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Abstracts

Critical Review of the Literature

Background: Positive Behavioural Support (PBS) based interventions for challenging behaviour should be routinely monitored and evaluated through the use of outcome measures. For PBS based interventions to develop and evolve, outcome measures must expand from only measuring behaviour change to measuring the broader issue of quality of life. It is essential that these measures are psychometrically robust.

Method: A systematic search was performed across four electronic databases to identify measures of challenging behaviour and quality of life. Measures were included if they were developed for adults with intellectual disabilities and reported psychometric properties in the original paper or subsequent validation studies. Measures were critically evaluated on their psychometric properties (specifically their reliability, validity, responsiveness and on their acceptability, feasibility, and precision). The Characteristics of Assessment Instructions for Psychiatric Disorders in Persons with Intellectual Developmental Disorders (CAPs-IDD) and established psychometric criteria guided the quality appraisal.

Results: Twenty-one measures were identified, all with varying levels of psychometric robustness. The Health of the Nation Outcome Scales for People with Learning Disabilities, Caregiver's Concerns-Quality of Life Scale, Behaviour Problem Inventory-Short, and the Choice Questionnaire were rated as having the strongest psychometric properties.

Conclusions: A combination of measures is recommended for services to use at an individual and service level for evaluating PBS based interventions. Further research is required to replicate these findings and develop new psychometrically robust instruments.

Keywords: Intellectual Disability, systematic review, challenging behaviour, quality of life, psychometric properties, reliability, validity, acceptability, feasibility.

Service Improvement Project

This project aimed to explore clinicians' views on current memory assessment processes and to evaluate the feasibility of a new assessment process, combining high quality assessment (including an MRI scan) with research opportunities, delivered by the Brain Health Centre (BHC). A two-part (pre- and mid- pilot) qualitative design was implemented and nine clinicians took part in semi-structured interviews. Thematic analysis was used to analyse the data. Findings from pre-pilot analysis suggested that memory clinics needed to be updated and clinicians were hopeful the BHC would help improve diagnosis of dementia. Other themes developed focused on the importance of improving patient care and post-diagnostic support. Themes from mid-pilot data included the impact of Covid-19 on service delivery, and the initial outcomes of the BHC pilot, including a process of refinement and learning. Clinicians reported on the strengths of the pilot and areas for improvement when considering expanding the roll-out of this new service.

Keywords: memory assessment, dementia, service improvement, thematic analysis.

Main Research Project

Background: People with Intellectual Disabilities (ID) often face barriers accessing psychological interventions – particularly in mainstream services. This can be due to a lack of reasonable adjustments, including the absence of adapted versions of routine outcome measures. Adapted versions of the Patient Health Questionnaire-9 (PHQ-9) and the Generalised Anxiety Disorder -7 (GAD-7) have been created for adults with ID and this study investigated their psychometric properties.

Method: The adapted PHQ-9 and GAD-7 and the Glasgow Depression and Anxiety Scales (GDS-ID, GAS-ID) were administered to 47 adults with ID. Twenty-one participants formed the clinical group and 26 formed the community group to test for discriminant validity. Concurrent validity was tested by correlating the adapted PHQ-9 and GAD-7 with the GDS-ID and GAS-ID. Reliability was investigated by internal consistency and test-retest analysis.

Results: The adapted PHQ-9 and GAD-7 were able to discriminate between the clinical and community sample in terms of the total score on the depression and anxiety measures. Participants in the clinical sample scored significantly higher on the adapted PHQ-9 (t (45) = -2.28, p = .03, 95% CI [-7.09, -.45]) and GAD-7 (t (45) = -3.52, p = .001, 95% CI [-7.44, -2.02]) than participants in the community sample. The adapted PHQ-9 correlated with the GDS-ID (r (47) = .86, p < .001) and the adapted GAD-7 correlated with the GAS-ID (r (46) = .77, p < .001). The adapted PHQ-9 (Cronbach's α=.84, *ICC*=.91) and the adapted GAD-7 (Cronbach's α=.86, *ICC*=.77) had good internal consistency and good test-retest reliability.

Conclusions: The adapted PHQ-9 and GAD-7 appear valid and reliable measures to use in routine clinical practice.

Keywords: Intellectual Disability, PHQ-9, GAD-7, psychometric properties, outcome measures

Critical Review of the Literature

A Systematic Review of Outcome Measures for Positive Behavioural Support based Interventions for Challenging Behaviours in Adults with Intellectual Disabilities

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Tizard Learning Disability Review (*TLDR*) is an accessible, readable and challenging high-quality source of information and intelligence for those working in the field of learning/intellectual disabilities.

Introduction

Outcome Measures for Adults with Intellectual Disabilities

Using routine outcome measures is a requirement for many psychological services and is considered best practice (Department of Health, 2010). Outcome measures can assess and monitor progress between treatment sessions and can be used to evidence service effectiveness. Routine outcome measures should therefore be part of standard therapeutic work and need to be aligned with client goals as well as system-wide objectives and national frameworks. They need to be clinically relevant, and culturally appropriate (NHS England and NHS Improvement, 2016). Additionally, commissioners require outcomes of clinical interventions to be evidenced and this is often linked to funding and investment in services.

The Learning Disability Professional Senate (2016) states that good outcome measures need to be reliable, valid, appropriate, precise, responsive, acceptable and feasible. Outcome measures often need to be adapted for individuals with Intellectual Disabilities (ID) to accommodate communication difficulties (e.g. with reading, writing, comprehension) and to ensure they are acceptable to the user. A broad spectrum of outcome measures has been developed for ID populations, however there is no "gold standard" or set of measures used consistently across services (Hatton & Taylor, 2013). The variety of instruments thus makes it difficult to choose the most suitable for the intended purpose (Zeilinger et al., 2013). Outcome measures vary considerably in style, length, psychometric properties, and they are designed for differing levels of ID (Hermans et al., 2011). Decision making for measure selection for any stated purpose can therefore be time consuming — while measures must be psychometrically robust, they also need to be feasible to implement in busy health and social care services (Learning Disability Professional Senate, 2016). However, without consistent use of outcome measures, improved tracking of intervention efficacy for ID populations will not occur. This poses challenges to

improving the evidence base by conducting randomised controlled trials (RCTs) within this population.

Challenging Behaviour in ID and Specialist Services

Challenging behaviours are common in individuals with ID, with prevalence rates estimated at 10 to 20% (Cooper et al., 2009; Heyvaert et al., 2010). 'Challenging behaviour' is a socially constructed term, involving both individual and environmental factors and covers a broad spectrum of behaviours, including physical and verbal aggression, damage to property, stereotyped and repetitive behaviours, delinquency, and self-injurious behaviours (Heyvaert et al., 2010; National Institute of Health and Care Excellence [NICE], 2015). Challenging behaviour has negative consequences for the individual, the family, and the wider system, including admission to inpatient assessment and treatment units. Regrettably, individuals with ID and challenging behaviour were often placed in hospitals or institutions out of borough and have been victims of abuse scandals (e.g. Winterbourne View and Whorlton Hall; Bubb, 2014, Willis, 2020). Furthermore, individuals with ID and challenging behaviour are often stigmatised and disempowered (Royal College of Psychiatrists, 2007). The Transforming Care agenda (Department of Health, 2012) has started to address these issues by improving health and care services so that more people with ID and challenging behaviour can live in the community, with the right support, close to home. This has led to implementing Positive Behaviour Support (PBS) as a framework to provide person-centred care and to monitor services.

Providing PBS based interventions to meet the needs of individuals with challenging behaviour and their families is a high priority for services. In recent years, Intensive Support Teams (ISTs) have been rolled out nationwide to help meet a service gap in previous provision. ISTs and Community Teams for People with Learning Disabilities (CTPLDs) frequently work with

individuals who present with challenging behaviours. One audit reported over 42% of referrals to a CTPLD was for challenging behaviour (Slater & Baillie, 2008).

