UNIVERSITY OF BATH

DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) A systematic review of bereavement interventions for service users with learning disabilities and the people who care for them; 2) Identifying suitable outcome measures for a post-diagnostic support group for adults with autism; 3) What's the problem? Exploring psychological therapists' attitudes towards asexuality.

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Award date:
2017

Awarding institution:
University of Bath

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Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

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Doctorate in Clinical Psychology

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June 2017

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Main Project

Asexuals are more likely than non-asexuals to suffer from mental health problems, possibly as a result of prejudice and discrimination. However, some asexuals are reluctant to seek support from mental health professionals for fear that they will be belittled or labelled as having a disorder. The current study set out to find out whether psychological therapists view asexuality as a disorder, and whether being familiar with asexuality makes them less likely to pathologise it (consistent with intergroup contact theory; Allport, 1954). An online survey of 209 psychological therapists was conducted. Participants filled out a new measure of asexual pathologisation, the Clinician Attitudes To Asexuality (CATA) scale. The CATA was found to have good internal and test-retest reliability. Participants reported a high level of familiarity with asexuality, however only a minority of the sample had received professional training on the topic. Participants who claimed to have met someone asexual were less likely to view asexuality as a problem, however this was not the case when controlling for bias against single people. Women were less likely to view asexuality as a problem than men, however being a member of a sexual minority group did not affect participants' views. There was no difference in views between trainee and qualified therapists. Clinical implications and limitations are discussed and suggestions are made for future research.

Service Improvement Project

People with autism spectrum conditions (ASD) experience high rates of social isolation and emotional problems as a result of stigma. Receiving a diagnosis can benefit individuals' self-perception, relationships and adjustment, as well as offering opportunities for accessing support. Post-diagnostic support groups can bring about improvements in understanding of ASD and awareness of autism-related strengths and weaknesses. The current study aimed to investigate the perceived benefits of an adult autism service's post-diagnostic support group and establish which standardised measures would be most appropriate for evidencing group outcomes. Seven service users were interviewed on their experiences of the group. Thematic analysis of interview data revealed four main themes; *support and belonging*, *knowledge about autism*, *life changes* and *acceptance*. On the basis of these themes, new and existing outcome measures were trialled in the group, including measures of wellbeing, self-esteem and positive distinctiveness. However, no significant changes from pre- to post-group were detected on these measures. These results are considered in the context of previous

research on ASD post-diagnostic support groups. Clinical implications are discussed and suggestions made for future research in this area.

Literature Review

Background: People with learning disabilities (PWLD) are at higher risk of developing complex grief than the general population. This may be due to multiple factors, including difficulties with communication, grief reactions going unrecognised or invalidated, and lack of confidence among carers and support staff to talk to PWLD about death. Many recommendations have been made around best practice for supporting PWLD with bereavement, however many of these are based on clinical experience and anecdotal evidence. The current review aimed to investigate the efficacy of bereavement interventions for both PWLD and paid/unpaid carers, and to evaluate the current evidence in light of previous theory and recommendations. **Materials and Methods**: A systematic search was carried out on electronic literature databases Psychinfo, Pubmed and Embase for bereavement intervention outcome studies for PWLD and their paid/unpaid carers. 523 studies were identified, 15 of which were included in the review. **Results**: Evidence was found for one-to-one psychotherapy and group bereavement support interventions for PWLD, as well as group educational interventions for paid staff. However, evidence was limited and of generally low quality, and interventions for family carers were almost entirely absent from the literature. **Conclusions**: Findings support previous recommendations for joined-up, multi-level approaches to bereavement support for PWLD, and point towards a care pathway for services including proactive education for service users and paid/unpaid carers, informal and formal bereavement interventions for service users and support for the wider system. Clinical and research implications are discussed and recommendations made for future research.

Literature Review: A systematic review of bereavement interventions for service users with learning disabilities and the people who care for them

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Supervisor: Dr. Cathy Randle-Phillips

Word count: 6918

Submission date: June 2017

Target journal: British Journal of Learning Disabilities

This journal was chosen as it is a leading journal in the field of learning disabilities, with a focus on developments in a wide range of areas including research, policy and practice.

(Impact Factor 0.391. See appendix B for author guidelines)

1. Introduction

Bereavement is a period of mourning following a significant loss, particularly the death of a loved one, which brings with it a number of psychological, emotional and behavioural changes (Bonnano & Kaltman, 2001). Grief is a normal reaction to loss and in many cases will resolve in time without specialist intervention (Howarth, 2011).

Some early grief theories emphasised stages of grief, such as Kubler-Ross' (1969) five stages of grief and Worden's (1991) tasks of grieving model. More recently, the dual process model (Stroebe & Schut, 1999) has conceptualised the grief process as oscillating between loss-orientated activities, such as remembering the deceased, and restoration-orientated activities, such as making connections with others and engaging in new activities. These processes occur in parallel, rather than in succession. Tonkin (1996) suggested that rather than letting go of our grief we grow around it, expanding our lives instead of waiting for the grief to reduce or disappear.

Bereavement in people with learning disabilities

People with learning disabilities (PWLD) are at higher risk of experiencing multiple losses than the non-disabled population, as they may more frequently experience friends and carers moving on and the loss of familiar surroundings due to moving homes (Persaud & Persaud, 1997). Until relatively recently PWLD were not believed to be capable of feeling grief, or of building strong enough relationships to experience loss (Lavin, 1998; Oswin, 1991). However, researchers investigating the nature and expression of grief in PWLD have found that they form attachments and grieve as much as anyone else, although their grief reactions may not always be displayed in expected or easily recognised ways (see Dodd, Dowling, & Hollins, 2005 for a review of responses to bereavement in PWLD).

PWLD may have difficulty communicating their grief and their expressions of grief may go unrecognised or be misattributed by others, who may assume they are a product of the learning disability rather than the bereavement (Oswin, 1991). PWLD may be left out of death rituals such as funerals and memorials (Raji, Hollins, & Drinnan, 2003) and may not even be told about a loved one's death until long after the fact. This may be due to a desire to protect the person, or a belief that PWLD are not capable of coping with the distress of bereavement (Bicknell, 1983; Hollins & Esterhuyzen, 1997; Tuffrey-Wijne & Rose, 2017). Oswin (1991) wrote of the "double taboo of grief and learning disabilities" (p.32), which makes families and carers reluctant to talk openly with PWLD about death and bereavement. These factors may contribute to the development of disenfranchised grief (Doka, 1989), which is experienced when a loss is not openly

acknowledged, mourned or socially supported. Not being given opportunities to understand or talk about death may make bereavements more shocking, unexpected and confusing for PWLD, which may lead to difficulties accepting the loss and working through the grief process (Mappin & Hanlon, 2005). This may result in prolonged grief and intense distress for years after the loss (Brickell & Munir, 2008).

PWLD may have trouble understanding concepts related to death and dying. Understanding of death concepts has been found to be linked with factors such as language ability and developmental age (Bihm & Elliott, 1982), and understanding of the biological workings of the body (McEvoy, Treacy, & Quigley, 2017). Furthermore, being treated like a child and not being encouraged to speak or act in adult ways may lead to a poorer understanding of aging and death (Dodd et al., 2005). Supporting PWLD to understand death and what happens when people die may help them to come to terms with loss and process their grief more effectively.

Carers and support staff

Paid and unpaid carers have a key role to play in supporting PWLD through bereavement and helping them to understand illness and death (Gray & Abendroth, 2016; MacHale, McEvoy, & Tierney, 2009). However, they may have trouble communicating openly with PWLD about death. Tuffrey-Wijne et al. (2017) conducted interviews with social care staff and found that various factors such as fear of talking about death, their own life and work experiences, and organisational cultures made it more difficult for them to communicate with PWLD about bereavement. MacHale et al. (2009) found that care staff were confident in their ability to recognise the signs of grief in their clients, but lacked confidence when it came to providing post-bereavement support. Several questionnaire and focus group studies have found evidence that paid and unpaid carers recognise the gaps in their competence and would welcome further training on bereavement support for PWLD (Handley & Hutchinson, 2013; McEvoy, Guerin, Dodd, & Hillery, 2010; Needham, 2016). Helping families and care staff to feel more confident in their ability to talk with PWLD about death and loss is therefore crucial for ensuring that PWLD are supported to understand bereavement.

The emotional impact of supporting bereaved PWLD has also been highlighted, with carers identifying a need for support and opportunities to reflect on their own experiences of loss (e.g. McEvoy et al., 2010; Needham, 2016) Gray and Truesdale (2015) conducted an expert consensus study on the bereavement training needs of staff working with PWLD. They highlighted the need to train staff in how to support and

communicate with bereaved PWLD, but also identified the need to support care staff in managing their own grief.

Bereavement interventions for people with learning disabilities

Oswin's (1991) seminal book looking at disenfranchised grief in PWLD made comprehensive recommendations for services around providing training for staff, opening up effective communication about death with PWLD, including them in funeral rites, and planning for the development of kinder, more compassionate care services. More recently, Kauffman (2011) made recommendations such as providing information about the loss, involving clients in the social environment following the death, fostering their interpersonal relationships and facilitating opportunities for expression of grief. Elliot and Dale (2007) made suggestions for practical support of PWLD when a bereavement is anticipated, such as facilitating continued contact with the terminally ill person if desired, acknowledging feelings and helping them to say goodbye. While helpful, these recommendations for practice are frequently based on clinical experience and anecdotal case examples, rather than empirical evidence derived from a cycle of research and implementation.

Read (2005) described a continuum of bereavement support model for PWLD, identifying four levels of potential support; the micro level (immediate family), meso level (support workers and bereavement counsellors), exo level (local LD services and support organisations) and macro level (national initiatives and directives). Read and Elliott (2007) incorporated this model into a proposed systems approach to supporting bereaved PWLD. This highlights the need for a joined-up approach in which proactive and reactive bereavement support is provided by different people across a range of organisational levels. This would include preparation for loss, in either an individual or group format (*education*); immediate family and carers supporting PWLD to participate in grief rituals (*participation*); training for carers to enable them to feel confident talking with PWLD about death and acknowledging their grief, thereby reducing disenfranchisement of grief (*facilitation*); and ensuring support staff are able to effectively assess individuals' support needs and refer on for formal intervention when necessary, for example in the case of complex grief reactions (*intervention*). The authors highlighted the need for empirical research investigating the effectiveness of the various bereavement support approaches available, in order to enhance evidence-based practice. Thus there is a need for high-quality reviews of bereavement intervention outcomes derived from empirical research.

Clute (2010) reviewed a wide range of literature describing interventions for bereavement in PWLD, including research studies, case studies, book chapters and unpublished theses, as well as literature on experiences of bereavement counsellors working with this population. Clute concluded that effective interventions fall under three main categories; informal support, such as empathetic listening, honouring service users' grief and including them in death rituals such as funerals and memorials; formal bereavement counselling, which is tailored to the individual's abilities and includes multimodal methods and practical activities; and raising public awareness of the need for a more open dialogue about death with PWLD, so that formal and informal support can be provided when required. Much of the literature reviewed by Clute (2010) does not provide empirical research evidence or detailed information on treatment outcomes, as there is a heavy reliance on anecdotal evidence and informal case examples. Furthermore, while the author's literature search methods and criteria are described, the review is not strictly systematic and does not include a quality appraisal, limiting the scope for using it to make evidence-based practice recommendations. In addition, the review is seven years old, meaning there has been time for research in this area to move on and take account of her conclusions. Perhaps most crucially, the review did not report on interventions for support staff and carers, who are a key component of PWLD's support networks and have demonstrated a need for training and guidance (MacHale et al., 2009; John McEvoy et al., 2010).

Aims of the review

The current review aimed to investigate the efficacy of bereavement intervention studies to date for both PWLD and carers. The review sought to answer three questions:

1) What does the current evidence tell us is effective for supporting PWLD who have been bereaved?
2) What is the current evidence for interventions focussing on staff and paid/unpaid carers working with PWLD who have been bereaved?
3) What are the clinical and research implications of this evidence for bereavement care for PWLD?

A quality appraisal was undertaken in order to assess the quality of individual studies according to a number of methodological factors and the quality of the overall body of research literature on bereavement interventions for PWLD. Quality was taken into consideration in the review, but given the likely dearth of literature in this field was not used as a basis for exclusion.

2. Methodology

2.1 Search strategy

A literature search was performed in order to identify studies evaluating bereavement-focussed interventions for PWLD, staff and unpaid carers. Psycinfo, Pubmed and Embase were searched on 21/02/2017 using the following keywords: Bereavement (MeSH term), grief (MeSH term), bereave*, griev*, mourn* AND learning disab*, learning impair*, intellectual* disab*, intellectual* impair*, mental* retard* and mental* handicap*. A date filter was included so only studies published since 1990 were included in search results, as preliminary searches indicated that very few relevant studies were published before this date and none of them fulfilled the inclusion criteria. Reference lists of included studies were screened for additional articles not identified by database searches. Publications citing included studies were checked using Google Scholar.

2.2 Selection of studies

References from literature searches were imported into Endnote and duplicates were removed. References were screened by title then by abstract to exclude irrelevant studies. The following criteria were used to identify relevant studies for inclusion:

Inclusion criteria
- Intervention studies of any design, including controlled and uncontrolled trials, experimental designs and case studies.
- Studies involving psychological therapies, psychoeducation or staff/carer training interventions.
- Interventions focussed on bereavement support for PWLD.
- Interventions delivered to PWLD or to their paid/unpaid carers.
- Reports outcomes of the intervention (quantitative or qualitative), either in terms of the service user's mental life (such as mood, behaviour or cognitions) or staff perceptions or attributions of bereavement in PWLD.
- Articles published in peer reviewed journals between January 1990 and February 2017.
- Articles published in English.

Exclusion criteria

- Studies not focussing on a service user or staff bereavement intervention (i.e. which are only concerned with the expression of grief in people with learning disabilities, staff attitudes or measurement of psychopathology).
- Studies not reporting clear and detailed outcomes of the intervention.
- Interventions designed to support people with learning disabilities with the prospect of their own mortality.
- Studies involving participants under 18 years of age.

2.3 Selected studies

The electronic database search produced 523 articles. Duplicates (n = 145) were identified and removed, leaving 378 studies. Title screening identified 253 studies for exclusion and a further 86 were excluded after checking abstracts. Full-text screening was carried out on the remaining 39 studies to check eligibility criteria. One member of the research team undertook full-text screening under close supervision from their research supervisor. This allowed for detailed discussions of several of the studies in order to jointly decide on whether or not they should be included. Fourteen studies were included and twenty-four excluded at this stage. Reasons for exclusion included: lack of detailed outcomes (n = 11), non-intervention studies (n = 6), intervention not focussed on bereavement support (n = 2), non-peer reviewed journal (n = 1), and study only published as a conference abstract (n = 4). After reference lists for the included studies were checked, one further study met inclusion criteria. Google Scholar citation checks did not yield any further eligible papers, making a total of 15 studies included in the final review. A diagram illustrating the study search and selection process is provided in Figure 1.
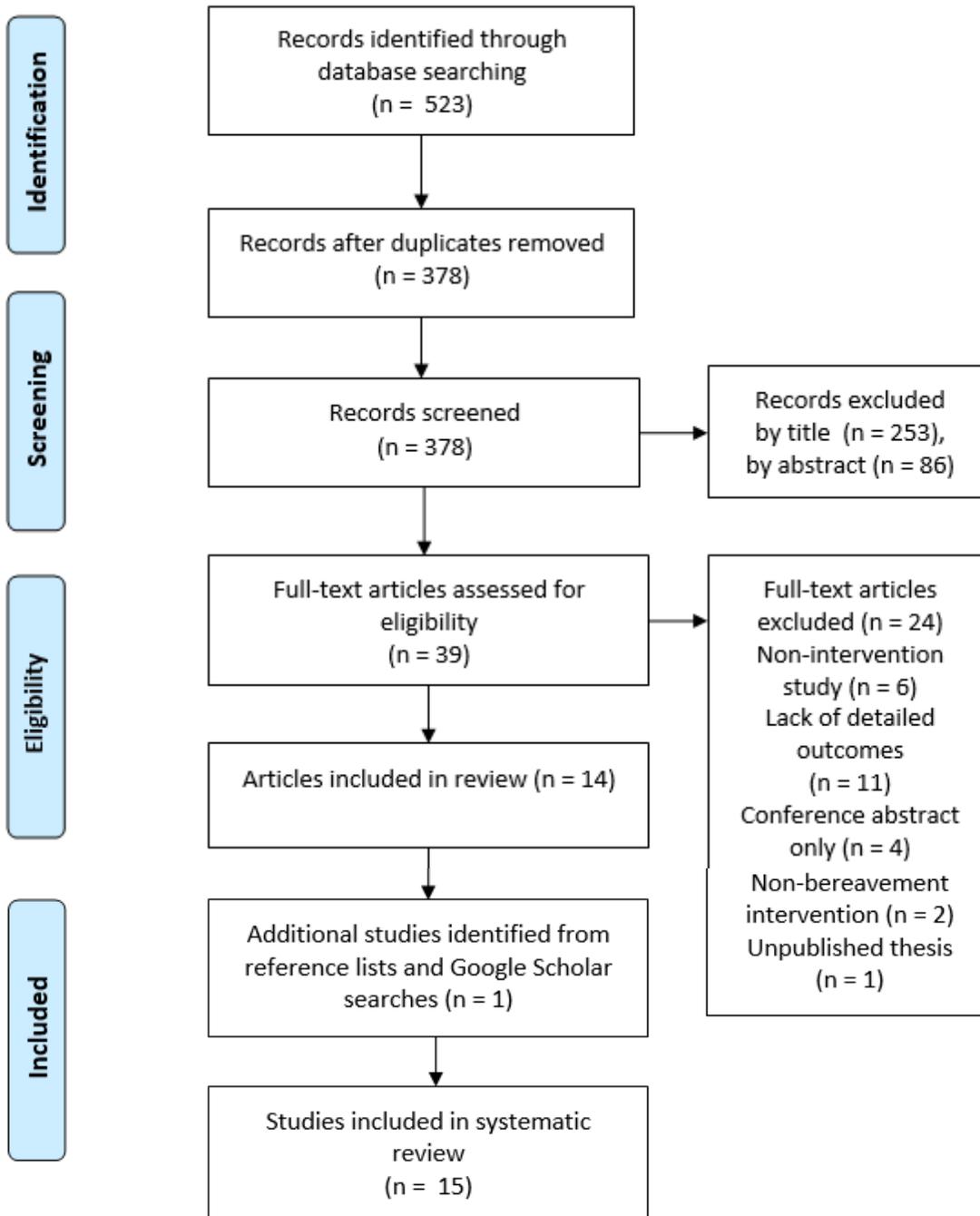
Figure 1. Flow chart depicting paper search process.

3. Results

3.1 Quality review

Quality assessment was carried out using the Downs and Black Quality Index (Downs & Black, 1998; see Appendix A). All included studies were assessed according to this tool,

which covers five domains: reporting, external validity, internal validity - bias, internal validity – confounding (selection bias), and power. Due to methodological differences between studies, not all items were relevant for every article reviewed. When this was the case, the item was marked as "N/A" (not applicable) and the article scored 0 on this item. The Downs and Black checklist comprises 27 items with a total possible score of 31. Scores were calculated for each study as an indicator of quality.

The results of the quality review are presented in Table 1.

In general the studies included in the review had low scores on the Downs and Black Quality Index. Out of a maximum score of 31, the highest score was 18 and the lowest was 2. Eleven of the fifteen studies scored 10 or below. Despite these low scores, it was felt that it was important to include the lower quality studies in the review due to the dearth of literature in this area.

The studies were generally clear in reporting their aims, interventions and sample characteristics (although important information was sometimes omitted, such as participants' level of intellectual functioning). Most studies also reported on their main outcomes to be measured and their main findings in appropriate detail. None of the studies reported adverse events, a tendency which is common to many psychological trials (Duggan, Parry, McMurran, Davidson, & Dennis, 2014)

One of the main problems in the methodology of the studies was validity. As in much research with learning disabled populations, participants were selected opportunistically from local care home and day services, reducing external validity. Small sample sizes meant that studies were significantly underpowered, and the general lack of control groups or blinding procedures reduced internal validity scores.

Another weakness was that half of the studies lacked clear outcome measures, reducing internal validity further. Among the studies that did use outcome measures, varied use of validated and idiographic outcome measures made comparison of outcomes across studies more difficult. There was little consensus between studies on the kinds of outcomes that were reported, which ranged from behavioural, mood and cognitive outcomes to reporting on the intervention process.

Table 1

Downs and Black quality review results. 1 = Campbell & Bell (2010), 2 = Summers & Witts (2003), 3 = Young & Garrard (2015), 4 = Dowling et al. (2006), 5 = Borsay et al. (2012), 6 = Boyden, Freeman & Offen (2009), 7 = Mappin & Hanlon (2005), 8 = Persaud & Persaud (1997), 9 = Read, Papakosta-Harvey & Bower (2000), 10 = Read & Papakosta-Harvey (2004), 11 = Stoddart, Burke & Temple (2002), 12 = Yanok & Beifus (1993), 13 = Bennett et al. (2003), 14 = Reynolds et al. (2008), 15 = Watters, McKenzie & Wright (2011).

Downs & Black item	Service user interventions												Staff interventions		
Reporting	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**
1. Hypothesis/aim/ objective	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2. Main outcomes to be measured	1	0	1	1	1	0	1	0	1	1	1	1	0	1	1
3. Patient characteristics	1	1	1	1	1	1	1	0	1	1	1	1	0	1	1
4. Interventions of interest	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
5. Distributions of confounders	N/A	N/A	N/A	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1	N/A	0	0
6. Main findings	0	N/A	1	1	1	0	1	0	1	1	1	1	1	1	1
7. Estimates of random variability for main outcomes	N/A	N/A	N/A	1	N/A	N/A	0	N/A	N/A	N/A	1	0	N/A	1	1
8. Adverse events reported	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
9. Characteristics of patients lost to follow-up	1	1	1	1	1	1	1	0	0	0	1	1	1	0	1
10. Actual probability values reported	N/A	N/A	N/A	1	N/A	N/A	0	N/A	N/A	N/A	0	0	N/A	0	1
Reporting total	5	4	6	10	6	4	6	2	5	5	7	7	4	6	8

External validity	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
11. Subjects asked to participate representative	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
12. Subjects prepared to participate representative	N/A	N/A	N/A	1	0	0	0	0	0	0	0	0	0	0	0
13. Staff & facilities representative	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
External validity total	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
Internal validity – bias															
14. Subjects were blinded	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	0	N/A	0	0
15. Those measuring main outcomes were blinded	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	UTD	N/A	UTD	UTD
16. "Data dredging" made clear	N/A	N/A	N/A	1	N/A	N/A	N/A	N/A	N/A	N/A	1	1	N/A	1	UTD
17. Analyses adjust for different follow-up periods	N/A	N/A	N/A	UTD	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1	N/A	1	1
18. Statistical tests appropriate	N/A	N/A	N/A	1	N/A	N/A	1	N/A	N/A	N/A	1	1	N/A	1	1
19. Compliance with interventions reliable	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1	N/A	1	1
20. Main outcome measures valid and reliable	1	N/A	N/A	1	1	N/A	1	N/A	N/A	N/A	1	UTD	N/A	1	1

Bias total	1	0	0	3	1	0	2	0	0	0	3	4	0	5	4
Internal validity – confounding (selection bias)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**
21. Patients in different groups from same population	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1	N/A	1	1
22. Subjects in different groups recruited over same period of time	N/A	N/A	N/A	UTD	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1	N/A	1	1
23. Subjects randomised to intervention groups	N/A	N/A	N/A	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	UTD	N/A	0	1
24. Randomised intervention assignment concealed	N/A	N/A	N/A	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	UTD	N/A	0	UTD
25. Adjustment for confounding in analyses	N/A	N/A	N/A	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1	N/A	0	0
26. Losses of patients to follow-up taken into account	N/A	N/A	N/A	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	UTD	N/A	UTD	1
Confounding total	0	0	0	4	0	0	0	0	0	0	0	3	0	2	4
Power															
27. Power to detect clinically important effect at 95%	N/A	N/A	N/A	0	N/A	N/A	0	N/A	N/A	N/A	0	0	N/A	0	0
Total quality score	6	4	6	18	7	4	8	2	5	5	10	14	4	13	16

Note. UTD = Unable to determine. N/A = Not applicable.

3.2 Study characteristics

Characteristics of the included studies are presented in Table 2.

3.2.1 Service user interventions

Twelve papers focussed on interventions for service users. Of these, three were case studies, one was a randomised controlled trial (RCT) of two individual interventions and eight were group interventions. One of the group intervention studies included a control group while the remaining seven evaluated a single intervention group. This controlled study was included with the single group studies as its methodology was of questionable rigour (due to unclear reporting of the randomisation process and use of outcome measures at post-intervention only) and resembled the other group interventions more closely than the RCT.

3.2.2 Carer interventions

The remaining three studies were group training interventions involving professional care staff. Two of these included a control group, one of which used un-blinded randomisation of participants. None of the studies focussed on educational interventions for unpaid carers such as family members.

3.3 Analysis of studies

3.3.1 Single case studies

Three of the studies included in this review were case studies of one-to-one psychological interventions with a person with LD. One case study described 8 sessions of psychoeducation in which an adapted workbook on death was used to help the client gain a better understanding of their loved one's death (Campbell & Bell, 2011). One described 12 sessions of psychoeducation and psychodynamic therapy, in which a book on family bereavement (Hollins & Sireling, 1989) was used to help the client understand what had happened to her father, and the client's ambivalent feelings about her family members were explored and normalised through discussion and drawings (Summers & Witts, 2003). Finally, a memory box was used to support a person with profound LD following the death of her brother (Young & Garrard, 2016).

Table 2

Characteristics of studies evaluating bereavement interventions for service users with LDs and care staff

Author	Study design	Participants	Intervention	Measures used	Analysis	Outcomes
1. Campbell & Bell (2010)	Single case study	● Service user (N = 1) ● LD: Mild ● F ● Age: 48 ● Living in family home. ● Country: UK	● 8 sessions 1:1 psychoeducation and bibliotherapy with client. ● Session with client's sister. ● Bereavement and loss workshop with care team.	● Conceptions of Death Questionnaire ● Concept of Living and Death Questionnaire ● Understanding Emotions Questionnaire	Changes reported narratively	● Improvements in understanding of death concepts and rituals reported. ● Workshop well received by care team.
2. Summers & Witts (2003)	Single case study	● Service user (N = 1) ● LD: Moderate-severe ● F ● Mid-forties. Country: UK	● 1:1 psychodynamic intervention ● 12 sessions ● Psychoeducation, bibliotherapy and visit to crematorium.	No outcome measures	None	Reduction in distress and angry outbursts observed. Physical symptoms resolved. Decrease in asking staff about the deceased.
3. Young & Garrard (2015)	Single case study	● Service user (N = 1) ● LD: Profound ● F ● Age: 26. ● Country: UK	● Building a memory box ● 6 visits from facilitators over 6 months	Discussed video recordings of the process with client, mother and carers	Discourse analysis of discussions	Process was motivating and source of emotional regulation for client. Perceived as beneficial by mother and carers.

Author	Study design	Participants	Intervention	Measures used	Analysis	Outcomes
4. Dowling, Hubert, White & Hollins (2006)	Randomised controlled trial ● Counselling intervention ● Integrated intervention	● Service users (N = 31) Integrated: 11 Counselling: 20 ● LD: Mild–moderate-severe ● 19 F/12 M ● Country: UK	● Bereavement counselling - 15 sessions, 1 hour - Based on Worden (1991) task model. ● Integrated intervention - Carers provided support at home and at day centre. - Based on Stroebe & Schut (1999) dual process model.	● Aberrant Behaviour Checklist – Community (ABC-C) ● Health of the Nation Outcome Scales for People with Learning Disabilities (HoNoS-LD) ● Behavioural observations ● Interviews with participants and carers	● Quantitative analysis of pre- and post- scores (Wilcoxon, independent t-test). ● Grounded theory analysis of interview data.	● Significantly improvement in counselling group compared to integrated group on all measures except HoNoS-LD inappropriate speech scale. ● Increased sociability and reductions in anger, anxiety and isolation observed in counselling group. ● Poor compliance in integrated group. No improvements noted.
5. Borsay, Halsey & Critoph (2012)	Single group intervention study	● Service users (N = 4) ● LD: Mild-moderate ● 3 F/1 M ● Age: 26-48 ● Country: UK	● Bereavement group ● 8 sessions, 90 mins ● Psychoeducation, group discussion and craft activities. Based on Boyden et al. (2009).	● CORE-LD ● Glasgow Depression Scale ● Generic outcome measure (rating how difficult bereavement was from 1 to 5)	No formal analysis	● 3 participants showed positive change on generic measure. ● Mixed results for CORE-LD and GDS. ● Positive feedback from participants.
6. Boyden, Freeman & Offen (2009)	Single group intervention study	● Service users (N = 5) ● Country: UK	● Psychoeducation and support group ● 8 sessions, 90 mins	Evaluation forms	None	Positive feedback that group had helped. Participants found structure, format & location of group appropriate.

Author	Study design	Participants	Intervention	Measures used	Analysis	Outcomes
7. Mappin & Hanlon (2005)	Single group intervention study	● Service users (N = 6) ● LD: "Significant"- Severe ● Attending day centre ● 3 F/3 M ● Age: 29-42 ● Country: UK	● Bereavement group ● 10 sessions, 90 mins ● Increasing understanding of death and dying, grief reactions, feelings & behaviours, and coping strategies.	● Death Concept Questionnaire ● Knowledge About Death Questionnaire ● Understanding Emotions Questionnaire	Quantitative analysis of pre- and post- scores (Wilcoxon signed ranks)	● No improvement in Death Concept Questionnaire (good initial understanding). ● Significant increases in Knowledge About Death and Understanding Emotions Qu's.
8. Persaud & Persaud (1997)	Single group intervention study	● Service users (N = 8) ● Attending local day centre ● Country: UK	● Psychoeducational bereavement group ● 10 sessions, 2 hours ● Education on death and grief, anger management exercises and visits to funeral director's, crematorium and cemetery.	Individual evaluation interviews	None	Report "outstanding examples of success". E.g. showing greater involvement with the group over time; willingness to speak about deceased; confronting parents about not being informed of grandparent's death; alleviation in fear of being haunted by the deceased.

