanyu-Sseruma, & Kwok, 2003).

Aims
The key aims of this review were to:

- synthesise the stigma literature on the UK population of older adults with HIV;
- develop a conceptual model of perceived stigma in HIV specific to older adults;
- disseminate findings to clinicians working in the areas of both HIV and with older adults;
- identify key gaps within the literature for future research.

Methodology

Search strategy
A search of three electronic databases (APA Psychnet, SCOPUS, and PubMed) was conducted on 16th July 2014. Search strategies were created for each database using the defined terms in Table 1. The term ‘AIDS’ was not used as this has a different use in the US (where it can be used in place of when ‘HIV’ is used in the UK). This was used to filter out a number of US papers. Searches specified peer reviewed journals and ‘grey material’. No publication date restrictions were set to ensure all relevant literature was included in the search. Articles were filtered by age groups and papers affiliated to the UK. Reference lists of key papers were also examined to identify related studies. Experts in the field were contacted regarding published reports, and current research, including UK based HIV charities (e.g. Terrance Higgins Trust).
Table 1

Defined search terms

(“HIV" OR “Human Immunodeficiency Virus**") AND ("aged" OR “elderly" OR “old person**" OR “older person**" OR “old people" OR “older people" OR “elder person**" OR “elderly person**" OR “elderly people" OR “old adult**" OR “elder adult**") AND ("stigma**" OR “discriminat**" OR “judgemental" OR “prejudic**") AND (“United Kingdom" OR “UK" OR “Great Britain" OR “Northern Ireland" OR “Wales")

Inclusion criteria
Each article was assessed for inclusion according to key themes raised by the Terrence Higgins Trust (Paparini, 2009) in a general review of older adults living with HIV in the UK:

1) Study setting: published in the UK;
2) Language: English;
3) Population: older adults with a diagnosis of HIV;
4) Article focus: stigma;
5) Study design: published peer-reviewed qualitative studies.

Process of literature search
The initial search yielded 598 records (APA Psychnet = 265; SCOPUS = 222; PubMed = 111); 456 after being filtered for age (APA Psychnet = 23; SCOPUS = 171; PubMed = 91); 38 after being screened for country of origin (UK). Studies conducted outside of the UK (e.g. US, Australia) were excluded due to the differences in health care system and cultural context. For example, heterosexual African Americans are not equivalent to heterosexual African people in the UK; they have more difficulties with drugs and less problems with immigration status (Power et al., 2010).

The titles and abstracts of remaining papers were screened for inclusion. Where it was unclear whether the article met the inclusion criteria, the full-text article was reviewed. This lead to 15 eligible studies. These studies were screened independently by the author of the meta-synthesis and an experienced qualitative researcher. Ten articles were excluded as they did not meet the inclusion criteria: stigma was not mentioned, they were not older adult specific, not published in the UK, were medically focussed or diagnostically driven, were quantitative (e.g. statistics around people with HIV), focussed on standards of care, or were not a research study (e.g. reviews). This resulted in five
studies that were eligible for quality assessment (see Figure 3). Although this literature review focussed on qualitative studies due to the meta-synthesis methodology, only two relevant quantitative papers were found; these were included within the introduction and discussion.

![Flow of studies through the process of the literature review.](image)

**Figure 3.** Flow of studies through the process of the literature review.

### Study quality assessment

The quality of research was checked using a quality checklist (Dolman, Jones, & Howard, 2013). The checklist included the previously validated Critical Appraisal Skills Programme (CASP, 2014) tool for appraising qualitative research (available from [http://www.casp-uk.net/](http://www.casp-uk.net/)) and the British Medical Journal (BMJ) Qualitative Research Checklist (BMJ, 2011). The studies were checked against 31 criteria (see Appendix 2). This appraisal covered 11 quality issues, resulting in a total score out of 62. Scores for the papers ranged from 39 to 47 with an average score of 42 (see Table 2). It is important to note that this is a subjective measurement of quality.

### Analysis

A data extraction form was developed to examine each paper in detail (see Appendix 3). This included elements of the design, participants (e.g. ethnicity, sexuality, and gender), analysis and results. Due to the small number and qualitative nature of these studies, a meta-synthesis was conducted. Meta-synthesis is an ideal methodology for interpreting qualitative literature and is recognised as a parallel technique to meta-analysis of
Participant quotations were extracted from each paper to allow them to be analysed independently of the papers’ results, using inductive thematic analysis (Braun & Clarke, 2006). The quotations were read a number of times by the first author and initial codes were noted down. These codes were then compared, combined and renamed into themes. Those that were not relevant to the overarching theme of stigma were excluded. The themes were then synthesised into common themes across all five papers to reach new interpretations and conceptual understanding (Noblit & Hare, 1988). The analysis was verified by an experienced qualitative researcher at each stage to ensure inter-rater reliability and analytic rigour (Mays & Pope, 2000). The perspectives and positions of the researchers were taken into account within this analysis; both are heterosexual women, one with a wealth of clinical experience of working with people with a diagnosis of HIV.

**Summary of papers**

Sample sizes of the key papers reviewed ranged from eight to 76 participants. Given that they are all using qualitative methodology, samples need to be large enough to achieve saturation, and small enough to allow a deep and rich understanding of the data (Sandelowski, 1995). Participants were recruited through a range of methods, some of which were biased in terms of the participants they would likely recruit, for example through gay press and gay bars (Flowers et al., 2011), or a specific London charity (Lawrence & Cross, 2013). Owen and Catalan (2012) take a wider approach, recruiting through HIV out-patient clinics, patient forums and drop-in centres, however they do not detail how such recruitment took place, and again all participants were London based. In a much larger national study, Power et al. (2010) recruited through charities and the media. They also held ‘survey completion parties’ to encourage African women to participate, and a large number of African men were invited to take part in the interview, ensuring minority groups were equally represented. Rosenfeld et al (2014) also ensure that their sample reflected the current demographic for older PLWH in the UK, although they report that target numbers of white heterosexuals were difficult to recruit.
Table 2

Summary of papers included in the review

<table>
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<th>Population characteristics</th>
<th>Data</th>
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</thead>
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<td><strong>Authors</strong></td>
<td><strong>Title</strong></td>
<td><strong>Recruitment method</strong></td>
</tr>
<tr>
<td>Lawrence &amp; Cross (2013)</td>
<td>Life transition with HIV: Some observations of the phenomenon of growing older with the infection</td>
<td>Adverts through a London HIV charity</td>
</tr>
<tr>
<td>Owen &amp; Catalan (2012)</td>
<td>‘We never expected this to happen’: narratives of ageing with HIV among gay men living in London, UK</td>
<td>HIV out-patient clinic, patient forum, drop-in centre</td>
</tr>
<tr>
<td>Power, Bell &amp; Freemantle (2010)</td>
<td>A national study of ageing and HIV (50 plus)</td>
<td>Terrance Higgins Trust, NSM’s HIV treatment update, gay &amp; HIV media</td>
</tr>
<tr>
<td>Rosenfeld, Ridge &amp; Von Lob (2014)</td>
<td>Vital scientific puzzle or lived uncertainty? Professional and lived approaches to the uncertainties of ageing with HIV</td>
<td>London based NHS clinics &amp; HIV-specific support organisations</td>
</tr>
</tbody>
</table>

*Note: MSM = Men who have sex with men; IPA = Interpretative Phenomenological Analysis; HAART = Highly Active Antiretroviral Therapy*
The five papers analysed included a total of 148 participants (see Table 3 for a summary). This included 95 males, 28 females, and 25 where gender was not specified within the paper. Sexual orientation was varied including MSM, gay men, and heterosexual males and females. However, the majority of participants were gay males or MSM, and a number did not specify sexuality. Ethnicity included White other/White British and Black African/Caribbean, with both being equally represented. However, nearly half of the participant’s ethnicity was not specified. Out of the 148 participants, 29 are specified as being from London, and 14 of the gay men as White Scottish. Given that certain groups (e.g. females, heterosexual non-Africans) are often underrepresented within HIV research, it is imperative for authors to report such characteristics.

The age range of the participants was from 22 to 86. Quotations from younger people in one paper (Flowers et al., 2011) were excluded from the meta-synthesis, meaning that the age range in this review is 50 to 86 years old. Across the papers, the number of years diagnosed with HIV ranged from one year to 28 years. Only one paper (Flowers et al., 2011) stated mean age at diagnosis (age 29). Another paper (Owen & Catalan, 2012) mentioned relationship status (3 with partners and 7 single) and diagnosis in relation to the arrival of Highly Active Antiretroviral Therapy (HAART; 4 diagnosed before, 3 during, 3 after).

The majority of papers used open-ended and semi-structured qualitative interviews to collect data, with one using a biographical narrative approach (Owen & Catalan, 2012). Analysis consisted of a mixture of Interpretative Phenomenological Analysis (IPA), narrative analysis, and thematic analysis. Qualitative methodologies have the advantage of building a rich account of individual experiences, whilst recognising the influence of societal and cultural perspectives. This is an appropriate methodology for understanding individual’s experiences in relatively unexplored areas. The subjective nature of qualitative research should also be noted, including the influence of the researcher, the importance of reflexivity, and the difficulty in generalisability. To increase reliability of the analysis, Flowers et al. (2011) rated interviews separately to ensure inter-rater reliability, whilst also acknowledging the influence of their own positions (e.g. as a gay man or heterosexual women). Lawrence and Cross (2013) refer to use of supervision and peer review, but do not state their own position in relation to the data. Owen and Catalan (2012) invited participants to review their own interview transcripts and be involved in the analysis, ensuring transcripts were not misinterpreted by the researchers. The larger study by Power et al. (2010) does not include a reflexive statement. Rosenfeld et al (2014) focus more on themes deducted by the interview data, alongside inductive
readings of the data. This variation in approaches and openness about researcher stance highlights the variability within qualitative methodology.

Table 3
Summary of participant characteristics for all papers included in the meta-synthesis

<table>
<thead>
<tr>
<th>Gender</th>
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<th>White/White British</th>
<th>Black African/Caribbean</th>
<th>Ethnicity not specified</th>
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<td>(n = 95)</td>
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<tr>
<td></td>
<td>Gay/bisexual</td>
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<td>9</td>
<td>17</td>
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<td></td>
<td>Not specified</td>
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<td>5</td>
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<tr>
<td>Female</td>
<td>Heterosexual</td>
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<td>(n = 28)</td>
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<td>Total</td>
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Note: MSM = Men who have sex with men

Table 4
Summary of themes

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<td>Isolation and rejection</td>
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<td>Support</td>
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<td>Social demographic</td>
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<tr>
<td>Impact of HIV</td>
<td>Financial</td>
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<td>Work</td>
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<td></td>
<td>Emotional</td>
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<td>Discrimination, judgement and managing</td>
<td>Societal</td>
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<td>disclosure</td>
<td>Family and friends</td>
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<td>Professional</td>
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<td>Ageing with HIV</td>
<td>Comparison to normal ageing</td>
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<td>Care</td>
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<td></td>
<td>HAART</td>
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<td></td>
<td>Lazarus Syndrome</td>
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<tr>
<td>Future</td>
<td>Uncertainty, apprehension and unpredictability</td>
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<td>Fear</td>
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</table>
Main findings

The meta-synthesis resulted in five main themes and 18 subthemes (see Table 4 for a summary of the themes and Appendix 4 for a theme map). The main themes included ‘HIV community’, the ‘impact of HIV’, ‘discrimination, judgement and managing disclosure’, ‘ageing’ with HIV and the ‘future’. These will be discussed in turn using quotations to illustrate them. Participant characteristics will be given where this information is available in the original article.

HIV community

Participants described a strong theme of there being an HIV community in terms of both positive and negative experiences. Within the HIV community, older adults talked about the loss of friends who had died from HIV, resulting in the eventual loss of the HIV community they once knew:

I don’t have a circle of friends like I used to. They all went, all of them. I never replaced them. (Single gay white British male, aged 54, diagnosed for 16 years)

There was also a strong feeling of isolation and rejection from both HIV communities (e.g. anger at disclosure) and those outside the HIV community (e.g. family), leaving older people feeling ‘forgotten’ and lonely in their old age. This is combined with the difficulty of making new friends as an older person with HIV:

…they (HIV positive people) are already quite isolated and they are not adjusted very well. They didn’t find a group to hang out with or some alternative to do…they are quite frightened because they operate quite well in their circle but not outside of it…I just felt a little bit like a loner really. (Older gay male)

Other older people described support from the HIV community, including support groups, which was linked to an optimism about the future and is a potential buffer against stigma:

I was just at peace and I can go to support and meeting other people and I thought to myself, you know this is a new life for me, I am living again. Why do I want to take this off? (Black African, aged 51)

People’s social demographic (e.g. being female, heterosexual, gay) impacted on their feelings of discrimination from outside the HIV community, as well as isolation and difficulty with fitting in with the HIV community:
The worst discrimination I have faced is from others with HIV. I have been …
shunned and denied their support…others with HIV have actually been very angry
about my being so public about my HIV... Many are scared of their own status
being disclosed by association with me. (White heterosexual female, age 57)

**Impact of HIV**
Participants talked about a second theme around the impact of being an older person
with a diagnosis of HIV, including the practical and emotional aspects. Some participants
described the financial impact, for example the guilt and stigma around claiming benefits,
and difficulty in considering themselves as ‘disabled’:

> I mean, I couldn't do a full-time job now… there's this tension – you are terrified
you're going to lose Disability Living Allowance – and there is this guilt thing for
claiming benefits as well. (Single gay white British male, aged 57, diagnosed for 20 years)

The impact of not being able to work was also important, particularly in relation to
isolation, and feeling left out of social interaction with others or the ‘…daily activities
what’s going on in the world’ (older gay male). Discrimination was also experienced
within the workplace, for example being regarded as ‘obstructive’, ‘unhelpful’ and
‘difficult’ (gay male, aged 58) and unsupported:

> Told my boss at work my HIV status … was given a year off … without pay, which
I requested. On my return a year later I was made to feel unwelcome, unsupported,
undervalued. I left after four days of returning. (Gay male, aged 50)

There was also an emotional impact of being diagnosed and living with HIV (e.g. ‘hurt’,
included an element of self-blame and a difficulty in seeing an end to the pain:

> I thought I could come out of this without being hurt, but the hurt's never gone
away…deep down inside I'm not happy at all…. it's like someone cutting my skin,
so deep you can’t reach to the bottom, and the pain just keeps oozing and oozing
and oozing out, never stops, that's how it feels: not nice. (Older gay male)

This emotional reaction also impacted on how people managed disclosure:
I went through a lot of stress. Did not know how my family would react. My doctor knew, my friends didn’t. I kept myself secluded. Would not go out, would not mix. (Gay male, aged 53)

**Discrimination, judgement and managing disclosure**

A third theme around discrimination, judgement and difficulties managing disclosure was described. This included the difficulties when discrimination is “often so subtle…and it is difficult to do anything about ‘subtle’” (gay male, aged 61). This was mentioned in relation to discrimination from the societal reaction, and the stigma felt from the outside world ‘looking at me’ and ‘mocking’ as a result of having HIV:

I noticed when I recycle rubbish I tear all my name off the cardboards, because, you know, there is lots of cartons on all that anti-retrovirals…It takes me ages to destroy any evidence so no one can see my name on HIV boxes in the recycling bin outside my flat. (Older gay male)

Judgements made about HIV status were also combined with discrimination due to sexual orientation:

… I was asked to leave (employment at a school) as a result of homophobic hatred stirred up by one colleague…the guy had whipped up so much hatred that I had to leave. Five teaching agencies have refused to put me on their books because of HIV status. (Gay male, aged 59)

Discrimination was also felt from **family and friends:**

…when I had my brain haemorrhage, and the hospital had to get in touch with my brother, and the response that I got from him was ‘we don’t want to know. Just when he dies put him in a bin bag and burn him’… (Older gay male)

Participants also felt judged and like they were treated differently by medical **professionals** who were ‘freaked out’ about them being HIV positive. This theme was particularly relevant for heterosexual females from which most of the quotes for this theme came. Disclosure within the medical setting was also difficult, leading to professionals being over precautious or unthoughtful in their approach. This also links to the theme about a comparison to normal ageing:
I asked the consultant what could I do in terms of hot flushes and feeling exhausted…and was quite shocked at his response which was ‘I don’t really know much about middle-aged women with HIV; my area of expertise is black Africans and the gay community.’ I just found that so dismissive. …There are a lot of doors that are shut for people whose face doesn’t fit. (Heterosexual female, aged 51)

This felt discrimination and judgement from doctors was also identified by participants across settings with other professionals including dentists:

Dental care was a nightmare to get. [I got] ridiculed and embarrassed due to my disclosure. (Gay male, aged 57).

Ageing with HIV
The fourth theme was age itself. Participants talked about their experience of ageing with HIV and the importance of the time at which they were diagnosed. Participants also made a comparison to normal ageing, including the similarities and differences. For example, some participants described difficulties in knowing whether physical issues are ‘specifically HIV-related or just related to ageing’ (Single gay white older male, aged 57, diagnosed for 18 years) and the uncertainties around this because ageing with HIV is ‘a new phenomenon’ (58-year old MSM):

Am I feeling tired because I’ve got HIV, or because of the side-effects of the drugs, or because of type 2 diabetes, or because of a stressful job or is it because I am 60? (White British male, aged 60)

Some participants felt that HIV had made them old before time, relating to a feeling of premature or accelerated ageing, being able to better identify with individuals older than themselves (e.g. joining elders groups), and a feeling of being ‘invisible’ in a gay community that is ‘about youth and beauty’:

Gosh, right now, err… its living a life like an old person in what appears to be a young man’s body… being quite debilitating in many ways. (Older gay male)

A number of participants expressed concerns about care and ‘fitting in’ to a care home as they got older. This included worries around stigma in the ‘older generations’ (cohort effects), and from care staff both towards being gay and HIV positive:
I fear hugely going into a home…I fear the attitudes towards HIV that I may find and ignorance from care staff. One of our HIV charity trustees died last year and a private care agency actually refused to provide him with care at home when he was dying of cancer … they did not want to come into contact with his bodily fluids … and if I get dementia … I may not be able to fight this disrespect and stigma or educate them on my care. (White heterosexual female, aged 57)

Within this was a subtheme of **HAART**, differences were identified between participants who had been diagnosed before and after HAART was introduced. This varied from HAART being a ‘miracle’, to concerns about the side effects of the drugs ‘accelerating’ the ageing process, and the physical effects of lipodystrophy causing people to ‘stare’:

> With lipodystrophy you might as well have AIDS tattooed on your forehead…people just stare at me all the time, that I become frightened to leave the house … also, old and wrinkly is not a good look, so the chances of meeting anyone who fancies you decrease with time and combined with the death of most of my friends in the ’80s and ’90s, means that there is no one left alive to be friends with. (Gay male, aged 59)

Related to HAART was the theme of **Lazarus syndrome**: participants described the difficulty in getting their head around the prospect of a longer life when they thought they would die young, the ‘missed opportunities’ having not made plans for old age (e.g. a pension), and losing the reason for living on:

> So it wasn’t an easy process, coming to terms with thinking about your future again when you felt previously it had been closed off to you. And it’s thrown a lot of people into a tail spin…It’s almost like you missed opportunities to make the best plans for future old age…you’ve got to give yourself reasons for going on because the paradox here is that while you’ve been given the means of living on, in a lot of cases, the reasons, the rationale, has been taken away. (Single gay black male, aged 69, diagnosed for 23 years)

**Future**

The final theme participants talked about was the future. **Uncertainty, apprehension and unpredictability** was a big part of this, including the difficulty seeing a future and having not made plans because they had not expected to live (related to Lazarus syndrome). The unknowns of living into old age with HIV were also a concern, such as the reactions of care home staff to an older person with HIV as previously discussed, and the effects of HAART:
…uncharted waters, as until relatively recently HIV people didn’t grow old. (White British male, aged 58)

Related to this was a fear of the future and what it would bring. This included fears that are common for older adults in general (e.g. financial, care, family and children), as well as specific fears around a future with HIV:

… but I might have ten more years of being okay. No one knows, so that’s a fear. Because I’ve had this virus for so long that it’s got to end. It’s like it hangs over you. I do feel that a lot more as I become older. … So I think it’s the fear of how much longer have I got? (White male, aged 52)

Positively, participants also expressed a sense of optimism for the future as a result of being HIV positive and linked to HAART, ‘living in the present’ and ‘living again’:

It’s the only thing I’m hanging on because I’ve got my life back, at least I can walk tall, I don’t have to be scared. I discovered that I am not going to die soon, I am going to live… (Black African, aged 51)

**Discussion**

This is the first meta-synthesis to bring together the experiences of stigma for older people living with a diagnosis of HIV in the UK. Key themes will be discussed, a conceptual model of perceived stigma specific to older adults will be described, and implications for services and future research will be explored.

Key themes arising from this meta-synthesis include: the positive (e.g. support) and negative experiences (e.g. rejection) from both within and outside of the HIV community; the practical and emotional impact of HIV; difficulties with discrimination, judgement and managing disclosure both within society, personal lives and with professionals; ageing with HIV including a comparison to normal ageing, perceived cohort stigma and the impact of medication; and future uncertainty and fear, as well as an element of optimism. A number of the themes identified for older adults (e.g. discrimination) are also shared with younger PLWH in the UK (Elford, Ibrahim, Bukutu, & Anderson, 2008a). However, these may be even more pertinent for older adults who generally have significantly higher rates of social isolation, loneliness, health concerns, and suicidal ideation (Davidson & Rossall, 2015; Vance, Struzick, & Raper, 2008). Additionally, a number of risk factors are associated with increased likelihood of mental health difficulties for older adults.
Given that people with HIV generally have a higher risk of psychiatric illness (Kohli et al., 2006), these risk factors are particularly pertinent for older adults with HIV, including: impaired health, and experiencing stressful life events (Wolitzky-Taylor, Castriotta, Lenze, Stanley, & Craske, 2010). Given these significant risk factors, suicidal ideation is likely to be even higher in stigmatised older PLWH (Parker & Aggleton, 2003; Robertson, Parsons, Van der Horst, & Hall, 2006).

There is an important intersection between HIV and ageing which leads to increased discrimination. Research in the US describes a ‘double jeopardy’ of ageism and HIV stigma, which leads to experiences of rejection, social isolation, discrimination and stereotyping (Emlet, 2006). This process appears to be similar in the UK population, as found in this meta-synthesis and in Sherr et al.’s (2009) study of British older people with HIV reporting increased physical and psychological burden than younger people.

Whilst these experiences were described by older adults with a diagnosis of HIV, it is important to consider other factors, including race, gender, sexuality and ethnicity. These cannot be separated and are intersectional. This is reflected in the social demographic subtheme that found that stigma is often context specific, and is different for a heterosexual woman to a gay man, for example.

The conceptual model of perceived stigma older adults with HIV

Given the research findings, the conceptual model of perceived stigma in HIV (Berger et al., 2001) has been adapted to comprise elements specific to older adults (see Figure 4). The impact of social demographic includes a number of elements specifically relevant to older adults, including age and time since diagnosis. It also includes components relevant to the general population with HIV, including health concerns, ethnicity and race, gender and sexuality. It is the intersection of these components which can increase the impact of stigma and discrimination for older PLWH. For example a mix of ageism, racism and sexism.

Stigma and discrimination was felt from both within and outside the HIV community (e.g. family and friends, professionals). These are all potentially increased by cohort effects; individuals born before the 1960’s (who are likely to be peers to the older PLWH) hold more homophobic and HIV phobic attitudes (Lyons, Pitts, Grierson, Thorpe, & Power, 2010). Changes to self-concept was not raised by older PLWH specifically. The original model separated out self and society whereas this meta-synthesis found them to be interconnected, e.g. old before time is relevant both to ageism and the self as older.
The impact of stigma can be widespread, including future uncertainty, social and emotional functioning, and psychological burden. As previously discussed, some elements are similar to those experienced by younger PLWH, but may be magnified through ageism, isolation and increased health difficulties (Davidson & Rossall, 2015).

![Conceptual model of perceived stigma in HIV for older adults.](image)

**Figure 4.** Conceptual model of perceived stigma in HIV for older adults.

**Service implications**

A strong theme within the papers reviewed was around stigma and discrimination from health care professionals. Research suggests that there are a number of barriers to General Practitioners (GPs) and practice nurses discussing sexual health with older people (Gott, Galena, Hinchliff, & Elford, 2004; Gott, Hinchliff, & Galena, 2004). These include: sexual health not being seen as relevant for older people; health professionals not wanting to cause offense and feeling uncomfortable approaching the subject; and feeling that they have not received appropriate training to do so (Gott, Hinchliff, et al., 2004). Other barriers include talking to people of the opposite gender, from a different culture (i.e. Black and ethnic minority groups as the majority of health care professionals are white), and of a different sexuality (i.e. non-heterosexual patients).

This literature review did not aim to make a direct comparison to US research, however evidence from the US proposes that social isolation and depression could be reduced through increasing strategies to make disclosure of HIV status easier for older adults (Vance & Burrage, 2006; Vance et al., 2008). This suggests health professionals working
with older adults and/or people with HIV would benefit from additional training to increase their confidence in this area. Given that primary care was the area showing the highest levels of HIV discrimination in the past year (Power et al., 2010), further research to understand health practitioner's attitudes towards and understanding of older adults with HIV specifically would be of great value.

Additionally, older adults described the support and rejection they had experienced from both within and outside the HIV community and the impact this had on their emotional wellbeing. Older PLWH have a number of disadvantages from social care and housing problems, poorer health and significant financial issues (Power et al., 2010) as well as weaker social support systems (Shippy & Karplak, 2005). Opportunities to attend support groups set up by supportive services specifically for older people could be beneficial with the aim of increasing self-efficacy and decrease stigma (Beer et al., 2014). This has been shown to increase resilience and have a positive impact on long term health and wellbeing for older people (Ong & Bergeman, 2004). The Health, Wealth and Happiness pilot project run by the Terrance Higgins Trust (2015) offered support, advice and counselling to older PLWH with positive results, including improved mental health and reduced social isolation. A number of forums (e.g. Positively Ageing Forum http://www.pafhiv.org.uk/) are also aiming to support older PLWH. Despite the growing need, funding for HIV care has been cut significantly in recent years (NAT, 2015). Policies for the future care of older gay men need to go beyond the ‘heterosexual assumption’ to ensure positive support (Heaphy & Yip, 2006).

**Research implications**

Given the significant increase in the number of adults ageing with HIV (BHIVA, 2009), the substantial increase in new diagnoses in recent years (Aghaizu, Brown, Nardone, Gill, & Delpech, 2013) and the increased risk of HIV acquisition for older adults (Kohli et al., 2006) further research in this area is imperative. This meta-synthesis has identified significant gaps in the literature with regards to the stigma experienced by older adults with HIV in the UK, with the majority of research focused on gay males.

Further research in the UK with more diverse groups including females, heterosexuals and older black and minority ethnic groups is required. This is particularly important given that the social demographic of older groups of people with HIV is likely to change in the future to more representation from these ‘forgotten’ groups (Sherr et al., 2009). This meta-synthesis identified limitations in recruitment methodology, which was often limited to specific groups (e.g. gay males) and regions (e.g. London). Expanding recruitment strategies and engaging minority groups (e.g. Powers et al., 2010 ‘survey completion parties’) will be beneficial.
A number of barriers to the lack of research with older adults with HIV have been identified, including variations in the definition of ‘older adults’, time of diagnosis, and research methodologies. The definition of ‘older adults’ within the HIV literature (generally age 50) is different to the age the National Health Service (NHS) considers ‘older’ (generally age 65 and above). This is due to the precedent set by the US Centers for Disease Control’s original age stratification of HIV/AIDS (Poindexter & Emlet, 2006). Elford et al. (2008b) identified possible differences between those diagnosed with HIV before or after they turned 50. It is therefore important for research to include time since diagnosis and chronological age, as also suggested by Owen and Catalan (2012). In addition, a large amount of HIV research is conducted online (e.g. Sigma) and therefore potentially only attracts the younger population.

It is important to note that this review focussed on stigma and discrimination and some older adults with HIV were optimistic about the future. These more optimistic voices are underrepresented in the papers analysed, thus it would be worthwhile conducting an investigation into the resilience and acceptance that might be created by living with HIV over decades. It could be hypothesised that research is biased by professionals’ own judgements about the difficulties experienced by older adults living with HIV.

This literature review did not aim to make a direct comparison between research from the UK and the US. Therefore future research directly examining the similarities and differences, including how US research may or may not be applicable to older adults with HIV living in the UK is required.

Limitations of review
The small amount of research in this area and the strict inclusion criteria used in this meta-synthesis produced only a small number of research articles for analysis. The data that was available were the quotes selected by study authors in their papers to best represent their analysis. For example, the quotes presented are likely to be those that best represent the resulting themes of the paper and best support the authors’ understanding of the data. Additionally, it is possible that the authors of the original papers identified dominant themes from occasional comments that were given equal weight to those about which many participants spoke, thus potentially biasing the meta-synthesis. However, it is also acknowledged within qualitative research that the number of instances a theme occurs does not necessarily equate to its importance (Braun & Clarke, 2006).
Given these limitations, quotes from all 142 participants from across the studies were not included within this meta-synthesis. It is recognised that when conducting a meta-synthesis the researchers will be limited in this way, and only able to analyse the data already interpreted by the original paper authors. It is possible that by contacting the authors, original data may have been available. However, it was beyond the scope of this study to approach the authors to request access to their transcription data. Additionally, this may not have been possible because of the original ethical approval of previous studies protecting participant confidentiality. Therefore, other themes relating to being an older adult living with HIV may have been missed by conducting a meta-synthesis.