Positive Behaviour Support

PBS is a person-centred multi-component framework for intervention which aims to reduce challenging behaviour and improve the quality of life of individuals and those around them (PBS Academy, 2017). PBS is recommended by NICE, (2015) and the British Psychological Society (BPS, 2004) and implemented by many ID services throughout the United Kingdom. PBS is an applied science that uses educational and systems change methods. It evolved from Applied Behaviour Analysis (ABA) and incorporated person-centred values and ideas from the normalisation/inclusion movement (Carr et al., 2002; Carr & Horner, 2007). Meta-analyses of behavioural interventions have shown PBS to be effective in reducing the frequency, intensity and severity of challenging behaviour (Harvey et al., 2009; Heyvaert et al., 2010; Heyvaert et al., 2012). However, measuring only these dimensions (as often the case with ABA) is not sufficient to evaluate the holistic effectiveness of PBS (or indeed any other behavioural intervention). Other dimensions should also be measured – the person's quality of life (QOL), range of activities or opportunities, reduction in inpatient admissions, a person's development of positive skills, and the person's and family/carers' wellbeing and satisfaction with the intervention (British Institute of Learning Disabilities [BILD], 2016; Royal College of Psychiatrists, 2007). A key component of PBS is that it is data driven, thus it lends itself well to collecting and regularly analysing outcome measures related to both challenging behaviour and to QOL.

The literature recommends a set of outcome measure should be used as opposed to a single outcome measure. For example, it has been proposed that commissioners need data on behaviour change, quality of life, and social validity (Inchley-Mort et al., 2014). Baker and Daynes, (2010) comment that it is unlikely behavioural outcomes can be represented by one instrument and

recommend a battery of measures should be used (e.g. quality of life scales, adaptive behaviour scales, challenging behaviour informant measures, and community participation measures). Nevertheless, there remains a lack of guidance and agreement about which outcome measures should be routinely used in relation to challenging behaviour in adults with ID (BPS, 2014).

Two systematic reviews of QOL measures for adults with ID have been published (see Li et al., 2013; Townsend-White et al., 2012), however one review only included self-report measures and there have been new outcome measures published subsequently. A review on community participation (Taylor-Roberts et al., 2019) has also been published. However, there is a need for a systematic and critical review of research focusing on the measurement of multiple and diverse outcomes for adults with ID who have challenging behaviour. In order for the promise of PBS to continue to develop and evolve, measuring outcomes must expand from only measuring behaviour change to also measuring the broader issues of QOL relevant to challenging behaviour in adults with ID (Kincaid et al., 2002; Unwin & Deb, 2014). A document produced by The Royal College of Psychiatry and the BPS (Banks & Bush, 2016) supports this recommendation. Furthermore, the investigation at Winterbourne View (Department of Health, 2012) highlighted a lack of clear outcome measures for people who present with challenging behaviour and there has been a recognition that such measures are part of a human rights based approach (Department of Health, 2009). Additionally, as suggested above in relation to commissioners, the National Development Team for Inclusion (NDTi) recommends the use of outcome measures for services to demonstrate they are good value for money and are able to provide high quality evidence-based interventions for a group that is often marginalised and vulnerable (NDTi, 2010).

No comprehensive review including a broad range of outcome measures for use in adults with ID whose behaviour challenges appears to have been conducted. The BPS (2014) produced a document recommending informant measures and included a summary of outcome measures for

mental wellbeing, challenging behaviour, quality of life, and for adaptive behaviours. However, the report did not conduct a systematic search of possible measures nor specifically assess the psychometric properties of the outcome measures using any quality appraisal tools to critically evaluate the measures. The current review aims to build on this initial work and systematically search and evaluate the quality of both self-report and informant/carer report outcome measures for PBS based interventions for adults with ID and provide recommendations about the best outcome measures that can currently be used by services.

Aim

The aim of this systematic review is to evaluate outcome measures available for PBS based interventions, specifically focusing on outcome measures for challenging behaviour and QOL. The review aims to critically evaluate the psychometric properties of these outcome measures and provide guidance on the most robust outcome measures for learning disability services to use. The review aims to answer the following research questions:

- What are the psychometric strengths and weaknesses of these outcome measures?
- How responsive (detects change over time), acceptable, feasible, and precise are these outcome measures?
- What outcome measures could services use to evaluate PBS based interventions?

Methodology

Figure 1 depicts the literature search process that was utilised and based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al. , 2009).

Search strategy

Online databases (PsychInfo, Medline, EMBASE and CINAHL) were searched for relevant articles in January 2020 resulting in a total of 30 articles meeting inclusion criteria. Searches were re-run in April 2021 and an additional six articles were included in the final

analysis. Search terms were identified from previous literature, meeting with a librarian, and using synonyms. Search strings for ID, outcome measures, challenging behaviour, QOL and psychometric properties (see Appendix A) were created using Boolean search operators and truncation symbols. The search was limited to include studies whose primary aim was to establish psychometric properties of the outcome measures. Measures included did not need to be utilised within a PBS study. Articles needed to be published in peer reviewed journals, be quantitative studies, and written in the English language. Reference lists of identified articles and of existing reviews in the field were checked. Grey literature searches included reviewing reports published by the British Psychological Society and searching on Google Scholar.

Inclusion criteria

Articles included in the review had to meet the following criteria:

- Included participants with ID. Any severity of ID was included, however Autism Spectrum Disorders (ASD) were only included if they were comorbid with ID.
- Participants aged 18 years or over (if study reported a wide age range, mean age had to be 18 or over to be included). Due to the scope and feasibility of this review, measures used with children with ID were not included as this review focused on adults and adult services.
- Reported on the psychometric properties of the outcome measures specifically for QOL or challenging behaviour; psychometric properties or related terms included in the title or abstract.
- Articles had to be evaluating psychometric properties of the English version of the outcome measure.
- Measures could be either self-report or informant based but had to focus on the person with ID (e.g. not carer's attitudes to the challenging behaviour).

The main author screened all titles and abstracts. A second independent reviewer (E.G) screened 60% of the articles at the screening stage. The double reviewing of 100 papers resulted in 89% agreement and a Kappa coefficient of .752 (ICC .768); this is in the good to excellent range (Landis & Koch, 1977). Additionally, a random sample of 20% of the full articles were independently reviewed by E.G. with inter-rater reliability deemed as good (ICC .803, $k = .66$). Advice was sought from a third reviewer (KT; supervisor with expertise in ID) regarding three discrepancies that were unresolved between the main author and second reviewer. Five articles from reference checks were not available at time of writing (no electronic versions accessible and unable to access hard copies due to Covid-19).