Author	Study design	Participants	Intervention	Measures used	Analysis	Outcomes
9. Read, Papakosta-Harvey & Bower (2000)	Single group intervention study	● Service users (N = 8) ● 4 F/4 M ● Age: 23-62 ● Country: UK	● Workshop on loss ● 6 sessions ● Identifying losses, exploring feelings and emotions, exchanging ideas with others	Evaluation questions after every session (answered by participants and facilitators)	Grounded theory on participant feedback and facilitator reflections	● Participants appreciated opportunity to explore thoughts and feelings on loss. ● Increased confidence and assertiveness observed; members contributing more frequently over time. ● Assertiveness skills maintained, e.g. expressing themselves more confidently, engaging in independence-promoting activities.
10. Read & Papakosta-Harvey (2004)	Single group intervention study	● Service users (N = 10) ● 5 F/5 M ● Age: 20-57 ● Country: UK	● Workshop on loss ● 6 sessions ● Based on Read et al. (2000) – identifying loses, sharing experiences, narrating personal losses, emotion management strategies.	Evaluation questions after every session (answered by participants and facilitators)	Grounded theory and narrative analysis on participant feedback and facilitator reflections	● Facilitators noted increased self-confidence and assertiveness; increase in contributions over time. ● Group members reported that learning about loss and grief was important for promoting independence and confidence.

Author	Study design	Participants	Intervention	Measures used	Analysis	Outcomes
11. Stoddart, Burke & Temple (2002)	Single group intervention study	● Service users (N = 21) ● LD: Borderline-severe ● 10 F/11 M ● Mean age: 49 ● Country: Canada	● Bereavement group ● 8 sessions, 90 mins ● Discussion of topics on loss and coping alongside practical activities, e.g. funeral home visit, drawing, writing a goodbye letter.	● Children's Depression Inventory – Short Form (CDI-SF) ● Hopkins Symptom Checklist – 25 (HSP-25) depression & anxiety subscales ● Knowledge of Death and Bereavement Questionnaire (KDBQ)	Quantitative analysis of pre- and post- scores (Wilcoxon rank sum)	● Reduction in CDI-SF to non-clinical level. ● Reduction in HSC-25 depression scale to mild range. No change in anxiety scale. ● These changes were seen more in participants with dual diagnosis than participants with single diagnosis.
12. Yanok & Beifus (1993)	Controlled group intervention study ● Intervention grp ● Control grp (no intervention)	● Service users (N = 50) Intervention: 25 Control: 25 ● From sheltered workshop programme ● Ages 22 – 66 ● Country: USA	● Group death and mourning educational programme ● 8 sessions, 50 minutes ● Lectures, psychoeducation using animate & inanimate objects, discussion, sharing experiences.	Knowledge of death questionnaire (post-intervention only).	Quantitative analysis of difference between groups (independent t-test)	Intervention group scored significantly higher than controls on all items.

Author	Study design	Participants	Intervention	Measures used	Analysis	Outcomes
13. Bennett (2003)	Single group intervention study	● Paid carers (N = 12) ● Working at a community home ● Country: UK	● Educational intervention on loss and bereavement for PWLD based on individual needs assessment interviews ● One day session	Evaluation interviews and anonymous structured questionnaire	None	Significant increase in understanding of bereavement and loss reported by 8 carers. 7 carers expressed intention to prepare residents for bereavement proactively. Session content & materials rated very suitable for carers' needs. Teaching methods rated very appropriate.
14. Reynolds, Guerin, McEvoy & Dodd (2008)	Controlled intervention study ● Intervention grp (training program) ● Control grp (no training)	● Staff members (N = 33) Intervention: 17 Control: 16 ● Working in community ID service ● 32 F/1 M ● Age: 20-59 ● Country: Ireland	● Bereavement training programme ● 2 days ● Increasing knowledge and skills for working with bereaved service users	● Confidence Questionnaire (visual analogue scales) ● Staff Support and Satisfaction Questionnaire (3SQ)	Two-way ANOVA of time (pre/post) and group (training/ control) on Confidence Questionnaire & 3SQ	● Significant interaction between time and group on confidence scores. Significant main effect of time for training group. Significant main effect of group post-training. ● No differences on 3SQ.

Author	Study design	Participants	Intervention	Measures used	Analysis	Outcomes
15. Watters, McKenzie & Wright (2011)	Controlled intervention study ● Intervention grp (training) ● Control grp (received training after delay)	● Paid care staff (N = 48) Intervention: 24 Control: 24 ● From local support provider organisations ● 39 F/9 M ● Age: 22-61 ● Country: UK	● Bereavement training programme ● One day session ● Theories of grief and bereavement, bereavement in LD, supporting PWLD through bereavement. ● Controls received training after intervention group.	Purpose-designed 10-question knowledge questionnaire on: ● grieving in non-disabled population ● grieving in LD ● supporting PWLD through bereavement	● Two-way ANOVA of time (pre/post) x group (training/ control) on knowledge scores. ● Repeated measures t-test of combined group pre- and post- scores.	● Significant main effect of time (higher scores after training). No significant effect of group or interaction of time x group. ● Combined group scores show significant increases in knowledge after training.

All three studies included some input from the service user's wider support system. In two of the studies the therapist met with the client's family and/or carers to validate their own grief reactions and discuss the client's informal support needs (Campbell & Bell, 2011; Summers & Witts, 2003), and in another the client's mother was involved in the memory box intervention (Young & Garrard, 2016). Campbell and Bell (2011) also mention a workshop for care staff providing information on supporting service users with LD through bereavement, which was reportedly well received.

These studies were amongst the lowest scoring on the quality review measure. A key critique of these studies is their lack of experimental designs. This makes it difficult to draw strong conclusions from their outcomes. Only one of the studies used formal outcome measures (Campbell & Bell, 2011), reporting an increase in understanding of death concepts, such as irreversibility and non-functionality, as well as a slight increase in emotional understanding. However, the results were reported descriptively rather than providing pre- and post-intervention scores, making it difficult to evaluate the degree of change on the constructs being measured. Other outcomes described include an increase in understanding of what happened to the deceased (Campbell & Bell, 2011; Summers & Witts, 2003) and decreases in distress and angry outbursts (Summers & Witts, 2003; Young & Garrard, 2016).

These outcomes suggest that delivering psychoeducation on death, normalising grief reactions and providing an opportunity to discuss feelings about loss can equip PWLD to begin dealing with their grief, thus helping to reduce disenfranchisement of grief. Young and Garrard (2016) also provide some preliminary evidence for the effectiveness of supporting people with profound learning disabilities to remember and remain connected with the deceased using concrete objects and reminders. All three of these studies demonstrate the potential for working with the wider system during one to one support, which may be helpful in cases where family members and carers are unsure how to talk to the client about their loss or are having trouble processing their own grief while caring for the client.

3.3.2 Randomised controlled trial: integrated intervention

Dowling, Hubert, White and Hollins (2006) conducted a randomised controlled trial comparing traditional bereavement counselling with an integrated intervention. The integrated intervention involved bereavement support delivered by two of the service user's usual paid or unpaid (e.g. family) carers, who received two days of training on bereavement issues and the therapeutic intervention. The intervention was based on

Stroebe and Schut's (1999) Dual Process model of grief, with one carer introducing loss-orientated activities in the home, such as looking at pictures of the deceased, while the other carer supported the service user to engage in restoration-orientated activities at the day centre. The bereavement counselling intervention involved 15 one-to-one sessions based on Worden's (1991) Task Model of grief. The bereavement counsellors received two days of training on adapting their practice to PWLD.

Participants in the counselling group showed a significant improvement on validated measures of challenging behaviour and psychological functioning, while participants in the integrated intervention group showed either no change or a deterioration on these measures. Grounded theory analysis of semi-structured interviews with clients and carers suggested that the bereavement counselling intervention was associated with reductions in anger, isolation and anxiety, as well as increases in communication and sociability. Carers commented that the intervention was effective, practical and easy to incorporate into clients' lives.

The integrated intervention was less well received, with 11 clients being withdrawn by their carers immediately after randomisation and only two of the remaining 11 completing the study. The authors report several barriers to implementing the integrated intervention, including lack of time, the intervention being given a low priority by carers, reluctance to talk with participants about their loss for fear of upsetting them, and some carers finding it difficult to talk about death with participants due to their own experiences of loss. Participants who received an inconsistent intervention from their carers showed no improvements on quantitative measures or in the bereavement issues identified in the pre-intervention interviews. In some cases, participants' disappointment at not being given the time promised to them to talk about their loss resulted in tension between them and their carers.

This was the highest rated study on the quality assessment index. Strengths include its randomised controlled design, use of validated outcome measures and qualitative analysis to present a comprehensive account of its outcomes. It fell down on several items including blinding of participants and researchers, and the fact that compliance with the integrated intervention was not reliable. The study's findings support the use of one to one counselling for bereaved PWLD. However, the integrated intervention may have been too demanding of the carers involved. The authors suggested that this kind of structured support may be impracticable for carers and even counterproductive when attempted half-heartedly. They suggest that carers delivering bereavement support to

PWLD need to have come to terms with their own losses, and have the confidence to offer support with an adequate level of commitment and consistency.

3.3.3 Group service user interventions

Eight studies reported loss and bereavement group interventions for service users.

Six of the studies described bereavement support groups which covered broadly similar themes and structure. These groups took place over eight or ten sessions and involved a mix of psychoeducation on death and mourning, opportunities to share experiences of bereavement and building coping strategies (Borsay, Halsey, & Critoph, 2013; Boyden, Freeman, & Offen, 2010; Mappin & Hanlon, 2005; Persaud & Persaud, 1997; Stoddart, Burke, & Temple, 2002; Yanok & Beifus, 1993). Two of these groups also took participants on visits to places where death rituals occur, such as funeral homes, crematoriums and cemeteries (Persaud & Persaud, 1997; Stoddart et al., 2002). All groups made use of practical activities and visual resources, such as videos, drawings and pictures.

Two workshops on loss were also conducted by Read and colleagues. Read, Papakosta-Harvey and Bower (2000) ran a six-session workshop which focussed on definitions of loss, sharing personal memories of loss and exploring family and social networks. Read and Papakosta-Harvey (2004) built upon this work with a similar format workshop with an added emphasis on encouraging group members to tell their stories of loss narratively.

The quality of many of the group studies under review suffered from very small sample sizes and lack of control groups (Borsay et al., 2013; Boyden et al., 2010; Mappin & Hanlon, 2005; Persaud & Persaud, 1997; Read & Papakosta-Harvey, 2004; Read et al., 2000; Stoddart et al., 2002). In the one study which did use a control group (Yanok & Beifus, 1993), it is unclear whether, and if so how, participants were randomised to the active and control groups. None of the studies included a clearly reported follow-up, meaning it is not possible to determine whether their outcomes were maintained long-term.

Four of the groups used outcome measures (Borsay et al., 2013; Mappin & Hanlon, 2005; Stoddart et al., 2002; Yanok & Beifus, 1993). A mix of validated and purpose-designed outcome measures were used, including measures of mood, psychological functioning, and understanding of death concepts and emotions. The remaining studies used informal evaluation and qualitative analysis of service user and staff feedback to

report their outcomes (Boyden et al., 2010; Persaud & Persaud, 1997; Read & Papakosta-Harvey, 2004; Read et al., 2000). As with the case studies, this makes it difficult to directly compare outcomes across the studies.

Improvements on validated measures of knowledge about death and understanding of emotions were noted by Mappin and Hanlon (2005), although they did not find any improvement in understanding of death concepts. Another study measuring group participants' knowledge of death using a purpose-designed questionnaire (Stoddart et al., 2002) found no change post-intervention. The authors of both studies speculate that this lack of change may be due to the participants having a good level of understanding about death before taking part in the group. Yanok and Beifus (Yanok & Beifus, 1993) administered a purpose-written questionnaire measuring knowledge of death and mourning following their educational program and found a higher score among active participants than a control group. However, the questionnaire was not administered to either group before the intervention, so any pre-existing differences between the two groups could not be accounted for.

Results for validated mood outcome measures were mixed. Reductions in depression were noted by Stoddart et al. (2002), particularly in participants with a dual diagnosis of LD and psychiatric disorder. Borsay et al. (2013) found mixed outcomes on validated measures of depression and psychological functioning in their small sample of four service users, although they did note improvements for three of the group members on a simple idiographic measure from 1-5 of how difficult the loss was for them.

Positive behavioural outcomes were reported. For example, Read and colleagues (Read & Papakosta-Harvey, 2004; Read et al., 2000) noted that participants showed increases in confidence and assertiveness which were maintained after the workshop finished (although it is not clear for how long). Persaud and Persaud (1997) reported several "outstanding examples of success" (p.174) among their participants, such as becoming more involved with the group over time, showing increased willingness to talk about their deceased loved one, and an alleviation in one participant's fear of being haunted by the deceased. However, the lack of any outcome measures or formal method of analysing the group's outcomes make it difficult to know how representative of the sample these examples of success were.

Several studies reported positive feedback from participants and carers on the group experience, particularly regarding the opportunity to meet with others, hear about others'

experiences and talk about thoughts and feelings on loss (Borsay et al., 2013; Boyden et al., 2010; Read & Papakosta-Harvey, 2004; Read et al., 2000)

These outcomes suggest that bereavement and loss support groups are an acceptable and appreciated intervention for service users, which may have positive benefits for clients' ability to talk about their grief and learn strategies for coping and moving forward. Groups may be helpful for increasing understanding and knowledge about death; however increases in knowledge outcome measures may not always be apparent, particularly if participants already have a fairly good understanding before the group. This suggests that the main benefits of these groups may come more from the opportunity to talk through feelings and share experiences of loss with others. It is difficult to draw conclusions on bereavement groups' potential for improving mood; however preliminary evidence from Stoddart et al. (2002) seems to suggest that clients with a diagnosed mood disorder may gain the most benefit from the group experience. However, given the size of the samples and poor quality methodology of many of these studies, further research is required in order to come to any stronger conclusions.

3.3.4 Carer interventions

All three carer intervention studies focussed on educating paid carers and support staff on key issues relating to bereavement in PWLD. Bennett (2003) ran a one day programme on loss, which included teaching on Worden's (1991) tasks of grieving, discussion of attendants' own experiences of loss and consideration of how to develop future bereavement care for service users taking these experiences into account. Watters et al. (2012) evaluated another one day training program which covered theories of grief, grief reactions and vulnerabilities in people with LDs, and bereavement support for PWLD. Reynolds et al. (2008) described a two day program including key concepts around bereavement and loss, experiences of bereavement among people with LDs and developing guidelines for supporting clients.

The three staff interventions varied in quality. Bennett (2003) scored lowest due to poor reporting and lacking a control group or formal outcome measures. The other two (Reynolds et al., 2008; Watters et al., 2012) scored higher due to more rigorous methodologies and better reporting practices.

Different outcomes were measured in each study. Bennett (2003) informally evaluated the impact of training on staff using interviews and a questionnaire. The intervention was positively rated and eight of the twelve attendees reported an increased understanding of bereavement and loss. Furthermore, seven expressed motivation to begin proactively

preparing their service users for bereavement. Reynolds et al. (2008) designed a staff confidence measure rated on 12.5mm visual analogue scales, and reported increased confidence in staff who received the educational intervention compared with controls who did not. Only one study (Watters et al., 2012) directly measured changes in staff knowledge. Using a purpose-designed questionnaire on grieving processes and bereavement support for people with LDs, they found that care staff scored significantly higher after the intervention.

These outcomes demonstrate that staff educational programs may be a useful way of enabling carers to deliver informal bereavement support, by increasing their knowledge of service users' experiences and care needs and increasing their confidence to talk openly about death with service users. Two of these studies included a control group (Reynolds et al., 2008; Watters et al., 2012), increasing the reliability of their outcomes. However, all three of these studies were cross-sectional in design, meaning there is no evidence that increases in staff confidence and knowledge were retained, and none of the studies included unpaid carers such as family members. Furthermore, none of these studies provide evidence that educating staff members about bereavement issues in PWLD made any difference to their practice, or had any implications for service users' wellbeing and ability to cope with loss. It is also notable that none of the staff intervention studies addressed the issue of the emotional impact of supporting PWLD through bereavement and the need to support care staff with managing their own grief (Gray & Truesdale, 2015).

4. Discussion

This review aimed to build upon Clute's (2010) review of bereavement interventions for PWLD. A systematic review was performed on peer-reviewed intervention outcome studies which included service user and carer interventions. A quality review was also carried out in order to assess the current state of research in this area, and to establish whether recommendations being made by Clute (2010) and others (such as Read & Elliott, 2007) are being implemented and evidenced robustly.

Clinical implications
The findings of this review support and build upon the recommendations of Clute (Clute, 2010) and Read and Elliott (Read & Elliott, 2007) regarding a joined-up, multi-level approach to supporting PWLD to cope with bereavement. Evidence has been found for providing education on death to PWLD, not just reactively but also proactively (Read & Elliott, 2007); for educating carers about bereavement issues in PWLD in order to

increase their knowledge and confidence to support service users; and for the usefulness of one-to-one and group support interventions for providing PWLD with opportunities to discuss and process their loss and associated emotions.

This evidence, alongside previous recommendations, supports the development of a pathway of bereavement support for PWLD, taking into account the needs of both service users and the wider system. This would involve:

1) **Proactive psychoeducation** on death and grieving for all PWLD in either group or individual formats, in order to prepare and empower them to cope with bereavement.

2) **Education for support staff and family members** on the difficulties bereaved PWLD face and how to support them, so as to reduce the risk of disenfranchised grief (Doka, 1989). This would ideally be offered as standard by LD support services, so that staff and families are prepared before bereavement occurs and are able to recognise the signs of grief in PWLD.

3) **Informal support provided by family and carers** in the first instance when bereavement occurs. This would include validation and normalisation of the individual's grief, involving them in grief rituals and supporting them to memorialise and maintain bonds with the deceased (Clute, 2010; Kauffman, 2011; Oswin, 1991; Read & Elliott, 2007).

4) **Formal bereavement interventions** for those who are struggling with complex grief, either one-to-one or in support groups, as indicated by individual needs assessments. This will require family and carers to have an awareness of the signs of complex grief and when referral to specialist services is warranted (see point 2).

5) **Involvement of the wider system in formal interventions**. This may take the form of family members or carers attending groups and therapeutic sessions as support for service users, and will depend on the needs and desires of each individual.

6) **Support for family members and carers** to validate their own grief and help them manage the emotional impact of caring for bereaved PWLD (Gray & Truesdale, 2015).

LD services adopting or already working to this kind of model could provide useful data on its effectiveness, for example by reporting rates of referrals into the service, the number of service users referred on to complex grief interventions (both 1:1 and group), outcomes of these formal interventions, and outcomes of family and staff training

interventions in terms of provision of informal support and psychoeducation to service users.

Research Implications

Clute (2010) identified the first level of bereavement support as informal support, including validation and honouring of grief, giving the individual opportunities to talk about their feelings and including PWLD in grief rituals. This level appears to be equivalent to the facilitation and participation elements of Read and Elliott's (2007) systems approach. While there is literature describing informal support from carers for PWLD following bereavement (Clute, 2010), it does not appear as if this type of support is being robustly researched and outcomed. It is notable that the only study included in the current review which involved unpaid carers providing bereavement support to PWLD is Dowling et al. (2006), who compared a formal bereavement counselling intervention with a structured integrated intervention led by paid and unpaid carers. Dowling et al.'s (2006) findings about the challenges of implementing the carer-led intervention suggest that carers need to be supported to come to terms with their own experiences and feelings about loss, in order to have the confidence to provide bereavement support to PWLD in a consistent and effective manner. This supports previous research suggesting that the grief-related emotional needs of people who care for PWLD need to be taken into account, as well as the needs of PWLD themselves (Gray & Truesdale, 2015).

After informal support, Clute (2010) highlights the need for formal individual or group interventions, such as life story work, death education and formal bereavement counselling. Read & Elliott (2007) also recognised the need for education and formal psychotherapeutic interventions. However, they emphasise that formal interventions should be offered when people are struggling to cope with bereavement or showing complex grief reactions, whereas proactive education and preparation for bereavement should be a central part of people's lives.

The main types of formal bereavement interventions identified for the current review were case studies of one-to-one psychoeducation and psychotherapy (Campbell & Bell, 2011; Summers & Witts, 2003; Young & Garrard, 2016), formal bereavement counselling compared with an integrated carer-led intervention (Dowling et al., 2006) and bereavement education and support groups (Borsay et al., 2013; Boyden et al., 2010; Mappin & Hanlon, 2005; Persaud & Persaud, 1997; Read & Papakosta-Harvey, 2004; Read et al., 2000; Stoddart et al., 2002; Yanok & Beifus, 1993). Most of these interventions showed positive outcomes, including improvements in knowledge about death, behaviour, mood and ability to express feelings around loss, as well as positive

feedback from service users and carers. However, various difficulties with the methodologies of these studies were noted, including small sample sizes, varied (or lacking) outcome measures and scant use of experimental designs or control groups. These methodological weaknesses should be addressed in future research in order to be able to draw firmer conclusions from study outcomes.

One potential limitation of the current review was the grouping together of both controlled and uncontrolled studies in the same categories. This decision was made in order to categorise studies according to similar types of intervention. However, the differences in design and quality between single group and controlled studies make it difficult to compare them directly, and it may have been preferable to separate them in the analysis.

Evidence from group studies seems to suggest that bereavement support groups are a helpful and positively evaluated format for educating PWLD about death and grief, as well as providing opportunities to share loss-related feelings and experiences with others. The case study literature highlights the usefulness of one to one psychotherapy for providing similar opportunities to learn about death and process loss. This format may be helpful for individuals who do not wish to take part in groups, or for those with more severe or profound communication difficulties who may struggle to benefit from the group environment. One-to-one interventions can be tailored to the individual's needs and can focus on practical memorial-based activities if communication is challenging (see Young & Garrard, 2016).

Robust evidence on the outcomes of formal bereavement counselling is generally limited. Dowling et al. (2006) found good outcomes among their bereavement counselling group, which outperformed the integrated carer-led intervention both in terms of validated outcome measures and feedback from participants' carers. Further RCTs would help to evaluate the effectiveness of formal counselling interventions. Further evidence on the types of people who may benefit most from counselling would also be helpful for understanding how this type of intervention should fit into bereavement care pathways. Better reporting of participant characteristics, such as level of intellectual functioning, would help with this.

Clute's (2010) final level of bereavement support is providing the wider community with knowledge of death and grief education, so that families and staff can be equipped to provide appropriate informal support and identify the need for formal intervention. Read and Elliott (2007) also identified the importance of educating carers in order to foster their comfort and confidence talking with service users about death. Three of the studies

included in this review reported outcomes of staff educational interventions aimed at improving knowledge of the bereavement support needs of PWLD and increasing staff confidence to engage with service users on this sensitive topic. Programmes included education on grief and bereavement in PWLD, practical advice and resources for supporting service users, and opportunities to reflect on personal experiences of loss. Staff members participating in these studies appeared to benefit from increases in their knowledge and confidence in supporting bereaved PWLD, and staff in one study expressed increased motivation to begin proactively preparing service users for bereavement. Dowling et al.'s (2006) study included two days' training for paid and unpaid carers leading the integrated intervention; however no outcomes were reported for this.

Evidence from these studies supports the systematic training of carers in providing effective support around bereavement for PWLD. Studies should extend their outcome measures in order to begin investigating whether educating staff results in better clinical practice with service users. Future research should also investigate whether training for family members confers similar benefits, as close family members have a large part to play in supporting PWLD in times of bereavement (especially given the fact that over half of PWLD live with family; Department of Health, 2009), and may not always know where to go for help (Handley & Hutchinson, 2013). The fact that only one study in the current review included unpaid carers in any capacity (Dowling et al., 2006) reveals a significant gap in the literature in this area.

Future research should investigate each stage of Read and Elliott's (2007) model, as well as addressing the methodological problems identified in this review. For example, there is a need for studies with larger samples, as well as more robust study designs including feasibility studies and RCTs. In cases where large-scale research is not possible, single case experimental designs and case series should be carried out. Increased use of quantitative outcome measures and formal analysis of qualitative data will help to draw firmer conclusions from study outcomes.

Conclusion

This review aimed to investigate the efficacy of bereavement interventions for PWLD and their paid/unpaid carers. Evidence from the reviewed studies supports multi-level, systemic bereavement support frameworks suggested by Read and Elliott (2007) and Clute (2010). However, overall the evidence was limited and of low quality. Further high quality research is required in order to replicate and expand upon these findings and to

investigate the benefits of educational interventions for unpaid carers, who are underrepresented in the research literature.

A bereavement care pathway has been proposed including proactive educational interventions for PWLD, staff and unpaid carers, support for service users moving from informal to formal interventions, and bereavement support for the wider system. There is a need for more robustly designed empirical research investigating the effectiveness of these approaches and for services using this model to begin sharing outcome data in order to inform evidence-based practice.

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Service Improvement Project: Identifying suitable outcome measures for a post-diagnostic support group for adults with autism

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Word count: 5284

Submission date: June 2017

1. Introduction

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013) describes Autism Spectrum Disorders (ASD) as a range of neurodevelopmental disorders characterised by persistent difficulties in communication and social interaction, restricted, repetitive patterns of behaviour, interests or activities, which are present from early childhood and which together limit and impair everyday functioning.

People with ASD experience high rates of social isolation and emotional problems, and it is probable that social stigma has an important role to play in this (Portway & Johnson, 2005). According to Social Identity Theory (Tajfel & Turner, 1979) we are driven to identify and define ourselves through membership of social groups. According to this theory, belonging to socially stigmatised groups may present a challenge to self-esteem. In an online survey of over 100 adults with ASD, Cooper, Smith and Russell (2017) found a significant relationship between autism identity and self-esteem. This relationship was mediated by positive distinctiveness. These results suggest that self-esteem in members of stigmatised groups (such as those with autism) may be improved by individual group members developing a more positive view of their group identity.

Punshon, Skirrow and Murphy (2009) used Interpretative Phenomenological Analysis (IPA) to analyse interview data from 10 adults diagnosed with Asperger syndrome (AS). One of the themes identified was the tendency for participants to hold negative internalised attitudes about themselves prior to diagnosis as a result of the negative reactions of others. According to this study, receiving a diagnosis allowed participants to change their negative beliefs about themselves and helped them explain their difference to others. It also allowed them access to support and the opportunity to interact with others who had the same diagnosis, giving them a sense of "fitting in". The authors suggest that receiving a diagnosis of AS marks the beginning of a process of adjustment as the individual works out what the diagnosis means for them, and that support from professionals and peers is invaluable for aiding this process. Similarly, Stoddart (2012) suggests that a diagnosis of ASD can give individuals access to specialist interventions, improve quality of life and relationships, and aid detection of mental health problems.

There is some evidence that post-diagnostic group interventions can be beneficial for people with ASD. For example, Hillier, Fish, Cloppert and Beversdorf (2007) trialled an 8-week social and vocational skills support group for 13 adolescents and young adults with ASD. They found significant improvements in empathy and frequency of

contributions to the session. They also found a decrease in measures of ASD-associated traits and peer relations; however these changes did not reach significance.

Gordon et al. (2015) conducted a controlled trial of a group psychoeducation intervention for 48 young people (ages 9-14) with ASD aimed at helping them understand their condition and their strengths and weaknesses. They found increases in knowledge about autism and awareness of autism-related strengths and difficulties, measured by the purpose-designed Autism Knowledge Quiz. Contrary to previous assumptions that educating young people about their neurodevelopmental disorder might increase self-stigma and thus lower self-esteem (see Jutel & Nettleton, 2011, and Singh, 2011; referenced in Gordon et al., 2015), there was no change found in self-esteem measured by the Rosenberg Self-Esteem Scale (Rosenberg, 1965).

Hayward et al. (2015, May) ran a psychoeducation group for 18 recently-diagnosed male adults with ASD. They found an increase in knowledge about autism using the Autism Knowledge Questionnaire (Gordon et al., 2015), however did not find any increase in self-esteem or wellbeing, as measured by the Rosenberg and Warwick Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007).

In summary, ASD is a lifelong condition which can be diagnosed in adulthood and is associated with social isolation and emotional difficulties. Stigma and social identity processes appear to be highly relevant to the difficulties experienced by those diagnosed in adulthood, and consideration of these factors should play a role in interventions designed to support people with the adjustment process. Evaluations of post-diagnostic group interventions have shown positive effects on adjustment and understanding of ASD.

Context of the project

The present study sought to understand the benefits and difficulties experienced by adults who attended an autism service's post-diagnostic support group, and consider which standardised measures might best capture the outcomes of the group.

The service's six-week post-diagnostic support group (PSG) aims to help service users who have recently been diagnosed to:
- understand what autism is and how it relates to them;
- understand and discuss legal and personal issues surrounding disclosure of their diagnosis;
- find out about other available support services;

- share their experiences with others and benefit from peer support.

Prior to this project, the service had been collecting data on the group's outcomes using the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) and the Connor-Davidson Resilience Scale (CD-RISC). However, they did not have any clear data on whether these measures were accurately measuring the outcomes the group was aiming to achieve.

The main aims of this project were:
1) To investigate the benefits of the post-diagnostic support group for service users.
2) To investigate which outcome measures are most appropriate for monitoring the group's effectiveness.