The literature search itself may have been limited by the parameters of the search terms used, for example using ‘AIDS’ as a search term, and including region (e.g. “United Kingdom” OR “UK” OR “Great Britain” OR “Northern Ireland” OR “Wales”). It is possible that papers published in these geographical locations may not have specific this in the paper title or abstract, therefore restricting the search. However, secondary searches using reference lists of key papers, and through contacts with experts in the field did not reveal any additional studies.

**Summary**

This is the first meta-synthesis to bring together the experiences of stigma for older people living with a diagnosis of HIV in the UK. The key themes identified have implications for health professionals working within both services for older adults and HIV, including the need for additional staff training and support for older people with HIV. Important directions and considerations for future research were identified.
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Service Improvement Project - Promoting Positive Coping and Self-management in Patients Undertaking Cardiac Catheterisation: Learning from Health Professionals

Cara Roberts-Collins (email: c.roberts-collins@bath.ac.uk)

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Internal supervisor: Dr Cathy Randle-Phillips

External supervisor: Dr Jackie MacCallam

Dr Andrew Medley

Target journal: Social Science and Medicine, Impact factor 2.558. This journal focusses on social science research on physical and mental health, health care, clinical practice and health policy and organization, and includes qualitative research (see Appendix 5 for Instructions to Authors).

Please see Appendix 6 for a lay summary of the research
Background

Pulmonary Arterial Hypertension (PAH) is a rare, life limiting and debilitating condition which ultimately leads to right heart failure and premature death (Galiè et al., 2009). Symptoms include dyspnoea, fatigue, chest pain, syncope, and peripheral oedema (Rich et al., 1987). Unsurprisingly, prevalence rates for anxiety (20-40%; Lüwe et al., 2004; Shafazand, Goldstein, Doyle, & Gould, 2004; White, Hopkins, Glissmeyer, Kitterman, & Elliot, 2006) and depression (21-55%; Badesch et al., 2010; Looper, Pierre, Dunkley, Sigal, & Langleben, 2009; McCollister et al., 2010; White et al., 2006) are high for patients with a diagnosis of PAH. Recent research has also highlighted difficulties with everyday functioning including relationships, finances, and social isolation (Guillevin et al., 2013). Other challenges include a perceived lack of understanding from others, uncertainty about the future, and coping with invasive treatment regimes (Yorke, Armstrong, & Bundock, 2014). There is preliminary evidence to suggest that interventions such as progressive muscle relaxation can effectively reduce levels of anxiety and depression and improve quality of life for patients with PAH (Li et al., 2015).

Cardiac catheterization (CATH) is an outpatient procedure used to confirm the diagnosis of PAH, evaluate the severity of impairment, and indicate when specific drug therapy is required (Galiè et al., 2009). The procedure involves the insertion of a catheter into the right atrium of the heart through a cannula in the femoral vein. Research suggests that the procedure can be highly anxiety provoking and stressful due to practicalities such as long waiting times, insertion of the catheter, and needing to lie still for long periods of time (Harkness, Morrow, Smith, Kiczula, & Arthur, 2003; Peterson, 1991). Other key psychological factors identified are a lack of perceived control, the possibility of an uncertain future and medical complications, beliefs about the competence of health professionals and efficacy of the technology used, and a range of personal coping strategies (Caldwell, Arthur, Natarajan, & Anand, 2007). Patients can also perceive the procedure as a traumatic event, with a risk of serious complications including death (Beckerman, Grossman, & Marquez, 1995). Notably, research suggests that patients are often poorly informed about the procedure and its risks (Fraser, 1984), and view themselves as being ‘passive participants’ in the procedure (Caldwell et al., 2007).

Illness representations

Accordingly, therefore, it seems important to better understand patients’ subjective beliefs about CATH and their preparedness to undertake it, not least in view of the inescapable necessity to integrate the procedure into their lives at regular intervals. A number of models of illness representations deconstruct and make sense of illness in different ways. Leventhal, Meyer and Narenz’s (1980) Self-Regulatory Model (SRM) offers a theoretical framework to help formulate subjective beliefs, representations and
coping responses in the face of health threats (see Figure 1). The model posits that individuals' cognitive and emotional mental representations of an illness or health threat is based on concrete and abstract information of illness stimuli, including: 1) 'lay' sources (e.g. cultural knowledge and social communications); 2) external social environment (e.g. parents or doctors) and; 3) current experience of illness (e.g. somatic and symptomatic information). It is the interpretation of this information that forms the process of help seeking, coping strategies and illness management (Bishop & Converse, 1996). The content of a cognitive illness representation can be ordered into a number of belief dimensions: causal attributions (biological, emotional, environmental, psychological); perceived consequences (impact on quality of life/function); coherence (knowledge and understanding of the condition); identity (beliefs about the illness label and knowledge of symptoms) and timeline (course/timescale of illness) (Linz, Penrod, & Leventhal, 1982; Meyer, Leventhal, & Gutmann, 1985).

The illness representation acts as a 'filter' for available information and impacts on coping strategies and styles; for example in a meta-analysis, Hagger and Orbell (2003) suggest that perceiving the illness as controllable is related to active or problem-focused coping and adaptive psychological well-being. On the other hand, low perceived control has been associated with avoidance coping and denial and increased psychological distress (Hagger & Orbell, 2003). Illness perceptions are also key in guiding coping strategies and illness related behaviours including treatment and medication (Petrie & Weinman, 2006).

Figure 1. Leventhal et al (1980) SRM of Illness Representations.
Alongside an assessment of patients’ subjective beliefs and coping responses, it is crucial to draw upon the beliefs and experiences of the health professionals seeking to support people undertaking this challenging procedure. Research suggests that clinicians can have very different views to the patients experiencing illness; for example, health care professionals can underestimate quality of life, and overestimate psychological difficulties (Lampic & Sjoden, 2000). It is important for professionals to understand their own biases and the individual preferences of each patient (Wessels et al., 2010). The dimensions of the SRM offer theoretical utility in framing an understanding of professionals’ perspectives in relation to their patients’ experiences. A shared understanding between patients and professionals is vital to promote collaboration, trust and a culture of mutual learning to ultimately benefit the service and patients (Foot et al., 2014). Moreover, it seems likely that patients’ psychological coping responses will be contingent, in significant part, upon the attitudes, beliefs and interventions of the healthcare professionals seeking to support them through these procedures (Greenhalgh, 2009).

**Self-management**

The Department of Health (DoH, 2006) guidance for supporting people with long-term conditions emphasises the importance of the patient developing a coherent understanding of their condition, thereby facilitating self-management skills and enhanced quality of life. A key focus, therefore, is on the shift in the role of the health professional from the ‘professional expert’ (instructing and deciding) to ‘guide’ (supporting and advising) (Greenhalgh, 2009). Healthcare professionals are key in using their skills to enable the patient to feel engaged, empowered and motivated (The Health Foundation, see Figure 2).

*Figure 2. The Health Foundation, Self-management support diagram.*
The current study

In preliminary discussions, nurses and medical Consultants at the PAH service at the Royal United Hospital (RUH) Bath talked about their understanding of patients’ concerns around the CATH procedure. These included worries and fears about exposing their body, how the procedure will feel and if it will hurt, what effect it might have on their heart, lying flat for a long time, being left alone after the procedure, and the risk of dying. When patients are referred for the procedure they receive a leaflet explaining it and can talk to the nursing staff over the telephone. Nurses within the department routinely spend considerable periods on the telephone to patients helping them prepare emotionally for the procedures, often confronted with high levels of anxiety. Accordingly, the nursing team and medical Consultants have a vital role to play in terms of providing psychological and emotional support, with a view to promoting patients’ coping and self-management skills.

Aims

The main aims of this research were to offer recommendations for service improvement through the exploration and understanding of:

- professionals’ beliefs and perspectives in relation to patients’ positive coping strategies for the CATH procedure;
- professionals’ role in promoting adaptive self-management amongst their patients, how they support preparation for the procedure and their confidence in providing psychological support;
- professionals’ beliefs about the psychological impact of the procedure, their own training needs and self-care, care-pathways and when to refer to Clinical Psychology.

Method

Ethical approval was given by the University of Bath ethics committee for this project (Reference Number: 14-162). It was also registered on the RUH Bath NHS Foundation Trust audit database (ID number: 2385, see Appendix 7).

Participants

Health professionals from the respiratory Pulmonary Hypertension (PH) team (8 staff members), CATH lab team (17 staff members), and Medical Therapies Unit (MTU; 12 staff members) were invited to participate. Ten key professionals involved in the CATH procedure took part. This included:
- Respiratory PH team (six professionals):
  - three PH Clinical Nurse Specialists
  - two PH Respiratory Consultants
  - one PH Coordinator
- CATH lab team (four professionals):
  - three Cardiac Nurses
  - one Cardiac Consultant

One of the PH Clinical Nurse Specialists also worked at the MTU. No other professionals from this team participated.

**Measures**

Semi-structured interviews were designed in parallel with a joint project which was focussing on patient experiences of positive coping with the CATH procedure. The aim of the interviews was to understand how best to support people psychologically and emotionally, from a professional and patient perspective. The design of the interviews was guided by the belief dimensions in the SRM (see Appendix 8 for draft questions and Appendix 9 for the finalised staff interview schedule). The interview itself consisted of 22 questions in the following areas: timeline, beliefs and decision-making about the procedure, perceived control, coping and self-management skills, consequences (physical, psychological, social, and economic), illness identity, coherence, and emotional representations.

**Procedure**

Meetings were set up with the respiratory PH team and the CATH lab team to inform them of the research though a short presentation and information sheets (see Appendix 10). The MTU were invited but were not available to attend these meetings. Professionals were given the option of giving informed consent at the meeting or taking the information away to consider. The consent form (see Appendix 11) asked for their contact details which were used to arrange appointments to conduct the interview, at a time and place suitable for the staff member. They were also asked to consent to the use of audio recording equipment to record the interview. The option of focus groups was offered, however due to staffing constraints, interviews were conducted on a one-to-one basis, all within the hospital setting. The interviews were conducted by the first author between June and September 2014 and lasted between 15 minutes and 40 minutes.

**Data analysis**

Interviews were transcribed verbatim, and analysed qualitatively using thematic analysis (Braun & Clarke, 2006). The analysis was theoretically driven and aimed to look at a detailed account of one aspect of the data; self-management and positive coping around
the CATH procedure, based on the SRM. A semantic approach was used to look explicitly at what was said by the professionals, and interpreted in relation to the literature. An essentialist/realist approach looked at the direct relationship between meaning and experience and language. Although the SRM of illness perceptions had been used to develop the interview schedule, the interview questions and structure was taken away for the analysis. This meant that the findings were iterative rather than being rigidly constrained by the framework of the model.

Once the interview responses had been fully transcribed and read repeatedly, initial codes and points of interest were noted down. Each transcript was then coded in a systematic fashion, collated into potential themes, reviewed, and further defined and named. This resulted in main (super-ordinate) and underlying (sub-ordinate) themes. At this stage, a second researcher who had not been immersed in the data coded the transcripts into main themes to ensure inter-rater reliability. A number of themes were merged or removed, depending on their relevance to self-management and positive coping. The themes were cross checked and triangulated with an experienced qualitative researcher to ensure analytic rigour.

Findings
The analysis resulted in four super-ordinate themes and six sub-ordinate themes (see Table 1 for a summary of themes and Appendix 12 for the map of themes). The super-ordinate themes were: acknowledging individual differences, a journey, the patient/staff relationship, and information and understanding. These themes will be discussed in turn using direct quotations to illustrate them (see Appendix 13 for the complete set of super-ordinate and sub-ordinate themes identified and additional illustrative quotes).

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Table 1
Summary of super-ordinate and sub-ordinate themes
Acknowledging individual differences

This super-ordinate theme ran throughout all of the other themes described by health professionals. They commented on the importance of individual past experiences, particularly in relation to health difficulties and procedures. Professionals described how these experiences and preconceptions impacted on patients' perception and coping around the CATH procedure, both in the present and in the future.

Past experiences. Within the theme of acknowledging individual differences was the sub-ordinate theme of past experiences. An initial theme of stories/knowledge from others was merged into past experiences as these stories were considered to become part of the individual's overall past experience. Professionals described how patients' view of the CATH procedure was dependent on their individual previous experiences of the procedure and other medical difficulties and procedures they had been through:

I think it helps when people have been through, have had experience of medical things before, so usually people who cope fairly well are people who have perhaps had other things done to them and don't necessarily expect things to run smoothly, but they can cope with it. (Consultant Cardiologist 1)

Hearing about other people’s experiences and stories, such as family members and meeting others on the ward were also important:

If they know someone who’s had it done that can be helpful, I suppose it depends on the experience of that person it could be good or bad, but assuming the person they speak to has had a good experience then often that can be reassuring as well. (Consultant Cardiologist 2)

Generally, if patients had had a positive first experience, then coming back again caused ‘far less anxiety’, although this often ‘depends on the patient’ (Consultant Cardiologist 1).

Personal coping style. Another sub-ordinate theme within acknowledging individual differences was personal coping style. Health professionals acknowledged that despite patients' previous experiences, their coping style also had a big impact on how they managed the procedure (e.g. ‘avoidant’, ‘laughing and joking’, ‘wanting all the details’, ‘laid back’, ‘tense’) and it was therefore important to treat them as an individual:

Some people want to know all the information and some would rather not know, you know…it’s the same when they go into the CATH labs, some people will be
really interested in what going on in the procedure and want to watch it on the screen and things like that, and some people just want to block it out. (Respiratory Nurse Specialist 1)

A journey
This second super-ordinate theme represents the patients and the professionals’ journey through and within each of the different teams (e.g. Respiratory, MTU, CATH lab). This includes the practical and emotional issues and consequences for both health professionals and patients, before, during and following the procedure.

Patient journey. Professionals described the patient's journey through the teams and the emotional and practical consequences of each of these stages. Emotional consequences covered a huge range and included feeling ‘scared’, ‘apprehensive’, ‘frustrated’, ‘traumatised’, ‘upset’ and ‘shocked’, as well as ‘hope’, ‘acceptance’ and ‘relief’. Practical consequences included the impact of the procedure on the day (e.g. travelling), the fear of the results and a potential diagnosis, a gateway to treatment, the impact on daily life (e.g. work), and uncertainty for the future:

I’m sure they must think about it a lot before the procedure, and then when they come in they will be thinking about it, so it’s really important they get a good first impression and they feel relaxed…they probably also worry about the results, what’s it then going to lead to…and any worry about dying and serious illness is bound to bring other emotions up as well, so when they go home I’m sure there are a lot of thoughts going round their heads. (Respiratory Nurse Specialist 2)

Staff journey and service constraints. Professionals described their journey alongside the patient (e.g. giving reassurance, holding their hand), and the communication between their team and the other teams the patient would meet along the way (e.g. Respiratory, MTU, CATH lab). They also talked about some of the constraints to meeting patient needs (e.g. cancelations, time):

…there are several tiers of service that actually work with this procedure and that’s sort of again a necessary problem, because in terms of the sort of preparation of the test it used to be done by the pre assessment nurses who actually work upstairs. They weren’t really adequately resourced to provide this, and it was extra work for them. (Respiratory Nurse Specialist 3)
Patient/staff relationship

Health professionals described the importance of the relationship and bond between themselves and the patient, including a sense of ‘duty’ to care for them, to reassure them, and to keep them safe. They talked about the support they give around practicalities (e.g. details of the procedure) and to promote dignity:

… it’s more how you rapport with them, it’s not what you say it’s how you say it, they want to trust the health care profession, the health worker, and if they trust them, and if they come across as honest, if they come across as sincere, caring, empathizing, then it’s easy to win them over…so the key is that relationship building. (Staff Nurse 1)

The sub-ordinate theme of ‘family’ was removed as professionals only briefly mentioned practicalities around family bringing patients to appointments and staying with them, alongside their own lack of capacity to support family members. This response was directly in answer to the question asked about family support and not in relation to any other questions.

Information and understanding

The final theme highlights professionals wanting to give as much information as possible to patients (e.g. verbally and through leaflets) and ensuring they understand specific details of the procedure.

**Information giving.** Within this super-ordinate theme was the sub-ordinate theme of *information giving*. Professionals were keen to give as much information to patients about the procedure as possible; from being told they need to have the procedure, to having it explained in more detail along their journey through the teams, being honest about what to expect, and being given information leaflets to take home:

…we’ve got written information as well, we’ve got leaflets, and we just talk through it all and see if there are any questions…I think it’s just important to keep them updated, so if there are delays and things like that, you know, tell them and be honest with them, and give them a realistic expectation. (Respiratory Nurse Specialist 1)

**Openness around the procedure.** Another sub-ordinate theme was *openness around the procedure*. The initial sub-ordinate theme of ‘normalising’ the procedure was merged within this theme. Professionals promoted honesty towards their patients,
particularly in relation to the details of the procedure itself. Again this was gauged depending on individual wants and needs:

Sometimes it can be the smallest thing, one thing for instance is when they are on the table, you know the table moves, and that’s an odd sensation, you know if you don’t warn them beforehand that it’s going to move, moving when their lying flat that’s a bit of a surprise… (Consultant Cardiologist 2)

The sub-ordinate theme of ‘choice’ was removed altogether due to limited examples in the data, and because choice was not always possible to offer. Professionals promoted choice as far as possible in terms of allowing patients to make an informed decision. However, patients were sometimes told that they need to have the CATH procedure to help to give them a diagnosis or to offer treatment options. Despite professional's best efforts and intentions, practicalities such as time pressure often limited the amount of choice that could be offered to patients.

**Discussion**

This is the first research study that has explored health professionals' perspectives and beliefs on positive coping strategies and self-management for patients with PAH undertaking the CATH procedure. It has important implications for the PH and CATH service in increasing patient control, choice and positive coping for those patients who find the procedure more difficult.

Previous research had suggested that patients can find the CATH procedure anxiety provoking due to waiting times, needing to lie still for long periods, and insertion of the catheter (Harkness et al., 2003; Peterson, 1991). Additionally, patients' perception of an uncertain future, possible medical complications and personal coping strategies play a key role (Caldwell et al., 2007). The current study has shown some similar findings in healthcare professionals’ perceptions of the importance of their ability to identify and acknowledge patient’s past experiences and personal coping style. Professionals also identified the importance of the practical and emotional journey they and the patient experience on the day of the procedure itself and following the procedure (e.g. diagnosis and treatment). A central element to this journey is the relationship between patients and professionals, and staff’s ability to gain the patients trust and build a positive rapport with them.

It is also important to note that despite the questions asked (e.g. Can you describe the emotional impact that the procedure has upon patients and upon you as clinicians
supporting the patients?), emotional issues were not openly discussed by professionals. This could be due to the busy and pressurised hospital environment in which they are working, with much more focus on the practicalities of care, as well as staff becoming more familiar with and perhaps more blunted to anxiety provoking procedures such as CATH. It is also possible that staff were avoiding the emotional impact of the procedure upon both themselves as clinicians supporting patients through the procedure, as well as the emotional impact on the patients themselves.

Despite the structure of Leventhal et al’s (1980) SRM of illness representations being taken away for the analysis, a number of the findings fit well with the model. The model proposes that the patients view of the procedure is based on ‘lay’ sources of information and coherence (information and understanding), social communication and causal attributions (past experiences), the external environment (staff/patient relationship) and current experience of illness. Identity (personal coping style) and perceived consequences and timeline (the patient journey) are also important attributions (Linz et al., 1982; Meyer et al., 1985). This suggests that acknowledging individual differences, promoting the patient/relationship, and increasing patient knowledge and understanding will impact on the individual’s subjective mental representation of their illness, the procedure and possible treatment outcomes.

**Self-management and positive coping**

A number of the themes described by professionals were similar to those which emerged from the parallel patient interviews (see Appendix 14 for a summary of patient themes). Both professionals and patients talked about the importance of interpersonal factors and the staff/patient relationship, including the value of informal chat, comfort and kindness (e.g. hand holding), being alongside the patient, and normalising their anxiety. Both groups also talked about the importance of recognising patients’ individual differences and experiences and the benefit of hearing about how other people had coped positively with the procedure. This shared understanding of interpersonal factors between patients and health professionals is important in promoting collaboration, trust and mutual learning, and shifting the role of the health professional from the ‘professional expert’ (instructing and deciding) to ‘guide’ (supporting and advising) (Greenhalgh, 2009).

Healthcare professionals are key in using their skills to enable the patient to feel engaged, empowered and motivated, and to support self-management. The Health Foundation framework for self-management (de Silva, 2011) suggests that proactive initiatives which seek to increase self-efficacy and support behaviour change work best; for example, active provision of information, goal setting and telephone coaching (see
Higher perceived control has been found to be related to active or problem-focused coping and better psychological outcome (Hagger & Orbell, 2003).

Figure 3. Continuum strategies to support self-management.

Recommendations and service implications
Given the findings, key service improvements were proposed with the aim of promoting positive coping, self-management, involvement, choice, and control amongst patients undertaking the CATH procedure:

- **Individualised information provision** – whilst patients need key information to allow them to make an informed choice about the procedure, it is recognised that some patients may like to know more and to have an opportunity to ask questions (e.g. by phoning the nurses).
- **Interpersonal factors** – the value of the patient/staff relationship was acknowledged in promoting positive coping. This included informal chat and comfort, and being alongside the patient to normalise anxiety. A recommendation was made for this to be continued.
- **Learning from peers** – the benefit of sharing patients’ experiences of coping with the CATH could be expanded through providing accounts from others, and reliable online resources.
- **Consultation with Clinical Psychology** – patients reported that when they perceived something to have gone wrong with the procedure (e.g. something getting stuck/panic), this caused increased anxiety for future procedures. A recommendation was made to flag such cases to the team Clinical Psychologist.
Practical recommendations – patients and professionals suggested practical recommendations to improve coping. This included distraction and a choice of music in the CATH lab, and magazines in the waiting areas.

Service constraints – is it important to acknowledge the impact of service pressures on health professionals and the differences between ‘ideal world’ solutions (e.g. having a specific staff member to follow the patient through each step of their journey through the teams) and what is practical within service constraints.

Meetings were set up with the PH and CATH lab teams at the RUH to feedback and provide an improved understanding of optimal healthcare team interventions. The MTU were not able to attend this session, therefore written feedback was shared with them (see Appendix 16) and followed up by the team Clinical Psychologist. Health professionals were positive about the key themes and recommendations, which were in line with their expectations. They acknowledged that having additional resources to promote positive coping would be beneficial for the service, resulting in the development of the following:

- **Patient leaflet** – direct accounts of patient experiences alongside photos (e.g. staff teams, CATH lab), to show the journey through the service, normalise anxiety, give practical advice (e.g. bring a book/music) and reliable information resources (see Appendix 16 for a draft leaflet).

- **Patient passport** – a simple checklist of preferences which will accompany the patient through each step the service so that interventions can be tailored to reduce their anxiety. It includes questions about previous traumatic procedures (CATH or other), and their personal coping style (e.g. distraction/chatting/prefer to be left alone). It was agreed with the staff teams that the passport was not needed for every patient, but as a resource for those who were experiencing more difficulty (see Appendix 17 for a draft passport).

- **Video** – professionals suggested producing a short video about what to expect at the hospital, the procedure itself, the CATH lab, and the teams. This will be available for patients who choose to access further information about CATH.

It is important that implemented strategies are followed up on by health professionals within the service and that patients are central in this feedback. Service improvements will continue to be supported by the team Clinical Psychologist through on-going education and support for staff.
Limitations
Qualitative methodology was used to collect the data meaning that it may therefore not be generalised to the wider population or applied in other health settings. This methodology does however give a very rich and detailed understanding of positive coping and self-management within the PH service at the RUH; an understanding which would have not been gained through quantitative methodology. Despite the limitations of qualitative research, staff teams thought that the findings may provide insights into how to support other groups of patients undertaking the CATH procedure.

Two teams (respiratory PH and CATH lab) were primarily involved in this research. It was difficult to recruit members of the MTU team to participate, which may be in part due to the team being unable to attend the initial meetings to discuss the research. This shows the importance of face-to-face contact in the later recruitment of participants, particularly within the context of a busy hospital setting. The MTU also provides care for patients undergoing a wide range of procedures from different medical specialties (e.g. Respiratory, Gastroenterology, and Neurology). Therefore, attending meetings and participating in research related to a specific procedure (i.e. CATH) for patients with PAH is not likely to be a priority for them and may have impacted on recruitment. It is possible that the MTU team would have talked more about the immediate preparation and recovery from the CATH procedure because this is where patients are placed during this period.

This research focussed on positive coping strategies, however professionals also talked about some individuals who do not cope so well with the procedure. Future research examining how the suggested recommendations impact on those who do not cope so well with the CATH, and understanding the impact of different coping styles in relation to this, would be worthwhile. It was also noted that staff did not talk specifically about emotional issues for themselves or patients in response to the CATH procedure. This was not something that was directly discussed in the feedback session with them, and is important to further consider. For example, discussing this with the team Clinical Psychologist and co-facilitating a session with staff to reflect on emotional issues not being discussed openly within the team, and how the team could think about this more within their day to day work.

Conclusion
This is the first study to examine health professionals’ perspectives on positive coping and self-management for patients with PAH undergoing the CATH procedure. It has important implications for patients who find the procedure more difficult, in increasing their sense of control, choice and positive coping. It has also given insight into the support
given by the health professionals in the PH service at the RUH Bath, and has relevant learning for other PH departments and patients undergoing CATH.

Learning from key health professionals involved in the procedure at different stages, this study emphasises the importance of health professionals gauging an individual patient's previous experiences and personal coping style, and ensuring openness and honesty about the procedure. It also highlights the emotional and practical journey experienced by professionals alongside the patients through the service, and the imperative role of a positive relationship between the patient and staff.
References


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Main Research Project - Exploring the Prerequisite Skills for Cognitive Behavioural Therapy: Relationship to Emotion Awareness and Treatment Outcome for Young People with Autism Spectrum Disorders

Cara Roberts-Collins (email: c.roberts-collins@bath.ac.uk)

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Internal supervisors: Dr Ailsa Russell
Dr Maria Loades

External supervisor: Anne Booth, Consultant Clinical Psychologist, Swindon CAMHS

Target journal: Behavioural and Cognitive Psychotherapy, Impact Factor 1.905. This journal focuses on work that contributes to theory and practice of cognitive and behavioural therapy (see Appendix 18 for the Instructions to Authors).
Background

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders characterised by qualitative impairments in social communication, and a restricted, repetitive pattern of interests and behaviours (American Psychiatric Association, 2013). It is estimated that 1% of children and young people (YP) have ASD (Baird et al., 2006). Additionally, around 70% of YP with ASD also experience high prevalence rates of anxiety disorders and depression (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; White, Oswald, Ollendick, & Scahill, 2009). The National Institute for Health and Clinical Excellence (NICE, 2013b) recommend adapted Cognitive Behavioural Therapy (CBT) for anxiety for YP with autism. Adaptations include training in emotion recognition, a structured approach (e.g. multiple-choice), regular breaks, involving parents/carers, and incorporating their special interest into therapy. There is emerging evidence supporting CBT to treat anxiety in YP with ASD (Ung, Selles, Small, & Storch, 2015).

Prerequisites for CBT

CBT is underpinned by the notion that thoughts, feelings, and behaviours (T-F-B) are linked. Emotional problems can arise when unhelpful thoughts or avoidance behaviours maintain negative affect. As part of CBT, people gather information about their T-F-B. Thus the ability to discriminate effectively amongst these phenomena, and understand the relationship between them is an essential or prerequisite competence for successful engagement (Reynolds, Girling, Coker, & Eastwood, 2006).

Research proposes that typically developing children can identify key cognitions and emotions needed for CBT. For example; Quakely, Coker, Palmer and Reynolds (2003) found that 80% of children aged 7-8 years, and 100% of 10-11 year olds, could differentiate between thoughts and behaviours. Further, Quakely, Reynolds, and Coker (2004) found that using cues (e.g., puppets) with children aged 4-7 years improved their ability to make this discrimination. Additionally, children aged 5-7 years reported post-event attributions, and linked thoughts and emotions (Doherr, Reynolds, Wetherly, & Evans, 2005). It is important to note, however, that this research focussed on non-clinical samples. To develop this further, Reynolds et al. (2006) found that children ‘at risk’ of developing a mental health problem were less able to discriminate between T-F-B than children at ‘low risk’. Notably, the authors suggest that metacognitive ability (i.e. to recognise, and to be able to think about the process of thinking) should be measured prior to engagement with CBT.

Research suggests that children with ASD perform as well as typically developing children (age 7-12 years old) in their ability to differentiate between T-F-B, and cognitive mediation, but do not perform so well on emotion recognition (Lickel, MacLean, Blakeley-
Smith, & Hepburn, 2012). This study, however, administered tasks designed for adults with an intellectual disability, meaning that scores were at ceiling level, and the task was therefore less sensitive at detecting group differences. Their task also focussed on emotion recognition in others, rather than internal emotion awareness; an important skill for CBT. Additionally, the children had not undertaken CBT. Lickel et al (2012) highlight the need for further research examining how performance on CBT skills tasks predict treatment outcome.