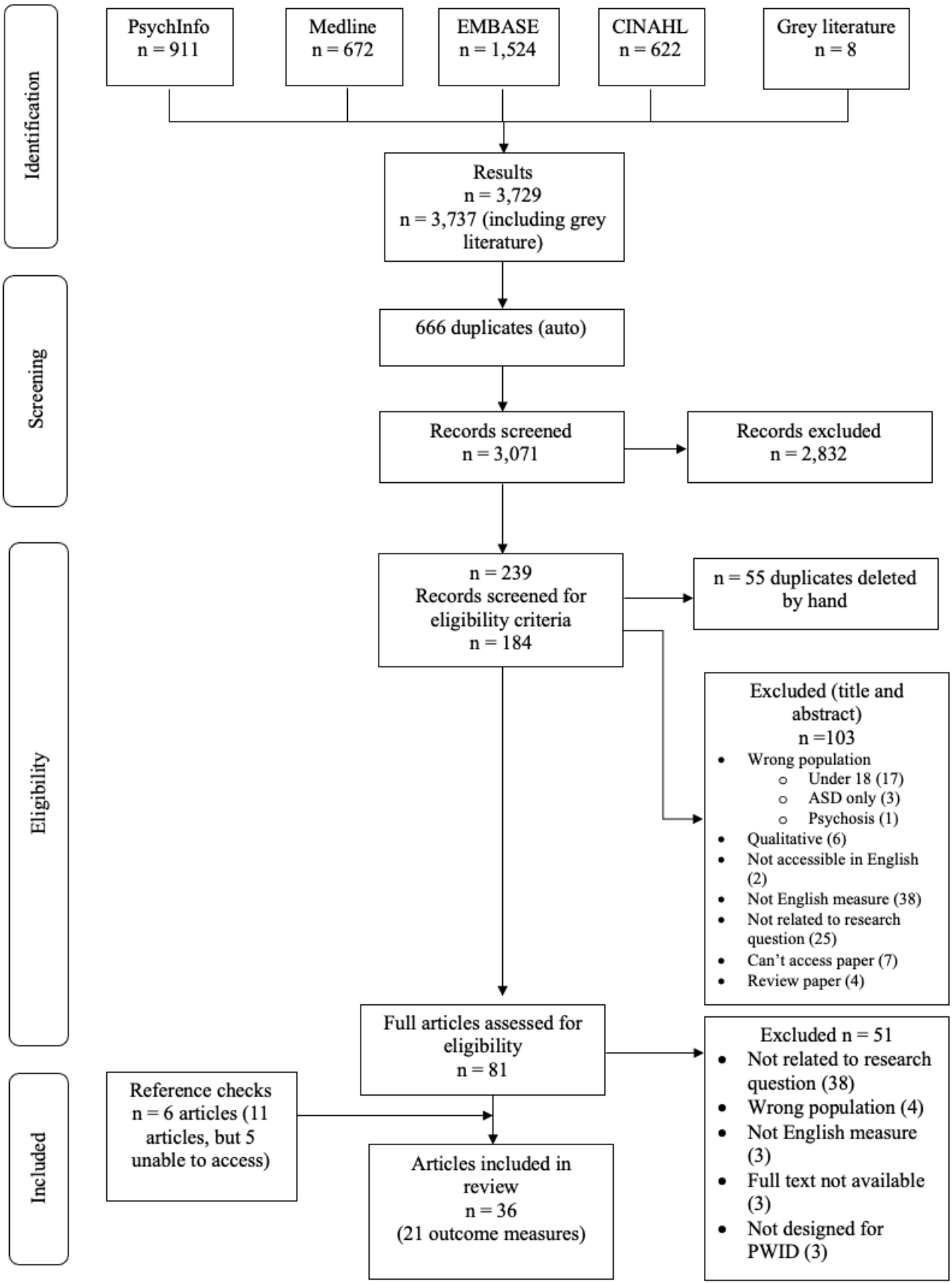

Figure 1. PRISMA flowchart of the systematic literature search process of reviewed papers.

Data Extraction and Quality Appraisal

Data were extracted into Excel and edited into tables by the main author. Extracted data included participant demographics, description of the outcome measure, and the psychometric properties of the measure based on the Characteristics of Assessment Instructions for Psychiatric Disorders in Persons with Intellectual Developmental Disorders (CAPs-IDD; Zeilinger et al., 2013). The CAPs-IDD has been designed to evaluate the quality of psychometric properties of mental health tools for people with ID and can be used as a general quality tool for assessing measures in the ID field (Flynn et al., 2017). It allows direct comparisons between available instruments and supports an evidence-based choice of the best instrument (Zeilinger et al., 2013). The CAPs-IDD was used alongside psychometric criteria from Cahill et al., (2008) and Fitzpatrick et al., (1998) to guide the quality appraisal. Dimensions evaluated included test development and measurement characteristics, validity, reliability, acceptability, responsiveness, and feasibility. Outcome measures were rated on a four-point scale (++ excellent; + good; - fair; -- poor) using standard interpretation guidelines (Flynn et al., 2017). See Tables 1 and 2 for psychometric definitions and coding criteria.

Table 1

Criterion	Definition
Reliability	A reliable measure is one that produces consistent results from the same respondent over time
Internal consistency	Measured by Cronbach's alpha, split-half reliability estimates
Test-retest reliability	Degree to which test scores remain unchanged when measuring a stable individual characteristic on different occasions
Inter-rater reliability	Degree of agreement among raters
Validity	The extent to which a measure really measures the concept that it purports to measure.
Content	The ability of a measure to tap all the relevant aspects of the attribute it is intending to measure.
Construct	Hypotheses generated and a measure tested to determine whether it actually reflects these prior hypotheses.
Convergent validity	A measure converges with other indicators of the same concept
Discriminant validity	A measure demonstrates low levels of correspondence with a measure that represents another concept
Criterion	Calibrate measure against a known standard or against itself.
Concurrent	A new measure administered at same time as pre-existing measure and the two are correlated
Responsiveness	Does the instrument detect changes over time that matter to the patient? It can be discriminative (between individuals) or evaluative (within an individual across time).
Acceptability	Is the measure acceptable to users? Practicality of administration Time taken to complete Length of instrument Translations Access by ethnic minorities Reading age
Feasibility	Is the measure easy to administer and process? Cost and burden to administrative staff Electronic scanning options Scoring systems Training package Training manual Support from measure developers
Precision	How precise is the measure? Interpretability Normative data

Definitions of psychometric properties (taken from Cahill et al., 2008)

Table 2
Coding criteria (adapted from Fitzpatrick criteria and Flynn et al., 2017)

	Criteria	Rating	Interpretation guidance source
Cohen's kappa	0.75-1	++	Landis and Koch
(for inter-rater	0.61-0.75	+	(1977)
reliability)	0.41-0.6	-	
	<0–0.4	- -	
Cronbach's alpha	0.9-1	++	Cicchetti (1994)
(for internal	0.8-0.9	+	
consistency)	0.7-0.8	-	
	0.0-0.7	- -	
Intra-class correlations	0.7-1	++	Cicchetti and Sparrow
(ICC)	0.5–0.69	+	(1981)
(for inter-rater reliability	0.49-0.3	-	
and test-retest)	<0.29	- -	
Correlation coefficient	0.7-1	++	Hinkle et al., (2002)
	0.5-0.7	+	
	0.3-0.5	-	
	0-0.3	- -	
Validity	Reports three types of validity tests	++	Cahill et al., (2008)
	Reports two types of validity tests		Fitzpatrick
	Reports one validity test	+	
	No validity estimates reported	-	
		--	
Responsiveness	Significant differences found between groups or within individuals.	++	Fitzpatrick
	Non-significant trends found between groups or within individuals.	+	
	Not addressed		
		--	
Acceptability	All components described	++	Fitzpatrick
	At least one component described	+	
	Not addressed	--	
Feasibility	All components described	++	Fitzpatrick
	At least one component described	+	
	None described	--	
Precision	All component described	++	Fitzpatrick
	At least one described	+	
	None described	--	

++ =Excellent, + = Good-Average, - = Fair, - - = Poor

Results

Twenty-one outcome measures were identified and studied for their psychometric properties, 14 measured QOL and seven measured aspects of challenging behaviour. Each outcome measure was evaluated and given a total score based on their ratings for each psychometric domain (3 points for ++, 2 points for +, 1 point for -, and 0 points for --), with

higher scores suggesting overall strong psychometric properties and lower scores indicating overall poor psychometric properties.