Project design
The project took a mixed methods design. Part A aimed to investigate the benefits of the post-diagnostic support group (PSG) for service users using thematic analysis of interview data. The results of the thematic analysis were used to suggest standardised outcome measures which might reflect the intended outcomes of the group.

Part B aimed to evaluate the usefulness of the existing and new outcome measures as indicators of change using quantitative analysis of pre- and post-group scores.

This study was approved by the University of Bath Psychology Ethics Committee (reference number 16-016; Appendix C). The local NHS Research and Development (R&D) team advised that R&D permissions would not be required as the project involved service evaluation rather than research. A proposal for the project was checked and approved by a member of the trust's Quality Academy team (Appendix D).

2. Part A

2.1 Method

2.1.1 Participants

Service users were eligible to take part if they were aged 18 or over, had a diagnosis of ASD and had attended a PSG within the past 12 months.

Letter packs were sent out to 45 service users, including an invitation letter (Appendix E), participant information sheet (Appendix F), reply slip and stamped addressed envelope. Eleven service users responded, two by email and nine by reply slip. Once service users responded to the invitation letter they were contacted by the researcher and given the opportunity to ask questions.

Seven service users consented to be interviewed. Interviewees ranged in age from early twenties to mid-fifties. Two were female and five were male. Six were employed either part time or full time. Length of time between attending the group and being interviewed ranged from 6 to 12 months.

2.1.2 Interview schedule

Interviews followed a semi-structured schedule designed to elicit information on both the positive and negative aspects of attending the group, as well as any changes they had noticed in themselves or their lives since attending (see Appendix G).

Interviewees were given the option of receiving a copy of the questions before the interview; all but one took up this offer and three brought written notes to their interviews. The interview schedule was followed in order, with follow-up questions inviting interviewees to clarify or expand upon their answers as appropriate. Interviews took between 30 and 60 minutes to complete.

2.1.3 Procedure

All interviews were conducted individually by the researcher in private rooms at locations used by the service in Bristol and Bath. Participants were compensated for their time with a £10 gift voucher.

Interviews were audio recorded and transcribed by the lead researcher, who then conducted a thematic analysis on the interview data by hand, following the methodology described by Braun and Clarke (2006). The focus of the analysis was on perceived benefits of attending the group, as well as changes which participants felt had occurred in their lives or in themselves as a result. Transcripts were coded and then these codes were grouped according to themes. The transcripts were re-read several times and the themes were further refined. Themes from two transcripts were then checked and approved by a second coder.

2.2 Results

Participants' talk about the group was categorised into four main themes; getting support, understanding autism, life changes and acceptance. Quotes were chosen which concisely illustrated each theme and sub-theme from across all seven transcripts, in order to represent the views of all interviewees as far as possible (see Appendix H). Service users are referred to by their participant number. Proposed links between the main themes and sub-themes are illustrated in Figure 2.

2.2.1 Support

Support from others with autism

Participants spoke about the value of meeting others with autism, which gave them opportunities to hear about others' experiences, find similarities and differences with others and talk to people who know what it is like to have the diagnosis.

> *It was beneficial to meet other people who also had a diagnosis, you know, in a fairly well safe and controlled environment.* (P7)

> *It was quite nice to spend time around other autistic people really. It was quite beneficial to do that.* (P1)

This is in line with one of the stated aims of the group; sharing experiences and benefitting from peer support.

Sense of belonging

They also talked about gaining a sense of belonging with others and becoming aware of a wider ASD community.

> *As far as attending the group's concerned, at least it showed I wasn't on my own. Often it feels like you're the only one in the world with it. It proved to me that wasn't the case.* (P4)

One of the female participants spoke of how helpful it was to meet other women with ASD.

> *But actually meeting another woman with autism who, like, who's had the same struggle of people not maybe accepting the diagnosis , going "Oh, you don't have autism, you're too social"… yeah it was really interesting and really useful.* (P3)

Professional support

Several participants stated that the group had given them more knowledge of what support was available to them more widely, and that knowing there were places they could turn to for professional support was reassuring to them.

It was also beneficial to see the NHS has obviously got things in place or have got people who know about autism. (P1)

As far as the beneficial side of it [goes], it's just knowing that there's someone there if I need help. (P2)

2.2.2 Understanding autism

Information about autism

All but one of the interviewees spoke about how helpful the information on autism provided by the course was.

It gave me a much clearer understanding of what Aspergers Syndrome is and what's known about it. (P7)

How autism affects me

Several participants stated that the group helped them learn about how autism relates to them, particularly in terms of their own behaviour and anxiety.

It kind of made me look at how I make, form friendships and relationships, and look at how my autism affects that and why. (P3)

Several participants spoke about how the group had allowed them to make sense of some of their past experiences and put them into context. This seemed to give these participants some sense of closure on the past and an ability to lay certain fears about themselves to rest.

I can go back now and go… figure out what's happened the last 40 years… Why did I do this and why did they do that. And things sort of started to click. So that's helped a lot. (P6)

This sense of gaining a better understanding of autism and how it has affected their lives seemed to be the jumping-off point for a range of changes and improvements in participants' lives, as reflected in the next theme.

2.2.3 Life changes

Participants mentioned a number of changes in their lives since attending the PSG. These were grouped into three sub-themes; social life, communication and wellbeing.

Social life

Several participants said they were going out more and getting more involved in social activities since the group.

And just recently I've started doing more [things] like this… Whereas before I was quite happy to stay in all day every day… I know how to be more social. (P6)

One participant (P3) mentioned that she was still in social contact with the other members of her group. Another (P2) spoke about how learning about autism had made him more determined to change things and improve his social life. However, he was aware of how difficult change would be.

It's difficult for me to change, even though I know now that I've got this problem and it's the problem that's been causing it. So from that point of view, it's still there and this is why I want to be more social and meet other people… but at my age it's, I wonder if I've left it too late. (P2)

Communication

Several participants mentioned ways in which they had become better at communicating with others, both about their condition and about what they need in social and work situations.

It's helped me to get a better understanding of how it affects me as an individual, as well with helping other people like colleagues, friends and relatives to understand why I do things or say things in a particular way. (P5)

I suppose I knew that… it was not wrong to ask for what I needed, right. (P4)

Wellbeing

Several participants spoke about experiencing improvements in their mental health.

Confidence and self-esteem began to build up again. (P4)

I don't know if it's the diagnosis or the group, but since September I've come off my antidepressants… [I'm] a bit more laid back. A bit more relaxed. (P6)

Participants also spoke about feeling they could cope with anxieties and difficult situations more effectively.

I learned some more techniques of how to manage anxieties. (P4)

If something doesn't go to plan I can get quite irate. But I know now how to work around that. (P6)

Two participants mentioned improvements in exercise and physical health, which appeared to be connected with this increase in mental wellbeing.

I mean there's a clear correlation between my mental health and my level of exercise. That's actually very important because I'm diabetic… So for me the absolute key to my entire life is my mental health. (P7)

Many of these positive life changes seemed to have come about as a result of participants' increased understanding of autism.

Overall the diagnosis and the education from the group has radically altered my self-perception, and actually in a very positive fashion, which has had a very significant positive effect on my mental health on an ongoing basis. (P7)

2.2.4 Acceptance

In all but one interview there seemed to be a common theme of acceptance, both of themselves and of their autism diagnosis.

Acceptance of diagnosis

One participant (P3) mentioned acceptance of her diagnosis as a particularly helpful outcome of attending the group.

I think it's being more comfortable with, yeah with my diagnosis and understanding it a lot more… I knew a lot about autism before I came to the group… what changed more was my view of my own autism. (P3)

Another participant (P1) mentioned that receiving the diagnosis had helped him to gain acceptance from and repair relationships with a close family member.

My mum was in total denial about it all… Then after diagnosis the penny slowly was dropping, she started to admit to herself that I wasn't perfectly normal as a child and so, [there was] sort of a wider healing process with interpersonal relationships, sort of thing. (P1)

Self-acceptance

Another participant (P4) spoke about not wanting to change for others, illustrating the struggle of living with autism and feeling pressured to conform to societal expectations.

I don't think I want to change… it's exhausting if they expect you to change, because it's every day, you have to be coping every day. (P4)

Several participants stated that they had discovered a newfound sense of freedom in putting aside others' expectations of them and not having to try and be "normal".

A lot of social rules have been lifted, almost, 'cos I've sort of realised that I don't have to live by those rules, really. (P1)

I don't need to be trying to be normal all the time. (P3)

2.2.5 Criticisms and suggestions

Participants also offered criticisms of the group, generally around practical issues, and suggestions for improvements. For example, some participants found it hard to attend the group during work hours. One suggested increasing the length of sessions in order

to fit in more material and discussion time. Two participants stated that the changes they had noticed had come about in the weeks or months since the group ended, and suggested that follow-up outcome measures be administered to capture this.

2.2.6 Drawing together thematic analysis findings

One of the main benefits of the group mentioned by interviewees was the experience of meeting others with autism and gaining a sense of belonging. This may help to foster feelings of self-acceptance and wellbeing. Furthermore, it seems that increasing their understanding of autism may have helped the participants to make sense of their own feelings and behaviours and to work out how to communicate better about their condition with others. This may then have had a cascade effect of improving participants' social interactions, thereby improving their confidence and general mental wellbeing, leading them to engage more actively with the world around them. These themes reflect Punshon et al.'s (2009) findings that receiving a diagnosis allowed people to access support from professionals and peers, make sense of their own difficulties and gain a sense of "fitting in".
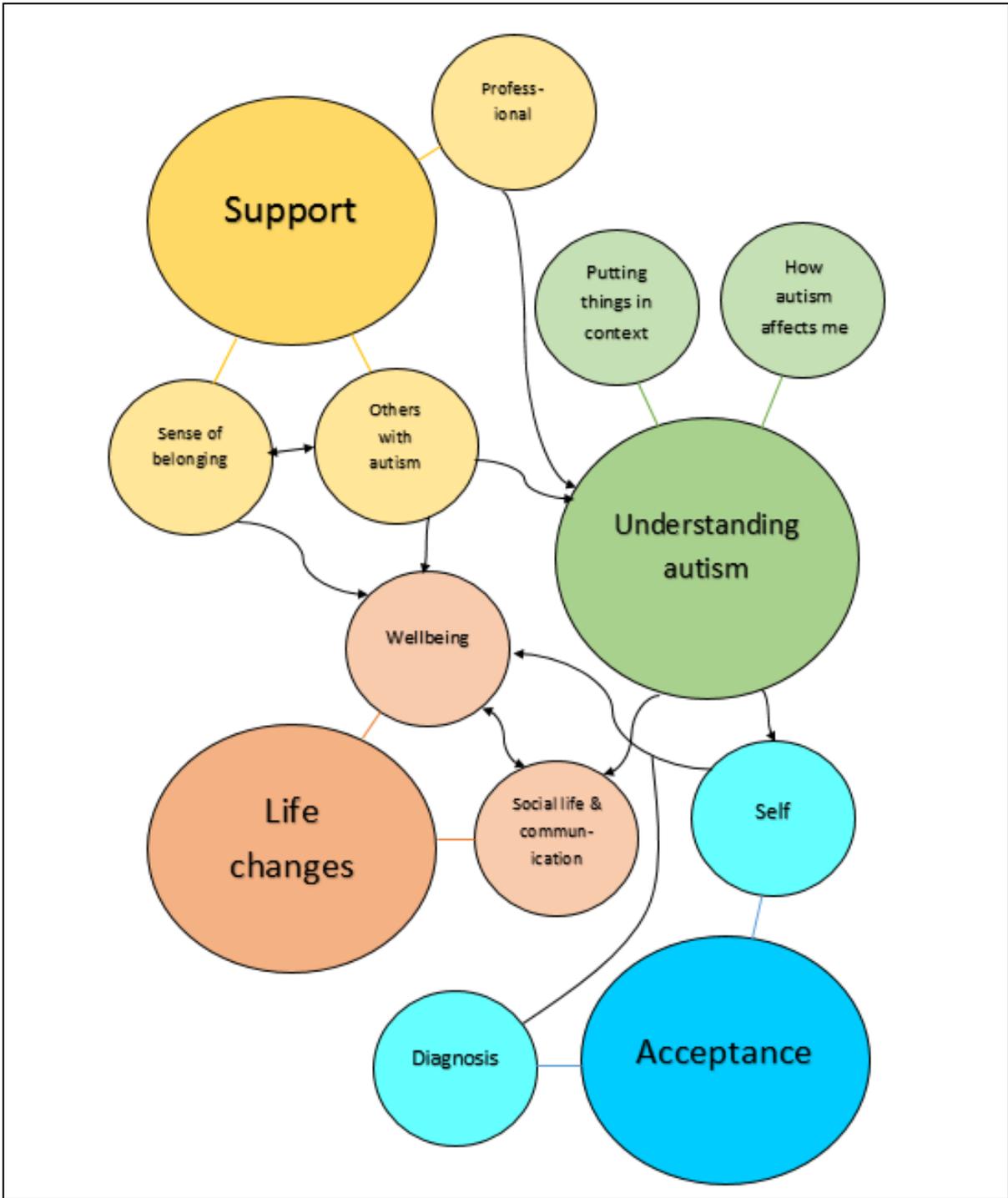
Figure 2. Diagram of themes and sub-themes derived from thematic analysis of service user interview data.

3. Part B

3.1. Method 3.1.1 Selection of new measures

The results of the thematic analysis were used to identify and recommend appropriate outcome measures for trial in future PSGs. This involved an iterative process of discussion between the researcher and supervisors, during which various options which appeared to reflect specific themes were suggested and considered. A final list of seven recommended measures was presented to the service (see Table 3). It was also recommended that the service's existing measures, the WEMWBS and CD-RISC (Table 4) continue to be used during the measures trialling period.

Table 3

Psychometric properties of outcome measures recommended to the service based on themes identified in the thematic analysis

Outcome measures	Psychometric properties	Themes captured
Rosenberg Self-Esteem Scale (Rosenberg, 1965)	Ten-item measure of global self-worth. Acceptable to high reliability levels (α = .72 to .90) have been reported (Gray-Little, Williams, & Hancock, 1997; Robins, Hendin, & Trzesniewski, 2001). The scale has been used in previous studies evaluating ASD support groups (Gordon et al., 2015; Hayward et al., 2015, May).	Wellbeing, self-acceptance
Autism Identity Questionnaire (Cooper et al., 2017)	Fourteen-item measure of identification with autism. Based on Leach et al.'s (2008) multidimensional scale of social identification, which has been found to have good reliability (α = .8 to .9) and construct validity.	Sense of belonging, self-acceptance
Autism Positive Distinctiveness Questionnaire (Cooper et al., 2017)	Eight-item measure of positive distinctiveness in autism. Adapted from Lhutanen and Crocker's (1992; cited by Cooper et al., 2017) collective self-esteem subscales, which were found to have good internal consistency (α = .83 to .88).	Sense of belonging, self-acceptance
Autism Knowledge Quiz (Gordon et al., 2015)	Consists of in interview on autism self-awareness (in which participants list their own strengths and difficulties) and 15 questions on general knowledge about ASD (including prevalence, causes, and anxiety). Score is determined by number of strengths and difficulties listed and number of questions answered correctly. No psychometrics data was presented by the authors.	Understanding autism

Brief Fear of Negative Evaluation Questionnaire (Leary, 1983)	Twelve-item measure assessing anxiety related to negative judgement by other people. Leary (1983) found it to have good internal consistency (α = .90). Has also been found to have good internal consistency in studies including adolescents (White, Maddox, & Panneton, 2015; α = .863) and adults (Maddox & White, 2015; α = .938) with ASD.	Social life and communication
Social Phobia Inventory (Connor et al., 2000)	Seventeen-item measure of fear, avoidance and discomfort in social situations. Connor et al. (2000) found adequate test-retest reliability (r = .78 to .89) and internal consistency (α = .87 to .94), as well as good construct validity. It has been used in previous studies with people with Asperger syndrome (e.g. Langdon et al., 2016, however reliability and validity was not reported for this sample).	Social life and communication
Quality of Life Questionnaire (Schalock, Hoffman, & Keith, 1993)	Forty-item measure of quality of life. It has been found to have good test-retest reliability (r = .87) and internal consistency (α = .90) (Schalock et al., 1993). Good internal consistency (α = .85) was also found with an ASD sample (Renty & Roeyers, 2006).	Wellbeing

The following newly recommended measures were selected for trial by the service:
- Rosenberg Self-esteem Scale
- Autism Identity Questionnaire
- Positive Distinctiveness Questionnaire
- Brief Fear of Negative Evaluation Questionnaire (BFNE)

The service also attempted to obtain the Autism Knowledge Quiz; however it was not possible to contact the authors in time to trial it along with the other new measures. (See Appendix I for outcome measures used in this project.)

Table 4

Psychometric properties and associated themes of outcome measures already used by the service

Outcome measures	Psychometric properties	Themes captured
Warwick Edinburgh Mental Well-being Scale (Tennant et al., 2007)	Comprises 14 items relating to positive attributes of mental wellbeing, encompassing the concepts of life satisfaction, the ability to develop positive relationships with others and the capacity to maintain a sense of self-acceptance, purpose and self-esteem (Stewart-Brown & Janmohamed, 2008). No clinical "cut-off" has been developed as the scale is not designed to identify individuals with exceptionally high or low wellbeing (Stewart-Brown & Janmohamed, 2008). It has been validated with student and adult samples, however has not been used with ASD populations to the author's knowledge. Stewart-Brown et al. (2011) found good internal consistency ($\alpha = .89$) and test-retest reliability ($r = .83$).	Wellbeing
Connor-Davidson Resilience Scale (Connor & Davidson, 2003)	The original scale comprises 25 items and measures ability to cope with adversity. It was found to have high internal consistency ($\alpha = .89$) and test-retest reliability ($r = .87$) with a non-ASC adult sample, and is sensitive to change over time (Connor & Davidson, 2003). The service uses the CD-RISC-10, a 10-item abbreviated version with high internal consistency ($\alpha = .85$) (Campbell-Sills & Stein, 2007). To the author's knowledge, the CD-RISC has not been used in previous research with people with ASD.	Wellbeing

3.1.2 Participants and procedure

Pre- and post-group WEMWBS and CD-RISC scores were collected for 54 service users who had attended 9 groups over the 6 months preceding the beginning of the project. Of these, 28 completed both pre- and post-measures. Twenty-six completed only pre-group measures. Reasons for non-attendance of the final group session were not recorded.

Data was also collected from 36 service users who attended four groups following the interviews and recommendations phase. These participants completed the original

measures (WEMWBS and CD-RISC) as well as the newly recommended measures (see Table 3). Twenty-nine completed measures pre- and post-group. The remaining seven completed only pre-group measures.

Demographic information about the group participants (e.g. age, gender) was not collected by the service.

3.2 Analysis

Pre- and post-group outcome measures data were entered into SPSS for quantitative analysis. Missing data points were replaced with the scale mid-point (e.g. 3 for a scale of 1-5). If two or more data points were missing from an outcome measure for any given case, the case's data for that outcome measure was excluded.

Normality of data was established by checking skewness and kurtosis, histograms, p-p plots, and Kolmogorov-Smirnoff and Shapiro-Wilk tests.

In order to ensure that outcome measure scores were representative of all group attendees, Mann-Whitney U tests were used to check for differences in baseline scores between service users who completed both pre- and post-measures and those who completed only pre-measures.

Paired samples t-tests were used to investigate if there was a significant difference between pre- and post-group scores on each measure.

3.3 Results

There was no significant difference in baseline scores on the WEMWBS or CD-RISC between service users who completed both pre- and post-group measures and those who completed only pre-group measures. During the new measures trial period, significant differences were found between completers (*Mdn* = 14.50) and non-completers (*Mdn* = 9.00) on the Rosenberg (U = 21.0, z = -2.00, p = .047) and between completers (*Mdn* = 38.00) and non-completers (*Mdn* = 52.00) on the BFNE (U = 29.0, z = -2.06, p = .039). These results suggest that service users who did not attend the last session had significantly lower self-esteem and significantly higher fear of negative evaluation at baseline than service users who attended the final session.

There was no significant difference between pre- and post-group scores for either the WEMWBS or CD-RISC in the period before the new measures were trialled (see Table 5).

Table 5

Mean pre- and post-group scores before new measure trial period

Outcome measure	Scale range	N	Pre mean (SD)	Post mean (SD)	Difference (SD)	95% CIs	p
WEMWBS	14-70	27	40.89 (11.79)	43.33 (11.47)	-2.44 (10.62)	-6.65 1.76	.243
CD-RISC	0-40	27	19.96 (6.13)	21.04 (6.96)	-1.07 (5.17)	-3.12 0.97	.290

There were no significant differences between pre- and post-group scores on any of the measures during the trial period (see Table 6).

Table 6

Mean pre- and post-group scores for recommended measures trialled alongside original measures

Outcome measure	Scale range	N	Pre mean (SD)	Post mean (SD)	Difference (SD)	95% CIs	p
WEMWBS	14-70	29	38.52 (11.13)	37.83 (9.90)	0.69 (5.26)	-1.31 2.69	.486
CD-RISC	0-40	21	18.14 (8.29)	18.95 (7.28)	-0.81 (4.11)	-2.68 1.06	.377
Rosenberg Self-Esteem Scale	0-30	28	14.57 (6.27)	14.11 (6.51)	0.46 (3.12)	-0.75 1.67	.438
Autism Identity	14-98	27	53.41 (9.99)	54.63 (12.73)	-1.22 (9.43)	-4.95 2.51	.506
Positive Distinctive-ness	8-56	26	31.12 (6.39)	32.23 (7.60)	-1.12 (5.16)	-3.20 0.97	.281
BFNE	12-60	26	37.96 (12.36)	37.85 (13.37)	0.12 (6.79)	-2.63 2.86	.932

Histograms depicting the distribution of change in scores by individual were investigated as an informal means of assessing change on each measure (see Appendix J). A range of changes in mean scores was observed for each measure, with a fairly even distribution on either side. It was noted that the majority of group participants showed either no change or a slight positive change in scores on each measure. Measures showing the most positive trend in this regard were the WEMWBS, CD-RISC and Positive Distinctiveness scales.

4. Discussion

This project aimed to improve an adult ASD service's understanding of the outcomes of their post-diagnostic support group (PSG) by investigating service users' perceptions of how the group has benefitted them and providing data on which outcome measures show change in pre- to post-group scores. It was hoped this would allow the service to select the most appropriate measures for monitoring the group's outcomes.

Thematic analysis of interview data from seven service users generated four main themes; meeting others with ASD, a sense of belonging and knowing where to go for professional help (*getting support*); increasing knowledge of autism and making sense of difficulties (*understanding autism*); improvements in social life, communication and general wellbeing (*life changes*); and acceptance of self and diagnosis (*acceptance*). These changes reflect the kinds of benefits proposed by Punshon et al. (2009), who emphasise the benefits of professional and peer support in adjusting to ASD diagnosis, updating negative self-appraisals and gaining a sense of "fitting in".

These themes were used to select new outcome measures for trial in subsequent PSGs. However, quantitative analysis of outcome measures data did not identify any significant differences between pre- and post-group scores on the measures. Informal investigation of histograms plotting distribution of change showed a range of change on all measures, with a fairly even distribution on both sides suggesting that about as many participants showed a deterioration in scores as showed an improvement. The most positive increases in scores were noted on the WEMWBS, CD-RISC and Positive Distinctiveness scales.

The lack of significant change on measures of wellbeing and self-esteem mirrors results found in previous studies of autism support groups. For example, Hayward et al. (2015, May) found an increase in the Autism Knowledge Questionnaire but no change in Rosenberg or WEMWBS scores following a psychoeducation group. Gordon et al. (2015) found an increase in autism self-awareness, however found no increase in Rosenberg

scores. They argue that a global measure of self-esteem such as the Rosenberg may not pick up on changes in specific subtypes of self-esteem, for example in the social domain, which may be most relevant to ASD support groups. Several of the outcome measures chosen for this study, such as the Rosenberg and the CD-RISC, are measures of fairly stable traits and may not be sensitive enough to detect short-term change. Follow-up meetings six to twelve months after the group may reveal whether emotional wellbeing outcome measures have changed in the longer-term as a result of wider changes in the person's life post-diagnosis.

The lack of change may also be due to the fact that these measures were simply unsuitable for measuring the outcomes being achieved by the group. The PSG is not intended to be an emotional wellbeing group, rather it is designed to educate people about ASD and give them an opportunity to make connections with others who have the same diagnosis. It is possible that change would have been detected if more relevant measures were trialled, such as the Autism Knowledge Quiz. Alternatively, more tailored methods of outcome measurement which are designed to measure the group's specific aims may be more appropriate than existing, standardised measures of emotional wellbeing and functioning.

Limitations

There were several limitations to the current study. The small sample size may have limited the power of the quantitative analysis, meaning subtle changes in scores may have been missed. Assuming a relatively small effect size (d = 0.2), a G*Power analysis indicated that approximately 150-200 participants would be required for these analyses to be adequately powered (β = 0.8) at an α level of 0.05.

Furthermore, the lack of a control group makes it difficult to ascribe any change (or lack of change) to group participation. Adding a control group would also allow the researcher to account for effects such as regression to the mean, which may have masked any actual effects of the group.

It is possible that group participants' wellbeing and ability to cope with difficulties did improve as a result of the group, but there was no change in outcome measure scores due to the fact that their awareness of their difficulties also increased. Alternatively, as suggested by two of the interview participants, it may be that longer-term benefits of the group are not detectable immediately after the last session, and outcome measures should be repeated after a follow-up period.

As argued previously, the measures used may not have been sufficiently sensitive to reflect subtle changes. For example, the Rosenberg Self-Esteem scale measures a fairly stable construct, perhaps making it less suitable as a measure of change. It is also possible that standardised mental health measures, such as the BFNE, are not entirely appropriate for measuring outcomes of a group like this, as its aims are focussed on increasing knowledge and self-awareness rather than addressing psychological difficulties.

The process by which the new outcome measures were selected for trial by the service was fairly informal, due to having limited time before the next round of PSGs in which the measures were to be used. A more formal meeting between the researcher, supervisors and team to discuss the final selection of measures may have been helpful, as this may have given the team an opportunity to more carefully consider the relevance and potential advantages and disadvantages of each suggested measure.

Service users gave generally positive feedback about the group. However, it is possible that the service users who responded to invitations to be interviewed were those who had experienced the group positively. Different attitudes about the group and areas of change may have been expressed if service users who did not feel they had benefited from the group had been interviewed. Furthermore, anxiety about meeting someone new may have caused some participants to hold back some of their more critical opinions, or avoid volunteering for the study at all.

Feedback to the service

Results of the thematic analysis were presented at a BASS team meeting in November 2016. Additional themes identified in the thematic analysis were also reported, including: participants' overall positive experience of the group; the role of the PSG as part of a wider process of change, starting at diagnosis; and practical issues encountered in attending the group (such as location, work commitments, and environmental conditions).

The team responded positively to this feedback. They stated that the analysis of service user interviews had been very helpful in informing their understanding of service users' experience of the group, and that these results would be used to adjust and improve the group's content and format in future.

Due to staff changes and time pressures, it was not possible to arrange a meeting in the time available to feed back quantitative results and recommendations to the service. A

meeting has been arranged in July 2017 in which the following recommendations will be made in order to help guide decision-making on outcome measures to be used in future PSGs:

● While quantitative analysis did not indicate any significant changes in outcome measures, the most positive change was detected on the WEMWBS, CD-RISC and Positive Distinctiveness scales.

● Of these, the WEMWBS appears to reflect several of the key themes identified in the thematic analysis, including positive relationships with others, self-acceptance and self-esteem. The Positive Distinctiveness Scale reflects the themes of self-acceptance and gaining a sense of belonging from others with autism.

● Consider acquiring the Autism Knowledge Quiz for trial in future PSG's if the service wishes to measure the group's effect on autism knowledge and self-awareness.

● Instead of using standardised measures, consider designing an idiosyncratic measure for the service based on the group's aims and the themes from the thematic analysis of interview data. This might include items such as "I have a good understanding of how autism affects me" (*understanding autism*), "I am able to communicate about my autism with others" (*life changes - communication*), and "I am comfortable with my diagnosis of autism" (*acceptance*). Once items have been developed they should be trialled in the group so that internal reliability of the new measure can be established.

Clinical implications and suggestions for future research
Research on ASD support groups has so far included fairly small samples. Future research should attempt to use larger samples and control groups in order to further investigate useful outcome measures which meaningfully capture the kinds of benefits identified in the current study's thematic analysis.

Service users perceived several key benefits to the support group; however it was challenging to find a standardised outcome measure that detected clinical change. Future research on ASD support groups should investigate alternatives to standardised measures which better reflect group outcomes. For example, group participants could come up with personal goals, such as socialising or increasing occupational opportunities, which could be measured week-by-week or pre- and post-intervention.

Preliminary analyses showed that non-completers had lower self-esteem and higher fear of negative evaluation at baseline than those who attended the final session. Measures of self-esteem and anxiety might be useful for identifying service users who are more at risk of dropping out from support groups. ASD services should consider ways of making groups more comfortable and attractive to anxious members.

Conclusion

Interviews with seven service users identified a range of potential benefits of attending an adult ASD service's post-diagnostic support group, including peer support, social and communication improvements and self-acceptance. Based on these results, a number of outcome measures were trialled in the group. No significant differences between pre-group and post-group scores were identified; however various limitations of the study make it difficult to draw firm conclusions from these results. Further studies with larger samples and control groups may help to identify and develop useful outcome measures for post-diagnostic support groups. Idiographic and goal-based outcomes should also be considered. The service found the service user feedback useful for shaping their plans for routine outcome monitoring of the group, as well as for developing the group's format and content in the future.