**Emotion Awareness**

Self-awareness is assumed not to be a unitary concept, spanning across both the psychological and physical self, as well as the relationship between the two; for example, ‘theory of own mind’ refers to the ability to understand one’s own emotions, thought processes and beliefs, and make sense of our behaviours (Williams, 2010). Children with ASD are known to struggle with introspection, awareness of their own and others emotions (Tanaka et al., 2012; Williams & Happé, 2010). Emotion awareness has been defined as “an attentional process that serves to monitor and differentiate emotions, locate their antecedents, but ignore the physical arousal that is part of the emotion experience” (Rieffe et al., 2011, p. 656). Conversely, alexithymia is the limited ability to recognise, differentiate, and verbalise an individuals’ own emotions (Kooiman, Spinhoven & Trijsburg, 2002).

Research with typically developing YP suggests that alexithymia and difficulties with emotion awareness (e.g. differentiating between emotions, communicating them to others, identifying their causes, and a focus on bodily arousal) are related to increased levels of depression, anxiety, and somatic complaints (Rieffe, Oosterveld, & Meerum Terwogt, 2006; Rieffe, Oowterveld, Miers, Terwogt, & Verena, 2008; Rieffe et al., 2010). In addition to this, groups of non-clinical YP with ASD show a number of differences when compared to typically developing YP. On an emotion identification task, children with ASD (mean age 10 years 2 months) have greater difficulty identifying and differentiating between their own emotions, as well as understanding the antecedents to their emotions (Rieffe, Meerum Terwogt & Kortonopoulou, 2007). Evidence from self-report questionnaires also suggests that for YP with ASD (mean age 11 years 5 months), viewing emotions as important information in helping analyse a problem, and the awareness of bodily symptoms during emotional experiences contribute less strongly to the prediction of internalizing symptoms (Rieffe et al., 2011). Additionally, this study found that worry and rumination were less strongly predicted by a tendency to hide emotions from others for YP with ASD.
It is important to note, however, that measures of internalizing symptoms (such as depression, anxiety, worry and rumination) are dependent on emotion awareness itself, and may therefore be biasing the results of these studies. These studies also do not include clinical samples of YP. Training in emotion recognition is recommended by NICE (2013) and can be improved with children with autism (e.g. Golan et al. 2010). However, no research to date has examined emotion awareness with YP with ASD who have attended CBT, or linked emotion awareness to the ability to identify thoughts, feelings, and behaviours.

**Socialisation to the CBT Model**

Alongside emotion awareness and the cognitive abilities to engage in CBT, YP need to be socialised to the model, i.e. to be able to: 1) apply principles; 2) express concordance; 3) demonstrate explicit understanding and; 4) make active plans in accordance with the model (Daniels & Wearden, 2011; Roos & Wearden, 2009). Within the adult literature, socialisation to the CBT model had been defined as:

“...the process by which a service user and clinician negotiate a shared understanding of the presenting difficulty. During the process, the clinician presents hypotheses and a formulation of the service-user's symptoms and experience in terms of the model to be used for intervention. The therapist provides information concerning the practical implications of the chosen model of therapeutic intervention, to allow the service-user to fully engage with and understand both the therapeutic process and the rationale for intervention.” (Roos & Wearden, 2009, pp.343).

Central to CBT is the concept of collaborative empiricism; working alongside the young person and their parents to develop a shared understanding of their difficulties, and a set of tools and principles which allow them to become a 'self-therapist' (Stallard, 2005).

**The Current Study**

The growing awareness of ASD and the high rates of comorbid disorders mean there is a greater need for effective treatments and to better understand treatment mechanisms (Wing & Potter, 2009). However, there is no evidence to suggest whether prerequisite skills for CBT, emotion awareness, or socialisation to the model are important in CBT with YP with autism. The current study therefore aims to assess emotion awareness and the prerequisites skills for CBT for YP with ASD, and how these elements relate to treatment outcome.
Aims
This study aims to consider the emotional and cognitive prerequisites for CBT in YP with ASD by:

1) Comparing levels of emotion awareness in YP with and without autism, and YP with autism who have attended CBT
2) Developing a task to assess the cognitive prerequisites for CBT in YP with ASD without an intellectual disability
3) Exploring whether the following are important in treatment outcome:
   a) Ability to distinguish T-F-B
   b) Emotion awareness
   c) Socialisation to CBT
   d) Psychoeducation

Hypotheses

- There will be significant differences on a task of emotion awareness between typically developing YP and YP with ASD.
- There will be significant differences on a task of emotion awareness between YP with ASD who have not attended CBT, and YP with ASD who have attended CBT.
- For YP with ASD who have completed CBT, there will be a significant positive association between ability to distinguish between and link T-F-B, therapy outcome, emotion awareness, psychoeducation, and socialisation.

Method
An independent-measures design was used with three participant groups to compare scores on an emotion awareness task. A within-subjects design was employed to investigate the association between prerequisite skills for CBT, emotion awareness, socialisation, psychoeducation and treatment outcome for the group with ASD who had attended CBT. Ethical approval was granted by the West of Scotland Research Ethics Service (ref. 15/WS/0111), the University of Bath Ethics Committee (ref. 15-156/15-107) and local NHS sites (see Appendix 19).

Participants
Three groups of YP aged 11-20 years old were recruited: 1) a control group of 242 YP (190 female, 52 male) without ASD and no prior experience of CBT were recruited through local schools and University open days; 2) 23 YP with ASD who had no prior experience of CBT were recruited through charities and social media; 3) 27 YP with ASD who had attended CBT. Thirteen of this group were recruited through local schools and University open days and only completed the emotion awareness task. The other 14
were recruited through clinicians within local NHS Trusts providing Child and Adolescent Mental Health Services (CAMHS). Inclusion criteria were: 1) a clinical diagnosis of an ASD (including Asperger’s syndrome) as assessed by the relevant local paediatric or CAMHS team, based on the ICD-10 criteria; and 2) receiving or had completed CBT informed therapy for an emotional disorder within the last 12 months. Exclusion criteria were: 1) currently an inpatient; and 2) a documented or suspected intellectual disability.

Measures

Emotion awareness. This was measured using the Emotion Awareness Questionnaire-30 item version (EAQ-30; Rieffe et al., 2008) (see Appendix 20). This self-report questionnaire consists of 30-questions which aim to identify how YP (aged 9-16 years) feel or think about their feelings. The EAQ-30 has good psychometric properties, criterion and concurrent validity and has been validated with YP with and without ASD (Rieffe et al., 2008; 2011). It has a six-factor structure of emotional functioning: 1) Differentiating Emotions; 2) Verbal Sharing of Emotions; 3) Bodily Awareness of Emotions; 4) Not Hiding Emotions; 5) Analyses of Emotions; 6) Attention to Others’ Emotions. Each question is rated on a three-point scale (1=not true, 2=sometimes true, 3=often true). A higher score represents a higher presence of this ability, apart from Bodily Awareness where higher scores indicate less attention to bodily symptoms.

Prerequisite skills for CBT. A novel CBT skills task was designed for this study in collaboration with a young person’s participation group (YPG; see Appendix 21). Participants were asked to read a short story about a boy with Generalised Anxiety Disorder and to answer four questions: 1) what T-F-B might Alex have? (score range 0-9); 2) draw arrows to show how the circles above could be connected (score range 0-6); 3) what needs to change for Alex to get better? (score range 0-2); 4) design an activity to help with Alex’s worry and tell us why it might help him (score range 0-3). The YPG gave advice on the design to ensure it was pitched at the appropriate developmental level. They chose how many stories were included, and which made the most sense, therefore enhancing ecological validity. A number of changes were made including adding more colour, the story being laid out on a separate page to the questions, and giving the option to read the story in their head or for it to be read aloud to them. To assist with language, the YPG and clinicians were asked about the words they used to describe elements of the CBT model.

The scoring criteria for the CBT task were developed in relation to socialisation: 1) explicit understanding (e.g. identifying and linking T-F-B), 2) making active plans (e.g. homework task), and 3) evidence of applying principles congruent with the model (e.g. identifying what needs to change) (Daniels & Wearden, 2011; Roos & Wearden, 2009).
Concordance could not be scored as this relates to agreement between the therapist and the client. The scoring criteria identifies the range of possible answers and scores, allowing a total score out of 20 (see Appendix 22). The CBT task was piloted with 14 clinicians trained in CBT, and one YP with ASD. The aim of this pilot was: 1) to check that the task could be understood by CBT experts who were expected to achieve high or ceiling level scores; 2) as a training exercise in scoring the task for the researchers and; 3) to check inter-rater reliability between the researchers for the scoring of the task. Clinicians scored an average of 17.43, with a number reaching ceiling level, as expected (see Appendix 23). The pilot resulted in the scoring criteria for question 3 being altered (to a maximum score of 2 instead of 3) because no CBT experts achieved the maximum score on this question. It was therefore assumed that this question would be too difficult for young people with ASD.

Inter-rater reliability was ensured by each of 34 tasks (20 YP, 10 of which were from another study using the task, and the 14 clinicians who had piloted the task) being scored independently by two researchers (ICC=0.937). Given the high inter-rater reliability, the remaining tasks were scored by one researcher only.

**Treatment outcome.** The Revised Child Anxiety and Depression Scale (RCADS; Chorpita & Ebesutani, 2014) is used as a routine outcome measure in CAMHS (see Appendix 24). Total scores from YP’s baseline and post-intervention self-report RCADS were collated from clinicians. The RCADS consists of 47-items rated on a 4-point Likert scale (‘Never’–‘Always’). It is used to assess depression and anxiety for YP aged 8-18 years. The RCADS has high internal consistency (α=0.78–0.88), and good convergent/divergent, discriminant, and factorial validity (Chorpita, Moffitt, & Gray, 2005). For this research, only the ‘total anxiety and depression’ score was collected. Based on normative data, T-scores are calculated where T>70 indicates clinical impairment, and reliable change is considered to be at least five points. Clinicians and YP also rated the YP’s improvement since attending therapy using the Clinical Global Impression–Improvement (CGI-I) scale (Busner & Targum, 2007). The CGI-I is a 7-point scale from 1 (‘very much improved’) to 7 (‘very much worse’). Scores of 1 or 2 are considered to represent successful treatment.

**Socialisation.** An adapted version of the socialisation interview was used (Mahoney-Davies, in preparation; see Appendix 25). This aimed to get a better understanding of what participants had learned from CBT, and whether they had received psychoeducation. Each utterance from the interview is scored against the socialisation criteria (see Appendix 26). Responses to the open questions were subject
to thematic analysis to capture YP’s experience of CBT (see Appendix 27). Clinicians were also asked to rate how ‘socialised’ to the CBT model they thought the young person was on a scale of 0 (not at all socialised) to 10 (very well socialised) (see Appendix 28).

**Procedure**

Prior to taking part in the research, all participants and parents/guardians were given information sheets (see Appendix 29 and 30). Informed consent was sought from those over 16 years old (see Appendix 31). For those under 16 years old, consent was sought from their parent/guardian (see Appendix 32) or school (see Appendix 33) and assent sought from the YP (see Appendix 34). They were informed that their participation was voluntary, information would be securely stored, and that they could withdraw at any time. All participants were assigned an identification number which is only associated with their name on a password protected database in accordance with the Data Protection Act (1998).

All three groups completed the EAQ-30 in person or via post. For those returning it by post, additional telephone calls and emails took place to ensure their understanding. All participants were given a debrief sheet, including contact numbers for support services, and details of the researcher (see Appendix 35). Those with ASD who had completed CBT within local CAMHS were seen at a convenient location away from CAMHS to complete the EAQ-30, socialisation interview and CBT task, taking 30-40 minutes in total. The YPPG felt it was important to include a ‘pass’ card so participants could move onto the next question if they wanted to, and they were given the option to end the session with a fun activity (e.g. card game). Two participants were seen at the University, and twelve were seen at home. Nine chose to have their parent present at the interview and five chose not to. Once they had taken part, all participants were also given a debrief sheet and received a £5 voucher to thank them for their time. With the consent of the YP, their clinician was contacted and asked to complete the socialisation scale, CGI-I, and give RCADS scores.

**Data analytic strategy**

Mixed analysis of covariance (ANCOVA) was planned to address the primary hypothesis (that there will be significant differences on a task of emotion awareness between typically developing YP and YP with ASD) and the secondary hypothesis (that there will be significant differences on a task of emotion awareness between YP with ASD who have not attended CBT, and YP with ASD who have attended CBT). The independent variable is the group (control vs. ASD, and CBT vs. no CBT). The dependent variable is the score on the six subscales of the EAQ-30. The covariate, age, is controlled for within this analysis. Where group x EAQ-30 scale interactions are significant, simple main
effects are carried out using univariate analyses. Bonferroni corrections are applied where multiple analyses are conducted.

The two groups with ASD were combined (n=50; 16 females, 34 males) to address the primary hypothesis. Given that the ASD group contained a greater proportion of males and the control group consisted a large number of females (n=242; 190 female, 52 male), fifty of the control group were matched by gender to those with ASD. Additionally, as age is known to impact on emotion awareness (Lickel et al., 2012), the control group were also matched to the ASD group by age. Matching was carried out using a database containing the age and gender of the participants with ASD alongside a database of the control group, each ordered by age. The first participant from the control group that matched the age and gender of each participant in the ASD group was chosen, resulting in a total of 16 females and 34 males of the same age in each group (total n=50).

Due to the exploratory nature of this study and the lack of previous research in this area, a large effect size is acceptable. A power analysis using G*power indicated that to examine the difference between two independent means, with a large effect size (d=0.8, α err prob=0.05, power=0.8), 21 participants were required in each group.

The final hypothesis for the 14 YP with ASD who had completed CBT in a local CAMHS service was addressed using non-parametric Spearman’s correlation analyses. Variables included their total score on the CBT skills task, therapeutic outcome (CGI-I), EAQ-30, psychoeducation, and socialisation score. Due to RCADS data only being available for 11 participants, these scores were excluded from the analysis.

Results

Participant Demographics

Three groups took part in the study: 1) A control group of YP without ASD and no experience of CBT (total n=242, matched sample n=50); 2) YP with ASD who had no experience of CBT (n=23); 3) YP with ASD who had attended CBT (n=27) (see Table 1). As previously described, the two groups with ASD were combined (n=50) to address the primary hypothesis. Pearson’s chi-square showed no significant difference between the three groups for gender, $\chi^2 (2) = 2.061, p=.357$. A One-Way Analysis of Variance (ANOVA) found no significant differences between the three groups for age, $F(2,97)=.710, p=.494$. 
### Table 1

**Participant age and gender for the groups**

<table>
<thead>
<tr>
<th></th>
<th>Number of participants</th>
<th>Gender</th>
<th>Mean age (SD)</th>
<th>Age range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Matched Control group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n = 50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16 female (32%)</td>
<td></td>
<td>15 years 9 months</td>
<td>11 years 2 months –</td>
</tr>
<tr>
<td></td>
<td>34 male (68%)</td>
<td></td>
<td>(2 years 5 months)</td>
<td>19 years 7 months</td>
</tr>
<tr>
<td><strong>Combined ASD group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n = 50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16 female (32%)</td>
<td></td>
<td>15 years 9 months</td>
<td>11 years – 20 years</td>
</tr>
<tr>
<td></td>
<td>34 male (68%)</td>
<td></td>
<td>(2 years 6 months)</td>
<td>4 months</td>
</tr>
<tr>
<td><strong>ASD, no CBT</strong></td>
<td>n = 23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 female (21.74%)</td>
<td></td>
<td>15 years 4 months</td>
<td>11 years 1 month –</td>
</tr>
<tr>
<td></td>
<td>18 male (78.26%)</td>
<td></td>
<td>(2 years 7 months)</td>
<td>19 years 8 months</td>
</tr>
<tr>
<td><strong>ASD + CBT</strong></td>
<td>n = 27</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11 female (40.74%)</td>
<td></td>
<td>16 years 1 month</td>
<td>11 years –</td>
</tr>
<tr>
<td></td>
<td>16 male (59.26%)</td>
<td></td>
<td>(2 years 5 months)</td>
<td>20 years 4 months</td>
</tr>
<tr>
<td><strong>Local CAMHS</strong></td>
<td>n = 14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 female (42.86%)</td>
<td></td>
<td>15 years 2 months</td>
<td>11 years –</td>
</tr>
<tr>
<td></td>
<td>8 male (57.14%)</td>
<td></td>
<td>(2 years 3 months)</td>
<td>18 years 3 months</td>
</tr>
</tbody>
</table>

*Note. ASD = autism spectrum disorder; SD = Standard Deviation*

Out of the group with ASD who had attended CBT, 14 had been seen within local CAMHS. A total of 35 YP who were attending CBT at CAMHS were invited to participate, and 14 (40%) consented to take part. Reasons for not partaking included pending exams and it not being appropriate in terms of their current mental health. Presenting problems for CBT included generalised anxiety, social anxiety, obsessional compulsive disorder, depression, and anger. Eight participants had completed CBT in the last 12 months. Six were still engaged in sessions, but had completed more than six sessions.

**Hypothesis 1:** There will be significant differences on a task of emotion awareness between typically developing YP and YP with ASD

A mixed ANCOVA examined the group x EAQ-30 interaction for the control group (n=50) and YP with ASD (n=50), with age as the covariate. Given that the assumption of sphericity was violated, $X^2(14)=49.88$, $p=.001$, and as estimates of sphericity are $\varepsilon>0.75$, Huynh-Feldt corrected values are reported.
The main effect of the EAQ-30 subscales was not significant within-subjects, suggesting that irrespective of group, average ratings on the EAQ-30 subscales were similar, $F(4.40,426.95)=2.07$, $p=.077$. The covariate, age, significantly interacted with the EAQ-30, indicating that when group is not considered, scores on the EAQ-30 are affected by age, $F(4.40,426.95)=3.91$, $p=.003$. However, the main effect of age between-subjects was not significant, suggesting age was similar across groups, $F(1,97)=0.14$, $p=.708$.

The group x EAQ-30 interaction was significant, suggesting that the profile of ratings across the scales are different for the groups, $F(4.40,426.95)=5.02$, $p=.001$. There was also a significant main effect of group between-subjects, with the ASD group scoring significantly lower overall on the EAQ-30, $F(1,97)=22.32$, $p=.001$ (Figure 1).

![Mean score of EAQ-30 subscales](image)

**Figure 1.** Interaction between group and the EAQ-30 subscales for the ASD and control groups

Given the significant group x EAQ-30 interaction, simple main effects were analysed using univariate analyses. Participants with ASD scored significantly lower on Differentiating Emotions, Verbal Sharing of Emotions, Attending to Others’ Emotions, and Analyses of Own Emotions. There were no significant differences between the groups for Not Hiding Emotions, or Bodily Awareness of Emotions (see Table 2).
Table 2

Mean scores and simple main effects of group for each subscale of the EAQ-30 for the control group and whole ASD group

<table>
<thead>
<tr>
<th>EAQ-30 scales</th>
<th>Control group (n=50)</th>
<th>Whole ASD group (n=50)</th>
<th>Simple main effects</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Differentiating Emotions</strong></td>
<td>2.27 (0.42)**</td>
<td>1.95 (0.57)</td>
<td>F (1, 97) = 10.26, p = .002</td>
</tr>
<tr>
<td><strong>Verbal Sharing of Emotions</strong></td>
<td>2.04 (0.60)**</td>
<td>1.70 (0.57)</td>
<td>F (1,97) = 8.54, p = .004</td>
</tr>
<tr>
<td><strong>Not Hiding Emotions</strong></td>
<td>1.90 (0.50)</td>
<td>1.85 (0.46)</td>
<td>F (1,97) = .22, p = .644</td>
</tr>
<tr>
<td><strong>Bodily Awareness of Emotions</strong></td>
<td>1.80 (0.51)</td>
<td>1.75 (0.50)</td>
<td>F (1,97) = .29, p = .594</td>
</tr>
<tr>
<td><strong>Attending to Other’s Emotions</strong></td>
<td>2.77 (0.24)**</td>
<td>2.20 (0.58)</td>
<td>F (1,97) = 41.63, p = .001</td>
</tr>
<tr>
<td><strong>Analyses of Own Emotions</strong></td>
<td>2.48 (0.45)**</td>
<td>2.19 (0.50)</td>
<td>F (1,97)=10.06, p = .002</td>
</tr>
</tbody>
</table>

*Note. ASD = autism spectrum disorder; EAQ-30 = Emotion Awareness Questionnaire; SD = Standard Deviation; **p<0.01, *p<0.05, p values adjusted for multiple comparisons using Bonferroni corrections

**Hypothesis 2: There will be significant differences on a task of emotion awareness between YP with ASD who have not attended CBT, and YP with ASD who have attended CBT.**

Within the ASD groups, a mixed ANCOVA examined the group x EAQ-30 interaction for the CBT group (n=27) and the no CBT group (n=23), with age as the covariate. Given that the assumption of sphericity was violated, $X^2(14)=27.81, p=.015$, and as estimates of sphericity are $\epsilon>0.75$, Huynh-Feldt corrected values are reported.

The main effect of the EAQ-30 subscales was not significant within-subjects, indicating that if group is ignored, average scores on the EAQ-30 were similar, $F(4.68,219.98)=0.80, p=.545$.

The covariate, age, did not significantly interact with the EAQ-30, suggesting that when group is not taken into consideration, scores on the EAQ-30 scales are not affected by age, $F(4.68,219.98)=0.97, p=.431$. The main effect of age between-subjects was also not significant, indicating that age was similar across groups, $F(1,47)=0.002, p=.967$. 
There was a significant group x EAQ-30 interaction, showing that the scales are differently affected by group $F(4.68,219.98)=5.44$, $p=.001$. The main effect of group between-subjects was not significant, indicating that the scores from the groups were generally similar, $F(1,47)=1.21$, $p=.277$ (Figure 2).

Figure 2. Interaction between group and the EAQ-30 subscales for the CBT and no CBT groups

Given the significant group x EAQ-30 crossover interaction, simple main effects were analysed using univariate analyses. Participants who had attended CBT scored significantly lower in their ability to Differentiate Emotions and significantly higher on Attending to Other's Emotions. There were no significant differences between the groups for Verbal Sharing of Emotions, Analyses of Own Emotions, Not Hiding Emotions, or Bodily Awareness of Emotions (see Table 3).
Table 3

Mean scores and simple main effects of group for each subscale of the EAQ-30 for the CBT and no CBT groups

<table>
<thead>
<tr>
<th>EAQ-30 scales</th>
<th>Mean Scores (SD)</th>
<th>Simple main effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASD + CBT (n=27)</td>
<td>ASD, no CBT (n=23)</td>
</tr>
<tr>
<td>Differentiating Emotions</td>
<td>1.75 (0.49)**</td>
<td>2.19 (0.57)</td>
</tr>
<tr>
<td>Verbal Sharing of Emotions</td>
<td>1.59 (0.48)</td>
<td>1.83 (0.64)</td>
</tr>
<tr>
<td>Not Hiding Emotions</td>
<td>1.74 (0.42)</td>
<td>1.98 (0.48)</td>
</tr>
<tr>
<td>Bodily Awareness of Emotions</td>
<td>1.66 (0.43)</td>
<td>1.86 (0.57)</td>
</tr>
<tr>
<td>Attending to Other’s Emotions</td>
<td>2.36 (0.43)*</td>
<td>2.00 (0.67)</td>
</tr>
<tr>
<td>Analyses of Own Emotions</td>
<td>2.26 (0.49)</td>
<td>2.11 (0.52)</td>
</tr>
</tbody>
</table>

Note. ASD = autism spectrum disorder; EAQ-30 = Emotion Awareness Questionnaire; SD = Standard Deviation; **p<0.01, *p<0.05, p values adjusted for multiple comparisons using Bonferroni corrections

Hypothesis 3: For YP with autism who have completed CBT, there will be a significant positive association between ability to distinguish between and link T-F-B, therapy outcome, emotion awareness, psychoeducation, and socialisation.

Ability to Distinguish Between and Link T-F-B

For the group with ASD who had completed CBT in a local CAMHS (n=14), YP scored higher on the feelings element than thoughts and behaviours. Seven (50%) of the YP could identify three feelings, whereas seven (50%) could identify only one thought. The majority (76.8%) could identify either one or two behaviours. Over half (57.1%) could link T-F-B, although only two participants (14.3%) could link them bi-directionally. Participants appeared to find it difficult to identify what needed to change, with 85.8% scoring 0 or 1 point. They found it easier to design an activity, however only 21.4% could describe why this activity might help (see Table 4).
Table 4

Mean, median, range, and frequency of scores on each segment of the CBT task

<table>
<thead>
<tr>
<th>CBT task</th>
<th>Thoughts (max=3)</th>
<th>Feelings (max=3)</th>
<th>Behaviours (max=3)</th>
<th>Linking (max=6)</th>
<th>Change (max=2)</th>
<th>Activity (max=3)</th>
<th>Total (max=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>1.17</td>
<td>2.07</td>
<td>1.57</td>
<td>3.29</td>
<td>0.71</td>
<td>1.5</td>
<td>10.79</td>
</tr>
<tr>
<td>(SD)</td>
<td>(0.83)</td>
<td>(0.10)</td>
<td>(0.85)</td>
<td>(1.49)</td>
<td>(0.73)</td>
<td>(1.16)</td>
<td>(3.77)</td>
</tr>
<tr>
<td>Median</td>
<td>1.5</td>
<td>2.5</td>
<td>1.5</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>10.5</td>
</tr>
</tbody>
</table>

Min – max (range) 1 – 3 (2) 1 – 3 (2) 0 – 3 (3) 0 – 6 (6) 0 – 2 (2) 0 – 3 (6) 18 (15)

Score frequency (number, %)

<table>
<thead>
<tr>
<th>Score</th>
<th>Thoughts</th>
<th>Feelings</th>
<th>Behaviours</th>
<th>Linking</th>
<th>Change</th>
<th>Activity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (7.1%)</td>
<td>1 (7.1%)</td>
<td>6 (42.9%)</td>
<td>4 (28.6%)</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>7 (50%)</td>
<td>6 (42.9%)</td>
<td>6 (42.9%)</td>
<td>0</td>
<td>6 (42.9%)</td>
<td>2 (14.3%)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4 (28.6%)</td>
<td>1 (7.1%)</td>
<td>5 (35.7%)</td>
<td>1 (7.1%)</td>
<td>2 (14.3%)</td>
<td>5 (35.7%)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>3 (21.4%)</td>
<td>7 (50%)</td>
<td>2 (14.3%)</td>
<td>8 (57.1%)</td>
<td>3 (21.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td>2 (14.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td>2 (14.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. SD = Standard Deviation

CBT Competencies, Socialisation and Relationship to Therapeutic Outcome

Due to the data not being normally distributed, non-parametric Spearman’s correlations examined the relationships between therapeutic outcome (CGI-I), emotion awareness, CBT skills, socialisation, and psychoeducation. Where multiple correlations are carried out using the same variable, p-values have been adjusted using Holm-Bonferroni corrections (see Table 5).

Table 5

Spearman’s correlational analyses: CBT competencies, socialisation and therapeutic outcome

<table>
<thead>
<tr>
<th>YP CGI-I</th>
<th>CBT task</th>
<th>Psychoed score</th>
<th>Socialisation score</th>
<th>Bodily awareness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic outcome</td>
<td>r=.567</td>
<td>r=.252</td>
<td>r= -.156</td>
<td>r= -.193</td>
</tr>
<tr>
<td>(Clinician CGI-I)</td>
<td>p=0.085</td>
<td>p=0.576</td>
<td>p=0.576</td>
<td>p=0.576</td>
</tr>
<tr>
<td>CBT task</td>
<td>r= -.027</td>
<td>r= 0.86</td>
<td>r= -.237</td>
<td></td>
</tr>
<tr>
<td>p=0.770</td>
<td>p=0.770</td>
<td>p=0.621</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. CGI = Clinical Global Impression–Improvement Scale
**Therapeutic Outcome.** Based on their overall experience of CBT, twelve participants (85.7%) reported a positive experience, and two (14.3%) reported a negative experience. On the CGI-I, four participants (28.6%) rated themselves as 1='very much improved', five (35.7%) rated themselves as 2='much improved' and five (35.7%) rated themselves as 3='minimally improved'. None rated themselves as having experienced 4='no change from baseline' or getting any worse. Two clinicians (14.3%) rated the young person as 1='very much improved', six (42.9%) as 2='much improved', five (35.7%) as 3='minimally improved', and one (7.1%) as 4='no change from baseline'. Spearman's correlations showed a non-significant relationship between clinician and YP rated improvement on the CGI-I.

**Emotion awareness.** There was a nonsignificant relationship between the EAQ-30 Bodily Awareness scale and the CBT task or clinician CGI-I score.

**CBT skills task.** The correlation between the total score on the CBT task and clinician CGI-I score was not significant.

**Socialisation.** Clinician socialisation scores were widely spread, with six (42.9%) describing the YP as 'not socialised at all' to 'somewhat socialised', and eight (57.1%) from 'somewhat socialised' to 'very well socialised'. Total socialisation score was not significantly correlated with the total score on the CBT task, or clinician CGI-I.