QOL Results

Seven of the QOL measures were self-report measures: Brief Assessment of Service Satisfaction in Persons with an Intellectual Disability (BASSPID; Lanovaz, et al., 2014), Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000), Lifestyle Satisfaction Scale (LSS; Heal & Chadsey-Rusch, 1985), Maryland Ask Me! Project; (MAMP; Bonham et al., 2004), mini-MANS-LD (Raczka et al., 2018), Multifaceted Lifestyle Satisfaction Scale (MLSS; Harner & Heal, 1993), Personal Wellbeing Index Intellectual Disability (PWI-ID; McGillivray et al., 2009). Three measures were informant-based: Caregiver's Concerns-Quality of Life Scale (CC-QOL; Unwin & Deb, 2014), Evaluation of Quality of Life Instrument (EQLI; Nota et al., 2006) and Health of the Nation Outcome Scales for People with Learning Disabilities (HONOS-LD; Roy et al., 2002). Four of the QOL measures had both a self and informant option: Choice Questionnaire (Stancliffe & Parmenter, 1999), Comprehensive Quality of Life Scale-Intellectual Disability (com-QOL-ID; Cummins et al., 1997), Maslow Assessment of Needs Scales – Learning Disabilities (MANS-LD; Skirrow & Perry, 2009), and the Quality of Life-Questionnaire (QOL-Q; Rapley et al., 1998). See Table 3 for a description of these measures. Tables 4, 5, and 6 report on the reliability, validity, acceptability, responsiveness and feasibility, and overall strengths of their psychometric properties.

Table 3
Description of QOL related measures and demographic data from studies

			Study Characteristics		
Measure	Description	Administration, number of items, rating, time to complete	Study	Sample (n, mean age, gender, country)	ID severity
BASSPID	Assesses service satisfaction and QOL. Items include following areas: service delivery, interpersonal relationships, respect of rights, physical environment. Visual support with smiley faces.	Administration: self-report questionnaire, administered by trained interviewers. Item: 15 Rating: 3-point scale, additional 2 open-questions Time: < 20 mins	(Lanovaz, et al., 2014)	N : 98; 57 males, 41 females Age: 39 (range 18 – 73) Country: Canada	57% mild; 41% moderate; 2% severe (based on available data, n=53)
CC-QOL	Proxy measure completed by caregivers assessing health related QOL. Reported as a holistic measure to assess outcome in adults with ID who exhibit aggressive behaviour. Comprises two parts to measure two constructs, namely outcomes for caregivers, in relation to concerns they have about the person they care for (CC) as well as QoL for the adult with ID. The Caregiver Concerns (CC) subscale and QoL subscale each comprises 8 items respectively.	Administration: informant-reported questionnaire Item: 16 Rating: 5-point scale Time: 5 mins	(Unwin & Deb, 2014)	N: 100; gender NR Age: NR (18 and over) Country: UK	Mild to profound
Choice Questionnaire	Instrument assesses the degree of personal control, or choice, exercised by PWID. Covers 6 life domains: domestic matters; co-residents and staff; money and spending; health; social activities, community access, and personal relationships; work and day activities; overall choice.	Administration: self-report by interview or completed by informant Item: 26 Rating: 3-point scale Time: NR	(Stancliffe & Parmenter, 1999)	N: 30; 15 males, 15 females Age: 35.6 (range 18 – 57) County: Australia	8 mild, 4 moderate, 18 severe
com-QOL-ID	Consists of 2 axes; one measures objective QOL, the other subjective QOL. Each axis comprises 7 domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Pictorial smiley to sad faces used.	Administration: self-report questionnaire. A parallel scale for a third-party to provide vicarious subjective responses is available if required. Item: 21 Rating: multiple rating scales dependent on pre-test results. Binary, 2-point, 3-point or 5-point scales Time: NR	(Cummins, McCabe, Romeo, Reid, & Waters, 1997)	N: 59; approximately gender balance. Age: 37.2 (range 17 – 63) County: Australia	NR
EQLI	Objective wellbeing. The instrument elicits staff evaluations of the satisfaction experienced by the individuals they support. Items examine the quality of service received, satisfaction with opportunities for social interaction, and environmental characteristics.	Administration: proxy questionnaire Item: 18 Rating: 5-point scale Time: NR	(Nota, Soresi, & Perry, 2006)	N: 248; 135 males, 113 females Age: 31.4 County: Italy, UK	Males:20% mild, 74.1% moderate, 5.9% severe Females:27.4% mild, 64.6% moderate, 8% severe
GCPLA	A measure of community participation and the use of leisure activities. Produces both quantitative and qualitative data. Items include services, public transport, indoor leisure, sport and recreation, activity, social, and facilities/amenities. Items are rated for frequency of activity and level of contact (e.g. supervised, alone).	Administration: self-report checklist/questionnaire administered as semi-structured interview Item: NR (53 checklist items) Rating: 5-point scale Time: NR	(Baker, 2000)	N:12; gender NR Age: 27.9 (range 20.2 – 38.7) County: UK	Severe to profound
GCPLA-R	Revised version of the GCPLA	Administration: proxy questionnaire Item: 23 items Rating: 6-point scale Time: NR	(Baker, Taylor-Roberts, & Jones, 2021)	N:153; 87 males, 66 females Age: 45.18 (range 18 – 74) County: UK	NR

BASSPID Brief Assessment of Service Satisfaction in Persons with an Intellectual Disability; *CC-QOL* Caregiver's Concerns-Quality of Life Scale; *com-QOL-ID* Comprehensive Quality of Life Scale- Intellectual Disability; *EQLI* Evaluation of Quality of Life Instrument; *GCPLA* Guernsey Community Participation and Leisure Assessment; *NR* Not Reported; *PWID* Person With Intellectual Disabilities.

Table 3 *Continued*

			Study Characteristics		
Measure	Description	Administration, number of items, rating, time to complete	Study	Sample (n, mean age, gender, country)	ID severity
HONOS-LD	Measures health and social functioning of people experiencing mental illness.	Administration: Proxy questionnaire Item: 18 Rating: 5-point scale Time: NR	(Roy et al., 2002)	N: 372; 236 males, 136 females Age: NR County: UK	152 mild, 121 moderate, 13 profound
			(Tenneij, Didden, Veltkamp, & Koot, 2009)	N: 79; 51 males, 28 females Age: 29.5 County: Netherlands	Mild, borderline, severe
			(Turton, 2020)	N: 2,109 Age: NR Country: UK	NR
LSS	Assesses satisfaction with their lives - satisfaction with their residence, their community setting, and their community services. Items grouped into community satisfaction, friends and free time satisfaction, satisfaction with services and general satisfaction.	Administration: Self-report questionnaire, administered as interview Item: 29 Rating: binary – yes/no Time: 20 mins	(Heal & Chadsey-Rusch, 1985)	N: 38; 18 males, 20 females Age: 31(range 20 – 61) County: USA	NR (intermediate care facilities/ apartments)
			(Yu, Jupp, & Tylor, 1996)	N: 49; 29 males, 20 females Age: males =39.4, females = 43.55 County: Australia	NR
MAMP	Assesses consumer perceived QOL, based on eight core quality of life domains. Measure is an adaptation of the QOL-Q. Six questions for each of the eight core QOL domains – social inclusion, self-determination, personal development, rights, interpersonal relations, emotional wellbeing, physical wellbeing, material wellbeing. Uses pictorial smiley faces as well as numbered scale.	Administration: self-report by interview questions/survey Item: 56 Rating: 3 responses (favourable, neutral, unfavourable) Time: 20-30mins	(Bonham et al., 2004)	N: 923; 526 males, 397 females Age: range 18 - 64 County: USA	32% mild, 20% moderate, 18% severe, 17% profound 10% average intelligence, 3% unknown
MANS-LD	Measure of subjective QOL. Can be used retrospectivly and prospectively. Items cover safety needs, love and belonging needs, self-esteem needs, and self-actualisation.	Administration: Self-report questionnaire or proxy Item: 19 Rating: 5-point scale Time: NR	(Skirrow & Perry, 2009)	N:12; gender NR Age: NR County: UK	NR
Mini-MANS-LD	Subjective QOL measure. Items include satisfaction with environment, safety, social relationships, esteem and self-actualization, overall life satisfaction. Items cover Maslow's hierarchy of needs. Pictorial and verbal scale, colour coded smiley faces. To be used in conjunction with a health related QOL measure (EQ-5D-Y).	Administration: Self-report questionnaire Item: 9 Rating: 5-point scale Time: 6 mins	(Raczka, Theodore, & Williams, 2018)	N: 33; 14 males, 19 females Age: 39 (range 22 - 69) Country: UK	87.89% mild; 12.11% moderate
MLSS	Is the modified version of the LSS. Assesses satisfaction with living arrangements, personal relationships, recreation and leisure, employment and degree of self-direction. Designed to be answered by individuals even with limited verbal skills.	Administration: Interview (structured) – self-report Item: 58 Rating: 5-point Time:20 mins	(Harner & Heal, 1993)	N: 149; 63 males, 86 females Age: 40 (range 18 -81 County: USA	59.67% mild, 24% moderate, 8% severe, 1% profound