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Main Research Project: What's the problem? Exploring psychological therapists' attitudes towards asexuality

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Word count: 5451

Submission date: June 2017

Target journal: Psychology and Sexuality

This journal was chosen because it has a focus on issues related to sexuality in psychological disciplines. It has published a number of articles on asexuality in the past. (See Appendix Z for author guidelines.)

1. Introduction

1.1 Literature review

Asexuality has been defined as a lack of sexual attraction to either sex (Bogaert, 2004, 2006). About 1% of the population is estimated to be asexual, based on Bogaert's (2004) analysis of 18,000 respondents to a 1994 UK survey on sexual attraction.

There is an ongoing debate within the asexual and medical communities about whether asexuality should be considered a sexual dysfunction. *The Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (DSM-IV) defined Hypoactive Sexual Desire Disorder (HSDD) as "persistently or recurrently deficient" sexual desire causing marked distress or interpersonal difficulty (American Psychiatric Association, 2000). Asexual activists have argued that this definition puts asexuality in the same position as homosexuality during the 1970's and 80's, when the DSM identified 'egodystonic homosexuality' as a disorder consisting of sexual attraction to the same sex causing distress (American Psychiatric Association, 1980). This definition of HSDD would still pathologise asexuals who are not distressed by their lack of sexual attraction *per se,* but experience the distressing effects of social stigma towards their asexual identity.

A task force was set up in 2008 by David Jay, founder of The Asexuality Visibility and Education Network (AVEN), and academic Andrew Hinderliter campaigning for revision of HSDD's definition in the DSM to accommodate asexuality (Hinderliter, 2013). HSDD has since been reclassified in DSM-5 as female sexual interest/arousal disorder and male hypoactive sexual desire disorder (Brotto, 2010a, 2010b), and diagnostic criteria now include a qualifying statement that self-identifying as asexual would preclude diagnosis. This means that people who experience their lack of sexual attraction as distressing can pursue appropriate medical treatment, whereas people who identify as asexual (i.e. experience no sexual attraction to anyone) are not unnecessarily pathologised or labelled with a sexual dysfunction.

Yule, Brotto and Gorzalka (2013) found that asexuals were more likely than heterosexuals to report mental health problems (including depression, anxiety and suicidality) in a web-based survey of physical and mental health. The authors argued that these problems may be linked to experiences of stigma, and point to the large body of research linking mental health status and experiences of stigma in gay and lesbian populations. The elevated risk of mental health problems among asexuals may be usefully understood as a result of 'minority stress' (Meyer, 2003), whereby members of

minority groups suffer mental health problems as a result of stigma, prejudice and discrimination.

According to Herek's (2010) 'differences as deficits' model of sexuality, deviating from (hetero-)sexual norms renders sexual minorities 'substandard' in the eyes of the majority, making them targets for prejudice and discrimination. According to this theory, lacking sexual desire would constitute a transgression of heterosexual norms, making asexuals appear deficient. This is similar to the idea of sexual normativity, which refers to the unconscious assumption that sexuality and the possession of sexual desire is the norm (Chasin, 2015). Przybylo (2011) describes Western culture as 'sexusociety', in which there is an all-encompassing and largely unconscious assumption that sexual desire is normal and innate. Yule et al. (2013) argue that living in a sexualised society may cause asexuals to feel lonely and 'different', which may profoundly affect their mental health.

Asexuals frequently report encountering dismissive and minimising attitudes from others; for example, that asexuality is a stage, that they have not yet met the right person, or that asexuality is a symptom of some deeper psychological problem (see for example Chasin, 2015; Swash, 2012). MacInnis and Hodson (2012) measured heterosexuals' attitudes towards other heterosexuals, homosexuals, bisexuals and asexuals. Using attitude thermometers (indicating favourable or unfavourable views on 1-100 scales) and measures of dehumanization, discrimination and future contact intentions, they found that participants viewed asexuals more negatively and as less human than other sexual minority groups. Hoffarth, Drolet, Hodson and Hafer (2015) expanded on this work, introducing a novel measure of prejudice, the Attitudes Towards Asexuals (ATA) scale (see 2.3 Measures). Similarly to MacInnis and Hodson (2012), Hoffarth et al. (2015) found evidence of negative attitudes and discrimination intentions towards asexuals, which were associated with measures of prejudice-relevant constructs such as right wing authoritarianism (RWA) and social dominance orientation (SDO). Less prejudice was found among respondents who were familiar with asexuality and knew at least one asexual person. This is consistent with intergroup contact theory (Allport, 1954), which states that interpersonal contact can help to reduce prejudice towards minority groups.

Since there is evidence that many asexuals experience stigma and mental health difficulties, it is likely that a significant number of asexuals are accessing mental health services for support. Foster & Scherrer (2014) carried out an online survey of asexual respondents' experiences with mental health professionals and physicians. While respondents considered their asexual identity to be normal and healthy, some reported not disclosing it to their clinicians for fear of negative and invalidating treatment. The

authors point out that decisions not to disclose may deprive asexual clients of opportunities to access appropriate care and support. These findings are backed up by accounts in the news and online media from asexuals reporting that they have encountered a lack of understanding from therapists which deterred them from seeking professional support for mental health problems (Decker, 2015; Kelly, 2015).

Research over the past few decades has found negative attitudes among psychiatrists and psychotherapists towards gay and lesbian clients (Bhugra, 1989; King, 2011; Lilling & Friedman, 1995). A recent survey of 1328 mental health practitioners in the UK found that a significant proportion (17%) reported having attempted to help at least one homosexual client change their sexual orientation (Bartlett, Smith, & King, 2009). It is therefore likely that negative and pathologising attitudes towards asexuality currently exist among mental health professionals. This may have negative effects on the therapeutic alliance and discourage asexual clients from disclosing their asexuality to therapists, or even from attending services altogether (Foster & Scherrer, 2014). However, it is currently unclear to what extent mental health professionals view asexuality as a dysfunction as no studies have so far attempted to investigate this important issue.

1.2 The current study

The current study aimed to investigate psychological therapists' attitudes towards asexuality by administering a short online questionnaire. It was hoped that this would provide a better understanding of how clinicians view this increasingly visible minority sexual identity and potentially reveal any unmet training needs. The study also aimed to validate a new measure of psychological therapists' tendency to pathologise asexuality.

1.3 Research questions

1) How familiar do psychological therapists claim to be with asexuality?
2) To what extent do psychological therapists view asexuality as a problem or psychological disorder?
3) Are therapists' attitudes towards asexuals related to their level of claimed familiarity with asexuality?
4) To what extent are therapists' attitudes affected by other factors such as gender, sexual orientation, bias against single people and right wing views?

The primary hypothesis was that participants who claimed to be familiar with asexuality would score lower on a measure of pathologising attitudes towards asexuals than participants who say they are unfamiliar with asexuality.

2. Method

2.1 Design

The study took a cross-sectional questionnaire design, including validation of a new outcome measure of pathologisation of asexuals.

2.2 Participants

Psychological therapists in the UK working in NHS or private settings were recruited to participate in an online survey. Recruitment took place via adverts on social media and emails sent to the researchers' professional contacts. Invitation emails with a link to the online survey and study information were sent to NHS psychological therapists via lead clinicians working in four local NHS Trusts.

Of the 210 participants recruited, one was excluded as they indicated they were an undergraduate student on placement in an Increasing Access to Psychological Therapies (IAPT) team, leaving a total sample of 209. Demographic characteristics of the sample are presented in Table 7.

Forty participants expressed interest in taking part in a follow-up survey, 24 of whom participated. The demographics of both groups were similar.

Table 7

Demographic characteristics of main sample and follow-up study sample. Follow-up refers to a
subsample who re-took the CATA measure two to four weeks after the original questionnaire

	Main study N	Main study %	Follow-up N	Follow-up %
Total sample	209	-	24	-
Qualification status				
Qualified	129	61.7%	16	66.7%
In training	80	38.3%	8	33.3%
Job title				
Clinical psychologist	146	70.2%	17	70.8%
IAPT therapist	23	11%	2	8.3%
Family therapist	16	7.7%	2	8.3%
Counselling psychologist	8	3.8%	1	4.2%
Psychodynamic psychotherapist	3	1.4%	0	0%
Other	12	5.7%	2	8.3%
Age				
18-30	76	36.4%	9	37.5%
31-40	61	29.2%	8	33.3%
41-50	35	16.7%	3	12.5%
51-60	31	14.8%	4	16.7%
61-70	6	2.9%	0	0%
Gender				
Woman	177	84.7%	21	87.5%
Man	31	14.8%	2	8.3%
Prefer not to say	1	0.5%	1	4.2%
Sexual orientation				
Heterosexual	163	78%	17	70.8%
Homosexual	15	7.1%	1	4.2%
Bisexual	13	6.2%	3	12.5%
Asexual	1	0.5%	0	0%
Transsexual	0	0.0%	0	0%
Other	7	3.3%	1	4.2%
Prefer not to say	10	4.8%	2	8.3%

Note. Participants who chose "Other" for job title listed: clinical neuropsychologist, health psychologist, cognitive analytical psychotherapist, CBT therapist (N=3), integrative therapist, integrative psychotherapist, humanistic integrative counsellor, psychotherapist (N=2) and transpersonal psychotherapist.

Participants who chose "Other" for sexual orientation listed: pansexual, sexually fluid, heterosexual but querying another category (N=2), and rejecting the notion of classifying themselves under one category (N=3).

2.3 Measures

2.3.1 Clinician Attitudes Towards Asexuals scale

A novel measure was designed in order to measure therapists' tendency to pathologise asexuality. The scale was based on Hoffarth et al.'s (2015) Attitudes Towards Asexuals scale and comprises a series of statements to which the participant responds on a scale from 1 (completely disagree) to 9 (completely agree). Higher scores indicate greater pathologisation of asexuality.

The lead researcher invited clinical psychologists from two local NHS community mental health teams to take part in focus groups in order to generate items for the scale. Two focus groups with five clinical psychologists (three in the first, two in the second) were conducted in July 2016. The focus groups took place in private meeting rooms on sites where the teams were based and lasted for an hour. Focus group attendees were invited to imagine the kinds of attitudes prejudiced clinicians might hold about asexual clients. Both sessions were audio recorded and transcribed in order to extract themes to inform items making up the CATA measure (see Appendix L for a brief summary of themes.)

Fourteen items were generated from focus group findings (Appendix M). These items were posted on an AVEN research forum thread with an invitation to forum users to comment and provide feedback. Several forum users commented that these items appropriately reflected the kinds of views that asexuals might encounter when visiting a mental health professional. Another commenter suggested including an item about romantic relationships. The scale items were refined on the basis of this feedback, and a final list of 16 items was used in the online survey (Appendix N).

2.3.2 Other measures

Familiarity with asexuality

Participants were asked whether they had heard of asexuality, met anyone asexual or worked with someone asexual. Answer options were *yes*, *no* or *not sure*. Participants indicated where they had gained their knowledge of asexuality, such as their personal lives or professional training.

Attitudes Towards Asexuals scale (ATA; Hoffarth et al., 2015)

A 16-item scale measuring prejudice towards asexuality. Respondents indicate agreement with a series of statements on 9-point Likert scales from 1 (strongly disagree) to 9 (strongly agree), with three items reverse-coded. Higher scores reflect a greater degree of bias against asexuals. The authors found the scale to have good internal reliability (α = .94).

Right-Wing Authoritarianism (RWA; Altemeyer, 1996)

Twelve items from Altemeyer's scale were administered (as in Hoffarth et al., 2015; MacInnis & Hodson, 2012). Items are rated from 1 (completely disagree) to 9 (completely agree), with six items reverse-coded. Higher scores indicate greater tendency towards following established social conventions and authorities and condemning those who do not. The scale has good internal consistency (α = .92; Altemeyer, 1998).

Social Dominance Orientation (SDO; Pratto, Sidanius, Stallworth, & Malle, 1994)

A 16-item measure of tendency towards group-based discrimination and preference for hierarchy within social systems. Participants rate their feelings on each item from 1 (very negative) to 7 (very positive). Eight items are reverse-coded. Higher scores indicate greater SDO. The authors found the SDO to have high internal consistency (α = .91).

Negative Stereotyping of Single Persons Scale (NSSP; Pignotti & Abell, 2009)

This 30-item scale measures attitudes towards marriage versus singleness and the perceived consequences and causes of being single. Statements are rated from 1 (completely disagree) to 7 (completely agree). The authors found a high degree of internal consistency (α = .95).

Attitude thermometers (MacInnis & Hodson, 2012)

Participants were asked to indicate their liking of men and women from five different groups (heterosexuals, homosexuals, bisexuals, asexuals and transsexuals) on scales divided into 10-point range increments, from 1-10 (extremely unfavourable) to 91-100 (extremely favourable). Averages of male and female attitude thermometers were calculated[1]. Higher scores indicate greater liking of the group.

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[1] Male and female attitude thermometers were highly correlated; heterosexuals (r = .79), homosexuals (r = .95), bisexuals (r = .91), asexuals (r = .99) and transsexuals (r = .99), all p values < .001.

Future contact intentions (Husnu & Crisp, 2010)

Four items concerning interest in and likelihood of interacting with a member of each of the five groups (heterosexuals, homosexuals, bisexuals, asexuals, transsexuals) were administered. Items were rated from 1 (not at all) to 7 (very). Items for each group were averaged, with higher scores indicating greater future contact intentions.

Discrimination intentions (MacInnis & Hodson, 2012)

Two items measuring how comfortable participants would feel renting property to or hiring members of the five groups were administered. Items were rated from 1 (extremely uncomfortable) to 11 (extremely comfortable) and averaged, with higher scores indicating lower levels of discrimination.

Clinician comfort and confidence

Based on MacInnis and Hodson's (2012) "Discrimination intentions", this consists of two questions asking how comfortable and confident participants would feel working clinically with members of the five groups. Items are rated from 1 (not at all) to 7 (very much), with higher scores indicating greater comfort and confidence.

2.4 Procedure

Data were collected via an online questionnaire (Appendix O). Participants following a link to the survey were presented with an information sheet and an invitation to contact the research team if they had any questions (appendix P). On the following page participants gave consent to go ahead with the study. Participants were asked to enter a nickname which served as an anonymous identifier for their data.

Once they had finished the survey, participants arrived at a debrief page explaining the purpose of the study and inviting them to take part in a follow-up survey (Appendix Q). Participants opting into the follow-up clicked a link to a separate webpage where they could enter their email address. These participants were sent an email with a link to the follow-up survey two to four weeks later.

The follow-up questionnaire included an information sheet (Appendix R), consent form and the CATA scale. Participants were asked to enter the nickname they had used for the original study, so that their follow-up and original data could be linked.

2.5 Ethical considerations

The University of Bath Psychology Ethics Committee granted approval for the study to take place (approval ID 16-212; Appendices S & T). HRA approval was granted for recruitment of psychotherapists through the NHS (IRAS project ID 212832; Appendix U). NHS Trust Research and Development (R&D) departments gave approvals for local collaborators to be approached and invitation emails to be sent using NHS email systems (Appendix V). Permission was granted by moderators of the AVEN forums for draft CATA scale items to be posted in order to invite feedback from forum users during the design stage (Appendix W).

The questionnaire was anonymous and did not ask participants to give identifying details or places of work. Participant email addresses were kept separate from study data in order to preserve anonymity. Use of participant nicknames meant that survey data could be removed if participants later decided to withdraw from the study. Participants were informed of the right to withdraw at any time and the procedure for doing so before the start of the survey, and were reminded of this again in the debrief.

2.6 Data analysis

Data were entered into IBM SPSS Statistics 22 for quantitative analysis. If only one data point was missing on any given measure, this point was replaced with the participant's modal score on that measure. If more than one data point was missing the participant's data on that measure was excluded from analyses.

Prior to the analysis, all data were checked for normality by examining histograms, skewness and kurtosis statistics, p-p and q-q plots, and Kolmogorov-Smirnov and Shapiro-Wilk statistics.

2.6.1 Validation of CATA scale

An exploratory factor analysis of CATA scale items was undertaken to examine the scale's dimensionality. Items falling within the main identified factors were retained for the ensuing analyses. Internal consistency of scale items was examined using intraclass correlations. Test-retest reliability was analysed using Pearson's r correlations on data from participants who retook the CATA two to four weeks after completing the main survey.

Convergent validity was examined by calculating Pearson's r correlations for the CATA scale with other measures of anti-asexual bias (ATA score and attitude thermometers), prejudice-relevant constructs (RWA, SDO), measures of anti-asexual intentions (discrimination intentions, future contact intentions) and attitudes towards working clinically with asexuals (clinician comfort and confidence). Partial correlations were calculated to establish discriminant validity by ensuring the above relations held when controlling for bias against single people (NSSP), as asexuals are, on average, less likely to be in a long-term relationship than non-asexuals (Bogaert, 2004).

Face validity of CATA items was ascertained by consulting with users of AVEN forums, who fed back on the relevance of the attitudes expressed in the scale.

2.6.2 Familiarity with asexuality

In order to test the study's primary hypothesis, independent samples t-tests were used to investigate whether there was a difference in CATA subscale scores between participants who answered yes and no to the question "Have you ever met someone asexual?" Analysis of covariance (ANCOVA) was undertaken to investigate whether differences held while controlling for singlism (NSSP score) as a potential confound. Participants who answered "not sure" were excluded from analyses.

2.6.3 Further analyses

Further analyses were undertaken to investigate other factors which may affect therapists' attitudes towards asexuality. A two-way analysis of variance (ANOVA) investigating the effects of gender and sexual orientation on CATA scores was conducted. It was expected that heterosexual and male participants would score higher on the CATA scale (indicating more pathologising attitudes towards asexuals) than LGBT and female participants, in line with previous findings on gender differences in prejudice against minority sexualities (Herek, 1988; Hoffarth et al., 2015). An independent samples t-test was used to compare the CATA scores of trainee and qualified therapists. It was hypothesised that trainee therapists would score lower on the CATA scale than qualified therapists, possibly as a function of being, on balance, younger and perhaps more likely to have been exposed to asexuality via up-to-date sexuality training or social media.

3. Results

3.1 Refinement of Clinician Attitudes Towards Asexuals scale

3.1.1 Factor analysis

Prior to the factor analysis, individual CATA item data were checked for normality and a correlation matrix was checked for particularly low or high correlations between scale items. On the basis of these investigations, items 8 ("It is completely possible for someone who does not experience sexual desire to be happy and fulfilled"), 13 ("I would feel comfortable working with an asexual client"), 14 ("Asexuality is a cultural trend which will sooner or later go out of fashion") and 15 ("Asexuality is to be expected in certain clients, for example disabled or older clients") were removed due to low levels of correlation with all other items ($r = .3$ or less) and, in the case of item 8, high levels of skewness and kurtosis.

A factor analysis using the Principal Axis Factoring method with Oblimin rotation was undertaken on the remaining 12 CATA scale items. The participant to item ratio and Kaiser-Meyer-Olkin (KMO) value (.874) indicated that the sample size was adequate for factor analysis. Bartlett's test of sphericity was significant, suggesting that factor analysis was a suitable method for analysing this data.

SPSS extracted two factors (based on an eigenvalue cut-off of 1), explaining 44.64% of the variance. Examination of the scree plot (Appendix X) appeared to support a one-factor model; however examination of the factor loadings indicated that the second factor was distinct from the first, with none of the items on factor 2 loading above .3 on factor 1 (see Table 8).

Examination of the pattern matrix suggested that the first factor, made up of 9 items, concerns asexuality as a distressing problem that can conceivably be addressed by a therapist (factor entitled "Asexuality as a problem"). The second factor, made up of the remaining 3 items, seems to be about asexuals being deeply disordered people (entitled "Asexuals as disordered"). Examination of the structure matrix supported this pattern. The correlation between the two factors was moderate ($r = -.67$). An item cut-off factor loading of .4 was chosen for inclusion in the scale in order to make sure subscales were satisfactorily cohesive while ensuring a sufficient number of items were retained. One item was removed due to its low loading on factor 1, leaving 11 items which were used in subsequent analyses.

Table 8

Means, standard deviations and rotated factor loadings for CATA scale items (factor loadings below .3 have been suppressed)

Item	Asexuality as a problem	Asexuals as disordered	Mean	SD
Asexuality is a difficulty that we as mental health professionals have a responsibility to address.	.830		3.14	2.03
Asexuality is a psychological disorder.	.618		2.38	1.72
Asexuals would feel better if they allowed a therapist to help them discover their true sexuality.	.579		2.33	1.55
Therapists should discuss with their asexual clients whether they want help reconnecting with their sexual feelings.	.450		4.69	2.12
If a client told me they were asexual I would wonder what has made them this way.	.448		5.24	2.40
If my client told me either they or their partner were asexual, I would assume their relationship was in trouble.	.446		3.00	1.89
If one of my "asexual" clients told me they have engaged in sexual activity in the past, I would question whether they are really asexual.	.429		2.54	1.76
If a client told me they were asexual I would assume this was a problem for them.	.422		2.67	1.78
When an asexual person seeks support from a mental health professional, it is probably because their lack of sexual desire is causing them distress.*	.316		2.74	1.79
Asexuals are repressing their sexual desires.		-.838	2.75	1.84
People who call themselves asexual have a fear of intimacy.		-.829	1.90	0.54
Most asexuals have probably experienced some kind of abuse or trauma in the past.		-.605	3.37	1.89

* Item removed from subscale due to low factor loading.

3.1.2 Reliability

Intraclass correlations were calculated for all 11 retained items in order to investigate internal consistency of the measure. The overall scale had good internal consistency (α = .87), as did the two subscales, *asexuality as a problem* (α = .81) and *asexuals as disordered* (α = .86).

CATA scores at times 1 and 2 were compared in the sample of 24 participants who retook the scale two to four weeks later using Pearson's correlations. The 11-item scale showed a good level of test-retest reliability (r = .84, p < .001), as did the two subscales, *asexuality as a problem* (r = .83, p < .001) and *asexuals as disordered* (r = .81, p < .001).

3.1.3 Validity

On examination of descriptive data, histograms, P-P and Q-Q plots it was noted that data at times deviated from optimal normality levels, however were satisfactory for planned analyses.

CATA subscale scores showed a moderate positive correlation with the NSSP scale (singlism): *problem* subscale r = .40, p < .001; *disordered* subscale r = .44, p < .001 (see Table 9). As expected, CATA subscale scores were positively related to ATA scores, and this relationship remained significant when controlling for NSSP: *problem* subscale r = .52, p < .001; *disordered* subscale r = .50, p < .001. CATA scores were also positively related to SDO: r = .25 & .26, p < .001; however this correlation was not significant when controlling for NSSP. Contrary to expectation, there was no relationship between CATA scores and the asexuals attitude thermometer or RWA.

Correlations between CATA subscales and measures of future contact intentions, discrimination intentions and clinician comfort and confidence were very small and largely nonsignificant after controlling for singlism (see Appendix Y).

Table 9

CATA subscales bivariate and partial correlations (controlling for singlism) with prejudice-relevant constructs

Scale	Scale	Mean	SD	Range	CATA 1 r	CATA 1 pr (NSSP)	CATA 2 r	CATA 2 pr (NSSP)
CATA (11-item scale)	1-9	3.19	1.27	1.00 – 7.18	-	-	-	-
CATA subscale 1 "Asexuality as a problem"	1-9	3.25	1.26	1.00 – 6.38	-	-	.68**	.61**
CATA subscale 2 "Asexuals as disordered"	1-9	3.04	1.66	1.00 – 8.00	-	-	-	-
ATA	1-9	2.02	0.75	1.00 – 4.38	.62**	.52**	.63**	.50**
RWA	1-9	2.00	0.83	1.00 – 4.67	.10	-.001	.12	.004
SDO	1-7	1.37	0.49	1.00 – 4.19	.25**	.12	.26**	.09
NSSP	1-7	2.11	0.84	1.00 – 4.87	.40**	-	.44**	-
Attitude thermometers	1-10							
Heterosexual		9.21	1.38	5 -10	.01	.07	-.08	-.04
Homosexual		9.17	1.43	4-10	-.01	.04	-.10	-.07
Bisexual		9.09	1.48	4-10	-.05	-.01	-.15*	-.12
Asexual		9.13	1.41	4.5-10	-.03	.06	-.12	-.04
Transsexual		8.94	1.62	2-10	-.07	.04	-.18**	-.09

** Significant at .01 level

* Significant at .05 level

3.2 Familiarity with asexuality

Table 10 shows frequencies for familiarity with asexuality items. Almost the entire sample (94%) claimed to have heard of asexuality prior to the study. The most common sources of knowledge reported were personal experience, their own reading and the media. The least common reasons for having heard of asexuality were work-related (professional training, clinical work and CPD events).

Table 10

Frequencies for familiarity with asexuality items

Familiarity item	N	%
Have you ever heard of asexuality before this study?		
Yes	197	94.3%
No	5	2.4%
Not sure	7	3.3%
If you have some knowledge of asexuality, where has this come from? (tick all that apply)		
Personal life	92	44%
Own reading	94	45%
Media – TV, news, social media, etc.	39	18.7%
Education	32	15.3%
Professional training	27	12.9%
Clinical work	10	4.8%
CPD event	10	4.8%
Have you ever met someone asexual?		
Yes	67	32.1%
No	42	20.1%
Not sure	100	47.8%
Have you ever worked clinically with someone asexual?		
Yes	32	15.3%
No	104	49.8%
Not sure	73	34.9%
How motivated do you feel to undertake training which includes information on asexuality?		
Not at all motivated	7	3.3%
Somewhat unmotivated	19	9.1%
Neither motivated nor unmotivated	41	19.6%
Somewhat motivated	105	50.2%
Very motivated	37	17.7%

Mean CATA subscale scores for participants answering "yes" and "no" to the question "Have you ever met someone asexual?" are presented in Table 11.

Table 11

Mean CATA subscale scores for participants who have and have not met someone asexual

	Asexuality as a problem Mean (SD)	Asexuals as disordered Mean (SD)
Met someone asexual		
Yes (N = 67)	3.13 (1.24)	2.91 (1.65)
No (N = 42)	3.71 (1.27)	3.44 (1.81)

Participants who answered "yes" to this question scored significantly lower on the CATA *problem* subscale than participants who answered "no", indicating less pathologisation of asexuality, t(107) = -2.38, p = .019. No significant difference was seen on the *disordered* subscale, t(107) = -1.58, p = .118.

ANCOVA was used to compare CATA *problem* subscale scores for participants who had answered yes or no while controlling for singlism (NSSP). The difference between the groups was approaching but did not quite reach significance, F(1, 106) = 3.74, p = .056.

3.3 Further analyses

Two-way ANOVA was conducted comparing CATA subscale scores between participants based on gender (woman vs. man) and sexuality (heterosexual vs. non-heterosexual). On the CATA *problem* subscale there was no interaction between gender and sexuality (F(1, 194) = 2.07, p = .152). There was no main effect of sexuality (F(1, 194) = 0.43, p = .511), however there was a main effect of gender, F(1, 194) = 11.47, p = .001, such that women (M = 3.15, SD = 1.24) had lower CATA scores than men (M = 3.84, SD = 1.25). There was no significant interaction (F(1, 194) = 0.11, p = .737) or main effects of gender (F(1, 194) = 2.59, p = .109) or sexuality (F(1, 194) = -.32, p = .570) on the *disordered* subscale.

Independent samples t-tests found no significant difference between trainee and qualified therapists on either the *problem* (t(206) = 0.66, p = .513) or *disordered* subscales (t(206) = 1.29, p = .199).

4. Discussion

An online survey of 209 UK psychological therapists working in the NHS and private practice was carried out to investigate therapists' familiarity with and attitudes towards asexuality, and to validate a new measure of pathologisation of asexuals.

4.1 CATA scale development

A new 11-item scale for measuring psychological therapists' attitudes towards asexuality was developed. Exploratory factor analysis identified two reliable factors representing the ideas that asexuality is a problem and asexuals are psychologically disordered. The CATA subscales had acceptable levels of internal and test-retest reliability. Convergent validity with the ATA scale was found. However, against expectation the CATA subscales did not correlate significantly with an asexuality attitude thermometer, and correlations with prejudice-relevant constructs (SDO, RWA) and intentions to discriminate against asexuals were not significant when controlling for singlism (NSSP).

The absence of correlations between the CATA and several of the prejudice-relevant measures may be an indicator that pathologisation of asexuals is not a form of prejudice per se. This would also account for why the CATA correlated only moderately with the ATA, a measure of prejudice towards asexuals. It may be that therapists who scored high on the CATA do not see asexuality as morally wrong or a reflection on asexuals as people, rather as an unusual aspect of their identity which constitutes a potentially distressing problem.

4.2 Findings and clinical implications

4.2.1 How familiar do psychological therapists claim to be with asexuality?

Almost the entire sample (94%) claimed to be familiar with the concept of asexuality. This may be because therapists who had not heard of asexuality were less likely to take part. Alternatively, participants may have claimed to be familiar with asexuality when they in fact knew little about it due to social desirability bias. However, the study's design did not allow researchers to distinguish between claimed and actual familiarity. The majority of participants reported gaining their knowledge from personal contexts such as their private lives, reading about asexuality and the media. Relatively few participants had heard of asexuality through their clinical work or training. This suggests that psychological therapists are gaining what knowledge of asexuality they have from similar sources to the general population.

4.2.2 To what extent do psychological therapists view asexuality as a problem or psychological disorder?

CATA scores tended to fall below the scale mid-point (subscale Ms = 3.25 and 3.09 on 1-9 scales), suggesting relatively low levels of pathologisation in the current study's sample. This is encouraging for asexual service users in UK mental health services. However, Hoffarth et al. (2015) point out that scores below the scale mid-point are fairly typical in measures of bias, and without any data to compare this result to it is difficult to draw any firm conclusions from this finding. Furthermore, the range of scores on the two subscales was fairly broad, indicating a wide range in levels of pathologisation of asexuals from low (1.00) to relatively high (6.38 and 8.00).