**Psychoeducation.** Three YP (21.4%) reported to have not received psychoeducation. Five (35.7%) described psychoeducation specific to their presenting problem. Six (42.9%) reported psychoeducation related to their presenting problem and more general psychoeducation. Psychoeducation was not significantly correlated with the CBT task or clinician CGI-I score.

**Discussion**
This research aimed to consider the prerequisite skills for CBT for YP with ASD through an emotion awareness measure, and a novel CBT skills task. A new task was developed and piloted with a group of YP with ASD who had attended CBT. The study explored whether the ability to distinguish T-F-B, emotion awareness, socialisation, and psychoeducation are important in treatment outcome.

In line with initial hypotheses, participants with ASD scored significantly lower than typically developing participants on a number of factors of emotion awareness: Differentiating Emotions, Verbal Sharing of Emotions, Attending to Others’ Emotions, and Analyses of Own Emotions. There were no significant differences between the groups for Not Hiding Emotions, or Bodily Awareness of Emotions. This finding is similar to previous research which showed that children with ASD (mean age 11 year 5 months)
have more difficulty than typically developing YP in identifying and differentiating between their emotions (Rieffe et al., 2007). The current study also extends this finding to older adolescents (mean age 15 years 9 months).

Research suggests that recognition of others’ emotions is significantly related to age for YP with ASD, but not for typically developing YP (Lickel et al., 2012). Typically developing adolescents experience an increase in complex emotion regulation which is influenced by social context (Zeman, Cassano, Perry-Parrish, & Stegall, 2006). Conversely, adolescents with ASD struggle with awareness of their own and others’ emotions (Tanaka et al., 2012; Williams & Happé, 2010), and have reduced social networks, which is a risk factor for mental health difficulties in itself (Koning & Magill-Evans, 2001). The differences across a number of domains of emotion awareness are therefore unsurprising.

Within the ASD group, those who had attended CBT scored significantly lower on Differentiating Emotions and significantly higher on Attending to Others’ Emotions. It could be hypothesised that a difficulty differentiating between emotions could contribute to the development or maintenance of problematic emotional responses, such as anxiety disorders and depression, precipitating CAMHS referrals. Previous research with a non-clinical group of children with ASD suggested that difficulties differentiating between emotions, communicating them, and identifying their causes is related to increased internalizing disorders such as anxiety and depression (Rieffe et al., 2006; 2008; 2010). Additionally, meta-analyses of clinical and normative samples in the general population have found significant links between dysregulated emotion and psychopathology (Aldao, Nolen-Hoeksema, & Schweizer, 2010). It is therefore recommended that in addition to psychoeducation in line with NICE guidelines (2013b), clinicians also recognise and build upon YP’s ability to differentiate between emotions in CBT (e.g. rather than more broadly “feeling bad”, identifying specific emotions such as “angry” or “sad”).

In terms of Attending to Others’ emotions, it is possible that YP with ASD who have attended CBT are focussing on how other people are feeling at the expense of their own internal state. This is similar to findings with adults with ASD, who focus more on external events than on inner experiences (Hill, Berthoz, & Frith, 2004). Within their CBT, and in line with NICE guidelines (2013b), YP may have received psychoeducation around understanding others’ emotions (e.g. reading facial expressions). However, they may have been taught less about understanding their own emotions. It is therefore recommended that clinicians recognise and build upon YP’s internal emotion recognition.
On the CBT task, YP were better at identifying feelings than thoughts or behaviours, and over half could make links between T-F-B. Thinking about what needed to change, and identifying why an activity might help was more difficult. Against hypotheses, the CBT task was not significantly related to Bodily Awareness on the EAQ-30, outcome on the CGI-I, psychoeducation, or socialisation. This could be due to the lack of sensitivity of the new CBT skills measure which needs further refinement with larger numbers of participants. Several mean scores on the task were relatively low, suggesting that the task may be too difficult. However, the task did result in a good range of scores, suggesting that it could measure improvement. It is important to note that this study was piloting a new task and it is therefore positive that YP with ASD could complete the task and talk about their experiences of CBT.

Similarly, outcome on the CGI-I was not related to Bodily Awareness, socialisation, or psychoeducation. Again this could be due to the small numbers of participants. It is important to note, however, that 85.7% of YP reported a positive experience of CBT. Both YP and clinicians reported at least minimal change, with only one clinician reporting ‘no change from baseline’. None reported their difficulties getting worse. This is important information given the high prevalence rates of anxiety disorders and depression for YP with ASD (Kim et al., 2000; White et al., 2009), and adds to the emerging evidence for CBT for YP with ASD (Ung et al., 2015).

Other factors that may be important in therapeutic outcome were not measured or controlled for in this study, including therapeutic alliance and therapist factors (Messer & Wampold, 2002). Successful completion of CBT tasks has also been associated with cognitive ability and age (Doherr et al., 2005; Quakely et al., 2003; Quakely et al., 2004). Further, ability to recognize and distinguish between T-F-B for YP with ASD had been associated with verbal intelligence (Lickel et al., 2012). Additionally, it has been suggested that the effectiveness of CBT may be impacted upon by core features of ASD (Puleo & Kendall, 2011). Measuring such factors were beyond the scope of the current study. However, it is important for future research to control for these, as well as other factors including the number of CBT sessions they had attended, the time since their CBT, and the quality of the CBT.

Limitations and Future Research

It is important to note the exploratory nature of this research and that these preliminary findings warrant replication with larger samples. This is particularly true in relation to the novel CBT skills task which was developed specifically for this research. The task involved answering questions about another person’s T-F-B. Parents of YP completing this measure commented on how this may have been challenging for those with ASD.
who have difficulties with Theory of Mind (Hill et al., 2004). Future research to pilot the task with YP with ASD who have not attended CBT, or are considered ‘at risk’ of developing a mental health difficulty is recommended to see whether the task differentiates between these groups. Moreover, this study did not compare the group with ASD to typically developing YP who have attended CBT. It could be hypothesised that those with ASD, and those ‘at risk’ of mental health difficulties are less able to discriminate T-F-B (Reynolds et al., 2006).

In terms of the sample itself, CAMHS clinicians were asked to identify YP who had attended CBT. It is possible that they may have been biased in their selection and chose YP who they thought responded well to therapy, or with whom they were doing ‘proper’ CBT. Participants then needed to make initial contact with the researcher, meaning that they would need to be motivated to engage in the research and therefore possibly more likely to be motivated to have been engaged in CBT. It would be worthwhile examining whether YP had attended CBT first and then received a diagnosis of ASD, or vice versa, as this may influence the way the CBT is delivered or adapted for ASD and therefore impact on understanding and socialisation to the model.

The EAQ-30 was developed for YP aged 9-16 years old (Rieffe et al., 2011; Rieffe et al., 2008). It was used with YP up to the age of 20 years old in this research, and therefore requires careful interpretation. There has also been some criticism of the use of self-report questionnaires for YP; however, evidence also suggests that YP are actually better at identifying their own internalising symptoms than informants (e.g. parents or teachers) (Achenback, McConaugh, & Howell, 1987; DiBartolo & Grills, 2006; Jellesma, Rieffe, & Meerum Terwogt, 2007).

**Clinical Implications and Conclusion**

Given the high prevalence rates of anxiety disorders and depression for YP with ASD, having a better understanding of the mechanisms behind treatment is imperative. This is the first research study to examine the prerequisite skills for CBT and internal emotion awareness in YP aged 11-18 with a diagnosis of ASD. This research highlights the importance of clinicians tailoring CBT to individuals with ASD. It demonstrates how it is imperative for clinicians to teach YP with ASD about differentiating between and understanding the antecedents to their own feelings and emotions. It also shows the complexities of research within this area, and the need for larger research studies to build our understanding of the mechanisms behind CBT.
References


National Institute for Health and Clinical Excellence. (2013a). \textit{Autism in under 19s: support and management}.


Executive summary

Background
Autism Spectrum Disorders (ASD) are neurodevelopmental disorders in which people have difficulties with social communication, and restricted, repetitive patterns of interests and behaviours. Research shows that young people with ASD have high levels of anxiety and depression. The National Institute for Health and Clinical Excellence (NICE, 2013) guidelines suggest using adapted Cognitive Behaviour Therapy (CBT) for young people with autism and anxiety difficulties. Recommended adaptations include training in understanding emotions, using a clear structure, taking breaks, involving parents/carers in sessions, and using a young person’s special interest in therapy sessions.

Skills to take part in CBT have been identified in the research literature, including the ability to understand thoughts, feelings, and behaviours. In order to use these skills, people need to have an awareness of their own emotions, and to be socialised to (or understand) the CBT model. However, there is currently no evidence to tell us whether understanding CBT skills (e.g. thoughts, feelings, and behaviours) and emotion awareness are important for therapy outcome for young people with a diagnosis of autism. Given the growing awareness of ASD and the high rates of difficulties this group experience, we need to get a better understanding of how treatments like CBT work.

Aims of this study
This study wanted to explore and get a better understanding of:
- differences in emotion awareness between young people with ASD and young people without ASD
- differences in emotion awareness between young people with ASD who had not had CBT, and young people with ASD who had taken part in CBT
- whether emotion awareness and CBT skills were related to therapy outcome
- young people’s with ASD’s experiences of CBT

Participants and Measures
Three groups of young people (aged 11-20 years old) took part in the study: 1) a group of 50 young people without a diagnosis of ASD who had not had CBT; 2) 23 young people with a diagnosis of ASD who had not attended CBT, and; 3) 27 young people with ASD who had attended CBT.

All three groups of participants filled in the Emotion Awareness Questionnaire (EAQ-30). This questionnaire asks 30 questions about how young people feel or think about their
feelings in six different areas: 1) Differentiating Emotions; 2) Verbal Sharing of Emotions; 3) Bodily Awareness of Emotions; 4) Not Hiding Emotions; 5) Analyses of Emotions; 6) Attention to Others’ Emotions. A new CBT skills task was developed and completed by 14 of the young people with a diagnosis of ASD who had attended CBT at a local Child and Adolescent Mental Health Service (CAMHS). They also took part in an interview about their experiences of CBT. Their relevant CAMHS clinician rated the young persons’ understanding of CBT, and shared their answers on routine CAMHS questionnaires.

Results

The main results were:

- **Emotion awareness**
  - The young people with ASD scored lower than the group without ASD on a number of areas of the EAQ-30: Differentiating Emotions, Verbal Sharing of Emotions, Attending to Others’ Emotions, and Analyses of Own Emotions.
  - Within the ASD group, the young people who had taken part in CBT scored lower on Differentiating Emotions and higher on Attending to Others’ Emotions than those who had not attended CBT.

- **CBT skills**
  - On the CBT skills task, participants could identify more feelings than thoughts or behaviours, and could link them together. They found it harder to describe what might need to change.
  - Their ability on the CBT skills task was not related to therapy outcome, socialisation (understanding) to the CBT model, or psychoeducation (e.g. learning about what thoughts and feelings are in therapy).

- **Experience of CBT**
  - Young people generally had a positive experience of CBT (85.7%), and neither the young people nor their clinicians felt that their difficulties had become any worse having attended CBT.
  - Qualitative analysis of the interviews resulted in six main themes: 1) CBT is helpful; 2) learning CBT skills; 3) developing an understanding of their difficulties; 4) the importance of therapist characteristics; 5) the pros and cons of family involvement; and 6) potential barriers to CBT.
Conclusion
This is the first study to look at the skills needed to understand and engage in CBT, as well as recognition of own emotions in adolescents with ASD. This study shows the importance of tailoring CBT to individuals and making sure that young people are taught to understand their own emotions in therapy sessions. More research is needed with larger groups of young people with ASD to find out more about how emotion awareness and CBT skills impact on therapy outcome.
Connective Narrative

Throughout my doctoral training in Clinical Psychology, my research and clinical work have developed across the lifespan. This narrative overview will describe the development of my research, how these projects are related to my clinical experiences on placement, and what I have learned from these experiences.

Children and Young People
My main research project and two of my case studies have involved working with children and young people. This is an area that I have been interested in since my first Assistant Psychologist posts in Child and Adolescent Mental Health Services (CAMHS), and an area in which I would like to work on completion of the course.

I was keen to conduct research with children and young people, and had initial research ideas involving siblings of young people with a physical health condition, and perfectionism with young people with Chronic Fatigue Syndrome (CFS). Due to course and service restrictions it was not possible to continue with either of these research ideas; for example the research needed to be primarily quantitative or mixed methods and involve a clinical population. This was frustrating at the time, and it was challenging to balance interests against the course requirements. However, I learned about some of the challenges of conducting research within a clinical setting, the importance of clear research questions and hypotheses, and good communication with services. These are skills I was able to build on in developing my research.

Following useful discussions with Dr Maria Loades (CAMHS tutor) and Dr Ailsa Russell (Clinical Director), we developed the idea of research into the prerequisites for Cognitive Behavioural Therapy (CBT) for young people with autism spectrum disorders (ASD). This was an area that I was keen to learn more about, particularly given previous clinical experiences of conducting and adapting CBT for young people with autism. This project was linked to a project conducted by a fellow trainee, Gerwyn Mahoney-Davies who was looking at whether socialisation to CBT is important for typically developing young people.

It was important to include young people in the development of the project to ensure that it was designed in a way that was young people friendly. I met with the Action for Children participation group to gather feedback on the language and layout of the proposed participant information sheets and consent form, and the overall research design. It always surprises me that no matter how ‘young people friendly’ you try to make things,
the young people themselves have a much better way of presenting or describing the information! This experience taught me how vital service user consultation is, and the importance of taking on board the views of young people. For example, advertising the study using a brightly coloured poster, using understandable language, and to include an option of a fun task at the end of the study. I will ensure that any future research I conduct also involves service users in each stage of the research development.

Once all of the research documents had been amended to fit with the young people’s input, the process of applying for NHS ethical approval began. The application itself was confusing and frustrating at first, particularly as the process appeared to change on a fairly regular basis. This was made easier with support from peers within my cohort who were at different stages of the process and could share their knowledge of the system. Sharing information between us helped to overcome some of the barriers (for example, who to contact, which ethics board to use) and make the process slightly more straightforward.

As my research was focussing on young people, the approval went to a full ethics panel with whom the project was discussed over a teleconference. This was a daunting process, particularly given that the majority of the panel had backgrounds in medicine or statistics. However, they were surprisingly supportive of the research. Research and Development (R&D) clearance was applied for with two NHS Trusts initially, each of which had different processes and required different information; again this was frustrating. Due to slow recruitment given my strict inclusion criteria, a third Trust was brought on board with the research later in the process. Part way through the research the Trust was up for tender, meaning further R&D approval, and a number of difficulties in contacting clinicians within the new service. It was important within this process that the senior managers within the Trusts were aware of and on board with the research. Although I had left plenty of time to go through the process of ethical and R&D approval, and had previous experience of this process, I was surprised about how long it took in the end, and will bear this in mind when conducting research in the NHS in future.

Overall there were a total of 12 CAMHS services involved in my research. Liaising with each of these services was challenging at times, particularly knowing who was in what role, when team meetings were, and keeping on top of the different systems used within each team. For example, whether they had a specific CBT clinic and which routine outcome measures were used. Differences between teams became apparent throughout the recruitment process, resulting in a number of minor ethical amendments (for example, to use the outcome measure used by the service rather than a specific
measure). I learned how imperative organisation was in this process. It was useful to have a key contact within each service, and clinicians within the CAMHS services were particularly helpful in directing me to appropriate contacts and team meetings. This includes Anne Booth (Consultant Clinical Psychologist) and Dr Kate Cooper (Clinical Psychologist). Kate had also been a previous trainee on the Bath training course and therefore had a good understanding of the course requirements and difficulties of recruitment.

One of the toughest parts of the research has been recruitment, given that the eligibility criteria are relatively strict; young people age 11-18, with a diagnosis of ASD, and who have attended CBT. Clinicians were understandably busy with their clinical work and research was not a top priority for them, some commented on how they were not doing ‘proper’ CBT, or that the young person did not have good outcomes which appeared to put the clinicians off inviting them to take part, despite encouragement that this did not matter. Within teams, it appeared that there were individual clinicians who were more likely to see this group of young people (due to a specific interest or their own confidence in adapting CBT). Meeting face-to-face and keeping in regular contact with these individuals was especially helpful, and the research would have not happened without them.

Meeting up with young people who wanted to take part in the research has been really rewarding and it has been fascinating to hear their stories. I have felt honoured to be invited into their homes, and I respect their ability to talk so honestly with a total stranger. A challenge for me was switching roles from a clinician (e.g. wanting to ask more questions, reflect and summarise back) to a researcher (e.g. just asking the research questions). This was particularly challenging when young people spoke about some of the difficulties they had been experiencing and I felt I had the clinical skills to be able to support them. I have learned about the importance of keeping clear boundaries in research, and the importance of communicating with young people’s clinicians around specific difficulties raised (e.g., risk). Practising research questions within fellow trainees in role plays was helpful, and is something I could build on in the future. Regular research supervision was also helpful, including discussions with Dr Jo Daniels (Clinical Tutor) who had conducted similar interviews for her own research. Research supervision with Ailsa and Maria has been invaluable in reflecting on these experiences and problem solving difficulties along the way, drawing on both of their experiences as researchers and clinicians.
These experiences of developing a realistic research proposal, involving young people in the design process, NHS ethics and R&D approval, and recruitment have taught me about the challenges and rewards of research within a clinical setting. I will take this learning forward in my career as a Clinical Psychologist. My case studies have also taught me about being a scientist-practitioner, in thinking about how individual cases can also be used to build the evidence base.

My core CAMHS placement in training was split between a community service and a child learning disabilities (LD) service. My experience in community CAMHS enabled me to focus specifically on developing my core skills in CBT. My case study demonstrated the positive outcomes of CBT for a young person with health anxiety and obsessional compulsive disorder. My placement in the child LD service gave me a totally different range and depth of experiences. This included working from more of an attachment based model, conducting complex assessments, and learning about consultation with staff and carers.

Using attachment theory and consultation models was a key part of my elective placement within the Thinking Allowed team. This is a brilliant service for looked after children, where the team are really passionate about their work. My case study in this service explored a young person’s ambivalence to therapy and the use of consultation models and team formulation within a residential care setting. This taught me about the importance of working with the network and systems around the young person (e.g. carers, social care). It also raised questions for me about what it means for a young person to turn 18, and the difficulties that they can face around the time of transition to adult services and independent living.

**Adults**

My service improvement project and two of my case studies focussed on adults of working age. I had some research experience of working with adults within a clinical health setting prior to clinical training, specifically around mindfulness for adults with Pulmonary Hypertension. I had had some contact during this project with Dr Jackie MacCallam (Clinical Psychologist) at the Royal United Hospital in Bath, and was keen to continue part of my research within a clinical health setting. The project examined positive coping and self-management for patients with Pulmonary Hypertension undergoing the Cardiac Catheterisation procedure. I was not familiar with this procedure, however a number of the medical staff had noticed that some patients found the procedure especially difficult and anxiety provoking. This project was initially supervised by Dr Andrew Medley who has a wealth of knowledge having worked in clinical health.
We felt that it was important to get a better understanding of both the staff and patients perspectives; the research was therefore developed jointly alongside a fellow trainee, Cate Anderson, who interviewed the patients for the project.

Through discussions with Jackie and Andrew, it felt important that the focus was on positive coping strategies, and that this information was gathered qualitatively to allow a better understanding of staff and patient experiences. Cate and I developed a parallel interview schedule for patients and professionals. It was important to find out about staff confidence about providing psychological support, staff beliefs about the psychological impact, training needs, self-care, care-pathways and when to refer to psychology.

It was important to check with the Trust R&D department regarding whether the project counted as ‘research’ or audit. They agreed that it could be registered as an audit so NHS ethical approval was not required, however this proved to be somewhat of a grey area. The R&D department were also helpful in checking the interview was written using lay language. University ethical approval was sought, which was a fairly straightforward process compared to full NHS ethics. Once the approvals had been processed, Jackie played a key role in facilitating meetings between us as the researchers and the clinicians within three teams involved in the Cardiac Catheterisation procedure. This taught me the importance of having a key staff member on board with a research project (e.g., as a research ‘champion’).

Given the busy hospital environment and nursing shift patterns, it was important for us to be flexible in joining meetings that were already happening, and changing meeting times if needed (e.g. due to an emergency). This was also valuable when meeting individuals for interviews. Only two of the three teams were able to attend meetings prior to individual interviews being carried out. Of the team who were unable to attend meetings, only one staff member took part. On reflection, this has taught me the importance of meeting clinicians face-to-face when involving them in research and allowing them to feel part of the process.

Following the data collection stage, Dr Andrew Medley left the course for another job. Dr Cathy Randle-Phillips was the new supervisor for the project. It was really helpful to have a number of cross-over meetings between supervisors to ensure Cathy was aware of the processes we had been through already. Having Cathy on board at this stage was really helpful as she is a highly competent qualitative researcher who was able to give invaluable input to the qualitative analysis stage. The key themes resulted in specific recommendations for the teams, including the development of a leaflet and a ‘patient
It has been really pleasing to see staff putting the recommendations into practice and benefitting from the project, having been so positive and encouraging throughout the research process. On reflection, however, the emotional impact of the procedure on staff themselves or their patients was not discussed openly by staff, despite being directly asked about it during the interview. This was also something I did not discuss with the staff during my feedback of recommendations to the team. This may be something that I avoided talking about with them due to my own uncertainties or anxieties about how to broach the subject with the team, potentially perpetuating the team’s avoidance of emotion. This is something that I will reflect back to the team Clinical Psychologist for further discussion with the team.

My two case studies with adults of working age have resulted in positive outcomes, despite being within quite different contexts. Both used a cognitive behavioural approach; one was using a more structured CBT approach with a female with depression, and the other was using adapted CBT for a female with a learning disability who was experiencing high levels of anxiety. Despite their different contexts, the CBT model was useful with both cases. This demonstrates the importance of adapting an approach to an individual, both in terms of the difficulties they are experiencing and their cognitive ability, resulting in positive outcomes. Working within the context of people with a learning disability also brought up questions for me around the stigma and discrimination experienced by these individuals, and the importance of treating them with respect whilst also taking their cognitive ability into consideration.

**Older adults**

My older adult case study also used a cognitive behavioural approach for anxiety, adapted within the context of Alzheimer’s disease. This was a difficult but rewarding piece of work, in which developing the therapeutic relationship and coming to terms with the diagnosis of Alzheimer’s disease was a key component.

Whilst on my older adult placement I observed a cognitive assessment of a lady who had been living with HIV for a number of decades. She described the impact that living with HIV had had on her family life, the experience of new medications and learning to live again, and the stigma she often felt, particularly as an older female living with HIV. This was an area in which I had very little knowledge but really fascinated me and made me want to understand more about how older adults with HIV experienced stigma. Following a number of discussions with my supervisor, Dr Catherine Butler, and exploration of charity websites for people living with HIV, I chose this as the topic for my literature review.
The process of the literature search itself was challenging, particularly as the area had very little research to date. Contacting researchers in the field, and charities (e.g. the Terrance Higgins Trust) was essential in the process to find relevant papers. A large number of papers on stigma for older adults with HIV are written by researchers in the United States or Australia. A key part of my literature review was to focus specifically on older adults within the United Kingdom. This was important given the differences in health care systems. Given the strict criteria for the literature search, very few relevant research papers were found. These were mainly qualitative papers so I therefore decided to use a meta-synthesis approach to get a better understanding of how older adults experience stigma around their HIV. A number of the resulting themes were similar to those described in the literature for adults of working age, with the intersection of ageing, time since diagnosis, and health concerns. This is particularly important given the ageing population. Despite the relatively small numbers of papers included in this review, it has taught me about the importance of being persistent with research within such areas in order to develop a better understanding for the future.

**Summary**
My experiences of research within clinical training have taught me how a wide range of approaches can be used within a clinical setting, from larger research project across many sites, to individual case studies.

The course has taught me the value in single case studies, particularly using an experimental design and when there is a lack of current research within a specific area. My placements have given me a huge variety of experiences, and have allowed me to practice the skills taught through the course and through supervision. This had allowed me to consolidate my ability to apply theory to practice, at the same time as developing the evidence base through my clinical work. My case studies have taught me the importance of adapting each intervention to the individual, including the use of idiosyncratic formulations and standardised measures.

My main research, service improvement project and literature review have taught me the importance of having a clear research question. On reflection, I have also learned the value of persistence in overcoming frustrations and barriers when carrying out larger research projects. I will also take away the importance in service user involvement, clinically informed and relevant research, at the same time as keeping the individuals concerned at the heart of the research.
I believe that larger research projects, service improvements and single case studies are all as important as each other in developing the evidence base in clinical psychology. I will take this learning forward into my future career as a Clinical Psychologist.
Acknowledgements

I would like to thank Dr James Gregory, my Clinical Tutor for overseeing my professional and personal development throughout the course.

I wish to thank Dr Ailsa Russell and Dr Maria Loades for their supervision of my main research project. Their research and clinical knowledge and experience of working with autism and young people has been invaluable. I would also like to thank Dr Jo Daniels for her role as a discussant on the socialisation element of this project, and the Action for Children young people’s participation group for their help in developing the project. Crucially, I would like to thank all of the clinicians from the local CAMHS services who were so supportive and played a vital role in the recruitment for my main project, as well as the young people and their families whose participation was greatly appreciated.

I would like to thank Dr Cathy Randle-Phillips, Dr Andrew Medley, and Dr Jackie MacCallam for their combined supervision and support with my service improvement project. Additionally, I wish to thank all of the staff who took part in this project from the Royal United Hospital, Bath, for their continued interest and participation.

I would like to thank Dr Catherine Butler for her enthusiasm and supervision of my critical review of the literature.

Finally, I would like to thank James, my family, friends and my fellow trainees for all of their support through clinical training.
Appendices
Appendix 1: AIDS Care Instructions to Authors

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- Manuscript format should be in the style of the American Psychological Association (6th edition). Manuscripts should be double spaced, with ample margins of at least one inch. Footnotes to the text should be avoided wherever this is reasonably possible. All identifying information should be removed from the Manuscript Files for Review prior to submission, as detailed above.
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Units in tables should appear in parentheses in the column heading but not in the body of the table. Words or numerals should be repeated on successive lines; ‘ditto’ or ‘do’ should not be used.

Proofs including proofs of illustrations are supplied for checking and making essential corrections, not for general revision or alteration. Proofs should be corrected and returned within 3 days of receipt.

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Manuscripts should be compiled in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

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Each manuscript should have 5 to 6 keywords.

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All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.

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Appendix 2: Quality Appraisal Form (Dolman et al., 2013)

APPRAISAL
Please grade the answers to each question by ticking 0, 1 or 2.
Unless otherwise specified, questions should be scored as follows:
0 – study does not meet criteria/answer question
1 – study partially meets criteria/gives a partially satisfactory answer to the question
2 – study fully meets criteria/gives a fully satisfactory answer to the question
If a question is not applicable to a particular study, please mark “n/a”

1. The research presents clearly stated aims
Is the study question focused in terms of the population studied? 0, 1, 2
Is the study question focused in terms of the outcomes considered? 0, 1, 2

Q1 Subtotal ………………..

2. A qualitative methodology is appropriate for this research (e.g., does the research seek to interpret or illuminate the actions and/or subjective experiences of research participants?)
Was a qualitative methodology appropriate? 0, 1, 2

Q2 Subtotal ………………..

Continue only if score on each of questions 1 and 2 is one or more

3. The context of the research was clearly described
Was the context of the research clearly described? 0, 1, 2

Q3 Subtotal ………………..

4. The research design was appropriate to meet the aims of the research
Was the research design appropriate to address the aims of the research? 0, 1, 2

Q4 Subtotal ………………..

5. Was the recruitment/sampling strategy appropriate to the aims of the research?
Does the study have clear inclusion criteria? 0, 1, 2
Does the study have clear exclusion criteria? 0, 1, 2
Was the sampling strategy appropriate for the aims of the research? 0, 1, 2
Were the subjects appropriate for the aims of the research? 0, 1, 2
Was the study sample representative of the research setting? 0, 1, 2
Does the study report on the level of nonparticipation? 0, 1, 2

Q5 Subtotal ………………..
6. Was the data collected in a way that addressed the research issue?
Is the study setting appropriate to the aims of the research? 0, 1, 2
Is the method of data collection clear? 0, 1, 2
Is the method of data collection appropriate to the aims of the research? 0, 1, 2
Is the process of data collection clear? 0, 1, 2
Were study instruments piloted? 0, 1, 2
Is data saturation discussed? 0, 1, 2

Q6 Subtotal ....................

7. Is the data verifiable? N.B. Data is audio or video taped (=2), researcher makes
notes during data collection (=1). 0, 1, 2

Q7 Subtotal ....................

8. Were ethical considerations appropriately considered?
Did researchers obtain informed consent from all participants? 0, 1, 2
Was data collected in a private setting? 0, 1, 2
Was data sufficiently aggregated during presentation to ensure anonymity? 0, 1, 2

Q8 Subtotal ....................

9. Was data analysis sufficiently rigorous?
Is the analytical process described in detail? 0, 1, 2
Were steps taken to identify data that was contrary to the main findings and
hypotheses of the study? 0, 1, 2
Were multiple analysts used to increase the rigour of the research? 0, 1, 2
Does the study report on level of inter-rater reliability? 0, 1, 2

Q9 Subtotal ....................