HoNOS- LD Health of the Nation Outcome Scales for People with Learning Disabilities; *LSS* Lifestyle Satisfaction Scale; *MANS-LD* Maslow Assessment of Needs Scales – Learning Disabilities; *MAMP* Maryland Ask Me! Project; *MLSS* Multifaceted Lifestyle Satisfaction Scale; *NR* Not Reported.

Table 3 *Continued*

			Study Characteristics		
Measure	Description	Administration, number of items, rating, time to complete	Study	Sample (n, mean age, gender, country)	ID severity
PWI-ID	Measures subjective wellbeing. Items ask people how satisfied they are with eight life domains: standard of living, personal health, achievement in life, personal relationships, personal safety, community-connectedness, future security, and religion/ spirituality. A reduced choice format, illustrated as a series of outline faces, from very sad to happy, is provided to enhance comprehension.	Administration: self-report questionnaire, conducted by trained interviewers Item: 7 Rating: 11-point scale. (5-,3-, 2-point scales available dependent on cognitive ability) Time: 45 min	(McGillivray, Lau, Cummins, & Davey, 2009)	N: 114; 62 males, 52 females Age range 18 – 60 County: Australia	82 mild, 32 moderate
QOL-Q	Measures four factors; satisfaction, competence, empowerment and social belonging.	Administration: self-report questionnaire and proxy (by 2 independent respondents) Item: 40 Rating: 3-point scale Time: 20-30	(Rapley, Ridgway, & Beyer, 1998)	N: 13; 7 males, 6 females Age: range 35 - 65 County: Australia, UK	NR
			(Stancliffe, 1999)	N: 63; 28 males, 35 females Age: 34.8 (range 18- 61) County: Australia	15 mild, 19 moderate, 29 severe

PWI-ID Personal Wellbeing Index Intellectual Disability; *QOL-Q* Quality of Life- Questionnaire; *NR* Not Reported

Table 4
Reliability of QOL related measures

Measure	Internal consistency (alpha)	Test-retest period and coefficients	Inter-rater coefficients
BASSPID	Overall .81	N: 32; Period: 10 weeks Coefficients: *r* =.76	N: 23 parents (compared with patient scores) Coefficients: *r* =.27
CC-QOL	CC .85, QOL .80.	N: 52; Period: 1 week Coefficients: ICC = 0.81 for CC and 0.80 for QOL	N: 50 Coefficients: ICC = 0.67 for CC and 0.63 for QOL.
Choice Questionnaire	Self-report .81, staff response .90.	N: NR; Period: NR Coefficients: *r*= .95 for self-report, .89 for staff report.	N: NR (staff reports only) Coefficients: *r*= .86
com-QOL-ID	Overall .56 for subjective scale, .68 for objective scale.	N: 34; Period: 1-2 weeks Coefficients: *r* = .87 for subjective scale, *r* = .82 objective scale	N: NR Coefficients: NR
EQLI	Overall .90. Factors 1-3 were .87, .85, .73 respectively.	NR	NR
GCPLA	(Baker, 2000) .93 for frequency of contact, .82 for type of contact	N: 9; Period: 2-weeks Coefficients: *r* =.87 (ranges .56 to 1.00). For carers (n=12), *r* = .83 (ranges .46 to 1.00).	N: 12 (carers) Coefficients: *r* =.83 (ranges .62 to 1.00).
	(Baker et al., 2021) Overall .75	N: 16; Period: 15 days Coefficients: *r* =.91 (ranges .61 to .95).	N: NR Coefficients: *r* = .69 (ranges .13-.85)
HONOS-LD	Ranged between .74 and .89	N:NR; Period: not clear Coefficients: *r* = 0.626 to 0.669	N: NR Coefficients: *k* = .60 - .85, *r* =0.96; ICC = .72 (N= 48)
LSS	Overall .85. Subscales ranged from .66 to .85	N: 27; Period: 4- 29 days Coefficients: *r* = .74 (total score). Ranged from .44 to .83	N: NR Coefficients: ICC =.95 (total score) Ranged from .60 to .98 2 raters scored 88% reliability (Yu, Jupp, & Tylor, 1996)
MANS-LD	NR	NR	NR
MAMP	Core domain scales ranged from .70 to .76.	NR	NR
Mini-MANS-LD	Overall .74	N: NR; Period: NR Coefficients: NR	N: NR Coefficients: NR
MLSS	Overall .88. Domains ranged from .56 to .92.	N:76; Period: 4- 64 days Coefficients: *r* = .70 (overall). Domains ranged from .11 to .85.	N: NR Coefficients: ICC = .99. Domains ranged from .81 to .97.
PWI-ID	Overall .76.	N:31; Period: 1-2 weeks Coefficients: *r* = .58, *ICC* =.57	NR
QOL-Q	Overall .90, range .67-.90 across domains.	N: NR Period:2 weeks Coefficients: *r* = .87 (range .80 to ..96)	N: 63 (staff: staff), 13 (staff: client) Coefficients: *r* = .83 to .88 (staff: staff). *r* = .82 for total score (staff: client). Empowerment factor not significant, *r* = -0.43).

Table 5
Validity of QOL related measures and other psychometric properties

Measure	Validity			Responsiveness	Acceptability	Feasibility
	Content	Criterion (concurrent)	Construct (factor analysis, convergent, discriminant)			
BASSPID	Based QOL theory. Experts, stakeholders, service users involved in development.	NR	Factor analysis Convergent: 93% consistency between closed and open questions.	NR	Reported acceptable by service users.	Free to use for clinical, educational, and research purposes.
CC-QOL	Experts, service users and carers involved in development. Interviewed care givers to assess face validity. Items broadly cover the 8 domains of QOL (Schalock et al., 2002). Modelled scale from other Health Related QOL in non-ID field.	Concurrent: correlations with MOAS CC: r =0.41; p <0.01 and QoL: r=-0.22; p<0.05 and with ABC irritability scale CC: r = 0.46; p < 0.01 and QoL: r = -0.21; p < 0.05.	NR	N= 61 Completed at baseline, 6 and 12 months. QOL scores remained stable over time (T1 mean = 19.34 (SD 5.79); T2 mean = 20.36 (SD 5.38); T3 mean = 20.51 (SD 4.63); F(2, 120) = 2.67, p = .07, n = 61). CC scores significantly reduced over time (x2(2) = 13.12, p = .001, n = 61).	Reported being user friendly, easy to complete by caregivers. Completed within 5 minutes.	Administered in clinic; Caregivers reported finding the items relevant, questionnaire was easy to understand, found the scoring system appropriate. Caregivers did not consistently miss out any items. Free to use
Choice Questionnaire	15 experts, extensive literature searching and empirical evaluation. Report satisfactory content validity. Questions are about who makes various choices and factors which prevent the person from having free choice.	Concurrent: correlated with QOL-Q Empowerment scores, *r* =.79 for self-report, *r* =.83 for staff reports.	Discriminant: tested against living environment (t-tests computed between semi-independent living vs group homes). Results for self-report t(24) = 4.26, p=.001, for staff report, t(37.8)=5.30, p<.00005.	NR	Wording deemed acceptable and prompts to questions helpful.	Free to use
com-QOL-ID	Based on QOL construct.	NR	No significant correlations between objective and subjective scores, with the exception of objective health correlating with health importance and health satisfaction. Described comparing with university students without ID but no correlations reported.	NR	No resistance from clients, pre-test found entertaining.	Research assistants trained in administration. Manual available upon request. Free to use