It is worth noting that Hoffarth et al.'s (2015) sample mean on the ATA scale was 3.26 (SD 1.63), while the current study's ATA mean was 2.02 (SD 0.75). This suggests that the current study's sample of psychological therapists may show less prejudice towards asexuals than Hoffarth et al.'s (2015) US general population sample. The current sample's relatively low CATA and ATA scores may be accounted for by the fact that the sample was made up of psychological therapists who, as mental health professionals, tend to have a good understanding of diversity and difference and take a compassionate stance towards their clients. It is likely that participants were aware that they were being invited to participate in their capacity as therapists, and some may even have filled out the questionnaire in their place of work. This may mean that they were more likely to be in a professional, non-judgmental frame of mind while participating, leading to generally low scores.

4.2.3 Are therapists' attitudes towards asexuals related to their level of claimed familiarity with asexuality?

It was hypothesised that participants who claimed to be familiar with asexuality would score lower on the CATA scale than participants who said they were unfamiliar with asexuality. There was a significant difference on the CATA *problem* subscale between participants who did and did not claim to have met someone asexual, suggesting that therapists who have met someone asexual are less likely to think of it as a disorder. This is consistent with intergroup contact theory (Allport, 1954) and previous findings that contact with members of social groups can reduce prejudice and intergroup conflict (Pettigrew & Tropp, 2006). It is possible that education on asexuality involving asexual service users may be beneficial for psychological therapists' understanding of asexuality as a sexual identity rather than a disorder.

It is notable that the difference in CATA *problem* scores between participants who claimed to have met someone asexual and those who did not became non-significant when controlling for singlism (NSSP scores). It is possible that bias against single people and pathologisation of asexuality may be underpinned by similar attitudes, which may account for the level of shared variance between the two scales. Hoffarth (2015) has suggested that anti-asexual bias may stem from the widely-held notion that sexual relationships are crucial for happiness. This relates to the concept of sexual normativity (see Chasin, 2015), which may underlie both negative attitudes towards single people and the assumption that asexuality is a disorder. This hypothesis is highly speculative, but may be worth investigating further in future research.

4.2.4 To what extent are therapists' attitudes affected by other factors?

It was hypothesised that male and heterosexual participants would score higher on the CATA scale than female and LGBT participants. As expected, women scored lower than men on the CATA scale, reflecting a tendency for women to score lower on measures of prejudice (e.g. Herek, 1988; Hoffarth et al., 2015; MacInnis & Hodson, 2012). However, there was no difference in scores between heterosexual and non-heterosexual participants. The non-heterosexual subgroup of the sample was fairly small (N = 36), which may account for this finding. Alternatively, it is possible that non-asexual LGBT participants are as likely as heterosexual participants to view lack of sexual desire as different and therefore deficient (Herek, 2010). Further research would be needed to begin investigating this hypothesis.

4.3 Limitations and future research

The current research was cross-sectional in design so long-term outcomes and predictors of attitudes towards asexuality could not be measured. Furthermore, the online questionnaire design and quantitative methods used did not allow for a deeper investigation of how therapists' CATA scores translate into pathologisation or discrimination towards asexuals in real-life practice. Further research could be undertaken using the CATA scale alongside qualitative methods investigating the experiences and views of psychological therapists who have worked with asexual clients. The views of asexual clients should also be sought in order to investigate how therapists' attitudes affect the therapeutic relationship and clients' experiences of therapy.

The definition of asexuality provided at the beginning of the questionnaire was brief and may have left some clinicians unsure of what it meant. For example, some therapists may have answered the questions assuming that asexuality includes people who lack

sexual desire and are distressed by this, thus conflating asexuals with people who may qualify for a diagnosis such as HSDD. This may account for some of the higher CATA scores observed in this sample. Providing a more exact definition of asexuality may have allowed for better discrimination between those who genuinely consider asexuality to be a disorder, regardless of whether the individual is distressed by their lack of sexual attraction, and those who were confusing asexuals with people who would qualify for an HSDD diagnosis.

Given the limited convergent validity found between the CATA and prejudice-relevant measures such as the RWA, SDO and asexual attitude thermometer, further research should investigate other possible correlates of the CATA scale.

Since relatively few participants reported receiving formal training on asexuality, it may be interesting for future research to investigate whether educational interventions on asexuality are associated with a reduction in CATA scores, and whether these reductions are maintained at long-term follow-up. The views and experiences of asexual service users should be sought in order to investigate whether educational interventions are associated with improved therapeutic relationships and service user experiences (see Foster & Scherrer, 2014).

4.4 Conclusion

A study of 209 psychological therapists in the UK was used to develop a new measure of pathologisation of asexuality. Participants reported a high level of claimed familiarity with asexuality, with participants claiming to be familiar scoring lower on the new measure. However, this was not the case when controlling for bias against single people, suggesting a relationship or common underlying factor between the constructs of viewing asexuality as a disorder and viewing single people negatively. As expected, women showed lower levels of pathologisation than men, however LGBT participants were no less likely to pathologise than heterosexual participants. Future research should now focus on investigating whether and how pathologising attitudes towards asexuality translate into therapists' clinical practice, and the effects of therapists' attitudes on asexual clients' experiences of therapy and the therapeutic alliance.

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Executive Summary

Asexuality is defined as a lack of sexual attraction to either sex. About 1% of the population is estimated to be asexual, based on Bogaert's (2004) analysis of 18,000 respondents to a 1994 UK survey on sexual attraction.

There is an ongoing debate within the asexual and medical communities about whether or not asexuality should be considered a sexual dysfunction. Following campaigning by asexual activists, the DSM-IV diagnosis Hypoactive Sexual Desire Disorder (HSDD) was redefined in DSM 5 so that people who identify as asexual would not be included under this diagnosis.

There is evidence that asexuals may suffer mental health problems at a higher rate than heterosexuals. This may be due to 'minority stress' (Meyer, 2003), whereby members of minority groups suffer mental health problems as a result of stigma, prejudice and discrimination. We live in an extremely sexualised society in which sexual relationships are highly valued. This may cause asexuals to feel marginalised and different from others, contributing to the development of mental health problems.

There is growing evidence that asexuals experience prejudice from the general population. Anecdotally, asexuals frequently report encountering dismissive and minimising attitudes from family, friends and acquaintances; for example, that they have not yet met the right person or that asexuality is a symptom of some deeper problem. Research has found that heterosexuals view asexuals as less human than other sexual minority groups, and that prejudice towards asexuals is associated with right wing authoritarianism (RWA), social dominance orientation (SDO), religious fundamentalism, sexism and gender role identification. Heterosexuals who are familiar with asexuality and know at least one asexual person have been found to be less prejudiced towards asexuals. This is consistent with intergroup contact theory (Allport, 1954), which states that interpersonal contact is one of the best ways to reduce prejudice towards minority group members.

An online survey of asexuals who have experienced psychological therapy found that some participants feared negative and invalidating treatment from clinicians, and did not disclose their asexual identity as a result. This may be depriving asexuals with mental health difficulties of opportunities to access appropriate care and support. Research over the past few decades has found evidence that some psychiatrists and psychotherapists hold negative attitudes towards lesbian and gay clients, and a 2009

survey of mental health practitioners found that 17% of respondents had attempted to help at least one homosexual client change their sexual orientation. In light of these findings and the recent debates around whether asexuality should be classed as a sexual dysfunction, it seems likely that some mental health professionals may hold negative attitudes towards asexuals.

This research study aimed to find out how familiar with asexuality psychological therapists claim to be, to what extent they view asexuality as a problem or sexual dysfunction, and to what extent their attitudes are related to their familiarity with asexuality and other factors such as gender, sexual orientation and right wing views. It was expected that being familiar with asexuality would be associated with more positive attitudes towards it.

Psychological therapists in the UK were invited to take part in the study via social media, the researchers' professional contacts and emails via lead clinicians working in several local NHS trusts. 209 psychological therapists working in the NHS and in private practice took part, including clinical psychologists, counselling psychologists, CBT therapists, family therapists and psychodynamic psychotherapists. Participants filled out an online questionnaire including measures of familiarity with asexuality, attitudes towards asexuals, a new measure of how much clinicians view asexuality as a problem, right wing authoritarianism, social dominance orientation, and bias against single people (as asexuals are, in general, more likely than non-asexuals to be single).

Participants tended to have low scores on the attitude measures, suggesting they held low levels of prejudice and generally did not view asexuality as a problem. Results showed that, where asexuality was viewed as a problem, this was associated with prejudice towards asexuals, bias against single people, right wing authoritarianism and social dominance orientation. 94% of the sample claimed to be familiar with asexuality. This knowledge came mainly from participants' own reading and personal experiences rather than through professional training. As expected, participants who said they had met someone asexual were less likely to view asexuality as a problem. Women were less likely to view asexuality as a problem than men, however being a member of a sexual minority group did not affect participants' views. There was no difference in views between trainee and qualified therapists.

Future research should now investigate how therapist pathologisation of asexuality affects therapeutic relationships and outcomes by investigating the views and experiences of therapists and asexual clients in greater depth. Given that familiarity with

asexuality may make therapists less likely to pathologise asexual clients, it may also be helpful to investigate whether educational interventions on asexuality are associated with improved therapeutic relationships and service user experiences. Future research could also explore the apparent overlap between pathologisation of asexuality and bias against single people, in order to find out whether any common attitudes underlie these two concepts.

One of the reasons I chose the Bath training course was its strong focus on research. Having enjoyed my experiences of research at undergraduate level and having worked in several research assistant roles, I came to clinical training excited at the prospect of being able to make contributions to the literature in a wide variety of areas. The projects I chose and developed reflect several of my own interests, some which I already held prior to training and some which I developed as a result of my clinical experiences.

Main Research Project

The idea for my main project came early in the course when one of the course tutors, Catherine Butler, mentioned at the end of a lecture that she was interested in supervising projects on sexuality. I had recently become aware of asexuality through a documentary and had been keen to find out more, so I wasted no time in approaching Catherine about supervising me on a project on this topic.

It soon became apparent to me how young the field of asexuality research was, and I was excited at the prospect of making a novel contribution to an area in which research is just getting started. I originally thought about developing a primarily qualitative project investigating asexual clients' experiences of psychological therapy, as there is evidence that some asexuals have had unpleasant experiences with mental health professionals due to assumptions that asexuality must be a psychological or biological disorder. However, I also got thinking about the mental health professionals who are (perhaps unknowingly) working with asexual clients. While there was some literature on the general population's attitudes towards asexuals, it was clear from my reading that no such research had yet taken place with psychological therapists. The idea of a project on social attitudes towards a minority sexuality group appealed to my interests in social justice and sexuality, and I was keen to get started. As the project began to take shape, I was aware of both my excitement at embarking on a research project in such an under-researched area, and the sense of responsibility I felt as a result to produce a high quality, useful piece of research.

As part of this project, I wanted to develop a new outcome measure for mental health professionals measuring their tendency to pathologise asexuality. It felt important to involve key stakeholders in the development of this measure, namely psychological therapists and members of the asexual community. I decided to conduct focus groups with clinical psychologists, and reached out to two psychology teams with whom I was, or had previously been, on placement. The teams were happy to help, however due to

clinical pressures it was difficult to find a time to hold the focus groups that was convenient for everyone. In the end, five clinical psychologists took part across the two focus groups. This was fewer than I would have liked, however the insights and ideas they came up with were incredibly helpful for developing the new measure's items. I then took my draft measure to the forums of the Asexual Visibility and Education Network (AVEN), the largest online community for asexuals, where forum users were kind enough to give me their feedback on the proposed items. I noted that several of the people who responded to my post were excited that research was being conducted on this topic. This has demonstrated to me the importance of involving service users in the research process and how important it is to enable people from minority groups to have their voices heard through research.

The first step in my ethical approvals process was fairly straightforward. I received approval from the university Psychology Ethics Committee to recruit participants through social media and professional contacts. I then applied for HRA approval to recruit NHS therapists through four local Trusts. While it was a relief to find out that NRES approvals would not be required, the process of gaining HRA approval turned out to be more arduous than I had expected. A particular highlight was when I found myself in an approvals triple-lock between the HRA (who wanted the university to confirm their sponsorship before granting approval), the university (who wanted the Psychology Ethics Committee to review their approval before confirming sponsorship), and the Psychology Ethics Committee (who could not re-approve the study without HRA approval). This was possibly the most frustrating part of my research experience while on the course. Luckily, with the support of Paul Salkovskis I was able to communicate with the different parties involved and work out a solution. It did not seem at the time as if the HRA advisors dealing with my case necessarily understood the processes entirely themselves, and it was slightly irritating that I felt it was up to me to bring about a resolution to this problem. One silver lining I have taken away from this experience is that I now feel somewhat better prepared for the kinds of administrative and logistical challenges to expect when I begin conducting research in the NHS as a qualified clinical psychologist. Seeking approvals from each recruiting Trust's Research and Development (R&D) department was an easier task, although differences in each department's requirements did demonstrate the wide range of standards and procedures followed by different organisations across the NHS.

Once all approvals had been granted, recruitment went fairly smoothly. I used a variety of recruitment strategies, including social media, emailing colleagues and clinical contacts, and disseminating invitation emails to NHS therapists via local collaborators in

each recruiting Trust. I was very pleased with the number of participants I was able to recruit, and felt grateful that so many of my colleagues and friends had helped by participating and spreading the word about the study.

My involvement in this research has provided me with several unexpected opportunities. In 2016 I was approached by AVEN moderators to contribute to a letter which was being written to the Office for National Statistics, urging them to include asexuality as a category on the sexual orientation question of the 2021 UK census. I have also been invited to speak about my research at the International Asexuality Conference in Madrid in July 2017. It is a true privilege to have conducted a research project in a field I feel so passionate about and which presents so many opportunities for new and meaningful contributions.

Service Improvement Project

Very soon after finding the idea for my main project, I had a conversation with my clinical tutor Ailsa Russell about the possibility of conducting a service improvement project in an autism service. I had volunteered in a social group for adults with Aspergers for several years before I started training, so I was interested in learning more about local services for people with autism.

Ailsa set up a meeting with Rona Aldridge and Rhian Jenkins, two clinical psychologists from the Bristol Adult Autism Service (BASS), who were very open to talking about possible projects. I was conscious of the need to allow them to come up with the research question, as service improvement projects must always have the needs of the service at their heart. Rona and Rhian suggested a project looking at the outcome measures being used by the service's post-diagnostic support group, as they were keen to find out whether they were using the most appropriate measures for monitoring the group's outcomes, given its aims and content.

It became clear that in order to answer this question, we would need to know what service users themselves felt they got out of the group. This led to my favourite part of this project, in which I got to interview service users about their experiences of the group. Via the service, I sent out letters inviting previous group participants to take part in the interviews. I was happy to receive several positive responses and ended up interviewing seven service users. Each of the interviewees surprised me with the frankness and openness of their answers. I greatly appreciated the opportunity to hear about their stories, experiences and varied journeys to diagnosis and beyond. I also enjoyed having the opportunity to conduct a formal qualitative analysis of my interview data.

The next stage of the project involved trialling new outcome measures with the post-diagnostic support group, based on the results of the thematic analysis. One of the challenges of this process was the limited time available to collect the data, as there was only so much time left once the qualitative stage of the study was complete. This limited the amount of data we could include in the quantitative analysis, as there were only a few groups running during the data collection period. To add to this pressure, not all groups across the region always administered the same outcome measures, meaning some data sets were not complete. However, despite these challenges we ended up with data from enough group participants to go ahead with the quantitative analysis.

Another challenge of this project was that it was difficult at times to meet with my external supervisors due to the demands of their clinical work. This was an insight for me into the realities of working in a busy NHS team, and made me wonder how easy it will actually be to remain involved with research after qualification. This has made me think about negotiating research hours into my future clinical contracts, as without this I can imagine it will be difficult to remain involved in research in the face of the clinical demands of my work.

Literature Review

Despite having a strong academic record, my literature review was the project I felt least confident about. This may be why it took so long for this project to begin taking shape. While I have conducted critical literature reviews in the past, I found the scale of this project and the idea of conducting a doctorate level systematic review quite intimidating.

I initially developed a proposal during first year around investigating theories of self-stigma in psychosis. This was due to my interest in psychosis, which stemmed from my work as a research assistant on a psychosis trial before the course, and my longstanding interest in issues relating to mental health stigma. However, after this proposal was passed, the demands of the course and my other two projects took over, leaving my literature review by the wayside. By the time I began thinking about making a start on this project, towards the end of my second year, I felt so daunted by the scale and theoretical nature of the subject matter that I decided to switch to a new project with a more concrete, limited scope. This coincided with the end of my learning disabilities placement. I had thoroughly enjoyed working in this area, which was to my slight surprise as I had come into training with no experience in learning disabilities. Writing my case study had got me thinking about the dearth of high quality literature in this area, and I felt that I could make a valuable contribution with a systematic review. While I was

disappointed to let my stigma-related project go, this was another area I found interesting, and one in which I felt my work might make a significant difference.

My supervisor, Cathy Randle-Phillips, and I arrived at the idea of a systematic review of bereavement support interventions for people with learning disabilities. What really struck me reading around this topic was how much literature exists making recommendations for best practice, yet how few research studies there are presenting high quality evidence for what works with this population.

Having been through the process of writing a systematic review, I now feel a lot more confident in my abilities to critique research and synthesise large amounts of information. These are key skills for a clinical psychologist, and for all my initial trepidation I am glad I have gone through this process.

Case studies

Writing a case study on each of my clinical placements has been a valuable experience. It has allowed me to dive deep into the literature behind each case, which has given me the opportunity to learn more about the conditions and populations I have been working with. It has also provided chances for me to reflect extensively on my practice with my placement supervisors. Having to find the heuristic value of each case study has helped me to develop my skills in making theory-practice links, and I have begun applying this learning to my clinical work more broadly.

Initially I found conducting single case experimental design (SCED) studies quite challenging. I often had difficulty collecting a full set of baseline measures with any given client, as many services are not set up to routinely allow collection of outcome measure data before a client's first psychology session. However, I have come to appreciate the value of SCEDs as small-scale yet useful contributions to the research evidence base. I feel that the small amount of extra effort involved is worthwhile and intend to use SCED methodology in my clinical practice after qualification.

Conclusion

As I face the prospect of life as a qualified clinical psychologist, my initial enthusiasm for research has not been dampened. I strongly feel that as highly trained, well-rounded professionals, clinical psychologists have a key role to play in contributing to the evidence base for psychological theories and therapies. Bringing together a portfolio of three diverse research projects has allowed me to gain experience in a range of research areas and methodologies, and has helped me begin to appreciate the challenges of

conducting research alongside clinical work in the NHS. I am committed to making research part of my professional life and I believe the lessons I have learned during my training will stand me in good stead for my future career.

Acknowledgements

I owe a great deal of gratitude to the many people who have supported me throughout my training. Without them, I would not be the practitioner or the person I am now.

Thanks must first go to my research project supervisors for helping me put this portfolio together. To Catherine Butler, for your infectious enthusiasm and drive. To Ailsa Russell, for your straight talk and help keeping me on track. To Cathy Randle-Phillips, for your warm manner and cool head. To Paul Salkovskis, for your sage guidance and irreverent humour. Thanks also to Rona Aldridge and Rhian Jenkins for being such great supervisors for my Service Improvement Project.

Even more thanks to Ailsa for supporting me as my clinical tutor. You have helped me make the most of my clinical supervision and learning opportunities and you have shown confidence in me throughout the course. Thank you for all your time and encouragement.

Thank you to my placement supervisors, who put so much work in to my clinical learning and development – Gill Turnbull, Hen Joannidi, Rebecca Guhan, Shaun Brassington, Claire Delaney, Leon Dysch and Kelly Paull. You have inspired me in such different ways and I owe you all so much.

Thanks to all who participated in my research, and to everyone who helped me publicise my main research project. I would like to give a special thanks to Catherine in this regard, for making such amazing use of her professional networks on my behalf!

Thank you to my family for believing in me the whole way through, even when I did not believe in myself. Thank you especially to my brilliant nephew and niece, for reminding me of what really matters and helping me maintain perspective when things got tough.

To my cohort – I feel so lucky to have trained with all sixteen of you. I have never before had the opportunity to work with such a supportive, kind, generous group of people. I have always felt completely safe being open and authentic with you all, and this has made the journey through training so much easier to bear. I am glad to call you all friends. Thank you.

Appendices

Appendix A. Downs and Black Quality Index (Downs & Black, 1998)

Item	Criteria	Possible Answers
Reporting		
1	*Is the hypothesis/aim/objective of the study clearly described?*	Yes = 1 No = 0
2	*Are the main outcomes to be measured clearly described in the Introduction or Methods section?* If the main outcomes are first mentioned in the Results section, the question should be answered no.	Yes = 1 No = 0
3	*Are the characteristics of the patients included in the study clearly described?* In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.	Yes = 1 No = 0
4	*Are the interventions of interest clearly described?* Treatments and placebo (where relevant) that are to be compared should be clearly described.	Yes = 1 No = 0
5	*Are the distributions of principal confounders in each group of subjects to be compared clearly described?* A list of principal confounders is provided.	Yes = 2 Partially = 1 No = 0
6	*Are the main findings of the study clearly described?* Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).	Yes = 1 No = 0
7	*Does the study provide estimates of the random variability in the data for the main outcomes?* In non-normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.	Yes = 1 No = 0
8	*Have all important adverse events that may be a consequence of the intervention been reported?* This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).	Yes = 1 No = 0

9	*Have the characteristics of patients lost to follow-up been described?* This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.	Yes = 1 No = 0
10	*Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?*	Yes = 1 No = 0
External validity		
11	*Were the subjects asked to participate in the study representative of the entire population from which they were recruited?* The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.	Yes = 1 No = 0 Unable to determine = 0
12	*Were those subjects who were prepared to participate representative of the entire population from which they were recruited?* The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.	Yes = 1 No = 0 Unable to determine = 0
13	*Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?* For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.	Yes = 1 No = 0 Unable to determine = 0
Internal validity - bias		
14	*Was an attempt made to blind study subjects to the intervention they have received?* For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.	Yes = 1 No = 0 Unable to determine = 0

15	*Was an attempt made to blind those measuring the main outcomes of the intervention?*	Yes = 1 No = 0 Unable to determine = 0
16	*If any of the results of the study were based on "data dredging", was this made clear?* Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.	Yes = 1 No = 0 Unable to determine = 0
17	*In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?* Where follow-up was the same for all study patients the answer should be yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.	Yes = 1 No = 0 Unable to determine = 0
18	*Were the statistical tests used to assess the main outcomes appropriate?* The statistical techniques used must be appropriate to the data. For example nonparametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.	Yes = 1 No = 0 Unable to determine = 0
19	*Was compliance with the intervention/s reliable?* Where there was noncompliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.	Yes = 1 No = 0 Unable to determine = 0
20	*Were the main outcome measures used accurate (valid and reliable)?* For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.	Yes = 1 No = 0 Unable to determine = 0
Internal validity – confounding (selection bias)		
21	*Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?* For example, patients for all comparison	Yes = 1 No = 0

	groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.	Unable to determine = 0
22	*Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?* For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.	Yes = 1 No = 0 Unable to determine = 0
23	*Were study subjects randomized to intervention groups?* Studies which state that subjects were randomized should be answered yes except where method of randomization would not ensure random allocation. For example alternate allocation would score no because it is predictable.	Yes = 1 No = 0 Unable to determine = 0
24	*Was the randomized intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?* All nonrandomized studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.	Yes = 1 No = 0 Unable to determine = 0
25	*Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?* This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In non-randomized studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.	Yes = 1 No = 0 Unable to determine = 0
26	*Were losses of patients to follow-up taken into account?* If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.	Yes = 1 No = 0 Unable to determine = 0
Power		
27	*Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance*	Size of *smallest*

	is less than 5%? Sample sizes have been calculated to detect a difference of x% and y%.	intervention group $<n_1 = 0$ n_1-$n_2 = 1$ n_3-$n_4 = 2$ n_5-$n_6 = 3$ n_7-$n_8 = 4$ $n_8+ = 5$

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- Family and carers
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- Click the 'Submit' button when you are finished reviewing.

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Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing. The files will be automatically converted to HTML and PDF on upload and will be used for the review process. The text file must contain the entire manuscript including title page, accessible summary, summary, text, references, tables, and figure legends, but *no* embedded figures. Figure tags should be included in the file. Manuscripts should be formatted as described in the Author Guidelines below.

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You may suspend a submission at any phase before clicking the 'Submit' button and save it to submit later. The manuscript can then be located under 'Unsubmitted Manuscripts' and you can click on 'Continue Submission' to continue your submission when you choose to.

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After submission you will receive an e-mail to confirm receipt of your manuscript. If you do not received the confirmation e-mail after 24 hours, please check your e-mail address carefully in the system. If the e-mail address is correct please contact your IT department. The error may be caused by spam filtering software on your e-mail server. Also, the e-mails should be received if the IT department adds our e-mail server (uranus.scholarone.com) to their whitelist.

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3 MANUSCRIPT FORMAT AND STRUCTURE

All manuscripts submitted to British Journal of Learning Disabilities should include: Accessible Summary, Keywords, Abstract, Main Text (divided by appropriate sub headings) and References. Manuscripts should not be more than 5,000 words in length including references.

Title Page: This should include: a short title to indicate content with a sub-title if necessary; the full names of all the authors; the name(s) and address(es) of the institution(s) at which the work was carried out (the present addresses of the authors, if different from the above, should appear in a footnote); the name, address, telephone and fax numbers, and email addresses of the author to whom all correspondence and proofs should be sent; a suggested running title of not more than 50 characters, including spaces should be provided in the header of each page.

Accessible Summary: As well as an abstract, authors must include an easy-to-read summary of their papers. This was introduced in 2005, and was done so in the spirit of making research findings more accessible to people with learning disabilities. The editorial board also believe that this will make 'scanning' the Journal contents easier for all readers. Authors are required to:
- Summarise the content of their paper using bullet points (3 or 4 at most),
- Express their ideas in this summary using straightforward language, and
- State simply why the research is important, and should matter to people with learning disabilities.

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Main Text: The text should then proceed through sections of Background/Introduction, Review of Literature, Research Questions/Hypotheses, Materials, Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style
Abbreviations and symbols:
All symbols and abbreviations should be clearly explained. Abbreviations should not be used when they refer to people (e.g. learning disabilities, not LD; developmental

disabilities, not DD; intellectual disabilities, not ID). Please also use "people with learning disabilities" wherever possible, not "learning disabled people".

References: List all sources in the reference list alphabetically by name. . In text citations should follow the author-date method. This means that the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998), and a complete reference should appear in the reference list at the end of the paper.

References are styled according to the sixth edition of the Publication Manual of the American Psychological Association. A sample of the most common entries in reference lists appears below. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

Journal article:
Phelps, L. (1996). Discriminative validity of the WRAML with ADHD and LD children. Psychology in the Schools, 33, 5-12.

Book edition:
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Appendix C: Emails confirming University of Bath Psychology Ethics Committee approval

psychology-ethics@bath.ac.uk
Fri 26/02/2016 13:27
To: Julia Cordey;

```
Dear Julia Cordey

Reference Number 16-016:

Thank you for satisfactorily attending to those amendments. I can now
confirm that you have full ethical approval for your study.

Best wishes with your research,
```

Dr Michael J Proulx
Chair, Psychology Research Ethics Committee

_____

J.H.Cordey@bath.ac.uk
Tue 16/02/2016 12:47

Dear Dr. Proulx,

Thank you very much for your email.

I have now received approval from Janet Brandling, who is a Research and Evaluation Specialist in the AWP Quality Academy team. It is AWP policy that service evaluation projects are approved by Janet rather than by Research and Develompent (please see attached letter.) This change has been reflected in the participant information sheet (attached).

I have amended my application form to show that AWP approval has been granted.

Please let me know if you need anything else.

Many thanks,
Julia

_____

psychology-ethics@bath.ac.uk
Tue 09/02/2016 14:27

Dear Julia Cordey

Reference number 16-016

The ethics committee have considered your application for the study above and have given it conditional ethical approval.

The committee have raised the following point which they would like you to attend to before giving the study full ethical approval:

1)   Please provide NHS R&D approval upon receipt.

Please send the revised document the Ethics Committee: psychology-ethics@bath.ac.uk

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

Best wishes with your research,
Dr Michael J Proulx
Chair, Psychology Research Ethics Committee

Avon and Wiltshire **NHS**

Mental Health Partnership NHS Trust

Avon and Wiltshire Mental Health Partnership AWP Trust

AWP Quality Academy

Fromeside- East Wing

Manor Road

Fishponds

BS16 2EW

0117 378 4238/ 07825 725296

Julia Cordey

Clinical Psychologist in training (University of Bath)

julia.cordey@nhs.net / jhc53@bath.ac.uk

07748 150775

Date: 8th February 2016

Dear Julia

Identifying suitable outcome measures for a Post-diagnostic Support Group for adults with autism
AWP Reference: 2016.E005 Cordey

This letter is to confirm that your evaluation is now approved based on your amending the two points below and also provides you with our reference number.

Please correct the following:
- You use the term researcher throughout the proposal. I think it is helpful to use the term evaluator so that there is no confusion that this is research rather than evaluation.
- You mention approval from R&D. In fact I provide governance for service evaluation as part of the Quality Academy, rather than R&D.

If you do need any further support or information, please contact us using the contact details above, quoting our reference number for your study.

The importance of disseminating all evaluation work cannot be over emphasised. It is only by sharing our learning that we can improve services across AWP. For this reason, the findings of all evaluation work should be reported to the Evaluation team via email. The team will

champion the results of service evaluations, to ensure those results are disseminated and acted upon, and that the results of evaluations are reflected in future service delivery. This includes publications for the public domain.

I very much look forward to receiving the results of your evaluation in due course.