10. Was there a clear statement of findings?
Does the study clearly report its findings? 0, 1, 2

Q10 Subtotal ....................

11. How valuable was the research?
Were service users, providers or advocates involved in the development of the study? 0, 1, 2
Were study participants invited to receive feedback on the research? 0, 1, 2
Were the study findings disseminated beyond the academic community? 0, 1, 2
Did the study articulate clear recommendations for future policy and/or practice? 0, 1, 2
Did the study articulate clear recommendations for future research? 0, 1, 2

Q11 Subtotal ....................

Total Score (out of a maximum of 62 points) .......................
Appendix 3: Data extraction form

| Date appraised:                     |
| Study authors/year:                |
| Title:                             |
| Journal:                           |
| Publication type:                  |

| Study design                        |
| Aims of the study                   |
| Geographic location of study and setting |
| Participant characteristics (inclusion/exclusion) |
| Method of recruitment               |
| Research methodology                |
| Reflexivity – researcher role/bias  |
| Ethical issues                      |
| Data analysis                       |
| Results                             |
Appendix 4: Theme map showing links between themes and subthemes

HIV community
- Loss
- Support
- Isolation/rejection
- Social demographic

Impact of HIV
- Work
- Financial
- Emotional

Discrimination, judgement and disclosure
- Societal
- Professional
- Family & friends

Ageing with HIV
- Old before time
- Care
- Comparison to normal ageing
- HAART
- Lazarus Syndrome

Future
- Optimism
- Uncertainty
- Fear
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Most Elsevier journals have a standard template available in key reference management packages. This covers packages using the Citation Style Language, such as Mendeley (http://www.mendeley.com/features/reference-manager) and also others like EndNote (http://www.endnote.com/support/enstyles.asp) and Reference Manager (http://refman.com/support/rnstyles.asp). Using plug-ins to word processing packages which are available from the above sites, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style as described in this Guide. The process of including templates in these packages is constantly ongoing. If the journal you are looking for does not have a template available yet, please see the list of sample references and citations provided in this Guide to help you format these according to the journal style.

The current Social Science & Medicine EndNote file can be directly accessed by clicking here.

If you manage your research with Mendeley Desktop, you can easily install the reference style for this journal by clicking the link below:
http://open.mendeley.com/use-citation-style/social-science-and-medicine

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Reference formatting
There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct. If you do wish to format the references yourself they should be arranged according to the following examples:

Reference style

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

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Reference to a journal publication:

Reference to a book:

Reference to a chapter in an edited book:
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Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article may do so during online submission. Where relevant, authors are strongly encouraged to include a video still within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. These will be used instead of standard icons and will personalize the link to your video data. All submitted files should be properly labeled so that they directly relate to the video file’s content. In order to ensure that your video or animation material is directly usable, please provide the files in one of our recommended file formats with a maximum size of 10 MB. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect: [http://www.sciencedirect.com](http://www.sciencedirect.com). For more detailed instructions please visit our video instruction pages at [http://www.elsevier.com/artworkinstructions](http://www.elsevier.com/artworkinstructions). Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

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The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item.

**Ensure that the following items are present:**

- One author has been designated as the corresponding author with contact details:
  - E-mail address
  - Full postal address
- All necessary files have been uploaded, and contain:
  - Keywords
  - All figure captions
  - All tables (including title, description, footnotes)
- Further considerations
  - Manuscript has been 'spell-checked' and 'grammar-checked'
  - All references mentioned in the Reference list are cited in the text, and vice versa
  - Permission has been obtained for use of copyrighted material from other sources (including the Internet)
  - Printed version of figures (if applicable) in color or black-and-white
  - Indicate clearly whether or not color or black-and-white in print is required.
  - For reproduction in black-and-white, please supply black-and-white versions of the figures for printing purposes.

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**AFTER ACCEPTANCE**
Social Science and Medicine - Guidelines for Qualitative Papers

There is no one qualitative method, but rather a number of research approaches which fall under the umbrella of ‘qualitative methods’. The various social science disciplines tend to have different conventions on best practice in qualitative research. However SS&M has prepared the following general guidance for the writing and assessment of papers which present qualitative data (either alone or in combination with quantitative methods). General principles of good practice for all research will also apply.

Fitness for purpose
Are the methods of the research appropriate to the nature of the question(s) being asked, i.e.
- Does the research seek to understand social processes or social structures &/or to illuminate subjective experiences or meanings?
- Are the settings, groups or individuals being examined of a type which cannot be pre-selected, or the possible outcomes not specified (or hypothesised) in advance?

Methodology and methods
- All papers must include a dedicated methods section which specifies, as appropriate, the sample recruitment strategy, sample size, and analytical strategy.

Principles of selection
Qualitative research is often based on or includes non-probability sampling. The unit(s) of research may include one or a combination of people, events, institutions, samples of natural behaviour, conversations, written and visual material, etc.

- The selection of these should be theoretically justified e.g. it should be made clear how respondents were selected
- There should be a rationale for the sources of the data (e.g. respondents/participants, settings, documents)
- Consideration should be given to whether the sources of data (e.g. people, organisations, documents) were unusual in some important way
- Any limitations of the data should be discussed (such as non response, refusal to take part)

The research process
In most papers there should be consideration of
- The access process
- How data were collected and recorded
- Who collected the data
- When the data were collected
- How the research was explained to respondents/participants

Research ethics
- Details of formal ethical approval (i.e. IRB, Research Ethics Committee) should be stated in the main body of the paper. If authors were not required to obtain ethical approval (as is the case in some countries) or unable to obtain attain ethical approval (as sometimes occurs in resource-poor settings) they should explain this. Please anonymise this information as appropriate in the manuscript, and give the information when asked during submission.
- Procedures for securing informed consent should be provided

Any ethical concerns that arose during the research should be discussed.

Analysis
The process of analysis should be made as transparent as possible (notwithstanding the conceptual and theoretical creativity that typically characterises qualitative research). For example
- How was the analysis conducted
  - How were themes, concepts and categories generated from the data
  - Whether analysis was computer assisted (and, if so, how)
  - Who was involved in the analysis and in what manner
- Assurance of analytic rigour. For example
  - Steps taken to guard against selectivity in the use of data
  - Triangulation
  - Inter-rater reliability
  - Member and expert checking
  - The researcher’s own position should clearly be stated. For example, have they examined their own role, possible bias, and influence on the research (reflexivity)?

Presentation of findings
Consideration of context
The research should be clearly contextualised. For example
• Relevant information about the settings and respondents/participants should be supplied
• The phenomena under study should be integrated into their social context (rather than being abstracted or de-contextualised)
• Any particular/unique influences should be identified and discussed

Presentation of data:
• Quotations, field notes, and other data where appropriate should be identified in a way which enables the reader to judge the range of evidence being used
• Distinctions between the data and their interpretation should be clear
• The iteration between data and explanations of the data (theory generation) should be clear
• Sufficient original evidence should be presented to satisfy the reader of the relationship between the evidence and the conclusions (validity)
• There should be adequate consideration of cases or evidence which might refute the conclusions
Appendix 6: Lay summary of the research

**Background:** Pulmonary Arterial Hypertension (PAH) is a rare and life limiting condition. Symptoms include breathlessness, fatigue, chest pain, and feeling faint. Cardiac catheterization (CATH) is a procedure used to diagnose PAH and to monitor treatment. The procedure involves inserting a catheter into a blood vessel in the thigh which is threaded into the right atrium of the heart. Research shows that the procedure can make patients feel anxious, but no research has looked at NHS staff’s views on this, and how they support patients.

**Aims:** This study was designed to understand how staff provide positive support for patients undertaking the CATH procedure. Based on this information, the study aimed to give recommendations for service improvement.

**Methods:** A short interview was designed based on the ‘Self-Regulatory Model’ of illness perceptions (Leventhal, Meyer & Narenz, 1980). Ten key staff members from respiratory Pulmonary Hypertension and CATH teams at the Royal United Hospital Bath were interviewed. This included Clinical Nurse Specialists and Consultant Physicians.

**Results:** Interviews were analysed using qualitative methods to look for themes within the data. This resulted in four main themes: (1) acknowledging individual differences; (2) a journey through the service; (3) the patient/staff relationship; and (4) information and understanding. Staff recognised the importance of gauging individuals’ previous experiences of illness and medical procedures, the practical and emotional journey experienced by both staff and patients, the importance of developing a positive relationship with the patient, and ensuring openness and honesty about the procedure.

**Discussion:** Based on these findings, specific recommendations were made to the service and the following documents were developed: 1) a leaflet including direct patient quotes of their experiences and the journey through the service; 2) a patient ‘passport’ giving them the opportunity to tell staff their preferences; and 3) a video showing the hospital environment.

**Implications:** This research has important implications for increasing patient control, choice and positive coping for patients who find the CATH procedure more difficult to cope with.
Appendix 7: University ethics approval

Re: Ethics 14-162  
Psychology Ethics Committee <psychology-ethics@bath.ac.uk>  
Mon 14/07/2014 11:06  
To: Cara Roberts-Collins;

Dear Cara

Reference Number 14-162

Thank you for satisfactorily attending to the queries raised by the committee. I can now confirm that you have full ethical approval for your study.

Best wishes with your research.

Dr Helen Lucey  
Chair Psychology Ethics Committee, University of Bath

Information about making an ethics application can be found at http://moodle.bath.ac.uk/course/view.php?id=52192

On 07/07/2014 15:05, crc33@bath.ac.uk wrote:

Dear Helen

Thank you for your email and conditional ethical approval for the project.

We had not planned for participants to be given a debrief form after taking part because Dr Jackie MacCallam (Clinical Psychologist) works within the department and will be available to be contacted and to answer any questions if needed. One thing we could do is give out a sheet stating this and giving Jackie’s contact details. You think this would be helpful?

Best wishes,

Cara

Quoting Psychology Ethics Committee <psychology-ethics@bath.ac.uk>:

Dear Cara Roberts-Collins

Reference Number 14-162

The ethics committee have considered your application for the study entitled ‘Promoting positive coping and self-management in patients undertaking cardiac catheterisation: learning from staff’ and have given it conditional ethical approval. The committee have raised the following points which they would like you to attend to before giving the study full ethical approval:

1. Can you clarify if participants need to be debriefed after taking part? If so, could you send a debrief form.

Please send the revised document to me - you can do this by email.

Please remember that you may not collect any data until you have ethical approval.

Yours sincerely

Dr Helen Lucey
Chair Psychology Ethics Committee, University of Bath
Confirmation of Service Improvement Project registration as an audit

Kitching Sarah (ROYAL UNITED HOSPITAL BATH NHS TRUST - RD1)

Thank you for your completed proposal form. I confirm that your project has been accepted and registered on the Trust audit database as ID 2385.

With best wishes

Sarah

Sarah Kitching
Quality Improvement Lead for Medicine
Qulturum – D1
Royal United Hospital Bath NHS Trust
Combe Park
Bath BA1 3NG

e-mail sarahkitching@nhs.net
Dir Line: 01225 825852
Visit our website at: www.ruh.nhs.uk
Appendix 8: Draft interview questions for staff and patients in parallel

<table>
<thead>
<tr>
<th>Themes to explore</th>
<th>Staff</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>What have you observed in how people cope positively?</td>
<td>What was helpful in coping with the procedure?</td>
</tr>
<tr>
<td>Emotional support</td>
<td>• Confidence in providing support</td>
<td>• What was helpful in supporting them?</td>
</tr>
<tr>
<td></td>
<td>• What support do they have?</td>
<td>• What helpful support did they get from staff?</td>
</tr>
<tr>
<td>Practical support</td>
<td>• What are patients calling about?</td>
<td>• Who do they contact?</td>
</tr>
<tr>
<td></td>
<td>• How do nurses respond to these calls?</td>
<td>• What do they want to know?</td>
</tr>
<tr>
<td></td>
<td>• Constraints in what they can/can’t do</td>
<td>• What was helpful?</td>
</tr>
<tr>
<td></td>
<td>• Do they shy away from asking certain things?</td>
<td>• Is there one question you wish you were asked?</td>
</tr>
<tr>
<td></td>
<td>• What has helped in the past?</td>
<td></td>
</tr>
<tr>
<td>Beliefs (self-efficacy)</td>
<td>• How important do they think the psychological impact is?</td>
<td>• Beliefs about procedures/risks</td>
</tr>
<tr>
<td>Perception (self-regulation)</td>
<td>• What do they believe patients need?</td>
<td>• Consequences of not having it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Beliefs about having it and what it means (life after CATH)</td>
</tr>
</tbody>
</table>
Appendix 9: Staff Interview Schedule

Staff Interview Schedule

Timeline

1. How are patients told about the procedure?

2. How do you think patients feel when they find out they need the procedure?

Beliefs and decision-making about the procedure:

3. Can you tell me about the support you provide to patients in terms of making decisions about the CATH procedure and preparing to undertake it?

4. How do you discuss the risks of the procedure with patients?

Perceived control, coping and self-management skills:

5. What are your perceptions of the psychological impact of having the CATH procedure?

6. To what extent do you feel psychological and emotional reactions impact on a patient’s capacity to manage the procedure? (e.g. anxiety)

7. In what ways do you tend to help and support patients to prepare for the procedure?

8. What concerns do patients tend to telephone you about?

9. On reflection, what’s the most helpful question or piece of advice you feel you can generally offer? (Run up to the procedure)

Consequences (Physical, psychological, social, economic)

10. How does the procedure impact on the patient’s everyday life?

11. What help and support are you aware of the patient receiving from family, friend’s carers?

12. What have you found is helpful in supporting the patient through the procedure?

13. How confident do you feel in providing support? Practical help/ emotional support, what was helpful in supporting you/patient?
14. How do people get through the procedure? What helps them manage/cope? What have you observed in people who cope well?

15. What do you believe patients need? Are there any constraints to meeting their needs? Is there anything you feel you shy away from asking?

16. How do patients respond to being helped to look after themselves? *Useful, helpful, less worried, nuisance, angry, interfering (in the way) / Importance of help*

**Illness identity**

17. What impact do you notice the procedure has upon patients in terms of physical symptoms and effects? *How difficult do patients find these to manage?*

**Coherence**

18. How effectively do you think the service explains the procedure to patients? And in your experience, what difficulties might people experience in understanding all the important information (e.g. outcomes/implications/benefits/risks)?

**Emotional representations**

19. Can you describe the emotional impact that the procedure has upon patients and upon you as clinicians supporting the patients?

**Timeline**

20. Do patients tend to change their perception of the procedure over time? *Does it go up and down / do you feel it is getting easier or harder to manage?*

21. What do patients report thinking will happen in the future? *Will it stay the same / change. Do you think anything else will happen in the future because of the procedure?*

**Anything else?**

22. Is there anything else that you would like to tell me about that I have missed?
Appendix 10: Staff Information Sheet

Information about the Project
Promoting positive coping and self-management in patients undertaking cardiac catheterisation: learning from health professionals

We would like to invite you to take part in our service evaluation project. Before you decide we want you to understand why the project is being done and what it would involve for you. Please read this information, talk to others about the project, and ask any questions if you wish. When we have explained the project, answered your questions, and you have had enough time to decide, you will then be able to choose whether to take part.

What is the purpose of the project?
This project aims to explore staff beliefs and perspectives on positive coping strategies and self-management in patients with Pulmonary Hypertension undertaking cardiac catheterisation. Self-management aims to shift the role of the health professional from the ‘professional expert’ (instructing and deciding) to ‘guide’ (supporting and advising) enabling the patient to take more control of their condition. Staff perspectives will be used together with patient views to develop the service and to help patients who find the procedure more difficult, including a written resource.

Why have I been invited?
You have been invited to take part because you are involved of the care of patients with Pulmonary Hypertension who undergo heart catheterisation at the Royal United Hospital Bath.

Do I have to take part?
Taking part in this project is voluntary and you have the right to withdraw at any point without having to give any reasons. If you withdraw from the project, we will keep your data as important information about the project unless you ask us to destroy it.

What will happen if I take part?
You will be invited to take part in a short interview or small focus group with Cara Roberts-Collins, a Trainee Clinical Psychologist from the University of Bath who is working alongside Dr Jackie MacCallam, Clinical Psychologist. The interview or focus group will take approximately 30 minutes of your time and can be undertaken at a time and place convenient for you.
What are the risks and benefits?
This project presents minimal risk or burden for you. Your feedback on the positive coping strategies patients use will be used alongside information from patient interviews to give us a shared understanding between staff and patients that should ultimately benefit the service and patients.

Confidentiality and Data Protection
All information that you provide will be kept completely confidential and anonymised. The only time we may break this confidentiality is if we find anything or you tell us anything which means that you or someone else are at risk of harm. In this case, we would talk to you first, and then talk to your care team to ensure you receive the appropriate care, support, or advice.

Any other information regarding the project that you provide, such as feedback, will be kept anonymous and confidential unless you specifically request otherwise.

Questions or concerns?
If you have any questions or concerns regarding the project at any time, please contact Dr. Jackie MacCallam (Clinical Psychologist):
Email: jackie.maccallam@nhs.net
Tel: 01225 825344 (answer machine checked regularly)
   Respiratory Outpatient reception - 01225 821923
   Pulmonary Hypertension coordinator - 01225 825352

Or Cara Roberts-Collins, Trainee Clinical Psychologist: c.roberts-collins@bath.ac.uk

WHAT NOW...?
If you would like to take part in this project, please complete a consent form and leave it for Dr Jackie MacCallam at the Respiratory Outpatient reception, RUH.

Thank you for your time

Cara Roberts-Collins
Trainee Clinical Psychologist
University of Bath

Dr Andrew Medley
Clinical Psychologist
University of Bath

Dr Jackie MacCallam
Clinical Psychologist
Royal United Hospital Bath

This project has been reviewed and given favourable opinion by the University of Bath ethics committee.
Appendix 11: Staff consent form

STAFF CONSENT FORM

Promoting positive coping and self-management in patients undertaking cardiac catheterisation: learning from health professionals

Please initial each box

1. I confirm that I have read and understood the Information about the Study (Version 1, dated 17th June 2014). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary, I do not have to answer every question asked, and that I am free to withdraw at any time, without giving any reason.

3. I agree for this interview/focus group to be audio recorded and that this data will be kept confidential and stored securely.

4. I agree for anonymised quotes to be used in the write up and/or publications of this study.

5. I agree to take part in the above study.

If you are happy to take part, please write your name, date, and signature here:

____________________________________________________

Name of staff _______________________ Date ______________________ Signature ______________________

Contact details

____________________________________________________

Name of Researcher _______________________ Date ______________________ Signature ______________________

Taking Consent _______________________
Appendix 12: Map of themes pre and post inter-rater reliability

Note. Boxes with dashed lines indicate themes removed following inter-rater reliability.
## Appendix 13: Complete set of super-ordinate and sub-ordinate themes, with example quotes

<table>
<thead>
<tr>
<th>Super-ordinate theme</th>
<th>Initial sub-ordinate themes</th>
<th>Final sub-ordinate themes</th>
<th>Example quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Importance of) acknowledging individual differences (and experiences)</td>
<td>Past experience and preconceptions</td>
<td>Past experiences</td>
<td>‘The ones who have had it done before have the familiarity of what is going to happen, so they know what to expect from it, and the second one is usually shorter so it’s better than the first one, so there is usually far less anxiety for the second one.’ (Consultant Cardiologist 1)</td>
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<tr>
<td></td>
<td>(Stories/knowledge from others)</td>
<td></td>
<td>‘Until they’ve had it done and a lot of them will say ‘I didn’t know what I was worrying about’ you know. But then again there is that group who really still just don’t like having it done, so, particularly people who are a bit needle phobic.’ (Respiratory Nurse Specialist 1)</td>
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<td></td>
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<td></td>
<td>‘…they can sometimes think ‘well actually that wasn’t too bad and I’m not too worried about having it again’. (Respiratory Nurse Specialist 3)</td>
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<td></td>
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<td></td>
<td>‘…we do have patients…like a follow up after 6 months they will come back again to do the same procedure, and during the second time back their feeling is much different from the first one, because on the second visit they already have an experience in the past, so they are more relaxed and more um calm. They know what to expect.’ (Staff Nurse 2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>‘There is obviously still the odd one who is still very anxious but having gone through once that helps as well, having experienced it, it’s better the second time around’ (Consultant Cardiologist 2)</td>
</tr>
<tr>
<td>Individual coping style</td>
<td></td>
<td>Personal coping style</td>
<td>‘you know we get a few of those, who are, you know, more difficult than others, that are always going to be anxious, and they are always going to potentially, you know, have more problems’. (Respiratory Nurse Specialist 1)</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>‘They express it sometimes, they express it in very different ways I think. They will want to talk about something else that isn’t related, or they’ll want to go over and over certain things.’ (Respiratory Nurse Specialist 2)</td>
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<td></td>
<td></td>
<td></td>
<td>‘It’s a very mixed reaction (when they find out they need the procedure). Some people are very accepting of what the doctor tells them. Other people will question it quite a lot’ (Respiratory Nurse Specialist 2)</td>
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<tr>
<td></td>
<td></td>
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<td>‘… the ones that do accept it and get on better are the ones that think ‘I don’t like having this done, but the end point is that I’m getting a drug which is actually helping me’, and they can see the positivity of that, whereas some people just can’t seem to get there, they can’t seem to see it as something not great, but that they need to go through, it’s just a lot bigger in their mind’. (Respiratory Nurse Specialist 3)</td>
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<td></td>
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<td>‘it depends individual cases really…there are some who are have a low threshold on pain, and then they react so quickly, and then there are some who, you know, they, there’s no, just no problem at all, you know not scared of anything.’ (Staff Nurse 2)</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>‘…there is another type of patient who when you start to explain what’s involved …they say ‘no, no, I don’t want to know I’ll just sign it’ you know they definitely don’t want all those details, you know that for them, that can be off putting, so again we try to tailor it to the individual’s needs…. they are probably the more anxious ones, I think so’. (Consultant Cardiologist 2)</td>
</tr>
<tr>
<td>A journey</td>
<td>The patient journey</td>
<td></td>
<td></td>
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<tr>
<td>-----------</td>
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</tr>
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</table>
| Practical, emotional and interpersonal consequences of the procedure for the patient | Impact on the day - ‘...they can be travelling a fair distance, be here for the whole day, have quite a few tests and two different people come and talk about it, so I expect it’s a lot in one day and a lot of the more elderly patients that maybe, its coming at the end of the day, it’s quite a bit of a shock and its quite a lot to take on board’. (Consultant Cardiologist 1)  

‘...most people I don’t think have a huge problem with having the test done, most people it’s usually the logistics of getting someone to bring them, getting someone to take them back, getting someone to stay with them overnight, and that’s what tends to cause the anxiety’ (Consultant Respiratory Physician)  

Impact on day to day life - ‘...there are a few of them who are getting so ill they can’t work and are getting benefits and things like that, sometimes that can be a huge thing, and that can affect their decisions on coming for treatment sometimes, and some choose to ignore it really, just try to carry on, if they think they might lose their jobs and things like that’. (Respiratory Nurse Specialist 1)  

‘It’s sort of an unpleasant reminder sometimes, for people that are having it done regularly, they’re chugging along quite nicely ... then they go ‘oh well we’ve got to do another catheter’ and they are like ‘oh no, not another catheter, I hate that’, and that’s sort of an unpleasant interlude in actually something quite positive…and that can be quite horrible for people sometimes’ (Respiratory Nurse Specialist 3)  

Future treatment - ‘...you can go from coming to clinic, to going onto like IV therapy which you’re dependent on 24 hours a day, ... those are the most ... And that involves a visit to London then as well, so they have to go to London to start on the medication’ (Respiratory Nurse Specialist 1)  

‘...some people are relieved to have a diagnosis, and relieved to think that some treatment might be planned. For some people the diagnosis means they don’t get any treatment when they’ve had the um, and that can be a problem for them, they think ‘well how am I going to manage? What’s going to happen now?’ um and other people um...want to have the diagnosis because of their symptoms, um, they are sort of disappointed when it comes out as negative.’ (Respiratory Nurse Specialist 3)  

‘...you know there are some who you can tell are very shaky, very nervous, because they are worried about the outcome, about the outcome of the procedure, they might need operation or you know.’ (Staff Nurse 2)  

Emotional impact - ‘I think there are some people who have got a real sort of fear of it…so obviously each time it becomes more of a palaver because they are less keen to have it done.’ (Consultant Respiratory Physician)  

‘emotion plays a role in how people manage their condition as a whole, I mean if people are worried, sad, depressed, it will impact on how they manage coming into hospital, and then their life' (Respiratory Nurse Specialist 2)  

‘It does provoke anxiety for people because they think, you know ‘what are they going to tell me when I’ve had this test done?’ as well as not looking forward to the test as well, um there is a lot tied up with it really I think.’ (Respiratory Nurse Specialist 3) |
<table>
<thead>
<tr>
<th>Team communication, confidence and constraints</th>
<th>Staff journey and service constraints</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff journey - ‘Sometimes it’s hard of course to try, to try and think back…and remember ‘what was, before I started medicine, what did I know and understand about hearts and anatomy that I…’ you’ve forgotten the starting point of the average person I think.’ (Consultant Cardiologist 2)</td>
<td>‘I think we perhaps underestimate how, how big a deal it is for patients, because from the point of view of what’s happening it’s quite a minor test, from the point of view of the doctors it’s a very routine test, hundreds of patients have it with no problem’ (Respiratory Nurse Specialist 3)</td>
</tr>
<tr>
<td>‘I used to be quite emotional every time there is some kind of patient crisis, I also cry before…. But now as you get along and you get older,… you’ve got a wide range of experience…you become quite strong, emotionally stronger … but sometimes I can still be, you know, still quite attached to the patients sometimes, if you know they are in a very distressed situation, sometimes they do sometimes get quite emotional’ (Staff Nurse 2)</td>
<td>‘…what we do in here is really like a snap shot of their journey through the hospital....’ (Staff Nurse 1)</td>
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<td>‘I try to sort of compartmentalise it, so this is what we need to do now, to know where we are at, and until we have done that, we could spend half an hour talking about this scenario, that scenario, but actually let’s do the test and let’s talk properly after the test.’ (Consultant Cardiologist 1)</td>
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<td>‘…knowing you’ve got a system that is sort of on a well-trodden path is also quite helpful, so the fact they get written information, the fact that there is a plan for when they arrive, and that there is somebody coming through at the same time’ (Consultant Cardiologist 1)</td>
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<td>they are usually referred to us by another chest consultant, another cardiologist, it’s usually been aired with them, and if anything that’s probably caused a bit of anxiety before they’ve come and actually us going through it can usually take away some of that anxiety (Consultant Respiratory Physician)</td>
<td>‘When they come there is quite a lot to do and I think it’s all very rushed and sometimes you just think ‘well maybe we can do this another day’ but you can’t because they have so far to travel and it’s best to get it all done’ (Respiratory Nurse Specialist 2)</td>
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<td>‘we see the patients here, they then go and have the procedure and we don’t see them till after it, so I sometimes feel it would be nice if we saw them pre as well, a familiar face, but practically that just can’t be done’ (Respiratory Nurse Specialist 2)</td>
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<td>‘…if you have kept people waiting and stuff like that then you feel rotten, or if they are cancelled! You know it’s really rotten for them’ (Respiratory Nurse Specialist 1)</td>
<td>‘…if you have kept people waiting and stuff like that then you feel rotten, or if they are cancelled! You know it’s really rotten for them’ (Respiratory Nurse Specialist 1)</td>
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<tr>
<td>‘There is the odd day where we’ve had to cancel this or they have had to wait for hours for an emergency case to go through or something, it’s those things that tend to cause more distress I think’ (Consultant Respiratory Physician)</td>
<td>‘There is the odd day where we’ve had to cancel this or they have had to wait for hours for an emergency case to go through or something, it’s those things that tend to cause more distress I think’ (Consultant Respiratory Physician)</td>
</tr>
<tr>
<td>‘…if it’s something that’s gone wrong that you feel shouldn’t have gone wrong then you talk about it and try and deal with it, try and work out what you could do better.’ (Respiratory Nurse Specialist 2)</td>
<td>‘…if it’s something that’s gone wrong that you feel shouldn’t have gone wrong then you talk about it and try and deal with it, try and work out what you could do better.’ (Respiratory Nurse Specialist 2)</td>
</tr>
</tbody>
</table>
| Patient/staff relationship (Interpersonal relationships and support from others) | Staff reassurance (Family support) | ‘We would reassure them, because we give them a leaflet with the risks, we have to point out the risks to them, but we would try and reassure them that those risks are quite minimal’ (Respiratory Nurse Specialist 2)  
…try to say to them, in terms of reassurance, I try to say to them ‘well we know that there can be side effects from this procedure, but we work very closely with the team that are involved, we always hear when there is a problem, and it’s very rare for us to hear of a problem, and if there is a problem it’s generally somebody who’s a cardiac patient, not a pulmonary hypertension patient’. (Respiratory Nurse Specialist 3)  
‘I’ll then try to put their mind at rest about what the procedure is, that it’s not a major operation, that it doesn’t require an overnight stay, that its usually very safe’ (Consultant Respiratory Physician)  
‘if they have problems, so if they bleed or if they have bruising and things you need to support them much more and empathise with them’ (Respiratory Nurse Specialist 1)  
‘I always offer to ring them actually, before the procedure’ (Respiratory Nurse Specialist 1)  
‘… dignity is a big one actually, because they do it here through the groin, you know that’s pretty personal isn’t it, there particulary… ’ (Respiratory Nurse Specialist 1)  
‘you be there for them really, I think you are kind of the patients advocate… if they are frightened to allay their fears, you can relay to the consultant or the cardiac lab, you can make them fully aware of what they are frightened of, if they’ve got any requests it’s your duty to make sure they are fulfilled, if they want someone to go in with them, or want someone to hold their hand, if there is any particular position they are in, yeah I do feel that we are the ones that they can come to.’ (Respiratory Nurse Specialist 2)  
‘…some of them talk and will engage and when they get engaged with one of the nurses sometimes we talk about other things ‘oh where are you from, have you been to the race track down there’ you know things like that, so if there is a bit of familiarity with the patient and the nurse and it enhances that rapport that patient, patient nurse relationship, so um some of them are, the way they cope I guess is that they engaged in us by conversation and building a rapport’ (Staff Nurse 1)  
all you need to do is just, just try to put yourself, you know, just have um some sort of empathy in what they are feeling, you know, just, and just be very supportive, and you know just always give them some kind of a reassurance that ‘you’re going to be fine’, ‘this is going to be a safe procedure’…you are in safe hands with the consultants…you don’t need to be, to be worried’ (Staff Nurse 2)  
‘…if I’ve scrubbed for a case…you have that that time when you’re pressing on the top of their leg, …. and you have that, you’re both there, so you’re doing something practical, so you’re not just standing there talking to somebody, …. it’s a great time to chat to the patient about how things are going, … it’s a great time to actually have more of a one to one, um, and I’m my experience, its rather nice that … (Staff Nurse 3) |
| Information (explanation) and understanding | Ensuring understanding and information giving | ‘… probably the most important thing for me is that they know why we are doing the test and what it could lead on to’ (Consultant Cardiologist 1)  
‘…educating them, updating them what’s going on, I think that helps a lot with their anxiety.’ (Staff Nurse 2)  
‘…we will always run the clinics with one of our nurse specialists in who will then spend some time with them in a separate room going through the procedure in more detail, so having that resource there helps…’ (Consultant Respiratory Physician) |
<table>
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<tr>
<th>Openness around the procedure (Normalising) (Choice)</th>
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</table>