Table 5 *Continued*

Measure	Validity			Responsiveness	Acceptability	Feasibility
	Content	Criterion (concurrent)	Construct (factor analysis, convergent, discriminant)			
EQLI	Experts involved and multiple phases of development, removing items after service user feedback.		Exploratory and Confirmatory Factor Analysis – support for 3-factor structure. Convergent; correlated with Quality of Life Index (n= 64). *r*=.31 to .63. Discriminant; correlations between EQLI and FBFS, *r* = .04 to .24.	NR	NR	Free to use
GCPLA	(Baker, 2000) 10 experts rated items as relevant to the concept of community participation and leisure. Modified from Seager's (1987) structured interview for community contacts	Concurrent: (n=11) Correlated scores with the LEC, *r* = .55 to.74. Correlated GCPLA with diary data, *r* = .68. Correlations between GCPLA and BPI and ABS	NR	NR	NR	Norms reported Free to use
GCPLA -R	(Baker et al., 2021). Focus groups with family, care staff, adults with ID, and professionals reviewed items.	Concurrent: correlated with diary data, *r*=.64, ICI, *r* =.63, Shortened Adaptive Behaviour Scale, *r* =.16	Principle Component Analysis Discriminant; correlations with gender, ($t(151) < 1$, $p > .37$) and with age ($r = -0.47$, $p < .001$, $n = 151$). Compared scores between adults with ID and a sample of staff	NR	NR	Free to use upon request
HONOS -LD		Concurrent: correlated with ABC, *r* = .49 to .52 Correlated with HoNOS, *r = .72 to .86*	Convergent: correlated with ABC, *r*= .67 to .76. Exploratory Factor Analysis (suggesting possible 3 sub-scales)	Significant ($p<.001$) difference between T1 and T2.	Clinicians rated it as simple to use. Reports acceptable to clinicians – language appropriate, instrument easy to understand and use	Requires training. Not free to use
LSS	Refined from the Residential Satisfaction Scale.	NR	Subscale correlations ranged from .009 to .918. Discriminant; 2 different groups based on facility types, showed significant differences in general satisfaction and community environment. Total satisfaction score, *r*=.168, $p<.05$ (between facility groups). Subscale correlations ranged from -0.26 to .59. LSS scores correlated against gender, time spent in wards, contact with family	NR	NR	Interviewers trained Freely available

ABC Aberrant Behavior Checklist; *ABS* Adaptive Behaviour Scale (Nihira et al., 1974); *BPI* Behaviour Problem Inventory; FBFS Fate Bene Fratelli Schedule (Nota & Soresi 2003); *ICI* Index of Community Involvement (Raynes, Pratt & Roses, 1979); *LEC* Life Experience Checklist (Ager, 1990) ; Quality of Life Index (Campo et al, 1996)

Table 5 *Continued*

Measure	Validity			Responsiveness	Acceptability	Feasibility
	Content	Criterion (concurrent)	Construct (factor analysis, convergent, discriminant)			
MANS-LD	Rooted in social validity (Wolf, 1978), Maslow's hierarchy of needs (Maslow, 1943) and human rights and human needs. Experts involved in development.	NR	NR	Used retrospective version and calculated before and after change (N=12, moved from institution to community). Significant changes reported.	Easy to use, accessible to SU's, carers, staff, service commissioners. Easy read and non-easy read versions.	Free to BPS Faculty for LD members.
MAMP	Service users created some of the questions. Pilots conducted with interviewers and researchers, dropped 7 items. Items relate to 8 core QOL domains.	The 8 QOL domains significantly correlated with each other ($p<.01$) but varied in magnitude of correlations, ranged from .35 to.69.	NR	NR	Adults with ID interviewed adults with ID. 68% answered all 56 questions.	Interviewer provided one-day training course.
Mini-MANS-LD	Items relate to the 8 QOL domains proposed by Schalock et al., 2002 and Maslow's hierarchy of needs. Experts and service users involved. Adapted from MANS-LD.	Pearson's correlation with PWI-ID. $r = .67$	Correlated with EQ-5D-Y (health state score), $r = .51$.	Evaluative: no significant changes in scores between first and second administration (~4 months later).	Rated easy to use by administrators and service users. Significantly easier to administer and significantly more acceptable by service users compared to PWI-ID. Quick to complete	Free to use
MLSS	Modified from LSS. Review of literature, experts involved in development of measure.		Convergent: Total MLSS score correlated with Personal Caretaker Questionnaire, $r = .44$. Total MLSS score correlated with QOL-Q, $r = .-.18$. 33% shared variance – MLSS reflects substantial lifestyle satisfaction variance of QOL scale. Discriminant: correlated against age, sex, level of ID, living facility by regression analysis.	NR	NR	Interviewer provided with training. Measure, training and scoring materials available for free by contacting first author.
PWI-ID	Theory of Subjective Wellbeing Homeostasis' (Cummins & Nistico 2002; Cummins & Lau 2004).. Developed by international group of scholars. Evolved from com-QOL measure.	NR	Exploratory factor analysis – factors confirmed using principle components analysis. 2 factors explained 57.9% of variance. All domains correlated significantly with 'life as a whole', ranged between 0.27 to 0.44.	NR	Easy, convenient to use, simple and concrete language and option to substitute numerical responses with 'smiley' faces.	Free to use
QOL-Q		NR	NR	NR	NR	NR

Table 6
Strengths of psychometric properties for QOL related measures

Outcome Measure	Reliability			Validity	Responsiveness	Acceptability	Feasibility	Precision	Score
	Internal consistency	Test-retest	Inter-rater						
BASSPID	+	++	- -	+	NR	+	+	NR	11
CC-QOL	+	++	+	+	++	++	+	NR	17
Choice Questionnaire	+/++	++	++	++	NR	+	+		15.5
Com-QOL-ID	- -	++	NR	+	NR	+	+/++	NR	9.5
EQLI	++	NR	NR	++	NR	-	+	NR	9
GCPLA/ GCPLA-R	+	++	+/++	++	NR	NR	+	+	14.5
HONOS-LD	+	+	++	++	++	++	+	NR	18
LSS	+	++	++	++	NR	NR	+	NR	13
MANS-LD	NR	NR	NR	+	+	++	+	NR	9
MAMP	-	NR	NR	+	NR	+	+/-	NR	6.5
Mini-MANS-LD	-	NR	NR	++	+	++	++	NR	12
MLSS	+/++	++	++	++	NR	NR	+/++	NR	14
PWI-ID	-	+	NR	+/++	NR	++	-/+	NR	10
QOL-Q	++	++	++	NR	NR	NR	NR	NR	9

++ = Excellent + = Good-Average, - = Fair, - - = Poor, NR = not reported

BASSPID Brief Assessment of Service Satisfaction in Persons with an Intellectual Disability; *CC-QOL* Caregiver's Concerns-Quality of Life Scale; *com-QOL-ID* Comprehensive Quality of Life Scale- Intellectual Disability; *EQLI* Evaluation of Quality of Life Instrument; *GCPLA* Guernsey Community Participation and Leisure Assessment; *HoNOS- LD* Health of the Nation Outcome Scales for People with Learning Disabilities*; LSS* Lifestyle Satisfaction Scale; *MANS-LD* Maslow Assessment of Needs Scales – Learning Disabilities; *MAMP* Maryland Ask Me! Project; *MLSS* Multifaceted Lifestyle Satisfaction Scale; *PWI-ID* Personal Wellbeing Index Intellectual Disability; *QOL-Q* Quality of Life- Questionnaire*; NR* Not Reported.