Yours sincerely
Janet Brandling

Appendix E: Service user interview invitation letter

Dear

At BASS, we are interested in finding ways to develop the service and make sure that what we are providing is meaningful and useful for people with autism. We are currently running a project investigating which aspects of the Post-diagnostic Support Group people find helpful. In particular, we are interested in finding out how best to monitor outcomes for people who attend the group and whether the questionnaires we are using are suitable.

To help with this project, a Clinical Psychologist in training from the University of Bath (Julia Cordey) would like to ask some questions to people who have attended the Post-diagnostic Support Group. This would involve talking to Julia about your views on the group at either an AWP clinic base or one of the BASS Advice Service sites.

We would like to invite you to talk to Julia as part of this project. It is up to you whether you wish to take part. Deciding not to take part will not affect the service you receive from BASS.

Enclosed is an information sheet with more details about the project. It will tell you what to do if you want to find out more or get involved. You may wish to discuss this with someone you trust, for example a parent, carer or friend.

Thank you for taking the time to read this letter.

Yours sincerely,

Rona Aldridge, Clinical Psychologist, BASS
Rhian Jenkins, Clinical Psychologist, BASS
Julia Cordey, Clinical Psychologist in training, University of Bath

UNIVERSITY OF
BATH

Avon and Wiltshire **NHS**
Mental Health Partnership NHS Trust

Participant information sheet

We would like you to invite you to take part in a service evaluation project. Before you decide if you would like to take part, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Title of Project

Identifying suitable outcome measures for a Post-diagnostic Support Group for adults with autism

Why is the project being done?

The BASS Autism Services for Adults would like to know which aspects of their Post-diagnostic Support Group people find helpful. To do this, we would like to interview around six to eight people who have attended the group about how it has helped them.

Do I have to take part?

No, you do not have to take part in the project. If you decide to take part and then later change your mind, either before your interview, during it or afterwards, you can withdraw without giving any reasons.

Taking part, or not, in the project will not affect the service that you are currently receiving or likely to receive in the future from BASS or any other NHS service.

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

If you decide to take part you will be interviewed by a Clinical Psychologist in training from the University of Bath called Julia Cordey who is working on this project with BASS. You will be asked questions about your experiences of the group. The interview should last around 30 minutes but may last up to an hour. You are welcome to bring along a trusted friend, carer or professional to the interview if you wish. We will ask your permission to audio record and transcribe your interview so that we don't miss anything.

We hope lots of people will be interested in this project. However, we can only interview up to eight people, so please do not be disappointed if you are not able to take part.

When and where will the project take place?

Interviews will take place during March and April 2016. The interview can be arranged to take place at an AWP clinic or a BASS Advice Service site close to you. Possible locations include the Percy Centre or NHS House in Bath, the Petherton Resource Centre or Create Centre in Bristol, and the Coast Resource Centre in Weston-super-Mare.

Will what I say be kept confidential?

Yes. All comments you make in the interview and any information which is collected about you during the course of the project will be kept confidential and will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. This means that all paper-based and electronic information will be locked and password protected with access restricted to study personnel. Any information about you will have your personal details (such as your name and age) removed so that you cannot be identified from it.

We hope to report our findings to relevant health professionals at meetings and conferences. The findings will also contribute to Julia's Doctorate in Clinical Psychology. You will not be identified in any reports or publications arising from the project. This project has been approved by the AWP Quality Academy team and by the University of Bath Psychology Ethics Committee.

Are there any advantages or benefits to taking part?

We cannot promise taking part in the project will help you directly, but the information collected from you and others will help us understand the ways in which the Post-diagnostic Support Group is helpful.

Are there any disadvantages/risks to taking part?

We think there will be minimal disadvantages in taking part. There will be some inconvenience in attending the interview, for which you will be asked to give between 30 minutes to 1 hour of your time. We are offering participants a £5 voucher to thank them for their time and effort.

If at any time you feel uncomfortable during the interview, please tell the interviewer immediately. You will not be required to discuss anything that you do not want to and you can request to end the interview at any time without giving a reason.

What if there is a problem?

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 project, you should initially contact one of the project leaders (Julia Cordey, Dr. Rona Aldridge or Dr. Rhian Jenkins), who will do their best to answer your questions. Their contact details are provided at the end of this information sheet. If you remain unhappy, you can contact the AWP Patient Advice and Liaison Service (PALS) on 01249 468261 or awp.pals@nhs.net.

What do I do next if I'm interested?

If you want to discuss anything about the project or get involved, you can get in touch with Julia, Rhian or Rona (contact details below). Alternatively, if you want Julia to get in touch with you please fill in the enclosed reply slip and return it in the freepost envelope.

Julia Cordey   Dr. Rhian Jenkins & Dr. Rona Aldridge
Clinical Psychologist in training   Clinical Psychologists
Department of Clinical Psychology   BASS Autism Services for Adults
University of Bath   Petherton Resource Centre
[Email]   [Email]
                                                       [Telephone]

Appendix G: Interview Topic Guide

The following questions were included in the interview schedule:

1) "Can you tell me what you found beneficial about the group?"
2) "Can you tell me about anything that you found less helpful about the group?"
   "Have you noticed any changes in your life since attending the group?"
3) "Can you tell me about any changes you may have noticed in yourself since attending the group?"
4) "Has anything changed about your views on having autism?"
5) "Is there anything else you would like to tell me about the group?"

Appendix H: Key themes, sub-themes and quotations from thematic analysis of interview data

Theme	Subtheme	Quotations
Support	Support from others with autism	*It was quite nice to spend time around other autistic people really. It was quite beneficial to do that.* (P1) *At least I can get help from people who've got this condition or something like it, so they know how it feels to be in my shoes.* (P2) *What I found beneficial was that I met other people with an autism spectrum condition. I have not met anybody before, or perhaps I did and I didn't know.* (P4) *But the main benefit at the time was, you know, meeting people that were in the same boat.* (P6) *It was beneficial to meet other people who also had a diagnosis, you know, in a fairly well safe and controlled environment. Being able to listen to their experiences and talk about mine.* (P7) *Just, you know, in general, sort of a support group environment is, you know, a bunch of people with similar experiences who share those experiences and find some positive benefit out of that.* (P7)
	Sense of belonging	*I didn't expect there to be lots of other adults that had been recently diagnosed, so I was surprised and [that was] beneficial.* (P1) *You see five other people, you instantly click with them, not necessarily personally, but you instantly recognise what you have in common.* (P1) *As far as attending the group's concerned, at least it showed I wasn't on my own. Often it feels like you're the only one in the world with it. It proved to me that wasn't the case.* (P2) *But actually meeting another woman with autism who, like, who's had the same struggle of people not*

		maybe accepting the diagnosis , going "Oh, you don't have autism, you're too social"… yeah it was really interesting and really useful. (P3)	
		Yeah, you know, knowing that I'm not alone, that others are experiencing that… same things. And that there were people who understood, and also a sense that people in general were talking about it more. (P4)	
		At the time it was just… being with other people in the same boat. Similar people. Because everyone's slightly different. But… you know. Everyone was kind of similar. Whereas after the diagnosis it just felt like it was just me for a bit. (P6)	
		And this awareness that there is an existing community of people with similar issues um… you know, I've had that… positive effect from it. (P7)	
	Professional support	*It was also beneficial to see the NHS is obviously got things in place or have got people who know about autism. (P1)*	
		It's obvious to us when someone has a genuine practical understanding, as opposed to someone having an understanding of what they've read or… it's different being taught something but to actually really understand it practically, they're two different things, so it's clear to us that the people who are running the course knew what they were on about and had a practical understanding. (P1)	
		As far as the beneficial side of it [goes], it's just knowing that there's someone there if I need help. (P2)	
		As far as [going to] the group is concerned, it has taught me that at least I can seek help if I want it from someone or go to the people and ask for advice, which is what I do sometimes. (P2)	
		They were understanding I suppose and… I find that when somebody is understanding I tend to open up	

		more, and if somebody isn't I tend to react differently. So the approach I think is very important. (P4)
		But the main benefit at the time was… you know, meeting people that were in the same boat and people who knew what they were doing. (P6)
		I think the staff were excellent. They were extremely knowledgeable and very competent. (P7)
Understand-ing autism	Information about autism	*…and obviously all the things they tell you on the course… so yeah it was just generally beneficial.* (P1)
		For me obviously some of it was stuff I already knew, but there were some elements that were… So there were some handouts that were a bit more science-based, clinical handouts to do with things like executive functioning and stuff like that… So yeah, I found the more scientific, clinical things more useful. (P1)
		The information that we were given, I think was quite useful. Although, like, it's easy to find stuff like online and um, [but] having it presented like, it's very specific information for the group, like, for you know, information about diagnosis, you know, that was really useful and, um, like the fact that it went through specific topics, each group was themed. (P3)
		I have a better understanding of theory of the mind, yes. As well with how anxiety… affects people across the spectrum. (P5)
		The anxiety stuff helped and the social stuff helped. (P6)
		It gave me a much clearer understanding of what Aspergers Syndrome is and what's known about it. (P7)
	How autism affects me	*I got to relate a lot of stuff about how autism affects me.* (P3)

		It kind of made me look at how I make, form friendships and relationships, and look at how my autism affects that and why. (P3)
		I suppose I know myself a bit better as well. (P4)
		It's helped me to get a better understanding of how it affects me as an individual. (P5)
		Having a better understanding for others across the spectrum as well, understanding the different um… ways of how anxiety affects people across the spectrum. (P5)
		I can go back now and go… figure out what's happened the last 40 years… Why did I do this and why did they do that. And things sort of started to click. So that's helped a lot. (P6)
		Now if I do things I can tell you "Oh that's why". There's a reason for me doing things, d'you know what I mean, there's a reason why I might, you know… not want to do something or I might want to do something whereas before it was just, I thought it was a bit obsessive or a bit, kind of, the opposite view really. (P6)
		It made me much more aware of… aspects of my life that are affected by the syndrome that I, even post, even after the diagnosis, did not, was not really aware of. (P7)
		There was a session on anxiety and although I was aware of having had severe anxiety problems I now had a context in which to put them that was completely different. (P7)
Life changes	Social life	*The group probably encouraged me to do it [going to open mic nights] because I then realised that once I wasn't on my own and perhaps getting up and doing things wasn't going to make people look at me in a foolish way or anything like that, which was the bigger problem I think. (P2)*

		It's difficult for me to change, even though I know now that I've got this problem and it's the problem that's been causing it. So from that point of view, it's still there and this is why I want to be more social and meet other people… but at my age it's, I wonder if I've left it too late. (P2)
		And I've even kept in touch with, well our group still meets up every few months… (P3)
		And also, um, having a better understanding about why I do or say things differently to everyone else within the family and with going out and socialising. (P5)
		And just recently I've started doing more [things] like this… Whereas before I was quite happy to stay in all day every day… I know how to be more social. (P6)
		I used to walk to dog in the middle of nowhere so I wouldn't have to bump into anyone. But now I go to the park three times a day now and there's always people over there. And most of the times I'll stop and have a chat, which is good. (P6)
	Communic-ation	*And also, being clear with other people, it means that I don't have to explain myself as much as I did before. It's much simpler… I can just be, like, "Well I'm autistic, I don't feel the same as you do." (P3)*
		And like, yeah letting people know and being like "Hey, if you notice that I'm being a bit overstimulated you can say something, and then I can be like 'oh yeah'." (P3)
		Being able to just be clear with people and being like "Hey I'm gonna try this thing and see if you can still have a conversation with me" because some people can't, some people really, they don't, they can't have a conversation when you're not responding to them in that way so I'm like "Well I'm happy to do those things

			if that's what you need to have this conversation." But also to be able to turn it off sometimes. (P3)
			I suppose I knew that… it was not wrong to ask for what I needed, right. (P4)
			It's helped me to get a better understanding of how it affects me as an individual, as well with helping other people like colleagues, friends and relatives to understand why I do things or say things in a particular way. (P5)
			It's given me a better understanding and, and to see things from other people's point of view and their strengths and weaknesses. (P5)
	Wellbeing		*Confidence and self-esteem began to build up again.* (P4)
			I learned some more techniques of how to manage anxieties. (P4)
			Yes, I've actually become a lot more self-confident and a better understanding of things. (P5)
			I don't know if it's the diagnosis or the group, but since September I've come off my antidepressants… [I'm] a bit more laid back. A bit more relaxed. (P6)
			If something doesn't go to plan I can get quite irate. But I know now how to work around that. (P6)
			I mean it's like the shopping thing at six o'clock in the morning, when they opened. I can go on a Saturday afternoon now, I just take my headphones. (P6)
			I've lost a bit of weight so I'm physically better. (P6)
			Overall the diagnosis and the education from the group has radically altered my self-perception, and actually in a very positive fashion, which has had a very significant positive effect on my mental health on an ongoing basis. (P7)
			Well it comes back to this idea of self-perception and communication and behavioural issues, and being

		able to set that in some kind of context and being able to say… 'Ok this is happening because of this.' And the awareness allows me to manage problems better. (P7)
		I mean in regard to their assessment, it may not have picked up much of a signal over the period of the group. But over the much longer period of several months, uh, my mental health has improved a lot and the only significant change in my life that I can associate it with is diagnosis and the support I've received since. (P7)
		I have taken more exercise. I have, um, lost weight. (P7)
		I mean there's a clear correlation between my mental health and my level of exercise. That's actually very important because I'm diabetic… So for me the absolute key to my entire life is my mental health. (P7)
Acceptance	Acceptance of diagnosis	*My mum was in total denial about it all… Then after diagnosis the penny slowly was dropping, she started to admit to herself that I wasn't perfectly normal as a child and so, [there was] sort of a wider healing process with interpersonal relationships, sort of thing.* (P1)
		I think my parents have been more forgiving now. They don't criticise me as much as they used to. Cos now they realise what it is. (P2)
		I think it's changed the way I think about my diagnosis. (P3)
		I think it's being more comfortable with, yeah with my diagnosis and understanding it a lot more… I knew a lot about autism before I came to the group… what changed more was my view of my own autism. (P3)
		I, it's still… and ongoing about on how it's changed my views on having Aspergers. (P5)

		I took a very positive view of the diagnosis in the first place. And… that has never wavered at all. (P7)
	Self-acceptance	*I'm just suddenly not really worried about uh, spending time alone. I have no problem with my own company ever, but I think I forced myself to do things or think I ought to be doing things, but I just realised I'm just better off doing what's best for me. (P1)*
		I feel a bit more, uh… I've got some kind of approval to live the way that seems normal to me really. (P1)
		I think there are some things I was hiding because it was obvious that some people would think that was peculiar, but now I don't worry about it… A lot of social rules have been lifted, almost, 'cos I've sort of realised that I don't have to live by those rules, really. (P1)
		It told me that perhaps that's who I am and that's what I am. (P2)
		I've come to accept the fact that I should accept this is who I should be for the rest of my life. But I don't think I will change, although I'd like to have more social life. (P2)
		I don't need to be trying to be normal all the time. (P3)
		I don't think I want to change. It's not right. And it's not only not right, it's exhausting if they expect you to change, because it's every day, you have to be coping every day. (P4)
		I kind of, you know, realised that yeah it is alright to feel like that. It's just me. (P6)
		I've had years of people thinking I was a bit weird… but now I kind of know it's alright to do what I do . Not to worry about what anyone else says. What they think is what they think. It's up to them. (P6)
		I mean I've recognised that I was very different from most people since I was fourteen onwards. Starting really at 11 and developing that consciousness. And

		now I have some kind of concrete, I mean as far as it goes, an explanation of the cause of [it]. Which, being a scientist, that's kind of very psychologically supportive. (P7)

Appendix I.1: Warwick-Edinburgh Mental Well-being Scale (Tennant et al., 2007)

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

Please tick the box that best describes your experience of each over the last 2 weeks STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)
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Appendix I.2: Connor Davidson Resilience Scale (Connor & Davidson, 2003)

	Completely disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Completely agree
I am able to adapt to change					
I can deal with whatever comes					
I see the humorous side of things					
Coping with stress strengthens me					
I tend to bounce back after illness or hardship					
I can achieve my goals					
Under pressure, I can focus and think clearly					
I am not easily discouraged by failure					
I think of myself as a strong person					
I can handle unpleasant feelings					

Instructions: Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, circle SA. If you agree with the statement, circle A. If you disagree, circle D. If you strongly disagree, circle SD.

1.	On the whole, I am satisfied with myself.	SA	A	D	SD
2.*	At times, I think I am no good at all.	SA	A	D	SD
3.	I feel that I have a number of good qualities.	SA	A	D	SD
4.	I am able to do things as well as most other people.	SA	A	D	SD
5.*	I feel I do not have much to be proud of.	SA	A	D	SD
6.*	I certainly feel useless at times.	SA	A	D	SD
7.	I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
8.*	I wish I could have more respect for myself.	SA	A	D	SD
9.*	All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10.	I take a positive attitude toward myself.	SA	A	D	SD

Scoring: SA=3, A=2, D=1, SD=0. Items with an asterisk are reverse scored, that is, SA=0, A=1, D=2, SD=3. Sum the scores for the 10 items. The higher the score, the higher the self esteem.

Autism Questionnaire 1

In the following questionnaires, when the term 'autism' is used, it refers to all conditions included on the Autism spectrum such as Asperger's Syndrome, High Functioning Autism, Autism, Atypical Autism, Pervasive Developmental Disorder (PDD) and PDD-Not otherwise specified.

	Strongly disagree	Disagree	Disagree somewhat	Neutral	Agree somewhat	Agree	Strongly agree
1. I feel a social bond with people with autism.							
2. I feel solidarity with people with autism							
3. I feel committed to people with autism							
4. I am glad to have autism.							
5. I think that people with autism have a lot to be proud of.							
6. It is pleasant to have autism.							
7. Having autism gives me a good feeling.							
8. I often think about the fact that have autism.							
9. The fact that I have autism is an important part of my identity.							
10. Having autism is an important part of how I see myself.							
11. I have a lot in common with the average person with autism.							
12. I am similar to the average person with autism.							
13. People with autism have a lot in common with each other.							
14. People with autism are very similar to each other.							

Autism Questionnaire 2

		Strongly Disagree	Disagree	Disagree Somewhat	Neutral	Agree Somewhat	Agree	Strongly Agree
1.	I often regret that I have been given an autism label.							
2.	Overall, people with autism are considered good by others.							
3.	In general, I'm glad to have autism.							
4.	Most people consider people with autism, on the average, to be more ineffective than other groups.							
5.	Overall, I often feel that people with autism are not worthwhile.							
6.	In general, others respect my autism.							
7.	I feel good about having autism.							
8.	In general, others think that people with autism are unworthy.							

INSTRUCTIONS: We are all members of different social groups or social categories. We would like you to consider your having an autism spectrum condition in responding to the following statements. There are no right or wrong answers to any of these statements; we are interested in your honest reactions and opinions. Please read each statement carefully, and respond by using the following scale from 1 to 7:

## Appendix I.6: Brief Fear of Negative Evaluation Scale (Leary, 1983)

Read each of the following statements carefully and indicate how characteristic it is of you according to the following scale:

1 = Not at all characteristic of me
2 = Slightly characteristic of me
3 = Moderately characteristic of me
4 = Very characteristic of me
5 = Extremely characteristic of me

_____ 1. I worry about what other people will think of me even when I know it doesn't make any difference.

_____ 2. I am unconcerned even if I know people are forming an unfavorable impression   of me.

_____ 3. I am frequently afraid of other people noticing my shortcomings.

_____ 4. I rarely worry about what kind of impression I am making on someone.

_____ 5. I am afraid others will not approve of me.

_____ 6. I am afraid that people will find fault with me.

_____ 7. Other people's opinions of me do not bother me.

_____ 8. When I am talking to someone, I worry about what they may be thinking about me.

_____ 9. I am usually worried about what kind of impression I make.

_____ 10. If I know someone is judging me, it has little effect on me.

_____ 11. Sometimes I think I am too concerned with what other people think of me.

_____ 12. I often worry that I will say or do the wrong things.

Appendix J: Histograms depicting distribution of score change on quantitative outcome measures

Appendix J.1: Warwick Edinburgh Mental Well-being Scale (Tennant et al., 2007).

Mean = .8214
Std. Dev. = 8.36249
N = 56
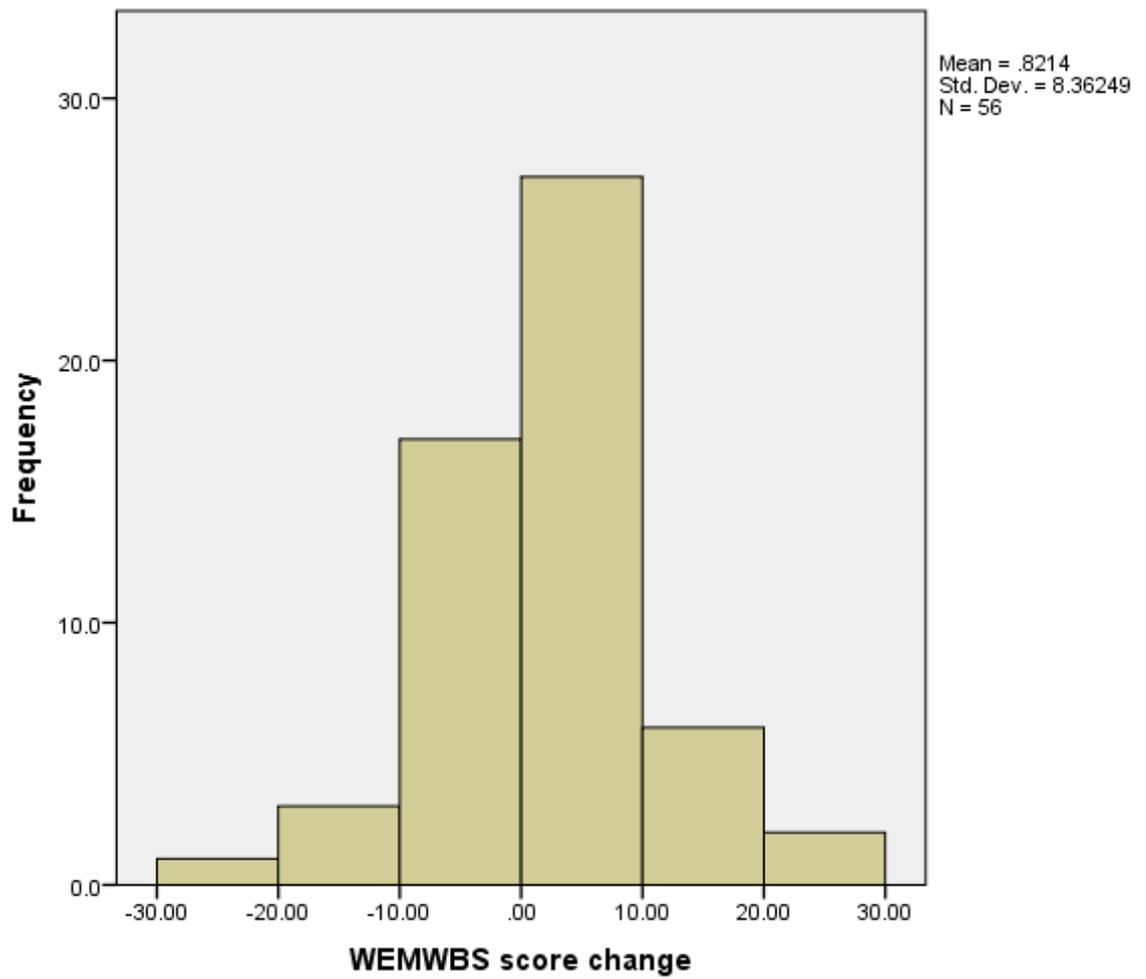
Higher scores indicate better wellbeing.

Appendix J.2: Connor-Davidson Resilience Scale (Connor & Davidson, 2003).

Mean = .9583
Std. Dev. = 4.68569
N = 48
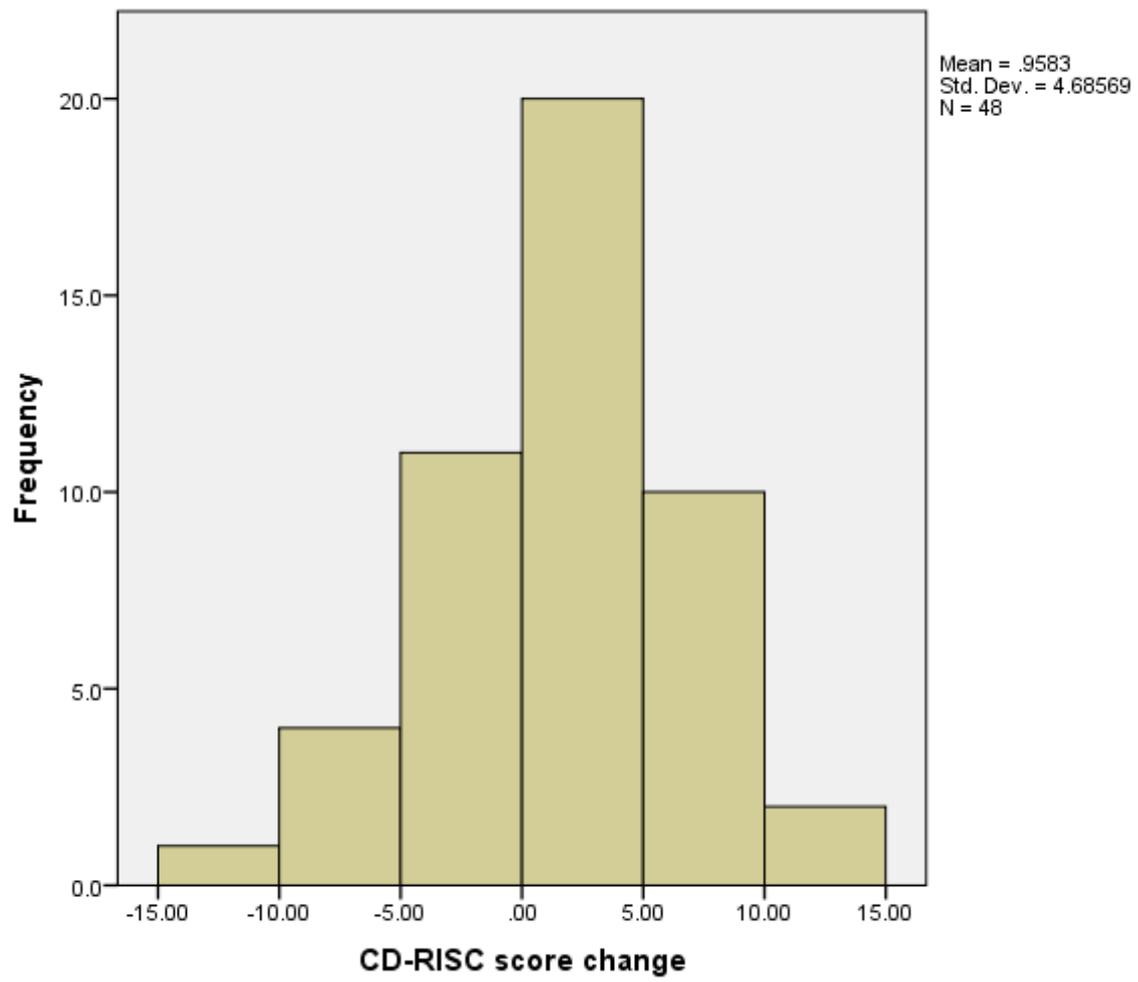
Higher scores indicate higher resilience.

Appendix J.3: Rosenberg Self-Esteem Scale (Rosenberg, 1965)

Mean = -.4643
Std. Dev. = 3.1208
N = 28
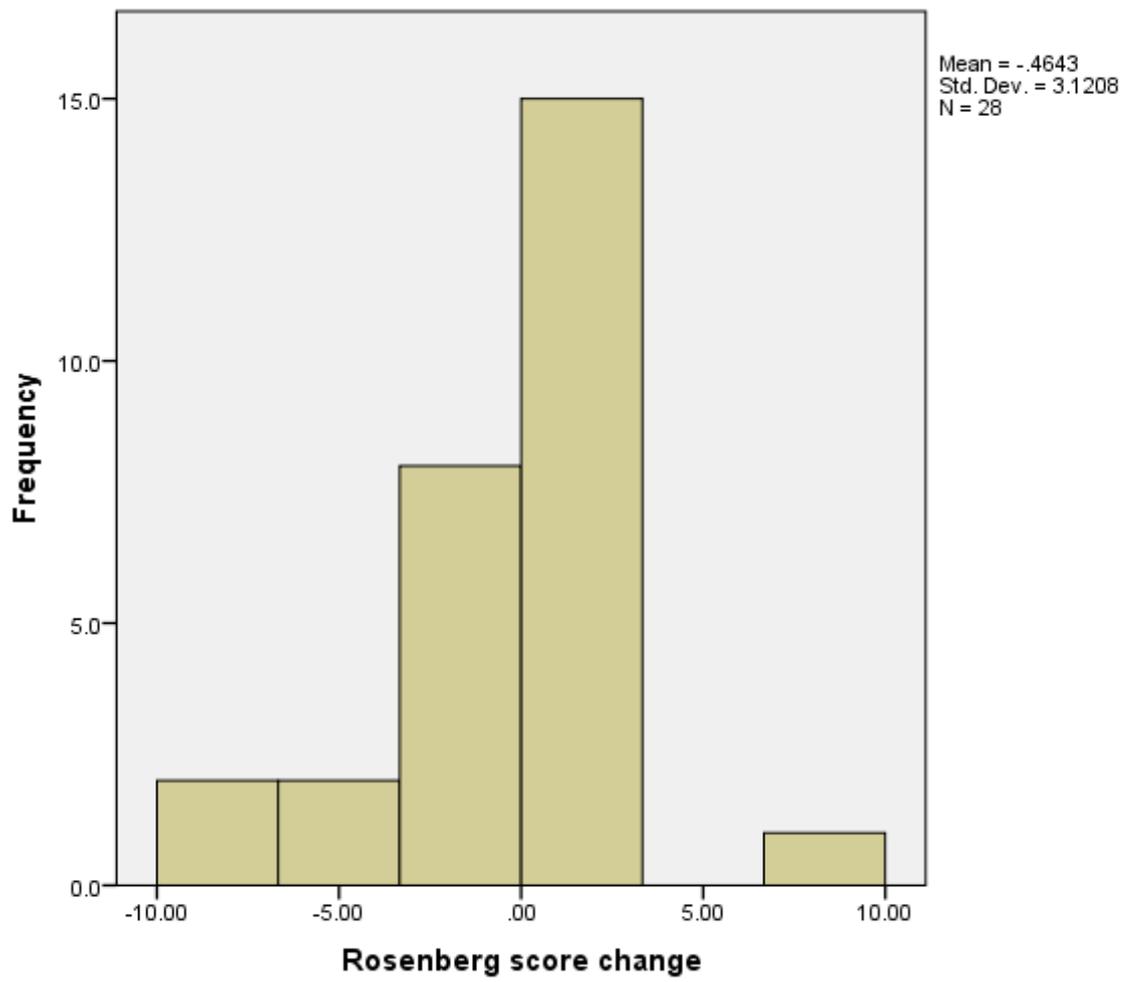
Higher scores indicate higher self-esteem.