- **Openness around the procedure**
  - "I think you have to be really careful how much information you give them before...you have to judge what they can actually take on board" (Respiratory Nurse Specialist 2)
  - ‘...usually there is quite a lot of assessment that goes on beforehand, and quite a lot of explanation about the possible condition, and then an explanation of the need to do this test to get more information.’ (Respiratory Nurse Specialist 3)
  - 'It (leaflet) gives them that extra bit of information doesn’t it, it’s always useful to have a backup, you do wonder how much, when you’re getting told, you take in, so having it in writing is just that back up as well. Easier for them to digest the information I guess.’ (Consultant Cardiologist 1)
  - 'I think that on the day of the procedure they are well educated, well informed, and you know, of what’s going to happen, so, I mean, you know, they have sufficient um information that was given to them during the preadmission.’ (Staff Nurse 2)
  - 'I feel the ones that coped well are the ones that seem very happy to go ahead and very accepting, and fully understand' (Respiratory Nurse Specialist 2)
  - "I think in terms of actually managing the procedure itself...a full explanation upfront of what it entails is helpful, reassures them it’s not painful, and although we will normally talk about the complications, although they’re real, they are very infrequent so again explaining that is helpful‘ (Consultant Cardiologist 2)
  - ‘...if there is somebody who likes to know what’s happening and you’ve given them a step by step they are more assured and say ‘I’m so glad you told me what was happening every step of the way’, you know, rather than just suddenly they’re in there and people are doing things to them’ (Staff Nurse 3)
  - 'We do try to explain that the figures we’ve got for the side effects are taken from all the patients that have this procedure, and a lot of those people that have had problems are those that are ill with cardiac problems…’(Respiratory Nurse Specialist 3)
  - ‘… we introduce them to the environment, ‘this is the CATH lab, there is where you are going to be going in... and when you are in there I will be looking after you…”’ (Staff Nurse 1)
  - when people come in, if they know who is in the room, know who people are, what to expect, and that people keep talking to them during the procedure (Consultant Cardiologist 1)
  - ‘It’s usually (helpful) making clear that it’s not a major operation, that it’s a day case procedure, and that the needle that we use is actually not that much bigger than a needle we would use for taking blood etc. Cause I think people could imagine that it’s a big needle.’ (Consultant Respiratory Physician)
  - 'I think it’s just important to keep them updated, so if there are delays and things like that, you know, tell them and be honest with them, and give them a realistic expectation.’ (Respiratory Nurse Specialist 1)

**Note.** Themes in brackets received fewer mentions and were excluded from the final list of themes.
## Appendix 14: Summary of patient themes with example quotes

<table>
<thead>
<tr>
<th>Super-ordinate</th>
<th>Sub-ordinate</th>
<th>Example quotes</th>
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<tbody>
<tr>
<td><strong>Individual process</strong></td>
<td>Vulnerabilities</td>
<td><strong>Fear of the unknown</strong>&lt;br&gt;I knew more or less what to expect it’s just that little bit of nervousness before you go in to have the procedure because although it’s explained you still don’t know how you’re going to react when you actually go in to have the procedure done (Interview 5)</td>
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<td><strong>Fear of the results</strong>&lt;br&gt;I think it’s probably going to be the same going into future ones because I think the worry’s always going to be – have I got worse? Have I got better? Are they going to increase the medication? Are they going to take me off the medication? Yeah things like that… (Interview 7)</td>
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<td>Strengths</td>
<td><strong>Worry about the practicalities</strong>&lt;br&gt;They forget you’re suffering with breathing problems and you have to walk miles to get to each place…and the carparks that’s the biggest problem of all (Interview 6)</td>
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<td><strong>Acceptance</strong>&lt;br&gt;Erm…I wasn’t bothered…I was quite…it was a case of that’s the programme for tomorrow and we’re going to do it and that was it…just sort of took it in that frame of mind…I wasn’t panicking on anything like that. (Interview 3)</td>
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<td><strong>Feeling informed</strong>&lt;br&gt;Yes I mean some people don’t want to know but I’m one of those people who do like to know because you are best able to deal with it and I think that helps you get over the initial…fears or anxieties about it…(Interview 5)</td>
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<tr>
<td><strong>Experiences</strong></td>
<td>The CATH journey</td>
<td>Well I didn’t know what was going to happen the first time anyway and the only thing I thought this time was it couldn’t have been too bad because I’ve had it done before… (Interview 6)</td>
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<td>…and then the third one…I got really panicky when I was having it done and when I came to the fourth time I really didn’t want to have it done I really got a sort of phobia I think…it seems the more I have it done the more I feel it which is silly really isn’t it (Interview 10)</td>
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<td>No it didn’t worry me at all &lt;doctor’s name&gt; put me at ease the way he explained it to me it’s just a needle that isn’t going to finish me off I’ve had a heart bypass when I was in Bristol…didn’t bother me at all…(Interview 4)</td>
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<td>Wider health experiences</td>
<td><strong>Trust in expertise</strong>&lt;br&gt;First time it was mentioned to me at &lt;place name&gt; by the consultant who thought I would be better to have it done at &lt;place name&gt; ’cause they had more experience there and did them much more regularly…erm so in that respect I felt more confident going to &lt;place name&gt; (Interview 3)</td>
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<td>If’ll be alright…and you know just having that faith and trust in people with the best will in the world, I know things go wrong but you have to put your trust in people because they are skilled and you have to trust them to look after you well. (Interview 5)</td>
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<td><strong>Feeling connected</strong>&lt;br&gt;…think it’s explaining what would happen and saying ‘well there might be a bit of a wait here’ and sort of keeping me up to date with when I would be due down for the procedure…so yeah keeping me informed was helpful…(Interview 8)</td>
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<td></td>
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<td>Well the friendliness of the nurses (helps on the day) and the way they talk to you and just the general friendliness in the unit…they’re pleasant, they talk to you, refer to you…tell you how long it was going to be…that type of friendly attitude within the department…They treated you as a human being to chat to rather than just here’s another patient get them through the system…(Interview 3)</td>
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<td></td>
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<td>As I say if people ask me when they’re waiting to go I say ‘no it’s fine honestly’ because someone did that to me the first time and it got me through the first one…(Interview 10)</td>
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<td>I suppose really just the feeling that although you’re the one in the theatre having it done you’re not on your own, it’s that sense of people standing by you…you know God’s on my side, my husband’s on my side it’s just knowing that you’re sort of cared for (Interview 2)</td>
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</table>
Appendix 15: Staff feedback summary sheet

Promoting positive coping and self-management in patients undertaking cardiac catheterization: learning from patients and staff
Cara Roberts-Collins and Cate Anderson, Trainee Clinical Psychologists, University of Bath
Email: cara.roberts-collins@bath.ac.uk or c.anderson@bath.ac.uk

Project aims: to explore patient and staff perspectives on positive coping strategies and self-management for patients with PH undertaking the heart catheterization procedure

Interviews were undertaken with ten patients, six members of the respiratory team and four members of the cath lab team

Patient themes

<table>
<thead>
<tr>
<th>Superordinate</th>
<th>Subordinate</th>
<th>Example quotes</th>
</tr>
</thead>
</table>
| Individual process | Vulnerabilities | **Fear of the unknown**  
I knew more or less what to expect it’s just that little bit of nervousness before you go in to have the procedure because although it’s explained you still don’t know how you’re going to react when you actually go in to have the procedure done (Interview 5) |
| | | **Fear of the results**  
I think it’s probably going to be the same going into future ones because I think the worry’s always going to be – have I got worse? Have I got better? Are they going to increase the medication? Are they going to take me off the medication? Yeah things like that… (Interview 7) |
| | | **Worry about the practicalities**  
They forget you’re suffering with breathing problems and you have to walk miles to get to each place…and the carparks that’s the biggest problem of all (Interview 6) |
| | Strengths | **Acceptance**  
Erm…I wasn’t bothered…I was quite…it was a case of that’s the programme for tomorrow and we’re going to do it and that was it…just sort of took it in that frame of mind…I wasn’t panicking on anything like that. (Interview 3) |
| | | **Feeling informed**  
Yes I mean some people don’t want to know but I’m one of those people who do like to know because you are best able to deal with it and I think that helps you get over the initial…fears or anxieties about it…(Interview 5) |
<p>| Experiences | The CATH journey | Well I didn’t know what was going to happen the first time anyway and the only thing I thought this time was it couldn’t have been too bad because I’ve had it done before… (Interview 6) |
| | | …and then the third one…I got really panicky when I was having it done and when I came to the fourth time I really didn’t want to have it done I really got a sort of phobia I think…it seems the more I have it done the more I feel it which is silly really isn’t it (Interview 10) |
| | Wider health experiences | No it didn’t worry me at all &lt;doctor’s name&gt; put me at ease the way he explained it to me it’s just a needle that isn’t going to finish me off I’ve had a heart bypass when I was in Bristol…didn’t bother me at all…(Interview 4) |</p>
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<td>Feeling connected</td>
<td>Being involved</td>
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<td>Staff themes</td>
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<td><strong>Superordinate</strong></td>
<td><strong>Subordinate</strong></td>
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<td>Acknowledging individual differences</td>
<td>Past experiences</td>
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<td>Personal coping style</td>
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<td>A journey</td>
<td>Patient journey</td>
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<td>Service journey and constraints</td>
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<td>Patient/staff relationship</td>
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they come across as sincere, caring, empathizing, then it’s easy to win them over...so the key is that relationship building.” (632)

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<thead>
<tr>
<th>Information and understanding</th>
<th>Information giving</th>
<th>Openness around the procedure</th>
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<td></td>
<td>“…we’ve got written information as well, we’ve got leaflets, and we just talk through it all and see if there are any questions...I think it’s just important to keep them updated, so if there are delays and things like that, you know, tell them and be honest with them, and give them a realistic expectation.” (213/253)</td>
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<td>“Sometimes it can be the smallest thing, one thing for instance is when they are on the table, you know the table moves, and that’s an odd sensation, you know if you don’t warn them beforehand that it’s going to move, moving when their lying flat that’s a bit of a surprise...” (854)</td>
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Feedback and recommendations

- The importance of recognising individual differences and experiences
  - Giving patients the information they NEED to know to make an informed choice about the procedure, and then having the opportunity to be given more information and to ask more questions if they choose to (increasing self-management and control).

- Interpersonal factors and the staff/patient relationship
  - Value of informal chat/comfort (e.g. hand holding) and being alongside the patient, normalising that is a difficult procedure and accepting the anxiety.
  - Staff described how in an ideal world a specific member of staff would follow the patient through each step of their journey through the teams. Could they introduce a ‘preference sheet’/patient passport outlining what is important to them (the patient) which can then follow them through the process (promoting choice and involvement).

- Learning from previous experiences and others
  - Is there a way of the service helping patients access accounts of others if they do not have previous direct experience of the procedure themselves? Or making a short video/photos about what to expect (e.g. staff/lab sights, sounds, etc.), feelings/symptoms after the procedure.
  - Are there any reliable online resources about the procedure that patients can look at?
  - Patients reported that when something went wrong with the procedure (e.g. something getting stuck/panic) this made future procedures much harder for them to cope with – important for staff to flag to Jackie when this happens.

- Practicalities
  - Within the lab setting, could they introduce something on the ceiling as a distraction? (E.g. nice picture?)
  - Choice of music in the lab? Headphones for patients?
  - Magazines in waiting areas?
  - Recommendations to patients - e.g. bring a book

Possible outcomes

- **Leaflet** - outlining the ‘journey’ through the service, including what to expect from a patient perspective (direct quotes), practical suggestions (e.g. bring a book, there won’t be magazines), reliable website, images of the dept./cath lab?

- **Patient passport** – simple checklist of preferences (e.g. previous bad/good experience of the procedure, like to know lots of info/no info, music, like distraction/chatting...)
Appendix 16: Draft patient leaflet

Patients with Pulmonary Hypertension were interviewed as part of a research project about their experiences of the cardiac catheterisation procedure (both). They talked about how they coped with it and what helped them through. Here are some of the things they said:

What happens?
They all tell you their name and what they are doing—might as well as you are going to cover you up now, press your monitor—and then it’s the local anaesthetic—it’s probably the worst bit because it hurts when it goes in and once that’s in you can feel pushing at that point but you don’t feel pain and you don’t feel it inside its quite strange, so I think they really use their best to make you feel as comfortable as they can in a bed situation... (patient)

...the first time is a bit more of a worry because you’re not quite sure what you’re going into behind those double doors... (patient)

Then they all take pictures and even the nurse gives you a photo to take home.

What do staff think?
As part of the research, we also asked staff how they help patients to cope with the cath.

I think you are kind of the patients' advocates... if they are frightened to stay in the room, you can sit down to the consultant or the cardiac lab, you can make them feel fully aware of what they are going through. If they want any requests... is it their duty to make sure they are fulfilled. If they want someone to go in with them... or to have someone to hold their hand... yeah I do feel that we are the ones that they can come to... (Respiratory Nurse Specialist)

Resources
- The Pulmonary Hypertension Association website: www.phassociation.uk.com
- There will be waiting around on the day... I'm sure they suggested bringing a book or music to listen to... (e.g. pod)

Thank you to all the staff and patients at the RUH who participated in this project.
- Kate Anderson and Cara Roberts-Collins, University of Bath

Your preferences
Please use this space to write any questions you have or any preferences for the cath. For example, some people want more information, some people might want more hand hold or have some music. This is helping them during the procedure.

Everyone is different. What would work best for you?

Cardiac Catheterisation: What patients and staff have to say about it
Appendix 17: Draft patient passport

### Cardiac catheter patient passport

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
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<tr>
<td>Are you someone that would like to be distracted during the CATH? E.g. Music, chatting, looking at something.</td>
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<td>Are you someone that wants to know all the details of the procedure?</td>
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<td>Would you like someone to hold your hand during the procedure?</td>
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<tr>
<td>Are you someone that would prefer people not to chat to you too much and to leave you to approach the staff if you need them?</td>
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<td>Have you had any past experience of difficult medical procedures? E.g. medical complications or feeling panicky.</td>
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Appendix 18: Behavioural and Cognitive Psychotherapy Instructions to Authors

BEHAVIOURAL AND COGNITIVE PSYCHOTHERAPY

EDITORIAL OFFICE
Professor Paul M Salkovskis – Editor
Ms Lydia Holt – Editorial Assistant
Department of Psychology, University of Bath
Bath, BA2 7AY, UK
Tel: 01225 38 6930. E-mail: journal.office@babcp.com

Editorial Statement

Behavioural and Cognitive Psychotherapy is an international multidisciplinary journal for the publication of original research of an experimental or clinical nature, which contribute to the theory, practice and evaluation of behaviour therapy. As such, the scope of the journal is very broad and articles relevant to most areas of human behaviour and human experience which would be of interest to members of the helping and teaching professions will be considered for publication.

As an applied science the concepts, methodology and techniques of behavioural psychotherapy continue to change. The journal seeks both to reflect and to influence those changes.

While the emphasis is placed on empirical research, articles concerned with important theoretical and methodological issues as well as evaluative reviews of the behavioural literature are also published. In addition, given the emphasis of behaviour therapy on the experimental investigation of the single case, the journal from time to time publishes case studies using single case experimental designs. For the majority of designs this should include a baseline period with repeated measures; in all instances the nature of the quantitative data and the intervention must be clearly specified. Other types of case report can be submitted for the Brief Clinical Reports section.

The following types of articles are suitable for Behavioural and Cognitive Psychotherapy:

- Reports of original research employing experimental or correlational methods and using within or between subject designs.
- Review or discussion articles that are based on empirical data and that have important new theoretical, conceptual or applied implications.
- Brief reports and systematic investigations in single case employing innovative techniques and/or approaches.

Articles should concern original material that is neither published nor under consideration for publication elsewhere, this also applies to articles published in languages other than English.
SPECIAL SECTIONS OF THE JOURNAL

Brief Clinical Reports

Material suitable for this section includes unusual case reports, accounts of potentially important techniques, phenomena or observations; for example, descriptions of previously unreported techniques, outlines of available treatment manuals, descriptions of innovative variations of existing procedures, details of self-help or training packages, accounts of the application of existing techniques in novel settings and so on. The brief clinical reports section is intended to extend the scope of the clinical section. Submissions for this section should be no longer than 1800 words and should include no more than six references, one table or figure, and an extended report that contains fuller details. If the report describes more than one study these limits can be exceeded, please make this clear to the Editorial Office in the cover letter if this is the case. There are no restrictions on the size or format of the extended separate document. This may, for instance, be a treatment manual or a fully detailed case report, therapy transcript and so on. If a submission is accepted for publication as a Brief Clinical Report, the author(s) must be prepared to send the fuller document to those requesting it, free of charge or at a price agreed with the editor to reflect the cost of materials involved. The extended document will also be mounted on the journal’s website and therefore we require an electronic version in Word or PDF format (this material will not be copyedited).

Empirically Grounded Clinical Interventions

This section is intended for reviews of the present status of treatment approaches for specific psychological problems. It is intended that such articles will draw upon a combination of treatment trials, experimental evidence and other research, and be firmly founded in phenomenology. It should take account of, but also go beyond, treatment outcome data.

Accelerated Publication

The accelerated publication section is intended to accommodate a small number of important papers. Such papers will include major new findings for which rapid dissemination would be of considerable benefit and impact. For example: reports of the results of important new clinical trials; innovative experimental results with major implications for theory or practice; other work of unusually high calibre. In order to respond to rapid development in the field, the journal includes an accelerated publication section. Authors wishing to submit manuscripts for the accelerated publication section must briefly indicate in a covering letter their reasons for requesting accelerated publication and should also indicate whether they wish the manuscript to be transferred to the normal (non-accelerated) review process if rejected for either of the stages of accelerated review outlined below.
Accelerated review will proceed in two stages:

1. In the first stage, an editor and a reviewer will decide whether, in principle, the study merits accelerated publication. Authors will be informed within 14 days of receipt of this stage if not passed, and the manuscript will be withdrawn at that stage or continue in the normal (non-accelerated) review track, depending on the preference specified by the author(s).

2. Once passed in principle, the paper will then be subject to peer-review by the same reviewers as in stage 1 using normal journal criteria. At the end of this stage, manuscripts will be either accepted (with or without minor alterations) or rejected for accelerated publication.

Acceptance will depend on unanimity between the reviewer and editor. If accelerated publication is ruled out at this stage, a manuscript will revert to normal review if this option has been indicated by the author(s), otherwise it will simply be returned.

In order to maximize the speed at which accelerated review proceeds, details of decisions on accelerated publication will be restricted to whether the manuscript has been accepted or not. If a manuscript is transferred to the non-accelerated review track, the normal journal conventions regarding review decisions will be adhered to. The entire accelerated review process from receipt to final decisions should take an average of 2 weeks. Articles accepted in this section will appear in the first possible printed issue of the journal.

**MANUSCRIPT SUBMISSION IN FRENCH, SPANISH, GERMAN OR ITALIAN**

To reflect the international nature of the journal, we will allow submission in French, Spanish, German or Italian for those who wish to submit papers to the journal but who may not have English as a first language. This recognizes the fact that authors who do not normally write in English may be reluctant to undertake the difficult and time consuming task of translation when they have little or no idea of the acceptability of the material. We will now seek to provide some preliminary information concerning the likely acceptability of an article prior to translation into English. Initial submissions to this journal can, as of now, be made in French, Spanish, German or Italian. Such submission will be sent to an assistant editor fluent in the submission language for an initial evaluation. If that editor and their referees regard the paper as viable, the author will be encouraged to submit a translation for consideration. International language editors and referees’ reports will inform the final review process. If the paper is accepted in English translation, the journal will also publish the original language abstract alongside the English one. However, please note that we do not wish to receive submissions of articles previously accepted for publication in a non-English language journal. We will allow submissions of non-English translations subsequent to publication in Behavioural and Cognitive Psychotherapy provided permission from the BABCP as copyright holder has been obtained and appropriate acknowledgement to the original publication in Behavioural and Cognitive Psychotherapy is made. Our policy is to publish only original articles.
PREPARING YOUR MANUSCRIPT

Articles must be under 5,000 words at the point of submission including references (except for Brief Clinical Reports, please see separate instructions). Manuscripts describing more than one study may exceed this, however please mention this is your cover letter to make it clear to the editorial office. Manuscripts should be double-spaced throughout allowing wide margins all round.

Authors who want a blind review should indicate this at the point of submission of their article, omitting details of authorship and other identifying information from the main manuscript. Submission for blind review is encouraged.

All submissions should be in digital format and submitted via this portal:
http://mc.manuscriptcentral.com/babcp

MANUSCRIPTS SHOULD CONFORM TO THE FOLLOWING SCHEME

a. Title page. The title should phrase concisely the major issues. Author(s) to be given with departmental affiliations and addresses, grouped appropriately. A running head of no more than 40 characters should be indicated, plus 4 keywords.

b. Abstract. The abstract should be structured under the headings: Background, Aims, Method, Results, Conclusions. It should include up to six key words that could be used to describe the article. This should summarize the article in no more than 250 words.

c. Text. This should begin with an introduction, succinctly introducing the point of the paper to those interested in the general area of the journal. The appropriate positions of tables and figures should be indicated in the text. Footnotes should be avoided where possible.

d. Reference note(s). A list of all cited unpublished or limited circulation material, numbered in order of appearance in the text, giving as much information as possible about extant manuscripts.

e. References. These should follow APA guidelines. References within the text should be given in the form of Jones and Smith (1973) or (Jones and Smith, 1973). When there are three or up to and including five authors the first citation should include all authors; subsequent citations should be given as Williams et al. (1973). Authors with the same surname should be distinguished by their initials. All citations in the text should be listed in strict alphabetical order according to surnames. Multiple references to the same author(s) should be listed chronologically, using a, b, etc., for entries within the same year. Formats for journal articles, books and chapters should follow these examples:


**f. Footnotes.** The first, and preferably only, footnote will appear at the foot of the first page of each article, and subsequently may acknowledge previous unpublished presentation (e.g. dissertation, meeting paper), financial support, scholarly or technical assistance, or a change in affliction. A concluding (or only) paragraph must be the name and full mailing address of the author to whom reprint requests or other enquires should be sent.

**g. Tables and Figures**
Manuscripts should not usually include more than five tables and/or figures. Tables and Figures should appear at the end of the main text and references, but have their intended position within the paper clearly indicated in the manuscript. They should be constructed so as to be intelligible without reference to the text. Tints and shading may be used, but colour should be avoided unless essential. Although colour is possible in the online version, when designing a Figure please ensure that any line variation/distinction demonstrated by colour can still be noted when in black and white so as to be decipherable in the printed issue. Tables should be numbered and given explanatory titles. Numbered figure captions should be provided. Please see the Cambridge University Press Artwork guidelines [here](#) for more details on creating artwork.

**h. Required Sections**

**Acknowledgements:** You may acknowledge individuals or organisations that provided advice, support (non-financial). Formal financial support and funding should be listed in the following section.

**Conflict of interests:** Please provide details of all known financial, professional and personal relationships with the potential to bias the work. Where no known conflicts of interest exist, please include the following statement: "(Authors names) have no conflict of interest with respect to this publication."

**Financial Support:** Please provide details of the sources of financial support for all authors, including grant numbers. For example, "This work was supported by the Medical research Council (grant number XXXXXXX)." Multiple grant numbers should be separated by a comma and space, and where research was funded by more than one agency the different agencies should be separated by a semicolon, with "and" before the final funder. Grants held by different authors should be identified as belonging to individual authors by the authors’ initials. For example, "This work was supported by the Wellcome Trust (A.B., grant numbers XXXX, YYYY), (C.D., grant number ZZZZ); the Natural Environment Research Council (E.F., grant number FFFF); and the National Institutes of Health (A.B., grant number GGGG), (E.F., grant number HHHH)." Where no specific funding has been provided for research, please provide the following statement: "This research received no specific grant from any funding agency, commercial or not-for-profit sectors."
Note on blind review
Where conflict of interest and acknowledgements would compromise blind review, the identifiable information may be omitted from the main manuscript, but should be included on the separate title page which is not seen by reviewers. Within the main text it is acceptable to replace identifiable information by using XXXXXX or similar.

STYLE
Abbreviations where used must be standard. The Systeme International (SI) should be used for all units: where metric units are used the SI equivalent must also be given. Probability values and power statistics should be given with statistical values and degrees of freedom (e.g. F(1,34) = 123.07, p<.001), but such information may be included in tables rather than in the main text. Spelling must be consistent within an article, either using British usage (The Shorter Oxford English Dictionary), or American usage (Webster's new collegiate dictionary). However, spelling in the list of references must be literal to each publication. Details of style not specified here may be determined by reference to the Publication Manual of the American Psychological Association or the style manual of the British Psychological Society. Where unpublished material e.g. behaviour rating scales, therapy manuals etc., are referred to in an article, copies should be submitted as an additional document (where copyright allows) to facilitate review.

ETHICAL STANDARDS
Where research involves human and/or animal experimentation, the following statements should be included (as applicable): “The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, and its most recent revision.” and “The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional guides on the care and use of laboratory animals.”

All manuscripts should indicate the nature of the ethical governance body, for example by providing ethics committee/audit committee approval reference numbers.

Behavioural and Cognitive Psychotherapy is committed to actively investigating any cases of suspected misconduct, even in the event of the manuscript being withdrawn. All manuscripts are screened for plagiarism before being accepted for publication. Behavioural and Cognitive Psychotherapy follows the COPE guidelines on retractions.

PEER REVIEW
All editors and reviewers are asked to disclose any conflict of interest when they are assigned a manuscript. If deemed necessary, alternative or additional reviews will be sought in order to maintain the balance of fair and through peer review.
TRANSFER OF FILES FOR SUBMISSION TO THE COGNITIVE BEHAVIOURAL THERAPIST
Editors for the Behavioural and Cognitive Psychotherapist (BCP) can choose to recommend submission of a manuscript not suitable for BCP to the Cognitive Behavioural Therapist (tCBT), thus effectively submitting to both journals sequentially. This allows the automatic transfer of the manuscript files including, at the discretion of the handling Editor, transmission of reviewers’ comments where this seems likely to facilitate manuscript handling. Selection of a manuscript to be transferred to tCBT is at the Editor’s discretion, and is then subject to the peer-review process of that journal. No guarantee of suitability for tCBT or acceptance is made. Those papers not passed on to tCBT by a BCP Editor can be submitted by the author via the usual channels.

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Upon acceptance of your paper, you may choose to publish your article via Gold Open Access (following payment of an Article Processing Charge). Current APC rates for Behavioural and Cognitive Psychotherapy can be found here.

Please note: APC collection is managed by Rightslink, who will contact authors who have elected to publish via Open Access.