The five QOL based measures with the strongest psychometric properties were the HONOS-LD,CC-QOL, Choice Questionnaire, GCPLA and the MLSS, respectively. From our analysis, the lowest psychometrically rated QOL measure was the MAMP.

The HoNOS-LD is an informant measure and has been tested with a large sample size.. It is a holistic measure covering quality of life in addition to challenging behaviour and mental health difficulties. It appears to have sound psychometric characteristics, with excellent inter-rater reliability, responsiveness and acceptability. However, the measure requires training and is not free to use - this could be a burden for services.

The CC-QOL is an informant measure and ranged between excellent to good across all psychometric domains assessed. Experts and service users were involved in the development of the measure and it is reported to have good face validity. Additionally, it has been shown to be responsive - showing changes over time, and it is acceptable and feasible; it is quick to administer, user friendly, and free to access. The analysis was conducted on a respectable sample size of 100 participants with a range of severity (mild to profound), however it does not state proportions of each level of severity, thus may not be representative of a broad range of people with ID.

The Choice Questionnaire can be used as a self-report measure or can be completed by an informant, providing greater flexibility. The questionnaire reports excellent test-retest, inter-rater reliability and validity. However, the authors report only satisfactory content validity. The measure uses a majority of open-ended questions with a few binary (yes/no) questions to overcome response bias and specifically tests for acquiescence. Furthermore, the measure reports on floor and ceiling effects which are often neglected in other measures and provides various response options to adjust

for these effects. However, it has only been evaluated on a small sample size and it does not report the length of time to administer the measure. It covers six life domains as opposed to the eight QOL domains proposed by Schalock et al., (2002) which are covered in other outcome measures and therefore may be less comprehensive.

The GCPLA is a measure of community participation as opposed to a measure covering a broader level of subjective QOL. The GCPLA is the only measure to report on precision by providing normative data. It reports excellent reliability however it does not explicitly report on acceptability. Psychometric testing was computed on a very small sample size which did not represent a range of ID severities. However, the revised version has been tested on a larger sample size, has been made shorter and items reviewed for their relevance by carers and service users, suggesting it is now more acceptable to use.

The MLSS (a modified version of the LSS), is a self-report measure, and is suitable for individuals with limited verbal skills. It has excellent reliability and validity, however it does not report on the acceptability of the measure and service users were not involved in the test development. The measure, training and scoring materials are all freely available on request.

Challenging Behaviour Results

A total of seven outcome measures (all informant based) were identified which measured aspects of challenging behaviour. They included the Aberrant Behaviour Checklist (ABC; Aman et al., 1985), Adult Scale of Hostility and Aggression: Reactive/Proactive (A-SHARP; Matlock & Aman, 2011), Behaviour Problem Inventory (BPI-01; Rojahn et al., 2001), BPI-Short (BPI-S; Rojahn et al., 20212), Challenging Behaviour Interview (CBI; Oliver et al, 2003), Modified Overt

Aggression Scale (MOAS; Oliver et al., 2007) and the Problem Behaviour Check List (PBCL; Tyrer et al., 2016). See Tables 7,8,9 and 10 for descriptions of measures, reliability, validity and overall psychometric strenghts.

Table 7
Description of Challenging Behaviour related measures and demographic data from studies

			Study Characteristics		
Measure	Description	Administration, number of items, rating, time to complete	Study	Sample (n, mean age, gender, country)	ID severity
ABC	An informant-based problem behaviour rating scale. Items fall into five subscales; Irritability, Agitation, Crying (15 items), Lethargy, Social Withdrawal (16 items), Stereotypic Behaviour (7 items), Hyperactivity, Non-Compliance (16 items), and Inappropriate Speech (4 items)	Administration: Informant questionnaire, administered by trained professionals Item: 58 Rating: 4-point scale Time: NR (10-15 mins)	(Johannes Rojahn, Aman, Matson, & Mayville, 2003)	N: 226; 126 males, 100 females Age: range 20 -91 Country: USA	3.1% mild, 7.1% moderate, 18.1% severe, 61.9% profound, 9.7% unspecified
			(Newton & Sturmey,1988)	N: 209; 119 males, 90 females Age: NR Country: UK	NR
A-SHARP	Measures severity of aggression and the 'direction' of aggression (reactive vs. proactive). Consists of five subscales; Verbal Aggression, Physical Aggression, Hostile Affect, Covert Aggression, and Bullying. The items on each subscale are rated first for severity (the Problem scale) and second for ''origin'' (i.e., to reflect extent to which behaviours are planned or reactive; the Provocation scale)	Administration: Informant questionnaire Item: 52 (48 are scored) Rating: 4-point scale (problem scale) and 5-point scale (provocation scale) Time: NR	(Matlock & Aman, 2014)	N:512; 315 males, 197 females Age: 41.5 (range 19 – 84) Country: USA	43.4% mild, 33.6% moderate, 22.5%severe/profound, 0.6% unknown.
			(Matlock & Aman, 2011)	Same sample as above	Same sample as above
			(Rojahn et al.,2017)	N:155; 108 males, 47 females Age: range 16 -71 Country: USA	NR
BPI-01	A behavioural problems rating scale for all ages and levels of functioning. Assesses three types of challenging behaviour; SIB (14 items), stereotypic behaviours (24 items), and aggressive/destructive behaviours (11 items). Aims to assess the presence, frequency and severity of problem behaviour in both adults and children.	Administration: Informant questionnaire or semi-structured interview Item: 49 Rating: 5-point frequency scale and 4-point severity scale. Time: NR	(González et al., 2009)	Study 1 N:100; 63 males, 37 females Age: 49 (range 15 – 86) Country: USA Study 2 N:425; 235 males, 190 females Age: 50.8 (range 18 – 87) Country: USA	3% mild, 7% moderate, 17% severe, 68% profound, 5% unspecified 1.4% mild, 5.4% moderate, 11.5% severe, 74.4% profound, 7.3% unspecified
			(Johannes Rojahn, Matson, Lott, Esbensen, & Smalls, 2001)	N:432; 233 males, 199 females Age: range 14 - 91 Country: USA	2.1% - mild, 4.9% moderate, 18.5% severe, 65.7% profound
			(van Ingen, Moore, Zaja, & Rojahn, 2010)	N:130; 92 males, 38 females Age: 39.7 Country: USA	87.89% mild, 12.11% moderate
			(Johannes Rojahn, Wilkins, Matson, & Boisjoli, 2010)	N: 57; 38 males, 19 females Age:51(range 23 – 81) Country: USA	1 mild, 2 moderate, 4 severe, 49 severe, 1 unspecified. (40 ASD diagnosis, 17 no ASD)

ABC Aberrant Behaviour Checklist; *A-SHARP* Adult Scale of Hostility and Aggression: Reactive/Proactive; *BPI-01* Behaviour Problems Inventory