Appendix J.4: Autism Identity Scale (Cooper et al., 2017).

Mean = 1.2222
Std. Dev. = 9.42718
N = 27
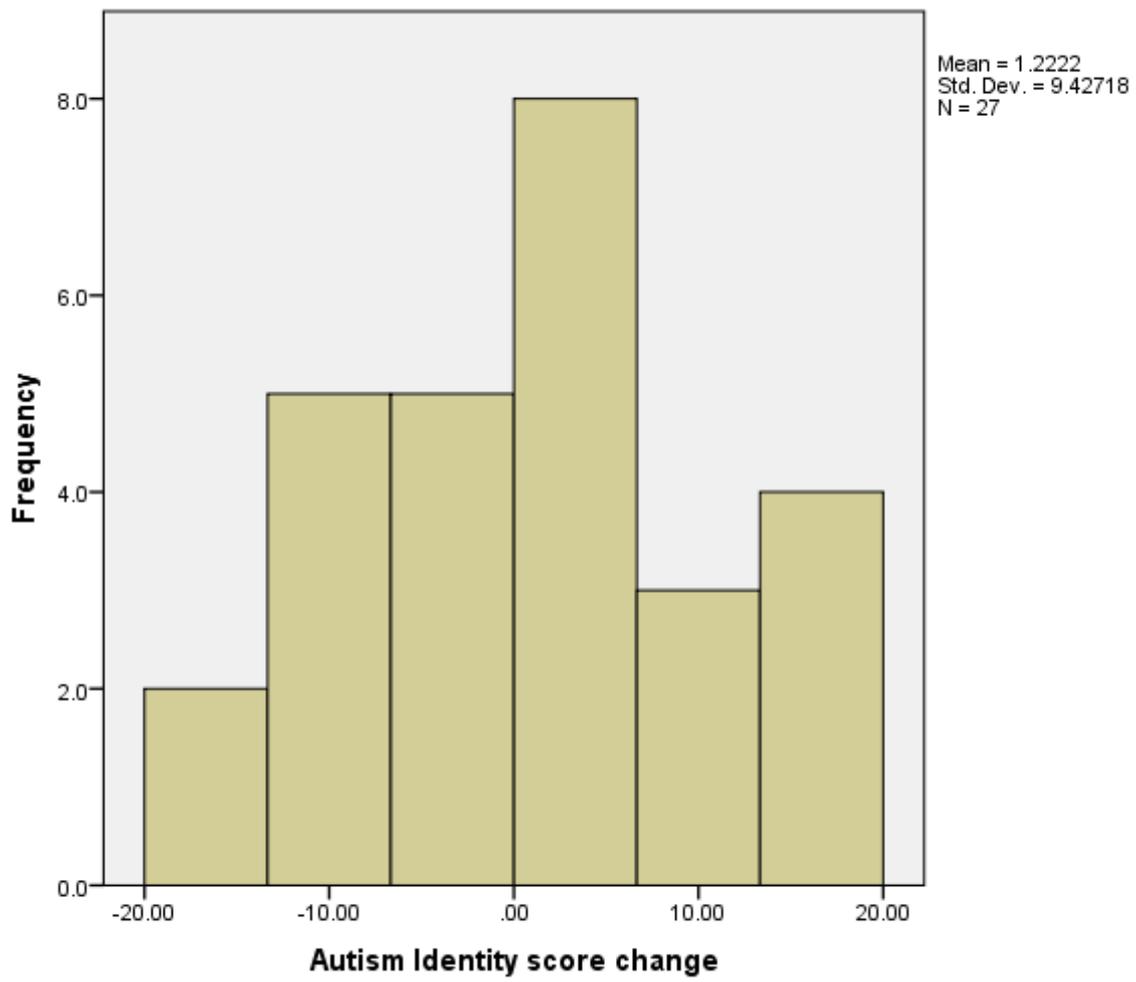
Higher scores indicate stronger autism identity.

Appendix J.5: Positive Distinctiveness Scale (Cooper et al., 2017).
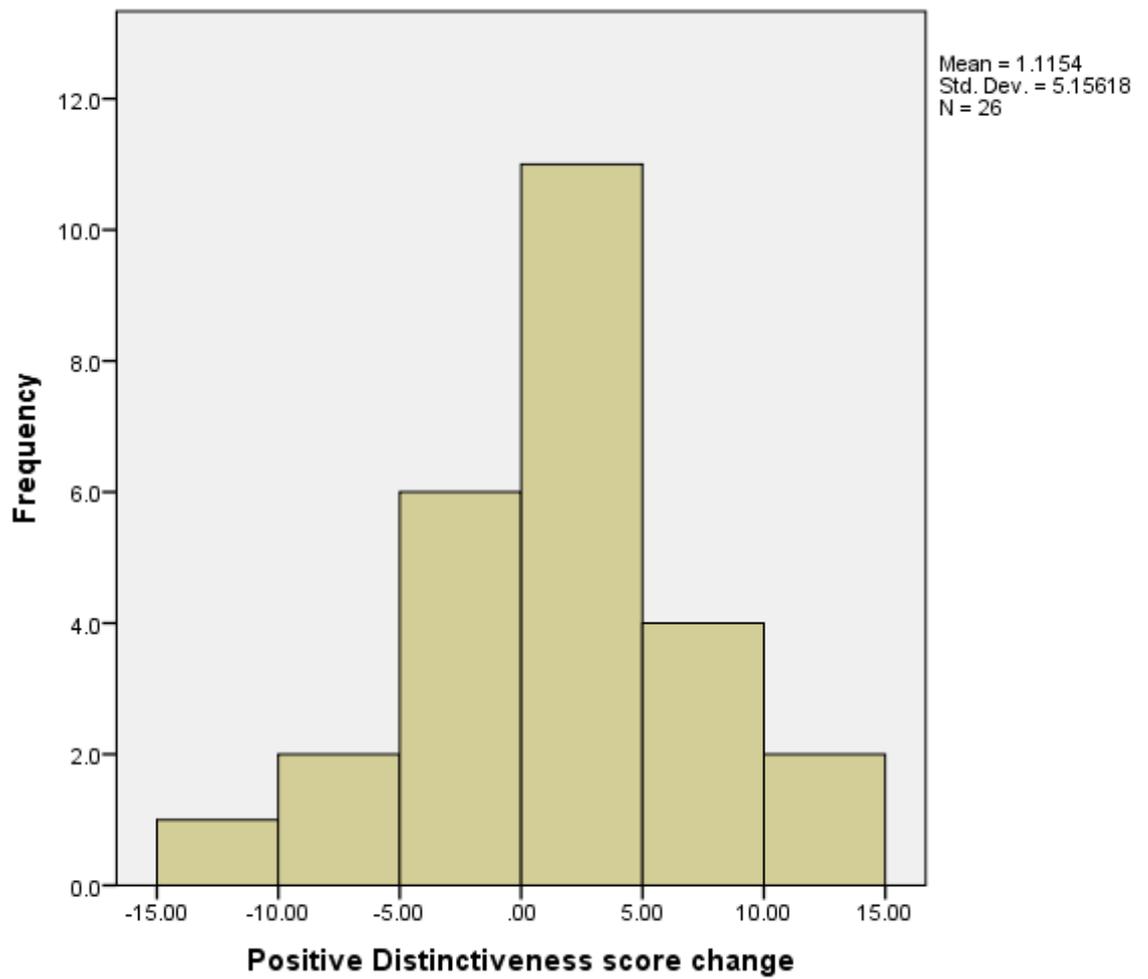
Higher scores indicate greater positive distinctiveness.

Appendix J.6: Brief Fear of Negative Evaluation Scale (Leary, 1983).
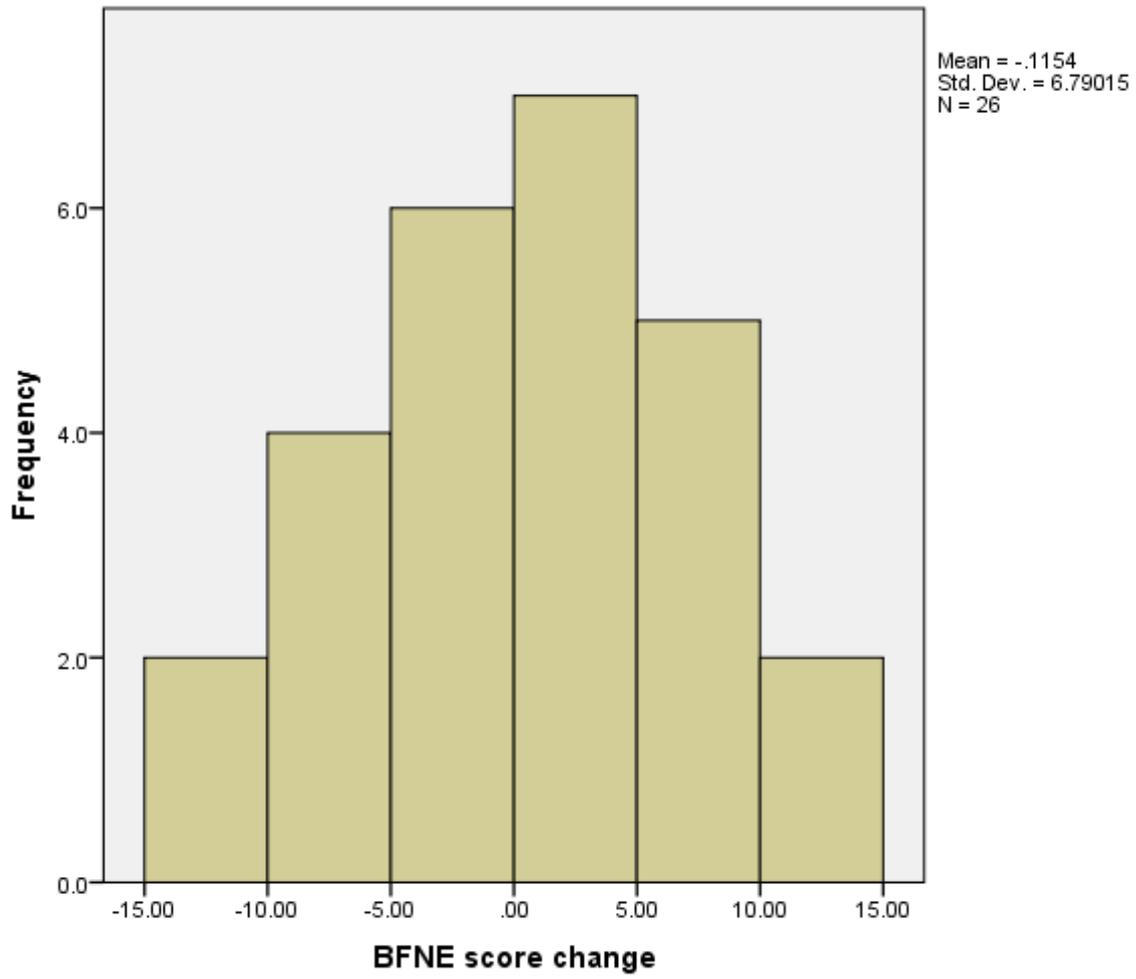
Higher scores indicate greater fear of negative evaluation.

Appendix K. Author guidelines for Autism (Sage)

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

1.2 Article Types

The Journal considers the following kinds of article for publication:

1. Research Reports. Full papers describing new empirical findings;
2. Review Articles

   (a) general reviews that provide a synthesis of an area of autism research;

   (b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author. Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.
3. Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.
4. Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search

engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. **Autism** strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

As part of the submission process, you will be asked to provide the names of 2 peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted
  Please note that the Editors are not obliged to invite/reject any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved,

regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the SAGE Journal Author Gateway.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the

authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

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3.3 Open access and author archiving

Autism offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

4. Preparing your manuscript for submission

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Reference style

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4.5 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

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5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts.

Visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

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As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages

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We encourage all authors to add their ORCIDs to their SAGE Track accounts and include their ORCIDs as part of the submission process. If you don't already have one you can create one here.

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You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

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Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

6. On acceptance and publication

6.1 Lay Abstracts

Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane (journalautism@gmail.com). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families). These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

6.2 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if

any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

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Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.4 Access to your published article

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7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Autism editorial office as follows:

Katie Maras
Department of Psychology
University of Bath, UK
Email: katiemaras.autism@gmail.com

Appendix L: Summary of themes generated from focus groups with clinical psychologists

Theme	Key examples of codes making up theme
Asexuality as a disorder	- Asexual identity linked to mental health issues - Asexuality as a reaction to trauma - Asexuality as trauma-induced fear of intimacy - Asexuality as repressed sexuality - Asexuality as a problem to be solved - Looking for what made the client this way - Wondering whether asexuality is part of or separate from the problem
Asexuality as sexuality vs. choice	- Asexuality as just a time in someone's life - Distinction between "asexual" and "gone off sex" - Conflating celibacy with asexuality - Someone who is married can't be asexual/celibate - Asexuality as a political statement
Factors affecting clinicians' attitudes to asexuality	- Clinicians who think sexual expression is important may not accept asexuality as part of the client - Feminist clinicians assuming asexual women have been made that way by society or relationship experiences - Psychology's uncomfortable history with sexuality – e.g. "treating" homosexuality - Having the opportunity to reflect on asexuality - Previous training - Sexuality, age, personal history
Awareness of asexuality	- Unfamiliarity with asexuality - Uncertainty what asexuality means - Never having met someone who identified as asexual in practice - Asexuality easy to miss as clinicians don't usually ask about it - Avoiding talking about it due to discomfort/unfamiliarity

Openness to asexuality	- Wondering what asexuality means to the client - Wanting to find out more about asexuality - Knowledge of client's asexuality is valuable for understanding their personal context - Responsibility to reflect on asexuality in order to become more aware of own assumptions
Stigma/stereotypes around asexuality	- Something wrong with someone who doesn't want to have sex - Asexuals as missing out on something - Asexuals as homosexual and in denial - Impact of being in a minority group
Social attitudes about sex	- Assumption that everyone wants sex - Sex as a fundamental drive we're born with - Not wanting sex means they are with the wrong person - Distorted portrayal of sex in the media - Impact of living in a sexualised world - Distress of asexuality caused by societal pressures to be sexual
Sexuality in later life	- Sexuality not asked about in older adult practice - Don't expect older clients to be sexually active - Avoiding asking older clients about sexuality - Asexuality seen as more normal in older people

Appendix M: Initial CATA items generated from background literature and focus groups.

1) If a client told me they did not have any sexual desire I would assume this was a problem for them.

2) When an asexual person seeks support from a mental health professional, it is probably because their lack of sexual desire is causing them distress.

3) People who call themselves asexual have a fear of intimacy.

4) Asexuals are repressing their sexual desires for some reason.

5) Most asexuals have probably experienced some kind of abuse or trauma in the past.

6) If a client told me they do not desire sex I would wonder what has made them this way.

7) It is completely possible for someone who does not experience sexual desire to be happy and fulfilled.

8) Lacking sexual desire is a difficulty that we as mental health professionals have a responsibility to address.

9) Therapists should discuss with their asexual clients whether they want help reconnecting with their sexual feelings.

10) Asexuals would feel better if they allowed a therapist to help them discover their true sexuality.

11) If one of my "asexual" clients told me they have engaged in sexual activity in the past, I would question whether they are really asexual.

12) If a client of mine identified as asexual I would want to find out more about what this means to them as a person.

13) The idea of being "asexual" is a cultural trend which will sooner or later go out of fashion.

14) Lack of sexual desire is to be expected in certain clients, for example disabled or older clients.

Appendix N: 16-item CATA scale developed from focus groups and asexual forum user feedback.

1) Asexuality is a psychological disorder.

2) If a client told me they were asexual I would assume this was a problem for them.

3) When an asexual person seeks support from a mental health professional, it is probably because their lack of sexual desire is causing them distress.

4) People who call themselves asexual have a fear of intimacy.

5) Asexuals are repressing their sexual desires.

6) Most asexuals have probably experienced some kind of abuse or trauma in the past.

7) If a client told me they were asexual I would wonder what has made them this way.

8) It is completely possible for someone who does not experience sexual desire to be happy and fulfilled.

9) Asexuality is a difficulty that we as mental health professionals have a responsibility to address.

10) Therapists should discuss with their asexual clients whether they want help reconnecting with their sexual feelings.

11) Asexuals would feel better if they allowed a therapist to help them discover their true sexuality.

12) If one of my "asexual" clients told me they have engaged in sexual activity in the past, I would question whether they are really asexual.

13) I would feel comfortable talking to a client about their asexuality.

14) The idea of being "asexual" is a cultural trend which will sooner or later go out of fashion.

15) Asexuality is to be expected in certain clients, for example disabled or older clients.

16) If my client told me either they or their partner were asexual, I would assume their relationship was in trouble

Knowledge of asexuality

Asexuality is defined as an enduring lack of sexual attraction to either sex.

1) Have you ever heard of asexuality before this study?

Yes / No / Not sure

2) If you have some knowledge of asexuality, where has this come from? (Please select all that apply)

Personal life

Own research/reading

Education (e.g. university lecture)

Professional training

CPD event

Other: _____

3) Have you ever met someone asexual?

Yes

No

Not sure

4) Have you ever worked clinically with someone asexual?

Yes

No

Not sure

5) How motivated do you feel to undertake training which includes information on asexuality?

Not at all motivated

Somewhat unmotivated

Neither motivated nor unmotivated

Somewhat motivated

Very motivated

Attitudes towards Asexuality Scale (Hoffarth et al., 2015)

Below are a series of statements concerning your opinions about asexual people. For each statement, please indicate the degree of your agreement or disagreement.

1 = Completely disagree, 2 = Strongly disagree, 3 = Moderately disagree, 4 = Slightly disagree, 5 = Neither agree nor disagree, 6 = Slightly disagree, 7 = Moderately agree, 8 = Strongly agree, 9 = Completely agree

1) Asexual women are not real women

2) Asexual men are not real men

3) Asexuality is probably just a phase

4) A woman who claims she's 'asexual' just hasn't met the right man yet

5) A man who claims he's 'asexual' just hasn't met the right woman yet

6) Asexual people are sexually repressed

7) Asexuality simply represents an immature, childlike approach to life

8) People who identify as 'asexual' probably just want to feel special or different

9) Asexuality is a 'problem' or 'defect'

10) There is nothing wrong with not having sexual attraction

11) A lot of asexual people are probably homosexual and in the closet

12) Asexuality is an inferior form of sexuality

13) You can't truly be in love with someone without feeling sexually attracted to them

14) Asexuality should not be condemned

15) Asexuals who have intimate relationships are being unfair to their partners

16) I would not be too upset if I found out my child were an asexual

<u>**Clinician Attitudes Towards Asexuals Scale**</u>

Below are a series of statements concerning your clinical views on asexuality and working therapeutically with asexual people. For each statement, please indicate the degree of your agreement or disagreement from 1 (completely disagree) to 9 (completely agree).

1 = Completely disagree, 2 = Strongly disagree, 3 = Moderately disagree, 4 = Slightly disagree, 5 = Neither agree nor disagree, 6 = Slightly disagree, 7 = Moderately agree, 8 = Strongly agree, 9 = Completely agree

1) Asexuality is a psychological disorder.

2) If a client told me they were asexual I would assume this was a problem for them.

3) When an asexual person seeks support from a mental health professional, it is probably because their lack of sexual desire is causing them distress.

4) People who call themselves asexual have a fear of intimacy.

5) Asexuals are repressing their sexual desires.

6) Most asexuals have probably experienced some kind of abuse or trauma in the past.

7) If a client told me they were asexual I would wonder what has made them this way.

8) It is completely possible for someone who does not experience sexual desire to be happy and fulfilled.

9) Asexuality is a difficulty that we as mental health professionals have a responsibility to address.

10) Therapists should discuss with their asexual clients whether they want help reconnecting with their sexual feelings.

11) Asexuals would feel better if they allowed a therapist to help them discover their true sexuality.

12) If one of my "asexual" clients told me they have engaged in sexual activity in the past, I would question whether they are really asexual.

13) I would feel comfortable talking to a client about their asexuality.

14) The idea of being "asexual" is a cultural trend which will sooner or later go out of fashion.

15) Asexuality is to be expected in certain clients, for example disabled or older clients.

16) If my client told me either they or their partner were asexual, I would assume their relationship was in trouble

Attitude thermometers (MacInnis & Hodson, 2012)

Please indicate how favourably or unfavourably you feel about the following groups
from 1-10 (extremely unfavourable) to 91-100 (extremely favourable).

1) Heterosexuals
2) Homosexuals
3) Bisexuals
4) Asexuals
5) Transgender people

Future contact/discrimination intentions (MacInnis & Hodson, 2012)

The following items ask how likely you are to interact with people from different
groups. Please indicate how likely you are to do the following things with a
member of each group *from 1 (not at all) to 7 (very much).*

● Heterosexual
● Homosexual
● Bisexual
● Asexual
● Transsexual

1) If given the chance, how likely are you to have a conversation with someone from
each of the following groups?

2) If given the chance, how interested are you in having a conversation with someone
from each of the following groups?

3) If given the chance, how likely are you to be friends with someone from each of the
following groups?

4) If given the chance, how interested are you in being friends with someone from each
of the following groups?

5) Imagine that you are landlord who is looking for a tenant. Indicate how comfortable
you would be renting an apartment to people from each of these groups.

6) Imagine that you are a manager who is looking to hire a new employee. Indicate
how comfortable you would be hiring people from each of these groups.

7) In your clinical practice, how comfortable would you feel working with someone from
each of the following groups in the future?

8) In your clinical practice, how confident would you feel working with someone from
each of the following groups in the future?

<u>Right Wing Authoritarianism</u> (Altemeyer, 1996)

Please indicate your agreement with the following statements from 1 (completely disagree) to 9 (completely agree). Answer 5 if you feel precisely neutral about a statement.

1 = Completely disagree, 2 = Strongly disagree, 3 = Moderately disagree, 4 = Slightly disagree, 5 = Neither agree nor disagree, 6 = Slightly disagree, 7 = Moderately agree, 8 = Strongly agree, 9 = Completely agree

1) Gays and lesbians are just as healthy and moral as anybody else.

2) Atheists and others who have rebelled against the established religions are no doubt every bit as good and virtuous as those who attend church regularly.

3) There are many radical, immoral people in our country today, who are trying to ruin it for their own godless purposes, whom the authorities should put out of action.

4) Our country will be destroyed someday if we do not smash the perversions eating away at our moral fiber and traditional beliefs.

5) The situation in our country is getting so serious, the strongest methods would be justified if they eliminated the troublemakers and got us back to our true path.

6) Everyone should have their own lifestyle, religious beliefs, and sexual preferences, even if it makes them different from everyone else.

7) People should pay less attention to the Bible and the other old traditional forms of religious guidance, and instead develop their own personal standards of what is moral and immoral.

8) The only way our country can get through the crisis ahead is to get back to our traditional values, put some tough leaders in power, and silence the troublemakers spreading bad ideas.

9) There is nothing wrong with premarital sexual intercourse.

10) What our country really needs, instead of more "civil rights," is a stiff dose of law and order.

11) Some of the best people in our country are those who are challenging our government, criticizing religion, and ignoring the "normal way" things are supposed to be done.

12) The facts on crime, sexual immorality, and the recent public disorders all show that we have to crack down harder on deviant groups and trouble-makers if we are going to save our moral standards and preserve law and order.

Social Dominance Orientation (Pratto et al., 1994)

Beside each object or statement, select a number from 1 (very negative) to 7 (very positive) which represents the degree of your positive or negative feeling.

1 = Very negative, 2 = Fairly negative, 3 = Slightly negative, 4 = Neither negative nor positive, 5 = Slightly positive, 6 = Fairly positive, 7 = Very positive

1) Some groups of people are simply inferior to other groups.

2) In getting what you want, it is sometimes necessary to use force against other groups.

3) It's ok if some groups have more of a chance in life than others.

4) To get ahead in life, it is sometimes necessary to step on other groups.

5) If certain groups stayed in their place, we would have fewer problems.

6) It's probably a good thing that certain groups are at the top and other groups are at the bottom.

7) Inferior groups should stay in their place.

8) Sometimes other groups must be kept in their place.

9) It would be good if groups could be equal.

10) Group equality should be our ideal.

11) All groups should be given an equal chance in life.

12) We should do what we can to equalize conditions for different groups.

13) Increased social equality.

14) We would have fewer problems if we treated people more equally.

15) We should strive to make incomes as equal as possible.

16) No one group should dominate in society.

Negative Stereotyping of Single Persons Scale (NSSP) (Pignotti & Abell, 2009)

Below are a series of statements concerning your opinions about people and relationships. For each statement, please indicate the degree of your agreement or disagreement from 1 (completely disagree) to 7 (completely agree).

1 = Completely disagree, 2 = Strongly disagree, 3 = Slightly disagree, 4 = Neither agree nor disagree, 5 = Slightly agree, 6 = Strongly agree, 7 = Completely agree

1) It's only natural for people to get married
2) Single people can be just as fulfilled as married people
3) People who claim to be satisfied being unmarried are just kidding themselves
4) If I had a child who grew up and did not marry, I would worry that he/she would never be happy
5) The intimacy of friendship cannot compare to the intimacy of marriage
6) People who do not marry are incomplete
7) My single friends seem to be missing something in their lives
8) People who do not marry can never be truly fulfilled
9) When single people say they are satisfied with their lives, I believe them
10) There is something wrong with someone who doesn't want to get married

Please rate the following statements from 1 (completely disagree) to 7 (completely agree). Being single results in…

11) Feeling lonely
12) Wanting to spend most of one's time meeting potential people to marry
13) Feeling depressed
14) Feeling envious of married people
15) Not being close to anyone
16) Feeling desperate for intimacy
17) Being obsessed with work
18) Dying alone
19) Becoming sexually promiscuous
20) Longing for a spouse

Please rate the following statement from 1 (completely disagree) to 7 (completely agree). People are single because they...

1) Are immature
2) Are irresponsible
3) Are eccentric
4) Are physically unattractive

5) Are selfish

6) Feel afraid of true intimacy

7) Are difficult to get along with

8) Are too picky

9) Want to be sexually promiscuous

10) Are incapable of making commitments

Information sheet v.2 29/11/16
IRAS ID: 212832

Information about the research

Thank you for taking the time to read this information about the Clinician Attitudes to Asexuality study. The study is entirely voluntary. If you have any questions about the study or the information provided here, please contact the researcher Julia Cordey (j.h.cordey@bath.ac.uk) or her supervisor Dr. Catherine Butler (c.a.butler@bath.ac.uk) before proceeding. They will talk it through with you and help you decide whether you wish to take part.

Why is the research being done?

This study is designed for psychological therapists to share their attitudes and opinions on asexuality. The researchers are interested in how much psychotherapists know about asexuality, whether they have ever worked with anyone asexual, and what their opinions are on asexuality. It is not necessary to know anything about asexuality before taking part. The researchers are interested in what anyone who works as a therapist thinks, regardless of prior experience or knowledge of asexuality.

Who can take part?

We are inviting psychological therapists to take part in the study. This includes anyone qualified or in training to deliver psychological therapies in the NHS and in private practice **in the UK**. Relevant roles may include clinical psychologists, counselling psychologists, forensic psychologists, family therapists, psychodynamic psychotherapists and IAPT therapists. If you are not sure whether you are eligible to take part, please contact the researcher Julia Cordey. We would like to recruit about 200 people to take part, although there is no limit to the number of people who can participate.

What will taking part involve?

The questionnaire can be completed anywhere. It will take about 15 minutes. It includes validated surveys which have been used in previous research on asexuality, as well as a new measure of clinician attitudes towards asexuality designed for this study. These surveys are designed to measure individual differences along a continuum of responses, and cover a range of opinions on asexuality as well as other topics which have been found to be related to asexuality. You will not be able to skip these questions and some

of them might surprise you, however you can withdraw at any stage without explanation by closing your browser window. Some optional items will give you the opportunity to give your answers in free text.

The questionnaire will not ask you for any identifying information such as your name or date of birth, however you will be asked to provide demographics details (such as gender and age) and your therapeutic job role (e.g. clinical psychologist).

All data will be kept confidential on the Bristol Online Surveys website. When data collection finishes data will be downloaded and stored securely on a password protected computer. Data will be stored securely in accordance with the Data Protection Act 1998 and destroyed 10 years after the study finishes.