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PROOFS, REPRINTS AND COPYRIGHT
Proofs of accepted articles will be sent electronically to authors for the correction of printers’ errors; authors’ alterations may be charged. Authors submitting a manuscript do so on the understanding that if it is accepted for publication exclusive copyright of the paper shall be assigned to the Association. In consideration of the assignment of copyright, 25 copies of each paper will be supplied. Further reprints may be ordered at extra cost: the reprint order form will be sent with the proofs. The publishers will not put any limitation on the personal freedom of the author to use material contained in the paper in other works.

AUTHOR LANGUAGE SERVICES
Cambridge University Press recommends that authors have their manuscripts checked by an English language native speaker before submission; this will ensure that submissions are judged at peer review exclusively on academic merit. We list a number of third-party services specialising in language editing and / or translation, and suggest that authors contact as appropriate. Use of any of these services is voluntary, and at the author’s own expense.

(Revised March 9th 2016)
Appendix 19: Ethical and R&D approvals

Miss Cara Roberts-Collins
Department of Clinical Psychology
6 West Level 0
Claverton Down
Bath
BA2 7AY

West of Scotland REC 3
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 08 June 2015
Direct line 0141 211 2482
Fax 0141 211 1847
E-mail rose.gallacher@ggc.scot.nhs.uk

Dear Miss Roberts-Collins

Study title: Exploring socialisation to Cognitive Behavioural Therapy and emotional awareness in young people with Autism Spectrum Disorders

REC reference: 15/WS/0111
IRAS project ID: 170744

Thank you for your e-mail of 7 June 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 03 June 2015

Documents received

The documents received were as follows:

Approved documents

The final list of approved documentation for the study is therefore as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
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<tr>
<td>Copies of advertisement materials for research participants [Young person poster]</td>
<td>1</td>
<td>24 April 2015</td>
</tr>
<tr>
<td>Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Bath Indemnity Insurance]</td>
<td>1</td>
<td>01 August 2014</td>
</tr>
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<td>GP/consultant information sheets or letters [Clinician information sheet]</td>
<td>2</td>
<td>03 June 2015</td>
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<tr>
<td>Interview schedules or topic guides for participants [Intro and interview schedule]</td>
<td>1</td>
<td>10 April 2015</td>
</tr>
<tr>
<td>Letter from sponsor [Sponsorship approval letter]</td>
<td>1</td>
<td>07 May 2015</td>
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<tr>
<td>Letters of invitation to participant [Letter to participants]</td>
<td>1</td>
<td>10 April 2015</td>
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<tr>
<td>Letters of invitation to participant [Letter to clinicians]</td>
<td>1</td>
<td>24 April 2015</td>
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<tr>
<td>Letters of invitation to participant [Letter to service managers]</td>
<td>1</td>
<td>07 May 2015</td>
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<tr>
<td>Document</td>
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<tr>
<td>Non-validated questionnaire [Thoughts, feelings, behaviours task]</td>
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<td>27 March 2015</td>
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<tr>
<td>Other [University of Bath liability]</td>
<td>1</td>
<td>01 August 2014</td>
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<tr>
<td>Other [Gerwyn Mahoney-Davies CV]</td>
<td>1</td>
<td>10 April 2015</td>
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<tr>
<td>Other [AR CV]</td>
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<tr>
<td>Participant consent form [Young person consent (over 16)]</td>
<td>2</td>
<td>03 June 2015</td>
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<tr>
<td>Participant consent form [Young person assent (under 16)]</td>
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<tr>
<td>Participant consent form [Parent consent form]</td>
<td>2</td>
<td>03 June 2015</td>
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<tr>
<td>Participant information sheet (PIS) [Participant debrief sheet]</td>
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<td>10 April 2015</td>
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<td>Participant information sheet (PIS) [Participant screening]</td>
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<tr>
<td>Participant information sheet (PIS) [Parent debrief sheet]</td>
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<td>15 May 2015</td>
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<tr>
<td>Referee’s report or other scientific critique report [Proposal marking</td>
<td>1</td>
<td>05 December 2014</td>
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<td>sheet]</td>
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<tr>
<td>Research protocol or project proposal [Research proposal]</td>
<td>1</td>
<td>30 January 2015</td>
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<td>Summary CV for Chief Investigator (CI) [Cara Roberts-Collins CV]</td>
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<td>Summary CV for supervisor (student research) [Dr Ailsa Russell CV]</td>
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<td>Validated questionnaire [Session Rating Scale]</td>
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<td>Validated questionnaire [RCADS]</td>
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<tr>
<td>Validated questionnaire [Emotional Awareness Questionnaire]</td>
<td>1</td>
<td>23 April 2015</td>
</tr>
<tr>
<td>Validated questionnaire [Child Session Rating Scale]</td>
<td>1</td>
<td>11 May 2015</td>
</tr>
</tbody>
</table>

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor’s responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/WS/0111 Please quote this number on all correspondence

Yours sincerely

Rose Gallacher
Assistant Administrator

Copy to: Professor Jane Millar
Ms Jana Safarikova, Research Governance Coordinator, Research and Development Department, Oxford Health NHS Foundation Trust
Our R&D ref: 15/019/2GT

Wednesday, 15 July 2015

Ms. Cara Roberts-Collins
Clinical Psychologist in Training
Taunton and Somerset NHS Foundation Trust
Musgrove Park Hospital
Taunton
Somerset
TA1 5DA

Dear Cara

Study title: Exploring socialisation to CBT and emotional awareness in young people with Autism Spectrum Disorders
REC ref: 15-WS-0111

Thank you for forwarding information on the above study. I can confirm the approval of 2gether NHS Foundation Trust for the above study to proceed.

Your project will now be added to the Gloucestershire Health Community Research Register which will identify the following:

- Study Title: As above
- Chief Investigator: As above
- Sponsoring Organisation: 2gether NHS Foundation Trust
- Host Organisation: 2gether NHS Foundation Trust
- Type of Study: PhD

It is important that all research conducted with NHS patients and/or staff complies with the Research Governance Framework. We would advise you to notify us at the above address, quoting our reference number for your study with regards to the following information.

- Protocol Changes/Amendments to the study
- Change of Principal Investigator/local Research Team at site

Chair: Professor Clair Chivers DSc
Chief Executive: Dr Frank Har Vest PhD, MBA

www.gloshospitals.nhs.uk
• Untimely closure of study
• Final study closure date
• Final recruitment figure of study

In relation to this I would like to take the opportunity to remind you of some of your responsibilities under this framework.

1. Health and safety: You are reminded of your responsibilities for health and safety at work under the Health and Safety at Work Act 1974. You have a legal responsibility to take care of your own and other people’s Health and Safety at work under the Health and Safety at Work Act 1974 as amended and associated legislation. These include the duty to take reasonable care to avoid injury to yourself and to others by your work activities or omissions, and to co-operate with your employer in the discharge of its statutory duties. You must adhere strictly to the policies and procedures on health and safety.

2. Codes of confidentiality/Data Protection: Anybody who records patient information (whether on paper or by electronic means) has a responsibility to take care to ensure that the data recorded is accurate, timely and as complete as possible. It is vital that you conduct your research in accordance with the principles of the Data Protection Act 1998 and codes of confidentiality.

3. Liability and Indemnity: Indemnity for your study will be as described in any applicable Clinical Trial Agreement or other Research Contract. Where such an agreement is not available, the Trust will indemnify its employees and researchers holding NHS Honorary Contracts for the purposes of Negligent Harm. NHS Trusts cannot provide cover for No Fault or Non-Negligent claims. Where this is required, it is expected that the Research Sponsor will provide such indemnity.

4. Intellectual Property: Intellectual Property is defined as the tangible output of any intellectual activity that is new or previously undescribed. It can include the following:
   i. Inventions, such as new medical devices, software;
   ii. Literary works, such as software, patient leaflets, journal articles;
   iii. Designs and drawings, such as posters, leaflets;
   iv. Brand names, such as logos and trademarks; and
   v. Trade secrets, such as surgical techniques.

For projects originating from outside of the NHS Trust with which this agreement is made, Intellectual Property rights will remain with the Lead Site/Investigator unless developed from observations made outside of the scope and influence of the project. The rights to Intellectual Property generated in such a fashion will remain with the Host Trust unless an agreement to the contrary has been signed by both parties. Where a Clinical Trial Agreement or other Contract exists, this will take priority over this clause.

5. Adverse Events/Incidents: Any adverse events you witness or suspect to have happened must be reported to your supervisor or manager as soon as you know about them and dealt with as described in the research protocol.

6. Fraud and Misconduct: Any suspicions of active fraud or misconduct must be reported to your supervisor or manager immediately and will be treated in the strictest confidence. The monitoring of research will also seek to reduce incidents of research misconduct and fraud.

7. Monitoring: As part of the Research Governance Framework, during the course of your research you may be monitored to ensure that procedures in the protocol approved by the ethics committee are
being adhered to. For locally sponsored studies this will be undertaken by the R&D Office. For externally sponsored studies this is likely to be arranged by the appropriate sponsor.

8. **Dissemination:** The Framework also requires the dissemination of research findings to the research subjects, NHS staff and the public. On completion of your research you will be expected to produce a summary of the project and an indication of how the results from the study will be disseminated. For studies where publication of research results is not the responsibility of the local Investigator, requests for such information will be made to the sponsor.

9. **Termination of Agreement:** The Trust also reserve the right to terminate the agreement for your research to proceed if, at any time, you are found to be in breach of the clauses in this Approval Letter or fail to adequately meet the requirements of the Research Governance Framework.

The documents reviewed and approved in relation to this study are listed on the following REC favourable Opinion Letter:

- **15/WS/0111- Original REC favourable Opinion Letter, dated 08 June 2015.**

If you need any further support or information, please do not hesitate to contact us at the above address, quoting our reference number for your study.

I wish you every success with your project.

Yours sincerely,

Mark Walker
Senior Research Governance Manager
(Gloucestershire R&D Consortium)

cc: Dr Maria Loades, University of Bath
    Gemmyn Mahoney-Davies, Taunton and Somerset NHS Foundation Trust
North Bristol NHS Trust Full R&D approval: R&D 3716: Young people's understanding of CBT

Smith Rebecca (NORTH BRISTOL NHS TRUST) <rebecca.smith30@nhs.net>
Wed 03/02/2016 15:09
Show all 11 recipients
To: Kate.Cooper@nbt.nhs.uk;
Cc: Cara Roberts-Collins; Pro-Vice-Chancellor for Research: research@oxfordhealth.nhs.uk; Maria Loades; Helen.Lewis@nbt.nhs.uk; Katie.tovey@nbt.nhs.uk; annette.clarke@nbt.nhs.uk;

Project Title: Exploring socialisation to Cognitive Behavioural Therapy and emotion awareness in young people with Autism Spectrum Disorders
IRAS number: 170744
REC Reference: 15/WS/0111
R&D Reference: 3716
Start Date: 03/02/2016
End Date: 30/06/2016

I am pleased to tell you that North Bristol NHS Trust has agreed to act as a Participant Identification Centre (PIC) for the above study sponsored by University of Bath.

We wish you every success with your study and are keen to support good research at North Bristol NHS Trust.

Agreement to act as a PIC is given on the understanding that this project be carried out according to ICH Good Clinical Practice guidelines and UK Statutory Instrument, and within the guidelines of the NHS Research Governance Framework for Health and Social Care.

Many thanks

Dr Rebecca Smith
Deputy Director of Research and HRA Approval Change Lead South West Research & Innovation
North Bristol NHS Trust

Floor 3 Learning & Research building | Southmead Hospital | Westbury-on-Trym | Bristol | BS10 5NB
T: 0117 4149332 | F: 0117 4149329
http://www.nbt.nhs.uk/researcheducation/research
Anne Booth
Consultant Clinical Psychologist
Oxford Health NHS Foundation Trust
Swindon Community Child and Adolescent Service
Marlborough House
Okus Road
Swindon
SN1 4JS

Dear Anne,

STUDY TITLE: Exploring socialisation to Cognitive Behavioural Therapy and emotional awareness in young people with Autism Spectrum Disorders
REC Ref No: 15/WS/0111

I am pleased to confirm that Oxford Health NHS Foundation Trust will collaborate as a Participant Identification Centre (PIC) for this research study until the study end date of 28th July 2016, as described in your application. The agreement commences as of the date of this letter. This confirmation is dependent on formal approval of the National Research Ethics Service and/or any other relevant regulatory body remaining in place.

Oxford Health NHS FT is restricted to identifying potential participants, providing a copy of the participant information sheet and advising the potential participant to contact a member of the research team.

As a researcher you are reminded of your responsibilities including adherence to the principles of the Research Governance Framework (RGF), Good Clinical Practice (GCP) and the Data Protection Act. It is a condition of this agreement that you inform the Trust R&D department of any amendments to the protocol, changes to the project and data and that you forward copies, submitted to the REC, of annual progress reports and the final study report on completion of the study.

I wish you every success with the study.

Yours sincerely,

[Signature]

Professor John Geddes
Director of R&D

CC: Miss Cara Roberts-Collins, Trainee Clinical Psychologist, Department of Clinical Psychology, University of Bath, Bath, BA2 7AY
Professor Jane Miller, Vice-Chancellor’s Office, 4 West 3.22, University of Bath, Bath, BA2 7AY

Oxford Health NHS Foundation Trust
Trust HQ, Wameford Hospital, Wameford Lane, Headington, Oxford OX3 7JX
Telephone: 01865 901000 www.oxfordhealth.nhs.uk
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OHFT PIC NHS Permission_YP Understanding CBT_OHFT PID 1098
Our Reference: AWP938

Miss Cara Roberts-Collins
Department of Clinical Psychology
6 West Level 0
Claverton Down
Bath
BA2 7AY

30 March 2016

Dear Cara,

Title of study: Exploring socialisation to Cognitive Behavioural Therapy and emotional awareness in young people with Autism Spectrum Disorders

REC reference: 15/W3/011
IRAS project ID: 170744
Approval date: 30 March 2016
End date: 30 September 2016

I am pleased to inform you that all the required documentation listed below have been received and all the relevant governance checks have now been completed. I am therefore happy to give PIC permission for the above study on behalf of Avon and Wiltshire Mental Health Partnership NHS Trust ("the Trust") for the sites listed below:

- Avon and Wiltshire Mental Health Partnership NHS Trust

<table>
<thead>
<tr>
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<th>Version</th>
<th>Date</th>
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<td>Copies of advertisement materials for research participants</td>
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<td>03 June 2015</td>
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<td>managers]</td>
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<td>1</td>
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<td>Other [AR CV]</td>
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<tr>
<td>Participant consent form [Young person consent (over 16)]</td>
<td>2</td>
<td>03 June 2015</td>
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<tr>
<td>Participant consent form [Young person assent (under 16)]</td>
<td>2</td>
<td>03 June 2015</td>
</tr>
<tr>
<td>Participant consent form [Parent consent form]</td>
<td>2</td>
<td>03 June 2015</td>
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<td>10 April 2015</td>
</tr>
<tr>
<td>sheet]</td>
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</tr>
</tbody>
</table>

Continued...

Chair: Anthony Gallagher
Headquarters: Jenner House, Langley Park, Chippenham. SN15 1GG
Chief Executive: Iain Tulley

Julian Walker
Research and Development
Avon & Wiltshire Mental Health Partnership NHS Trust
Fromeside
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 1EG
0117 378 4386
Julian.Walker@nhs.net
Please be aware that if there are any amendments to the above approved documents they must be sent to Hannah Antoniades, Research and Development Operations Manager for approval.

You are reminded that you must report any adverse event or incident whether or not you feel it is serious, quoting the study reference number. This requirement is in addition to informing the Chairman of the relevant Research Ethics Committee. You are also required to submit to the Research and Development Operations Manager (Hannah Antoniades) a final outcome report on completion of your study, and if necessary to provide interim annual reports on progress. Should publications arise, please also send copies to Hannah Antoniades for inclusion in the study’s site file.

You must also abide by the research and information governance requirements for any research conducted within the NHS:

- Work must be carried out in line with the Research Governance Framework which details the responsibilities of everyone involved in research.
- You must comply with the Data Protection Act 1998 and where required, have up to date Data Protection Registration with the Information Commissioners Office. Where staff are employed, this includes having robust contracts of employment in place and ensuring that staff are made aware of their obligations through training and similar initiatives.
- You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice: (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253)
- You must have appropriate policies and procedures in place covering the security, storage, transfer and disposal of information both personal and sensitive, or corporate sensitive information. Any information security breach must be reported immediately to the Trust.
- Where access is granted to sensitive corporate information, this must not be further disclosed without the explicit consent of the Trust unless there is an override required by law. Where disclosure is required under the Freedom of Information Act 2000, the Trust will assist you in processing the request.

Please note that, as a public authority, the Trust is obligated to comply with the provisions of the Freedom of Information Act 2000, including the potential disclosure of information held by the Trust in connection with this study. Where a request for potential disclosure of personal, corporate sensitive, or contract information is made under the Freedom of Information Act 2000, due regard shall be made to any duty of confidentiality or commercial interest.

Yours sincerely

Dr Julian Walker
Director of Research and Development
Avon and Wiltshire Mental Health Partnership NHS Trust
Appendix 20: Emotion Awareness Questionnaire – 30 item version (EAQ-30)

The way I feel

Please fill out your first name..........................
And your date of birth......................................
And whether you are a boy or a girl........................

On the next pages, you will find 30 short sentences. Every sentence is a statement about how you can feel or think about your feelings. You can mark each sentence if this is true, sometimes true or not true for you. Choose the answer that best fits you. You can only mark one answer. If you find that difficult, choose the answer that fits you most of the time. Different children have different feelings and ideas about their feelings. Therefore, there are no right or wrong answers, because it is just about what you think.

For example the sentence

“When I feel upset, I try to forget about it”

If this statement is true for you, then mark “true”

\[
\begin{array}{ccc}
\text{not true} & \text{sometimes true} & \text{true} \\
\square & \square & \square
\end{array}
\]

If this statement is sometimes true for you, then mark “sometimes true”

\[
\begin{array}{ccc}
\text{not true} & \text{sometimes true} & \text{true} \\
\square & \square & \square
\end{array}
\]

If this statement is not true for you, then mark “not true”

\[
\begin{array}{ccc}
\text{not true} & \text{sometimes true} & \text{true} \\
\square & \square & \square
\end{array}
\]
<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Not True</th>
<th>Sometimes True</th>
<th>True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I am often confused or puzzled about what I am feeling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I find it difficult to explain to a friend how I feel</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Other people don't need to know how I am feeling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>When I am scared or nervous, I feel something in my mummy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>It is important to know how my friends are feeling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>When I am angry or upset, I try to understand why</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>It is difficult to know whether I feel sad or angry or something else</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>I find it hard to talk to anyone about how I feel</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>When I am upset about something, I often keep it to myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>When I feel upset, I can also feel it in my body</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>I don't want to know how my friends are feeling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>My feelings help me to understand what has happened</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>I never know exactly what kind of feeling I am having</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>I can easily explain to a friend how I feel inside</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>When I am angry or upset, I try to hide this</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I don't feel anything in my body when I am scared or nervous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>If a friend is upset, I try to understand why</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>When I have a problem, it helps me when I know how I feel about it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>When I am upset, I don't know if I am sad, scared or angry</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>When I am upset, I try not to show it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>My body feels different when I am upset about something</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I don't care about how my friends are feeling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>It is important to understand how I am feeling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Sometimes, I feel upset and I have no idea why</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>When I am feeling bad, it is no one else's business</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>When I am sad, my body feels weak</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>I usually know how my friends are feeling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>I always want to know why I feel bad about something</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>I often don't know why I am angry</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>I don't know when something will upset me or not</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please check that you have marked all of the sentences.

Thank you!
Appendix 21: CBT skills story and task

Story

Alex worries a lot. He worries that something really bad might happen to people close to him. If he does not have something to worry about he’ll worry that he has missed something important and will try to find it. He jumps to the worst possible conclusions and his body constantly feels tense. His thoughts go through his mind quickly and one worry will often lead to another. He has trouble sleeping and can’t get his mind to stop thinking.
Thoughts, feelings and behaviours task

Please read the short story about Alex and answer the four questions below. There are no right or wrong answers.

1. What thoughts, feelings, and behaviours might Alex have? Please write these in the circles below.

   ![Thought](image)
   ![Feelings](image)
   ![Behaviour](image)

2. Draw arrows to show how the circles above could be connected

3. What needs to change for Alex to get better?

   _________________________________________________________
   _________________________________________________________
   _________________________________________________________
   _________________________________________________________
   _________________________________________________________

4. Design an activity to help with Alex’s worry and tell us why it might help him

   _________________________________________________________
   _________________________________________________________
   _________________________________________________________
   _________________________________________________________
Appendix 22: CBT skills task scoring

CBT skills task scoring
Maximum score = 20

1. **Score 1 point for each thought, feeling and behaviour within its relevant bubble** (e.g. thoughts in the thought bubble) up to a maximum of three per bubble. These can be thoughts, feelings and behaviours quoted from the story or relevant hypothetical responses. Physical sensations (e.g. heart beating fast, body tense) can only be scored in the feelings bubble. Worry can be scored as a feeling or a behaviour. Score range 0-9 (*explicit understanding*).

2. **Score each arrow with a direction** (e.g. three sets of double ended arrows = score of 6, three sets of single ended arrows = score of 3, two single ended arrows (i.e. connecting thoughts-feelings and feelings-behaviour = score of 2). Score range 0-6 (*explicit understanding*).

3. **Score range 0-2 (applying principles)** –
   a. **Score 2** for an answer that describes a change in thoughts or behaviours (e.g. ‘realise his thoughts are not facts’, ‘reducing catastrophic thoughts/beliefs’, ‘change unhelpful behaviours’, ‘stop jumping to the worst possible conclusion’, ‘being more aware of how his body is feeling’). Answers that describe what needs to change are not scored here, but can be scored as part of question 4 if applicable.
   b. **Score 1** for an answer that mentions thoughts, feelings or behaviours, but does not say what needs to change (e.g. ‘psychoeducation’, ‘learn about thoughts/worry’ ‘control his worry’).
   c. **Score 0** for an answer that suggests something completely unrelated to changing T-F-B, or which suggests a change in T-F-B but one which is not helpful or informed by CBT principles (e.g. ‘Alex should text the people close to him every day to check they are ok’, ‘see a therapist’, ‘stop worrying’).

4. **Score range 0-3** - score for each activity relevant to the model (*active planning*)
   a. **Score 3** for an answer if the activity designed and reason why it might help him both fit with the CBT framework (e.g. ‘this will help challenge his thoughts and look at things from a different perspective’ - i.e. one aspect influencing the other).
   b. **Score 2** for an answer that designs an activity and a reason for why it might help, but does not directly link T-F-B (e.g. ‘this will help him because he will be able to notice when he’s thinking a certain way and how he feels when he is thinking like this’).
   c. **Score 1** for an answer that designs an activity, but does not give a reason why this might help (e.g. ‘keep a thought diary’).
   d. **Score 0** for a suggestion of activity unrelated to the CBT framework, or no suggestion made at all (e.g. ‘Ask his mum what to do when he gets upset’).
### CBT skills task scoring matrix

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Total (max score)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) T-F-B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoughts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(3)</td>
</tr>
<tr>
<td>Feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(3)</td>
</tr>
<tr>
<td>Behaviours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(3)</td>
</tr>
<tr>
<td>2) Number of each arrow</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(6)</td>
</tr>
<tr>
<td>3) Change</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(2)</td>
</tr>
<tr>
<td>4) Activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(3)</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(20)</td>
</tr>
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Appendix 23: Mean, median, and range of scores on each segment of the CBT skills task for CBT clinicians

<table>
<thead>
<tr>
<th>CBT skills task</th>
<th>Q1. Identifying T-F-B</th>
<th>Q2. Linking T-F-B</th>
<th>Q3. Change</th>
<th>Q4. Activity</th>
<th>Total Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rater 1</td>
<td>Rater 2</td>
<td>Rater 1</td>
<td>Rater 2</td>
<td>Rater 1</td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>7.71</td>
<td>7.36</td>
<td>6</td>
<td>6</td>
<td>1.86</td>
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<tr>
<td><strong>(SD)</strong></td>
<td>(0.91)</td>
<td>(1.01)</td>
<td>(0)</td>
<td>(0)</td>
<td>(0.36)</td>
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<tr>
<td><strong>Median</strong></td>
<td>8</td>
<td>7.5</td>
<td>6</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td><strong>Min – max (range)</strong></td>
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<td>5 – 9</td>
<td>6 – 6</td>
<td>6 – 6</td>
<td>1 – 2</td>
</tr>
<tr>
<td></td>
<td>(3)</td>
<td>(3)</td>
<td>(0)</td>
<td>(0)</td>
<td>(1)</td>
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</table>
Appendix 24: Revised Child Anxiety and Depression Scale (RCADS) – Self-report version

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  I worry about things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2  I feel sad or empty</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3  When I have a problem, I get a funny feeling in my stomach</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4  I worry when I think I have done poorly at something</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5  I would feel afraid of being on my own at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6  Nothing is much fun anymore</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7  I feel scared when I have to take a test</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8  I feel worried when I think someone is angry with me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9  I worry about being away from my parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 I am bothered by bad or silly thoughts or pictures in my mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 I have trouble sleeping</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 I worry that I will do badly at my school work</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 I worry that something awful will happen to someone in my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 I suddenly feel as if I can't breathe when there is no reason for this</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 I have problems with my appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 I have to keep checking that I have done things right (like the switch is off, or the door is locked)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 I feel scared if I have to sleep on my own</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 I have trouble going to school in the mornings because I feel nervous or afraid</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 I have no energy for things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 I worry I might look foolish</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------</td>
<td>-------</td>
<td>-----------</td>
<td>-------</td>
</tr>
<tr>
<td>21</td>
<td>I am tired a lot</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I worry that bad things will happen to me</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>23</td>
<td>I can’t seem to get bad or silly thoughts out of my head</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>24</td>
<td>When I have a problem, my heart beats really fast</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>25</td>
<td>I cannot think clearly</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>26</td>
<td>I suddenly start to tremble or shake when there is no reason for this</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>27</td>
<td>I worry that something bad will happen to me</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>28</td>
<td>When I have a problem, I feel shaky</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>29</td>
<td>I feel worthless</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>30</td>
<td>I worry about making mistakes</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>31</td>
<td>I have to think of special thoughts (like numbers or words) to stop bad things from happening</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>32</td>
<td>I worry what other people think of me</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>33</td>
<td>I am afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds)</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>34</td>
<td>All of a sudden I feel really scared for no reason at all</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>35</td>
<td>I worry about what is going to happen</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>36</td>
<td>I suddenly become dizzy or faint when there is no reason for this</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>37</td>
<td>I think about death</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>38</td>
<td>I feel afraid if I have to talk in front of my class</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>39</td>
<td>My heart suddenly starts to beat too quickly for no reason</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>40</td>
<td>I feel like I don’t want to move</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>41</td>
<td>I worry that I will suddenly get a scared feeling when there is nothing to be afraid of</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>42</td>
<td>I have to do some things over and over again (like washing my hands, cleaning or putting things in a certain order)</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>43</td>
<td>I feel afraid that I will make a fool of myself in front of people</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>44</td>
<td>I have to do some things in just the right way to stop bad things from happening</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>45</td>
<td>I worry when I go to bed at night</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>46</td>
<td>I would feel scared if I had to stay away from home overnight</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>47</td>
<td>I feel restless</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
</tbody>
</table>
Appendix 25: Socialisation Interview

Introduction

Thank you for helping us out with this project. First of all we need to go over the information sheet and check if you have any questions about today. I will then ask you to complete a short questionnaire and answer some questions about therapy. I will then ask you to do a quick task. This will take about 30-40 minutes in total. If you would like to we will finish with a fun activity!

[Consent – 5 mins]

[EAQ:30 – 5 minutes]

Interview (15-20 mins)

I will start by asking you some questions about therapy, or something we would call ‘cognitive behaviour therapy’ or ‘CBT’. What do you like to call it? This part will take about 15-20 minutes. I have five main questions we are asking everyone who takes part but I will ask other questions if I need to clarify anything.

You can stop taking part at any time and don’t have to answer every question. Because it can be difficult to say ‘no’ to a question, I will give you this card to hold up if you don’t want to answer a question, or to ask for the question to be asked in another way. Do you have any questions before we start?

Socialisation interview schedule

1) Tell me about your experience of having CBT/therapy.
   a. Could you tell us a few good things and a few bad things about therapy? (YP can choose whether to start with good or bad prompt if only good or bad mentioned).

2) Did you find anything useful about your CBT/therapy? What did you find useful? (E.g. learn about avoidance, bad things weren’t going to happen, people didn’t hate me etc)

3) Did you learn any skills in CBT/therapy? Can you tell about these skills? What skills were they?
   a. After you finished therapy did you keep using any skills? Which skills did you keep using?

4) Were you asked to do things between sessions? What did you have to do?

5) ASD Group – Did you learn about emotions in therapy? (psychoeducation)
   a. Did you learn about anxiety?
   b. Did you learn about being sad?
6) Compared to when you were first seen for therapy, would you say things are:
   1) Very much improved
   2) Much improved
   3) Minimally improved
   4) No change
   5) Minimally worse
   6) Much worse
   7) Very much worse

7) Would you like to add anything else?

**Vignette (5 mins)**

Next I am going to give you a short task to do. There is a short story to read and four questions to answer. Would you like to read this story or would you prefer for me to read it to you? I'll be here if you have any questions.