There will be no direct benefits to you of taking part. However, it is hoped that the information collected will help further our understanding of the training needs of mental health practitioners and improve access to psychological therapies for people who identify as asexual. There are no risks anticipated in taking part in the study. You will be asked to give about 15 minutes of your time. When and where you choose to do this is up to you.

Do I have to take part?

You do not have to take part. If you do not wish to take part please close the window of your internet browser. If you do decide to proceed, you can choose to withdraw from the study at any time. We will ask you to choose a "nickname" that only you know, so that if you decide to withdraw at a later date you can give the researchers your nickname and they will be able to delete your answers.

Who has approved the research?

This study has received ethical approval from the University of Bath Psychology Ethics Committee and the Health Research Authority (IRAS ID: 212832).

What if there is a problem?

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, please contact the researcher Julia Cordey (j.h.cordey@bath.ac.uk) or her supervisor Dr. Catherine Butler (c.a.butler@bath.ac.uk) in the first instance. If you are still not satisfied, they will advise you on who to contact next.

What happens next?

At the end of the questionnaire you will have the opportunity to enter your email address if you wish to hear about further research on asexuality in the future.

The researcher would also like to invite participants to take part in a short follow-up study 2-4 weeks after filling out the questionnaire. This will involve answering a few questions from the original questionnaire again and will take under 5 minutes. This will help the researchers work out how reliable their new measure of clinician attitudes towards asexuality is. If you wish to take part in this, please enter your email address and the researcher will email you in 2-4 weeks with a link to the follow-up questionnaire. You will be asked to enter the same nickname you used for the original so that your second set of data can be connected with your first.

The email address you enter will not be connected with any of the data you submit as part of this study. There will be no way for the researcher to link your data with your identity and your anonymity will remain protected.

Data collection will finish in March 2017. This study will form part of Julia's thesis for the Doctorate in Clinical Psychology. The results will be written up for publication in a peer-reviewed journal and may be presented at conferences.

What do I do next if I am interested?

If you have any questions about the study, please contact Julia Cordey (j.h.cordey@bath.ac.uk) or Dr. Catherine Butler (c.a.butler@bath.ac.uk) before proceeding. If you are satisfied with the information, please proceed to the next page where you will be asked to fill out a short consent form.

Appendix Q. Debrief statement

Thank you for taking part in this study. Your data has been added to the data from other participants for anonymous group analysis.

We are interested in whether familiarity with asexuality influences the kinds of attitudes clinicians hold towards it. We would also like to investigate other factors which might influence clinicians' attitudes, including social attitudes and opinions on relationships, as these sorts of opinions have been found to be related to attitudes about minority sexuality groups in previous studies. You may therefore have been surprised by some of the questions. If you are interested in reading a recent study which used these scales, a reference has been provided at the bottom of this page. The researchers welcome future contact if you wish to discuss these matters further.

If you would be prepared to be contacted by the researchers in 2-4 weeks time in order to take a short follow-up questionnaire, or if you are interested in hearing about future research projects on asexuality, please follow the link below and enter your email address. Your contact information will be kept securely and will not be connected to the answers you have submitted for this study.

https://bathreg.onlinesurveys.ac.uk/hearing-more-about-asexuality-research

If you would like to withdraw from the study, email the researchers with the nickname you chose at the beginning of the questionnaire and your data will be removed and destroyed.

This study will form part of Julia Cordey's thesis for the Doctorate in Clinical Psychology. Results will be written up for submission to peer-reviewed publications and may be presented at conferences. You will not be identified anywhere in any academic papers resulting from this research.

If you have any questions about this study please contact Julia Cordey (j.h.cordey@bath.ac.uk) or Dr. Catherine Butler (c.a.butler@bath.ac.uk). To find out about the results of this research, please visit the Facebook page "CATA research" from May 2017.

Thank you for your time.

Reference: Hoffarth, M. R., Drolet, C. E., Hodson, G., & Hafer, C. L. (2015). Development and validation of the Attitudes Towards Asexuals (ATA) scale. **Psychology & Sexuality**, 1-13.

Appendix R. Follow-up questionnaire information sheet

Follow-up information sheet v.2 29/11/16
IRAS ID: 212832

Information about the research

This study is designed for psychological therapists to share their attitudes and opinions on asexuality. The researchers are interested in how much psychotherapists know about asexuality, whether they have ever worked with anyone asexual, and what their opinions are on asexuality.

The researchers would like to validate one of the measures used in the original questionnaire. This involves asking a number of participants to fill out the measure again several weeks later.

Why am I being invited?

You are being invited as you participated in the original survey and indicated that you would be happy to be contacted about taking part in a follow-up.

Do I have to take part?

Participation is voluntary. If you do not wish to take part please close the window of your internet browser. If you do decide to proceed, you can choose to withdraw from the study at any time by emailing the researchers with your nickname and asking them to delete your data.

What will taking part involve?

You will be asked to re-take a short section of the original questionnaire. This should take about 3 to 5 minutes.

We will ask you to enter the "nickname" you chose for the original questionnaire. This is so that your data from this follow-up can be matched up with your original data. Your data and nickname cannot be linked with your identity.

Will my data be kept secure?

All data will be kept confidential on the Bristol Online Surveys website. When data collection finishes data will be downloaded and stored securely on a password protected computer. Data will be stored securely in accordance with the Data Protection Act 1998 and destroyed 10 years after the study finishes.

What do I do next if I am interested?

If you have any questions about the study, please contact Julia Cordey (j.h.cordey@bath.ac.uk) or Dr. Catherine Butler (c.a.butler@bath.ac.uk) before proceeding.

If you are satisfied with the information, please proceed to the next page where you will be asked to fill out a short consent form.

Appendix S. Email confirming University of Bath Psychology Ethics Committee approval

N.Gjersoe@bath.ac.uk
Tue 13/09/2016 13:27

To: Julia Cordey;

Dear Julia Cordey
Reference Number 16-212: An investigation of psychological therapists' attitudes towards asexuality
The ethics committee have considered your ethics proposal for the study above and have given it full ethical approval.

Best wishes with your research.

Dr Nathalia Gjersoe
Chair, Psychology Research Ethics Committee

Appendix T: University of Bath confirmation of sponsorship letter

UNIVERSITY OF BATH

Professor Jonathan Knight BSc, MSc, PhD
Pro-Vice-Chancellor Research

Vice-Chancellor's Office
Bath BA2 7AY
Tel: 01225 386141
Email: Pro-vc-research@bath.ac.uk

Julia Cordey
Department of Psychology

6 September 2016

Dear Julia,

An Investigation of Psychological Therapists' Attitudes towards Asexuality

I am pleased to confirm that the University is prepared to act as a sponsor under the Department of Health's Research Governance for Health and Social Care (2005) subject to the following:

1. The University requires you, as the Principal Investigator, to conduct the study in compliance with the requirements of the Framework so it is able to meet its obligations as sponsor. The requirements are:

   - Developing proposals that are scientifically sound and ethical.
   - Submitting the design for independent expert review.
   - Submitting the study (or proposal) for independent ethical review.
   - Conducting a study to the agreed protocol (or proposal), in accordance with legal requirements, guidance and accepted standards of good practice.
   - Preparing and providing information for participants.
   - Ensuring participants' welfare while in the study.
   - Arranging to make findings and data accessible following expert review.
   - Feeding back results of research to participants.

2. University professional indemnity and insurance will apply to the study as appropriate, within the UK.
3. As the Principal Investigator/Chief Investigator for the study, the University requires you to comply with the University policy on research data and all systems of good practice.
4. Amendments to the study and any reports should be submitted to the sponsor.
5. An end of study report should be submitted to the sponsor using the final report form available here: http://www.bath.ac.uk/ris/developing-a-proposal.bho/submitting/applying-for-sponsorship-in-the-NHS/index.html
6. Any SAEs (serious adverse events) and any other incidents should be reported to the sponsor within 24 hours on the appropriate form available here: http://www.bath.ac.uk/ris/developing-a-proposal.bho/submitting/applying-for-sponsorship-in-the-NHS/index.html
7. Please note that this study could be subject to monitoring as part of our obligations as research sponsors. You will be informed separately if this is the case.

Yours sincerely

Professor Jonathan Knight
Pro-Vice-Chancellor, Research

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NHS
Health Research Authority

Ms Julia Cordey
Department of Clinical Psychology
University of Bath
Bath
BA2 7AY

Email: hra.approval@nhs.net

20 December 2016

Dear Ms Julia Cordey

Letter of HRA Approval

Study title:	An Investigation of Psychological Therapists' Attitudes towards Asexuality
IRAS project ID:	212832
Protocol number:	N/A
REC reference:	16/HRA/4761
Sponsor	University of Bath

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England
The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA Approval, including:

- Working with organisations hosting the research
- Registration of Research
- Notifying amendments
- Notifying the end of the study

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

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **212832**. Please quote this on all correspondence.

Yours sincerely

Rekha Keshvara
Assessor

Email: hra.approval@nhs.net

Copy to: *Prof Jonathan Knight, University of Bath*

Appendix A - List of Documents

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

Document	Version	Date
Contract/Study Agreement [Julia Cordey CATA Statement of Activities]	1	18 August 2016
Copies of advertisement materials for research participants [Julia Cordey CATA social media advert]	1	18 August 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Julia Cordey CATA evidence of sponsor indemnity]		18 July 2016
IRAS Application Form [IRAS_Form_12092016]		12 September 2016
IRAS Application Form XML file [IRAS_Form_12092016]		12 September 2016
IRAS Checklist XML [Checklist_12092016]		12 September 2016
Letter from sponsor [Julia Cordey CATA sponsor letter]		06 September 2016
Letters of invitation to participant [Julia Cordey CATA invitation email]	1	18 August 2016
Letters of invitation to participant [Julia Cordey CATA follow-up invitation email]	1	18 August 2016
Non-validated questionnaire [Julia Cordey CATA questionnaire]	1	18 August 2016
Other [HRA SoA]	1	08 November 2016
Other [CATA Debrief]	2	29 November 2016
Other [HRA SoE]	1	29 December 2016
Participant consent form [Consent form]	2	29 November 2016
Participant consent form [Follow-up consent form]	2	29 November 2016
Participant information sheet (PIS) [Follow-up Information Sheet]	2	29 November 2016
Participant information sheet (PIS) [PIS]	2	29 November 2016
Referee's report or other scientific critique report [Julia Cordey CATA original proposal with reviewer comments]	1	14 August 2015
Referee's report or other scientific critique report [Julia Cordey CATA proposal 2nd submission]	1	02 November 2015
Research protocol or project proposal [Julia Cordey CATA study protocol]	1	18 August 2016
Summary CV for Chief Investigator (CI) [Julia Cordey CATA CI summary CV]	1	31 July 2016
Summary CV for supervisor (student research) [Julia Cordey CATA academic supervisor summary CV]	1	05 September 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Julia Cordey CATA lay summary]	1	18 August 2016

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Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* **and** *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* **sections in this appendix.**

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Prof Jonathan Knight
Tel: 01225383162
Email: pro-vc-research@bath.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	Statement of Activities will act as an agreement of an NHS organisation to participate.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study
4.3	Financial arrangements assessed	Yes	The applicant has confirmed in the statement of activities that the sponsor will not provide any funding to sites.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Not Applicable	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type for the research; all sites will undertake the same activity.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

It is indicated in the Statement of Activities that Local Collaborators will be allocated at the participating NHS Sites.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
The study is limited to completing an online questionnaire by the NHS staff participants. Therefore, Honorary Research Contracts or Letters of Access are not expected for this study.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
• The applicant has indicated that they <u>do not intend</u> to apply for inclusion on the NIHR CRN Portfolio.

Appendix V. Emails confirming approval from NHS Trust Research and Development Departments

Johnson Nigel <Nigel.Johnson@glos.nhs.uk>
Tue 10/01/2017 10:45
To: Julia Cordey;
Cc: Genevieve Riley <genevieve.riley@nhs.net>;
Walker Mark <mark.walker@glos.nhs.uk>;

Dear Julia,
RE: IRAS 212832 Confirmation of Capacity and Capability at 2gether NHS Foundation Trust
Full Study Title: An Investigation of Psychological Therapists' Attitudes towards Asexuality
REC ref: 16/HRA/4761
This email acknowledges that Gloucestershire Research Support Service is able to confirm capacity and capability to deliver the above referenced study on behalf of 2gether NHS Foundation Trust.
If you wish to discuss further, please do not hesitate to contact the Senior R&D Manager Mark Walker.

Kind Regards
Nigel
Nigel Johnson| Research Governance Support Officer| Gloucestershire Hospitals NHS Foundation Trust/2gether NHS Foundation Trust/Gloucestershire Care Services/Gloucestershire Clinical Commissioning Group
Gloucestershire Research Support Service | Leadon House | Great Western Road | Gloucestershire Royal Hospital |Gloucester| GL1 3NN

Tel: 0300 4225467(GRH 5467) | Fax: 0300 4225469

Allen Francesca (Somerset Partnership) <Francesca.Allen@sompar.nhs.uk>
Thu 02/02/2017 12:53
To: Julia Cordey;
Cc: Harewood Andrew <Andrew.Harewood@sompar.nhs.uk>;
Burbach Frank <Frank.Burbach@sompar.nhs.uk>;

Dear Julia

RE: IRAS 212832. Confirmation of Capacity and Capability at Somerset Partnership
Full Study Title: Clinician attitudes to asexuality

This email confirms that **Somerset Partnership NHS Foundation Trust** has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation.

We agree to start this study on **6 February 2017**, as previously discussed.

Frank will send out the recruitment email (attached) but there is no link to the online survey included – could you advise please? Also, can you just confirm who you would like to receive this email? All psychological therapists from both secondary and primary care mental health services?

With your permission we will add a sentence to the email confirming that this project has received NHS approval.

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

Sent on behalf of:

Andy Harewood
Head of Research & Clinical Effectiveness
Somerset Partnership NHS Foundation Trust
Mallard Court
Express Park
Bristol Road
BRIDGWATER
TA6 4RN
Telephone: 01278 432045
Mobile: 07768844124
Twitter: @AndyHarewood

Irene Blair <I.Blair@bath.ac.uk>
Wed 11/01/2017 15:00
To: Julia Cordey;

Dear Julia,

2017/001: An Investigation of Psychological Therapists' Attitudes towards Asexuality.
IRAS 212832

Thank you for providing the documents for the above study. Please accept this email as assurance that Bath R&D has reviewed the documents and considers the study to be feasible in Sirona. Bath R&D is happy to support their participation in the study. As you have indicated that the Statement of Activities will form the study agreement with participating organisations, questions 6, 7 & 8 of the document should be completed in conjunction with your contacts at Sirona (Helen or Linda); the green sections of the form should also be completed by one of your contacts before it is returned to you. Please email a copy of the completed document to me.

Kind regards,

Irene

Irene Blair
Research Governance Facilitator
Bath Research and Development
University of Bath
01225 384197
http://www.bath.ac.uk/health/brd/

ARMSTRONG-JAMES, Laura (AVON AND WILTSHIRE MENTAL HEALTH PARTNERSHIP NHS TRUST) <laura.armstrong-james@nhs.net>

Mon 06/02/2017 11:02

To: Julia Cordey;

Cc: Catherine Butler;
Linda Walz <Linda.Walz@sirona-cic.org.uk>;
Pro-Vice-Chancellor for Research;

Dear Julia,

Title of study:	An Investigation of Psychological Therapists' Attitudes towards Asexuality
AWP ref.	983AWP
R&D confirmation date:	6 February 2017
Recruitment end date:	31 March 2017
Study end date:	26 May 2017

Thank you very much for applying to undertake your research in AWP, we pride ourselves on a straight forward and rapid process for research governance.

We are pleased to advise we are able to grant R&D Confirmation at Avon and Wiltshire Mental Health Partnership NHS Trust ("the Trust") to cover the locations as stated above. Please find attached the AWP logo to use on any local documents you will be issuing i.e. information sheets and consent forms.

Under the conditions of approval, you are required to:

1.   Update recruitment figures regularly via EDGE (a Clinical Management System). This enables us to keep a clear track of all Trust-wide study activity, which we need to report to our research funders. **Failure to comply with this will result in your research being suspended, so please make sure you complete this on a monthly basis.** We will set up an account for you, and your login instructions will be emailed to you. Please refer to the attached EDGE guidance document.

2.   Notify us if you plan to recruit participants from any clinical team not outlined above.

3.   To meet AWP R&D audit requirements and adhere to Good Clinical Practice guidelines, you will also need to ensue you create and manage a study site file. If you need more information on this please contact the AWP R&D department or visit the NIHR website:

http://www.crn.nihr.ac.uk/learning-development/good-clinical-practice/gcp-resources-templates-and-reference-documents/

The R&D Management Permission in the Trust is valid until 26 May 2017. If you require any extension to this in the future please contact us to arrange.

We hope you are successful in your recruitment aims and objectives.

Study Amendments:

For further information regarding how to notify us of any amendments to your study please refer to the amendments guidance found at:

http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/

Event reporting:

You are reminded 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.

At the end of your research:

You are required to submit to the Associate Director of Research & Development (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 for inclusion in the study's site file. This way we can ensure those involved within the Trust are aware of your findings and can consider your recommendations. Please send a copy of your final report to **awp.research@nhs.net**.

General Research Governance Information:

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.

Best wishes,

Hannah Antoniades
Associate Director of Research & Development
Avon and Wiltshire Mental Health Partnership NHS Trust

Appendix W. Emails confirming permission from AVEN to seek feedback from forum users

Re: RE: Research project on clinician attitudes to asexuality

From: timewarp_pt@quantentunnel.de
Tue 09/08/2016, 08:34
To: Julia Cordey

Dear Julia,

This looks good to me. I've just posted it on the research subforum. Feel free to comment. Also if you'd like me to edit anything, feel free to ask.

All the best,
Thorsten

RE: Research project on clinician attitudes to asexuality

From: Julia Cordey
Mon 08/08/2016, 21:51
To: timewarp_pt@quantentunnel.de

Dear Thorsten,

Thanks very much for your email. It has been a while since I initially got in touch, and I really appreciate you decision to honour the previous approval.

I have included my message for the research forum below. I have created an AVEN forum account (username Halcyon Daze) so I can engage with any discussion which occurs on the thread and receive private messages from anyone who does not wish to feed back publicly.

Please let me know if the message below sounds ok. If you think any of the wording needs adjusting just let me know.

Many thanks,
Julia

Hi,

I am a trainee Clinical Psychologist in the UK. As part of my degree I am conducting a survey study of psychological therapists to find out how familiar they are with asexuality, and to explore how positively or negatively they feel about it.

As part of this project I am designing a new questionnaire to include in the survey, which is designed to measure how much therapists endorse prejudiced or inaccurate views of asexuality in the context of their clinical work. (For anyone who is interested, this new questionnaire is closely modelled on an existing questionnaire called the

Attitudes Towards Asexuals (ATA) scale by Mark Hoffarth (Hoffarth, Drolet, Hodson & Hafer, 2015).)

I have drafted some items for the new questionnaire (see below). Respondents will be asked to rate these statements from 1 (strongly disagree) to 9 (strongly agree).

I would appreciate any feedback or comments you may have about these statements. Do they reflect the kinds of views you may have come across, or could imagine a therapist thinking if they worked with an asexual client? Have I missed anything really obvious? My goal is to select the most relevant items and refine the wording based on feedback from this thread.

Thank you very much for taking the time to read this post, and thanks in advance for any feedback you may wish to offer! If you have anything you would like to contribute but would prefer not to say on this public thread, you are welcome to send me a private message (username: Halcyon Daze).

 Many thanks,
Julia

Proposed items:

1) If a client told me they did not have any sexual desire I would assume this was a problem for them.
2) When an asexual person seeks support from a mental health professional, it is probably because their lack of sexual desire is causing them distress.
3) People who call themselves asexual have a fear of intimacy.
4) Asexuals are repressing their sexual desires for some reason.
5) Most asexuals have probably experienced some kind of abuse or trauma in the past.
6) If a client told me they do not desire sex I would wonder what has made them this way.
7) It is completely possible for someone who does not experience sexual desire to be happy and fulfilled.
8) Lacking sexual desire is a difficulty that we as mental health professionals have a responsibility to address.
9) Therapists should discuss with their asexual clients whether they want help reconnecting with their sexual feelings.
10) Asexuals would feel better if they allowed a therapist to help them discover their true sexuality.
11) If one of my "asexual" clients told me they have engaged in sexual activity in the past, I would question whether they are really asexual.
12) If a client of mine identified as asexual I would want to find out more about what this means to them as a person.
13) The idea of being "asexual" is a cultural trend which will sooner or later go out of fashion.
14) Lack of sexual desire is to be expected in certain clients, for example disabled or older clients.

Re: Research project on clinician attitudes to asexuality

From: timewarp_pt@quantentunnel.de
 Sun 31/07/2016, 09:29

To: Julia Cordey; aven.pt@gmail.com

Dear Julia,

This has been quite a while already. Some things have changed: there's now a dedicated Research Approval Board, a research subforum under Announcements, and I have followed Steph as AVEN's DRC. But still I think approved is approved.

I'll move the Project Team discussion about your project to the Research Approval Board forum, so people see it has been approved. If anybody has any objections they can say so, but I doubt it.

As for the post itself: in the new research subforum only we can start posts, and members can then reply to them. That way we ensure that everything posted there has been approved by the Research Approval Board (or in your case still by the Project Team). So once you are ready to post, please get in touch with me so I can start a new thread. I could either include all your information in my post, or you can add it in the next post (the first option is probably easier, because people immediately find all the relevant information).

Best wishes,
Thorsten (timewarp)

RE: Research project on clinician attitudes to asexuality

From: Julia Cordey
 Fri 29/07/2016, 18:14
To: AVEN Project Team (research@asexuality.org)

Dear AVEN Project Team,

I contacted you a year ago about a research project I am undertaking as part of my Doctorate in Clinical Psychology at the University of Bath (please see below). This will involve administering a set of questionnaires to UK psychologists about their attitudes towards asexuality. Apologies I haven't been in touch for so long!

As part of this project I have been developing a new measure of attitudes towards asexuality specifically for psychological therapists, and was hoping to run it past members of the AVEN forums to get their feedback. I'm getting close to being able to post my measure on the forum, probably within the next month or two, so wanted to get in touch again to remind you about the project and make sure this still sounds ok with you!

Please don't hesitate to send me any questions about the project or my plans for collecting feedback from AVEN members. I look forward to hearing from you.

Many thanks,
Julia

Date: Sat, 25 Jul 2015 12:54:03 -0400

Subject: Re: Research project on clinician attitudes to asexuality

From: research@asexuality.org

To: juliacordey@hotmail.com

Re: Research project on clinician attitudes to asexuality
AVEN Project Team <research@asexuality.org>
 Sat 25/07/2015, 17:54

Hello Julia,

The Project Team has decided to approve your request to make a thread on AVEN asking for advisers/ feedback while developing your study. However we would like to caution that allowing the community to directly impact how a study is structures may have a negative impact that could deviate from its purpose. Our advice would be to have the core questions already determined/ created and then refined by the community/ advisers. This is our recommendations however you do not need to follow it.

We do ask however to take care to only anonymously mention the experiences of posting members without identifying information (This includes usernames) as this will be on the open forum.

Feel free to post your thread in the Announcements forum whenever you are prepared. When you do please email the Project Team (This email chain) and we will make a post verifying that it has already been approved.
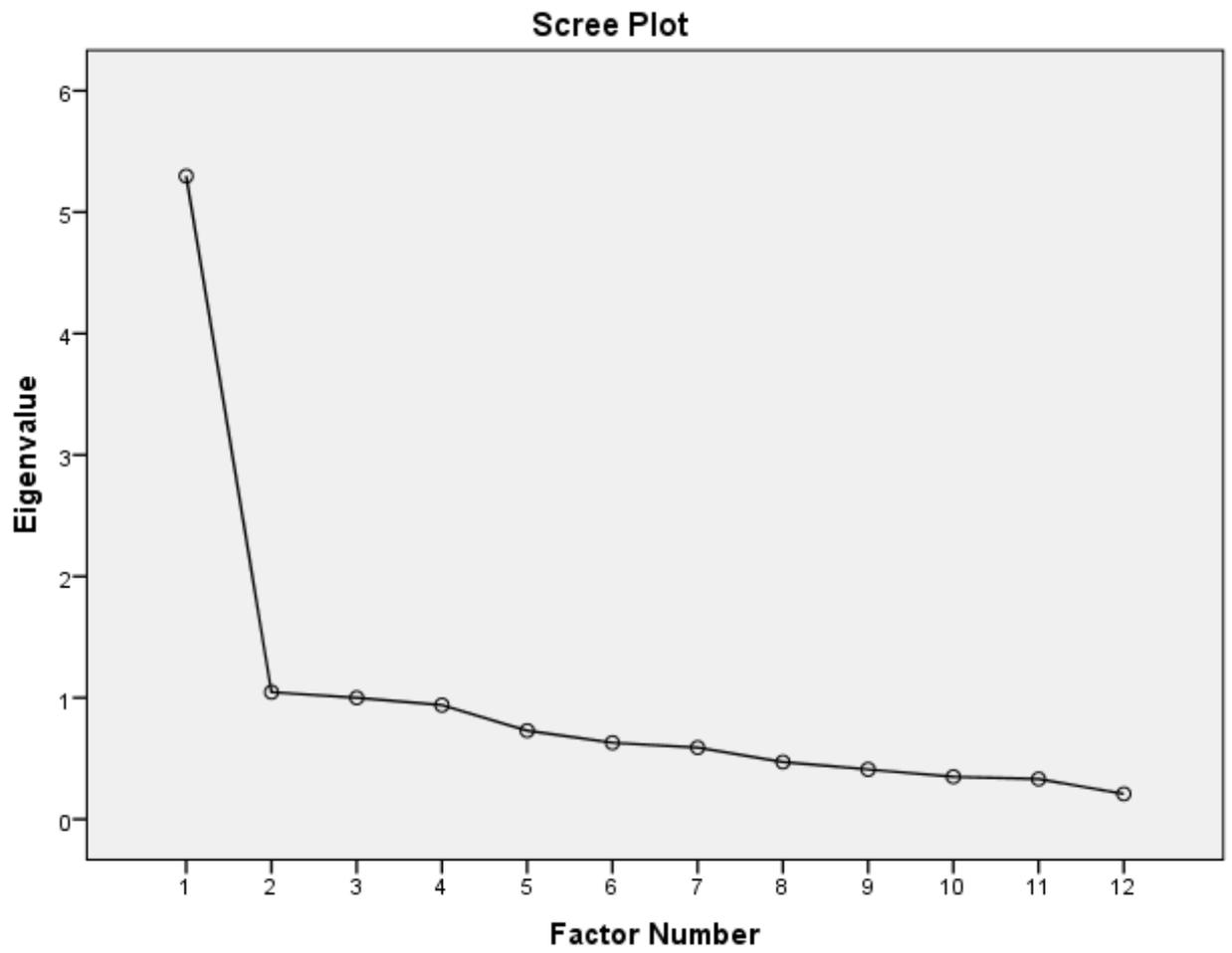
Thank you very much and good luck!

Steph
Dedicated Research Contact

(On behalf of the AVEN Project Team)

Appendix X. Scree plot from factor analysis of 12-item CATA scale.

Scree Plot

Appendix Y. Supplementary convergent validity correlations

Scale	Mean	SD	Scale range	CATA 1 r	CATA 1 pr (singlism)	CATA 2 r	CATA 2 pr (singlism)
Future contact intentions			1-7				
Heterosexuals	6.26	0.96		.002	.04	-.03	.01
Homosexuals	6.25	0.95		-.02	.02	-.05	-.01
Bisexuals	6.17	0.98		-.08	-.03	-.11	-.05
Asexuals	6.10	1.04		-.09	-.01	-.11	-.02
Transsexuals	6.00	1.11		-.12	-.02	**-.18***	-.06
Discrimination intentions			1-11				
Heterosexuals	9.79	1.86		**-.15***	-.10	**-.15***	-.11
Homosexuals	9.77	1.86		**-.15***	-.10	**-.15***	-.11
Bisexuals	9.74	1.87		**-.16***	-.11	**-.16***	-.12
Asexuals	9.78	1.87		**-.14***	-.09	**-.14***	-.09
Transsexuals	9.56	1.89		**-.20****	-.11	**-.19****	-.09
Clinician comfort and confidence			1-7				
Heterosexuals	6.55	0.83		.01	.06	.01	.05
Homosexuals	6.47	0.86		-.05	.04	-.05	.03
Bisexuals	6.40	0.92		-.07	.01	-.06	.02
Asexuals	6.04	1.07		**-.19****	-.11	**-.23****	**-.16***
Transsexuals	5.80	1.18		**-.15***	-.03	**-.23****	-.12

Appendix Z: Author guidelines for Psychology and Sexuality (Taylor and Francis)

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

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  - Formatting and templates
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- Using third-party material in your paper
- Submitting your paper
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Please include a word count for your paper.
A typical article for this journal should be no more than 6000 words; this limit does not include tables, references, endnotes.

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Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.
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References

Please use this reference style guide when preparing your paper. An EndNote output style is also available to assist you.

Checklist: what to include

1. **Author details**. Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the title page. Where available, please also include ORCID identifiers and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations 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 your paper is accepted. Read more on authorship.
2. A non-structured **abstract** of no more than 200 words. Read tips on writing your abstract.
3. **Graphical abstract** (Optional). This is an image to give readers a clear idea of the content of your article. It should be a maximum width of 525 pixels. If your image is narrower than 525 pixels, please place it on a white background 525 pixels wide to ensure the dimensions are maintained. Save the graphical abstract as a .jpg, .png, or .gif. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.
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5. 3-5 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

6. **Funding details**. Please supply all details required by your funding and grant-awarding bodies as follows:
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   For multiple agency grants: This work was supported by the [funding Agency 1]; under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx].
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14. **Units.** Please use SI units (non-italicized).

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