**Debrief and activity (5 mins)**

[Give debrief sheet]
Appendix 26: Socialisation Interview scoring criteria

Interview scoring criteria

The coding categories:
1. Explicit understanding
2. Concordance
3. Active planning
4. Evidence of applying the principles
5. Language
6. (psychoeducation)

Socialization to the Treatment Model
Extract utterances related to the young person’s understanding, description or discussion of CBT. Enough of the utterance must be extracted to ensure that extract can be coded, i.e. Relevant context.

Both body sensations aspects and emotional/mental aspects (e.g. anxiety, negative thoughts) are relevant to extract, particularly any utterances directly pertaining to CBT.

Each utterance will be coded and will be scored 1 for each category it relates to (i.e. each utterance could potentially score a total of 5, although this is unlikely). A total score will be derived for the overall number of utterances and the total in each category. If no utterances are linked to the area this will be scored as a 0. It is therefore possible for a category score to be 0 if the participant does not make utterances relevant to this category. The total number of utterances will vary in each interview, meaning that there is no upper total limit to scores.

Coded: Absent (0)
       Present (1)

Utterances made by the young person

1) **EXPLICIT UNDERSTANDING**: Utterances indicating an understanding of CBT principles including thoughts, feelings and behaviours. See language table for possible utterances. E.g.:
   a) I talked about the way my thoughts were related to how I felt
   b) The therapist helped me to notice things I felt in my body
   c) I learned that avoiding things was keeping my anxiety going

2) **CONCORDANCE**: Simple statements in active agreement/concordance with the CBT model e.g. any utterance where you can reasonably identify that there is active agreement from the patient with the therapist suggestions. E.g.:
   a) I did some scary things that my therapist told me might help because I thought it might make me feel better (or idea related to reasons behind it/agreement)
   b) When my therapist said….that really made sense to me because…
   c) We (therapist and young person) worked together…..
   d) That was really good…

3) **ACTIVE PLANNING**: Active agreement of plan to proceed and implement behavioural change or intervention. When considering rating questions as active planning, consider the context as to whether this is true active planning.

This may be activity planning/plans to alter behavioural patterns, with therapist (e.g. in sessions) or autonomously (e.g. homework). E.g.:
   a) I tried/tested out/practiced….at home
Active planning may also take the form of agreement of a suggested plan. E.g.:

b) My therapist asked me to do… for homework.

4) **EVIDENCE OF APPLYING THE PRINCIPLES**: Predominantly after therapy, continued use of CBT skills they learned and anything above and beyond what was planned during sessions and what was asked by the therapist. E.g.:

   a) 6 months later still using…
   
   b) Therapist asked me to do….and I also did….because (reason why related to CBT)

5) **LANGUAGE**: Use of key psychological language employed that is specific to the CBT model. The language used must be in the context of discussing presenting difficulties, intervention or relating to the CBT model in some way. Consider whether the young person would have used this term/word prior to engaging in CBT, and whether a peer would use this term. If not, consider coding. Language can be coded several times in any utterances, although duplicates can only be coded once per interview. *Note: language used will be age dependent and CBT terminology is often simplified into everyday language for younger people.*

Language scoring:

<table>
<thead>
<tr>
<th>Thoughts</th>
<th>Feelings</th>
<th>_behaviours</th>
<th>Physical sensations</th>
<th>Connecting T-F-B</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Negative automatic) thoughts</td>
<td>Emotions</td>
<td>Doing differently</td>
<td>Body reactions</td>
<td>Cycle (e.g. of anxiety)</td>
<td>Good and bad coach</td>
</tr>
<tr>
<td>Thought challenging/challenge thoughts</td>
<td>(feeling words e.g. anxious, sad, upset, worried)</td>
<td>Avoidance/avoid things</td>
<td>Fight/flight (caveman etc.)</td>
<td>Spiral</td>
<td>Coping strategies/how to cope</td>
</tr>
<tr>
<td>Thinking bias</td>
<td>Thinking traps</td>
<td>Reassurance seeking</td>
<td></td>
<td>Vicious cycle</td>
<td>Relaxation</td>
</tr>
<tr>
<td>Reframing</td>
<td>Balanced thoughts</td>
<td>Checking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence in a court case</td>
<td>Mind reading</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blowing things up</td>
<td>Builders wall/apprentice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Weighing the evidence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6) **PSYCHOEDUCATION**: Specific reference made to having talked and learned about recognising emotions within therapy. A score of 1 is given if emotions are discussed in relation to a specific difficulty (e.g. anxiety). A score of 2 is given if they have talked about psychoeducation in relation to a specific difficulty and more generally (e.g. ‘I learnt about different emotions too, like anxiety, feeling sad…’).

Scores given for psychoeducation are not included in the total socialisation score.
# Socialisation interview scoring matrix

<table>
<thead>
<tr>
<th>Participant ID:</th>
<th>Interview date:</th>
<th>Interview length:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Coding:</th>
<th>Explicit Understanding</th>
<th>Concordance</th>
<th>Active planning</th>
<th>Applying principles</th>
<th>Language</th>
<th>(Psychoed)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utt. No.</td>
<td>Time</td>
<td>Utterance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL**
Appendix 27: Experiences of CBT for Young People with a diagnosis of ASD

Background
Collaborative empiricism is central to the concept of CBT; working alongside the young person and their parents (who play an active role in therapy) to develop a shared understanding of their difficulties, and a set of tools and principles which allow them to become a ‘self-therapist’ (Stallard, 2005). It is therefore important to also understand young people’s experiences of CBT. Qualitative research has identified key elements of adolescents’ experience of CBT (Donnellan, Murray, & Harrison, 2013). These include the impact of CBT on change (e.g. identifying different perspectives and increasing self-efficacy), the manner in which CBT is delivered (e.g. structure), the importance of engagement (e.g. preconceptions of CBT), and the therapeutic relationship. However, no research has explored these experiences for young people with a diagnosis of autism.

Method
In order to get a better understanding of young people’s experiences of CBT, responses from six of the open-ended interview questions from the socialisation interview were analysed using qualitative thematic analysis (Braun & Clarke, 2006). The questions included: 1) Tell me about your experience of having CBT/therapy; 2) Did you find anything useful about your CBT/therapy? 3) Did you learn any skills in CBT/therapy? 4) After you finished therapy did you keep using any skills? 5) Were you asked to do things between sessions? 6) Would you like to add anything else?

Qualitative Analysis
A qualitative analysis (Braun & Clarke, 2006) was conducted using the transcribed interview data for the 6 open-ended questions. The analysis was theoretically driven and interpreted in relation to the literature. The interviews were transcribed, coded and organised into initial themes by the researcher. These themes were reviewed and refined following discussions with a second researcher who coded the transcripts to ensure inter-rater reliability. The analysis resulted in five super-ordinate (main) themes, and ten sub-ordinate (underlying) themes (see Table 1 for a summary of themes, Table 2 for illustrative quotes, and Figure 1 for a thematic map).
The majority of young people said CBT is helpful, for example in helping them cope, getting back to school, and understanding 'normal' anxiety. They described specific CBT skills they had learned. They talked about the practical application of these skills as useful (e.g. role play, practising skills in session, testing out thoughts, tracking mood, breathing, ‘methods’ and ‘techniques’). They described the experience as different to ‘counselling’ in that it was more structured. For example it was logical, it happened at the same time each week, and there were specific tasks to undertake.

Young people discussed the importance of developing their understanding. This included learning about their own emotions (e.g. anxiety, fight or flight) and understanding how other people might be feeling. They also talked about linking T-F-B (e.g. identifying triggers and vicious cycles), and the importance of the clinician taking account of their ASD within this understanding by using their specific interests in sessions (e.g. Maths, drawing).

Participants spoke about their therapists’ characteristics, enjoying being with the therapist and the importance of the therapy being led by the young person (therapeutic relationship), and working together in collaboration (e.g. decision making). There were

<table>
<thead>
<tr>
<th>Super-ordinate</th>
<th>Sub-ordinate</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBT is helpful</td>
<td>Practical application</td>
</tr>
<tr>
<td>CBT skills</td>
<td>Structure</td>
</tr>
<tr>
<td>Developing an understanding</td>
<td>Emotions (own and others)</td>
</tr>
<tr>
<td></td>
<td>Linking T-F-B</td>
</tr>
<tr>
<td></td>
<td>Specific interests</td>
</tr>
<tr>
<td>Therapist characteristics</td>
<td>Therapeutic relationship</td>
</tr>
<tr>
<td>Family involvement</td>
<td>Working together</td>
</tr>
<tr>
<td>Barriers to CBT</td>
<td>Practicalities</td>
</tr>
<tr>
<td></td>
<td>Lack of understanding</td>
</tr>
<tr>
<td></td>
<td>Ambivalence towards CBT</td>
</tr>
</tbody>
</table>
mixed experiences of family involvement, with some young people finding this useful so their parent knew what was going on and could support them at home. Others felt annoyed with having their parents in their sessions (e.g. if they interrupted or spoke for them in sessions).

A number of barriers to CBT were discussed, including practicalities around time and not having enough sessions, and difficulties remembering to do homework. Other barriers included a lack of understanding, for example not knowing ‘why’ they were being asked to engage in certain activities, or not understanding emotions. Some young people expressed ambivalence towards CBT, including the perception that it ‘only worked to an extent’.

Discussion
The qualitative analysis found similar themes to research with typically developing young people around the impact of CBT on change, the manner in which CBT is delivered (e.g. structure), engagement, and therapeutic relationship (Donnellan et al., 2013). Young people with ASD also talked about how helpful CBT was, the importance of the practical application of skills to facilitate understanding (e.g., of own and others’ emotions), the collaborative nature of CBT, and the pros/cons of involving family. Additionally, they reported potential barriers to CBT including a lack of understanding, practicalities (e.g. time, remembering) and ambivalence towards therapy. These are important to bear in mind given the recommended adaptations to CBT for young people with ASD (NICE; 2013a; 2013b): training in emotion recognition, a structured approach (e.g. multiple-choice), regular breaks, involving parents/carers, and incorporating special interests into therapy.

This qualitative study shows the importance of clinicians adapting CBT for YP with ASD, including the practical application of skills, and involving family where this is appropriate. At the same time, keeping the structure in place, building a good therapeutic relationship, and addressing potential barriers to engagement (e.g. lack of understanding, practicalities, and ambivalence to the model).
Table 2: Super-ordinate and sub-ordinate themes and illustrative quotes

<table>
<thead>
<tr>
<th>Super-ordinate</th>
<th>Sub-ordinate</th>
<th>Illustrative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CBT is helpful</strong></td>
<td></td>
<td>Yes it was all very good for me…it’s made me feel so much better and it’s helped me a lot (16 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>it’s just made a big difference, like, in my life and be able to kind of cope with different situations a lot better and think of like other ways to deal with them, um, yeah I think it has really helped me… something that I’ll take on and continue using for the rest of my life (16 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>it’s (anxiety) almost completely gone, I don’t think I feel any more (anxiety) than err a normal person probably would (15 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The sessions we had were really good…I think I got better with coping (17 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I found it helpful, definitely yeah helpful, well I’ve stopped most of my thoughts (11 year old male)</td>
</tr>
<tr>
<td><strong>CBT skills</strong></td>
<td>Practical application</td>
<td>…learnt to breathe whenever I had panic attacks (15 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>it’s not just talking it’s like also about doing different activities as well to find out why I do certain things and like how I can stop doing them (16 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…when we went onto methods of how to stop whatever negative thought process we outlined and kind of practicing them and just talking through the theory … and running through scenarios to try and implement what you’re learnt (18 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…draw a graph it was about adrenaline and the fact that if you, the longer it is the less, it goes down and everything (17 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Role plays (15 year old male)</td>
</tr>
<tr>
<td></td>
<td>Structure</td>
<td>Starting with things that are less scary…going up a ladder and testing things out (12 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…when I had counselling I did find it quite boring but with the Cognitive Behavioural sessions it like, I find it more interesting, cause we don’t just kind of talk, we do certain activities and stuff like that (16 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…usually it’s a Tuesday around midday for an hour (15 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>they’re always normally targeted, they’re always good methods (11 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Well we were doing things I wouldn’t expect to do, we were kind of doing things drawn out on paper. And we were making plans of what to do in sessions and what things we needed to speak about more (15 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>It’s logical though, I like that (17 year old female)</td>
</tr>
<tr>
<td>Developing understanding</td>
<td>Emotions (own and others)</td>
<td>I learnt a lot about anxiety and about how I was feeling (fight or flight) (15 year old male)</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…now I can understand what, um, how I feel, you know (13 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…learn what my emotions are, cause sometimes I’ll be feeling something but I won’t know why I feel it, or like, what I’m feeling and sometimes I’ll explain it to my therapist and we’ll be able to pin point what it was and why I was feeling that way, and it’s kind of taught me different emotions that I didn’t really know I could feel before…and also how to deal with them (16 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…think it also taught me to understand people a little bit more, cause now I can look at someone, you know as an autistic person it’s very hard to look at someone and go ‘they’re doing this because they’re sad’, but somehow you can slightly work out what they’re doing…I learnt that from the triangle which was helpful (17 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I think it’s helping to work out how emotions work, as opposed to understanding emotions themselves (17 year old female)</td>
</tr>
<tr>
<td>Linking T-F-B</td>
<td></td>
<td>…useful to break down what might actually be triggering each thing and how to kind of stop whatever cycles were going on, that were unhelpful or unnecessary, and also then ways of coping with it (18 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>specifically for anxiety it’s useful to work out what is it that’s making me feel suddenly really like um, upset, scared or anxious, um and you know kind of drawing it out and looking at it and seeing ‘so this happens and when you feel like this you think this’ so if we can stop thinking this…. You can sometimes translate that to other things, so yeah its I think it does help you with other things that you’re not specifically having it for cause you can kind of apply it yourself…(18 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>And the vicious circle… that’s what is, that’s what I am (15 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>cause I can now work out that behaviour, emotions, something else, and something else, they all fit together And if you change one of them, you can change the rest of them, like a little diamond… and it all links together, and it goes round in a circle, and if you stop one you can change it (17 year old female)</td>
</tr>
<tr>
<td>Using interests</td>
<td></td>
<td>(therapist) used to always say that it seemed quite strange because where I did Maths, like mostly Maths based subjects are quite rational, um, and there is always one answer, but I seemed quite irrational with my OCD and then it didn’t quite make sense, that helped to link it, cause I was like I’m really rational one side but really irrational on another (17 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…it’s not drawing random stuff like I normally do, it’s drawing methods…we have been working on these characters (11 year old male)</td>
</tr>
<tr>
<td>Therapist characteristics</td>
<td>Therapeutic relationship</td>
<td>She went through them with me in a calm and clear manner, not making me feel uncomfortable and didn’t push me too hard too fast (16 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>… being able to talk to somebody who kind of understands, and you don’t necessarily feel judged (17 year old female)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>it’s been quite fun to talk to (therapist)...someone I can talk to personally (11 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I liked being with (therapist) (15 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>…it wasn’t so much I set you a task and you go and do it, it was more like I would set like goals for me to do…then like I’d discuss them with (therapist) (16 year old male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>they asked me which one I kind of wanted to tackle (18 year old male)</td>
</tr>
</tbody>
</table>
### Family involvement

- so mum could like know what was going on and know everything at home, that she knew everything I had spoken about with (therapist) (15 year old male)

- family can transfer skills to other situations too (12 year old male)

- whenever I’m in there trying to speak, cause it’s kind of basically I’m there, I’m there for me, not my mums there so she can just say about what I am, and so whenever she butts in when I’m talking I start biting (15 year old female)

### Barriers to CBT

#### Practicalities

- Time - this was tricky and probably needed a longer piece of work (12 year old male)
  - don’t think I’ve really had it long enough to be able to learn anything from (therapist) (15 year old female)

- Remembering - I can’t think…I probably was taught them (skills) but I’ve forgotten (15 year old female)
  - Umm, if I remember it yes (keep using skills), I have a very bad memory (11 year old male)

#### Lack of understanding

- I think sometimes I don’t always understand why I’m doing certain activities…I don’t really understand how they kind of affect me, … my therapist will kind of send me off to do little activities and I, most of the time won’t understand why…(16 year old female)

- I sometimes don’t know that I’m worried or what I’m worried about so I can’t always write the worries down (15 year old male)

- it’s quite difficult to measure feelings and things…giving an objective number for feelings which are like very difficult to kind of categorise or sum up in a number or like brief sentence and making progress towards a goal isn’t always that applicable…how do you measure how close you are to that goal, cause it’s like it’s not numerical or easily like quantifiable data, its, so that can be a bit difficult to properly categorise it (18 year old male)

- …I didn’t understand that they were doing things in a certain way (17 year old female)

- … but half the time I didn’t really understand what anyone was saying (15 year old female)

#### Ambivalence towards CBT

- …guess like there will be more problems that you can’t put on this little square, so I don’t think it’s a major good thing, way of working (17 year old female)

- (Therapist) kept making me cry, and it made me feel uncomfortable in general, somebody asking really really really personal questions… I didn’t think it worked (15 year old female)

- It takes away your comfort blanket, and it makes things seem really irrational, so like why I do things, makes it seem, you’re having to think about why you do things and then you realise how stupid it is, or how irrational it seems to like your normal rational brain 17 year old female)

- …sometimes I just felt really angry all the time I was in there (15 year old female)

- It only really works to an extent, like you can look at it all you want but depression and stuff is also chemical. So saying that you’re going to change one thing isn’t going to fix it completely if that makes sense (17 year old female)
Figure 1: Thematic map

*Note.* Boxes with dashed lines indicate themes removed following inter-rater reliability

CBT is helpful

- Ongoing use
- Practical application

CBT skills

- Structure of CBT
- CBT skills
- Understanding
  - Emotions (own & others)
  - Specific interests
  - Linking T-F-B
  - Impact of ASD

Therapist Characteristics

- Therapeutic relationship
- Working together

Family involvement

- Lack of understanding
- Negative experience
- Practicalities
- Ambivalence to CBT

Barriers to CBT
Appendix 28: Clinician rating scale

Participant ID: 

Please initial the box

1. I have read and understood the Clinician Information Sheet (Version 2, dated 3rd June 2015) and agree for the data I provide to be used in the research study.

Signed (Clinician): 

Date: 

The above section will be detached and stored confidentially.

Participant ID:

On a scale of 0-10, how ‘socialised’ to the CBT model was the young person? [By ‘socialised’ we mean ‘understood the basic CBT model, the connection between thoughts, feelings and behaviours and the general principles of CBT such as collaborative working, homework’ etc.]

Please circle the appropriate answer below.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all socialised</td>
<td>Somewhat socialised</td>
<td>Very well socialised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Compared to the young person’s condition at admission to your service, would you say their condition is: (please tick)

- Very much improved
- Much improved
- Minimally improved
- No change from baseline
- Minimally worse
- Much worse
- Very much worse

Total RCADS T-score pre-treatment: 

Total RCADS T-score post-treatment: 
Appendix 29: Young person information sheet

CBT Research Invitation

We are inviting young people aged 11-18 who have an Autism Spectrum Condition (including high functioning autism and Asperger syndrome) to take part in a research project about Cognitive Behavioural Therapy. Please read the information below and decide if you want to take part. The research is being run by Gerwyn Mahoney-Davies and Cara Roberts-Collins who are Clinical Psychologists in Training at the University of Bath.

What we are researching

Lots of young people have difficulties such as feeling low or anxious. They are often treated using something called ‘Cognitive Behavioural Therapy’ (CBT).

What will happen if I take part?

You will be asked to speak to Gerwyn or Cara about your experience of CBT. We will need to audio record what you say so that we can listen back to it. You will also be asked to complete a short task. This may take around half an hour in total. We are interested in how you found the process of receiving CBT rather than why you were referred to therapy. You don’t have to tell us personal things and you can skip questions you do not want to answer. None of your personal information will be told to anyone else.

Your CBT therapist will also be asked to tell us about how well they think you understand CBT and asked to provide copies of some of the questionnaires you completed during CBT. We won’t ask them any personal information about you and we won’t tell them what you say about your experience of CBT.
Thank you for taking the time to read this information sheet

---

**Risk and Benefits**

We don’t think there are any risks to taking part in this project although it may bring up thoughts and feelings from your treatment. There is support in place in case you get upset. We hope that the information you give us could help other people who have CBT in the future. You will also be given a £5 high street voucher to thank you for taking part.

The things you tell us will be private and confidential. You will be identified by a number rather than your name. If you tell us anything that concerns us we will need to follow this up.

---

**Do I have to take part?**

No. It is your choice whether you take part. There are no problems with not taking part. If you decide to take part and then change your mind that is fine. You can withdraw at any time.

What we find out from the study will be put into a report. Your name or any other information that might identify you will not go into this report.

---

**How to take part**

If you would like to take part we can come to your home or other convenient location, or we can meet you at the University of Bath.

If you would like to take part please contact Gerwyn or Cara by email on gmd30@bath.ac.uk or crc33@bath.ac.uk or telephone 07478 942153.
Appendix 30: Parent Information Sheet

Young people’s understanding of CBT.

Parent information
Your son/daughter has been invited to take part in a research project looking at their understanding of Cognitive Behaviour Therapy (CBT). They have been invited because they have had CBT in the past.

Please read this information carefully to help decide if you are happy for their involvement.
We want to find out about young people’s experience of receiving CBT. There have been lots of research studies showing good outcomes for young people receiving CBT but little that has asked them specifically how they found the experience.

Do I have to take part?
No. If you do agree to take part then we will ask your son/daughter to speak to us about their experience of CBT and to complete a short questionnaire. This should take no longer than half an hour. You can be present at this interview subject to consent from your son/daughter.

Their CBT therapist will also be asked to complete a questionnaire asking how much they think your son/daughter benefited from CBT. As part of this research we also want to see whether a better experience of CBT led to better outcomes, so we will also ask the therapist to provide copies of the questionnaires that your son/daughter completed during therapy.

Your son/daughter will be given the contact details of Cara Roberts-Collins or Gerwyn Mahoney-Davies, who are Clinical Psychologists in Training who will be available to offer appropriate support if they become upset.

Confidentiality
Confidentiality will be maintained – the name of your son/daughter will not be on the questionnaires. They will be given an identification number and no names or identifiable details will be written in the report. If risk issues are disclosed during the interview, this will be followed up by the researcher, and the debrief sheet will contain further resources the young person can access.

How will questionnaires be stored?
The questionnaires will be kept securely and electronic information will be kept on a password protected computer.
What will happen with the findings?
The findings will be written into a report which will form part of Doctorate in Clinical Psychology research. This report will also be submitted for publication in a journal so may be available to a large amount of people. The write up will be confidential and your son/daughter will not be identifiable.

What if something goes wrong?
If you have any concerns or wish to complain about any aspect of the way you have been approached or treated as part of this study, you should initially contact the researchers, Cara Roberts-Collins or Gerwyn Mahoney-Davies, who will do their best to address your concerns. Their contact details are provided at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this through [INSERT TRUST DETAILS] or you can contact the Sponsor of this study, the University of Bath. The University of Bath, as Sponsor of the study has indemnity (insurance) arrangements in place. Every care will be taken to ensure your child’s safety during the course of this study.

For more information please contact the researchers:

Cara Roberts-Collins  
Clinical Psychologist in Training  
Department of Psychology  
University of Bath  
Email: crc33@bath.ac.uk  
Phone: 07478942153

Gerwyn Mahoney-Davies  
Clinical Psychologist in Training  
Department of Psychology  
University of Bath  
Email: gmd30@bath.ac.uk  
Phone: 07478942153

Supervised by Dr Ailsa Russell, Clinical Director (A.J.Russell@bath.ac.uk) and Dr Maria Loades, Clinical Tutor (M.E.Loades@bath.ac.uk) University of Bath, Department of Clinical Psychology

Local collaborator: [INSERT NAME HERE]

If you would like to talk to an independent person regarding the study, please contact [INSERT TRUST PALS DEPARTMENT]

Thank you for taking the time to read this information sheet
Appendix 31: Young person consent form

CONSENT FORM (over 16)

Young people’s understanding of CBT

Please initial each box

1. I have read and understood the Information about the Study (Version 2, dated 3 rd June 2015). I have thought about the information and have had any questions answered.

2. I understand that taking part is voluntary, I do not have to answer every question, and I can stop taking part at any time, without giving a reason.

3. I understand that I may have a parent with me for the interview if I want.

4. I agree for the interview to be audio recorded and that this data will be kept private and stored securely. I understand that any quotes used from the interviews will be anonymised.

5. I agree for the researchers to contact my CBT therapist and to have access to the questionnaires I filled in during therapy.

6. I understand that relevant sections of my care record and data collected during the study may be looked at by responsible individuals from the sponsor or host organisation or from regulatory authorities where it is relevant to taking part in this research.

7. I would like to hear about the results once the study has finished.

8. I agree to take part in the above study.

If you are happy to take part, please write your name, date, and signature here:

Name of young person __________________________  Date __________________________  Signature __________________________

Contact details

Name of Researcher __________________________  Date __________________________  Signature __________________________

Participant number
Appendix 32: Parent Consent Form

PARENT/GUARDIAN CONSENT FORM

Young people’s understanding of CBT

1. I have read and understood the Information about the Study (Version 2, dated 3rd June 2015). I have thought about the information and have had any questions answered. 

2. I understand that my child’s participation is voluntary, they do not have to answer every question, and can stop taking part at any time, without giving a reason.

3. I agree for their interview to be audio recorded and that this data will be kept private and stored securely. I understand that any quotes used from the interviews will be anonymised.

4. I agree for the researchers to contact their CBT therapist and to have access to the questionnaires they filled in during therapy.

5. I understand that relevant sections of my child’s care record and data collected during the study may be looked at by responsible individuals from the sponsor or host organisation or from regulatory authorities where it is relevant to taking part in this research.

6. I would like to receive feedback on the study once it has been completed.

7. I agree for my child to take part in the above study.

If you are happy for your child to take part, please write your name, date, and signature here:

________________________________________________________ __________________________
Name of parent/guardian Date Signature

Contact details

________________________________________________________ __________________________
Name of Researcher Taking Consent Date Signature
Appendix 33: School Consent form

SCHOOL CONSENT FORM

Exploring Emotion Awareness

I, _____________________________ on behalf of _____________________________ (School name), agree for consenting students of the School to participate in the study Exploring Emotion Awareness, being conducted by Cara Roberts-Collins at The University of Bath. I have received written information about the study, have been given the opportunity to ask questions about the study and these have been answered to my satisfaction. I understand that all personal information will remain confidential to the Investigator, and arrangements for the storage of any identifiable material have been explained. I understand that participation in this study is voluntary and that individual participants, or the School as a whole can withdraw at any time without having to give an explanation.

Signature

______________________________________

Name (in capitals)

______________________________________

Position

______________________________________

Date

______________________________________

_________________________  _________________________  ________________
Name of Researcher
Taking Consent                Date                    Signature
Appendix 34: Young Person Assent Form

ASSENT FORM (under 16)

Young people’s understanding of CBT

Please initial each box

1. I have read and understood the Information about the Study (Version 2, dated 3rd June 2015). I have thought about the information and have had any questions answered.

2. I understand that taking part is voluntary, I do not have to answer every question, and I can stop taking part at any time, without giving a reason.

3. I understand that I may have a parent with me for the interview if I want.

4. I agree for the interview to be audio recorded and that this data will be kept private and stored securely. I understand that any quotes used from the interviews will be anonymised.

5. I agree for the researchers to contact my CBT therapist and to have access to the questionnaires I filled in during therapy.

6. I understand that relevant sections of my care record and data collected during the study may be looked at by responsible individuals from the sponsor or host organisation or from regulatory authorities where it is relevant to taking part in this research.

7. I would like to hear about the results once the study has finished.

8. I agree to take part in the above study.

If you are happy to take part, please write your name, date, and signature here:

_________________________  _____________________  __________________
Name of young person       Date                      Signature
_______________________________________________________________________
Contact details

_________________________  _____________________  __________________
Name of Researcher    Taking Consent     Date                      Signature
Appendix 35: Young Person Debrief Sheet

Young people’s understanding of CBT

Debrief sheet

Thank you for taking part in our research project!

We are trying to understand more about what young people think about ‘Cognitive Behavioural Therapy’ (CBT). The information you have given us could help other people who have CBT in the future.

Talking to us may have brought up thoughts and feelings from your own treatment. There are people you can talk to about these, like staff at school (e.g. counsellor), or your doctor. There are also other resources you can access:

<table>
<thead>
<tr>
<th>Useful resources</th>
</tr>
</thead>
</table>
| **ChildLine** - [www.childline.org.uk](http://www.childline.org.uk)  
Tel: 0800 1111 |
| **Young Minds** - [www.youngminds.org.uk](http://www.youngminds.org.uk) |
| **Samaritans** - [www.samaritans.org](http://www.samaritans.org)  
Tel: 08457 90 90 90  
Email: jo@samaritans.org |
| **NHS medical help** - Tel: 111 |

If you have any questions about the research when you leave please email Gerwyn ([gmd30@bath.ac.uk](mailto:gmd30@bath.ac.uk)) or Cara ([crc33@bath.ac.uk](mailto:crc33@bath.ac.uk))

Cara Roberts-Collins and Gerwyn Mahoney-Davies

Clinical psychologists in Training

University of Bath