Table 7 *Continued*

			Study Characteristics		
Measure	Description	Administration, number of items, rating, time to complete	Study	Sample (n, mean age, gender, country)	ID severity
BPI-01 and BPI-S	As above	As above	(Barnard-Brak, Rojahn, & Wei, 2013)	N: 1122 Other details not clear	Not clear
BPI-S	A shortened version of the BPI-01.	Administration: Informant questionnaire or semi-structured interview Item: 30 Rating: 5-point frequency scale and 4-point severity scale Time: NR	(Mascitelli et al., 2015)	N: 232; gender NR Age: 36.5 (range 16 – 71) Country: USA, UK	23.3% mild, 33.1% moderate, 28.4% severe, 14.2% profound
			(Rojahn et al., 2012)	N:1122; gender NR Age: 34.4 (range 2 -90) Country: USA, UK, Netherlands	NR
			(Bowring, Totsika, Hastings, & Toogood, 2018)	N:265; 134 males, 131 females Age: 41.4 Country: UK	124 mild, 83 moderate, 32 severe, 26 profound
CBI	Interview with informant to assess severity of challenging behaviour. Two parts; Part I, respondents are asked to determine whether the participant has shown one of the following five types of behaviour within the last month: self-injury, physical aggression, verbal aggression, disruption of the environment and inappropriate vocalizations. Part II of the interview consists of 14 questions designed to assess the severity of each topographical class of behaviour identified in Part I.	Administration: Structured interview – informant Item: Part 1 – five items, Part II – 14 scale items Rating: 4-point scale Time: NR	(Oliver et al., 2003)	N:40; 26 males, 14 females Age: 36 (range 17 – 58) Country: UK	Moderate to severe
MOAS	Based on the OAS, the MOAS measures four types of aggression; verbal, against objects, against self, against others. Measures severity and frequency.	Administration: Informant checklist Item: 16 Rating: 5-point scale Time: NR	(Oliver, Crawford, Rao, Reece, & Tyrer, 2007)	N:14; 9 males, 5 females Age:35 (range 23 – 58) Country: UK	5 mild, 8 moderate, 1 severe (5 had ASD)
(IBR-MOAS)	A modified version of the MOAS. Includes verbal aggression towards self.	Administration: Informant questionnaire Item: 20 Rating: 4 Time: NR	(Cohen et al., 2010)	N: 3,547 Age: 49.3 Country: USA	883 mild, 539 moderate, 670 severe, 1,390 profound, 64 none
PBCL	Described as a short but comprehensive instrument for all aspects of challenging behaviour. Items cover: personal violence, violence against property, self-harm, sexually inappropriate, contrary, demanding and disappearing behaviour.	Administration: Informant questionnaire Item: 7 Rating: 5-point scale Time: NR	(Tyrer et al., 2016)	N: not clear (?200); Age: NR Country: UK, Jamaica	NR

BPI-S Behaviour Problems Inventory – Short; *CBI* Challenging Behaviour Interview; *MOAS* Modified Overt Aggression Scale; *IBR-MOAS (*Institute for Basic Research) Modified Overt Aggression Scale; *PBCL* Problem Behaviour Check List; *NR* Not Reported

Table 8
Reliability of Challenging Behaviour related measures

Measure	Internal consistency (alpha)	Test-retest period and coefficients	Inter-rater coefficients
ABC	.91 (Irritability, Agitation, Crying), .92 (Lethargy, Social Withdrawal),.88 (Stereotypic Behaviour), .90 (Hyperactivity, Non-Compliance), .84 (Inappropriate Speech)	NR	NR
A-SHARP	(Matlock & Aman, 2014) Median correlation 0.65. Correlations ranged from 0.67 to 0.78.	NR	N: 39 Coefficients: ICC = 0.72 (Problem subscales), 0.65 (Provocation subscales)
	(Rojahn et al., 2017) Over all .95 (problem), .90 (provocation). Verbal Aggression: .93 (problem), .82 (provocation); Physical Aggression: .84 (problem), .86 (provocation); Hostile Affect .92 (problem); Covert Aggression .80 (problem); Bullying .76	NR	NR
BPI-01	(González et al., 2009) 0.65 -0.87 (Stereotyped and Aggression subscales), 0.40 – 0.48 (SIB subscale)	(González et al., 2009) N:80; Period: NR Coefficients: *k* = 0.64 (SIB), 0.36 (Stereotyped), 0.50 (Aggression/Destructive)	(González et al., 2009) N:NR Coefficients: *k* = 0.49 (SIB), 0.29 (Stereotypy), 0.46 (Aggression/Destruction)
	(Rojahn et al., 2001) Overall .83. SIB .61, Stereotype .79, Aggression/Destruction .82.	(Rojahn et al., 2001) Coefficients: ICC = .76	(Rojahn et al., 2001) Coefficients: ICC = .91
	(van Ingen et al., 2010) SIB 0.61, Stereotyped .90, Aggression/Destruction .79.	(van Ingen et al., 2010) N: 130; Period: 8 weeks (for community sample) Coefficients: ICC = 0.91 (SIB), 0.90-0.88 (Stereotyped), 0.87-0.89 (Aggression/Destruction).	(van Ingen et al., 2010) N:130 Coefficients: ICC= 0.83 -0.85 (SIB), 0.84 - .66 (Stereotyped). 0.82 (Aggression/Destruction)
	(Barnard-Brak et al., 2013) SIB .74, Steretyped .92, Aggressive/Destuctive .89		
BPI-S	(Mascitelli et al., 2015) Overall 0.91 (frequency subscales) SIB 0.85, Stereotype 0.86, Aggression/Destruction 0.89	(Mascitelli et al., 2015) N:146; Period: 42 days (ranged from 31 -57 days) Coefficients: *r* = 0.90 (SIB), 0.91 (Stereotyped) 0.83 (Aggression/Destruction) for frequency scales. Severity scales; 0.83 (SIB), 0.76 (Aggressive/Destructive).	(Mascitelli et al., 2015) N: 147 Coefficients: ICC 0.46 to 0.66
	(Rojahn et al., 2012) SIB 0.70 (frequency) 0.68 (severity), Stereotyped 0.88 (freq) 0.86 (sev), Aggressive/Destructive 0.89 (freq) 0.89 sev).		
	(Barnard-Brak et al., 2013) SIB .68, Stereotyped .85, Aggressive/Destructive .87.		
CBI	NR	N:22; Period: NR Coefficients: *k* =0.86 (range 0.70 – 0.91)	N: 22 Coefficients: *k* = 0.67 (range 0.50 – 0.80)
MOAS	NR	NR	N: 23 informants (60 paired ratings of 14 participants with 23 carers) Coefficients: ICC = 0.93 total MOAS score. ICC ranged from 0.49 to 0.90 for subscales.
(IBR-MOAS)	Ranged from .74 to .85	N: not clear; Period: not clear Coefficient: ICC = 0.84 to 0.96	N: not clear Coefficients: ICC = 0.70 to 0.83
PBCL	Overall 0.7	NR	N: 38 Coefficient: *k* = 0.91

Table 9
Validity of Challenging Behaviour related measures and other psychometric properties

Measure	Validity			Responsiveness	Acceptability	Feasibility
	Content	Criterion (concurrent)	Construct (factor analysis, convergent, discriminant)			
ABC	Developed by factor analysis.	Predictive validity; compared against external criterion – presence or not of a DSM-IV diagnosis.	Convergent; multiple comparisons with BPI. Predicted subscales (stereotypy) significantly correlated. Divergent; evidence of lack of correspondence between BPI aggression/Destruction subscale and ABC stereotypy subscale, as predicted. Factor analysis - 5 factors, a total of 55.1% of the variance accounted for by the 5 factors	NR	NR	Trained all raters
A-SHARP	Empirically developed. Developed by experts and use of factor analysis	Concurrent; Problem subscale correlated with Aggressive/Destructive BPI subscale, *r* = .70 (severity) and .67 (frequency). Correlations ranged from .15 to .71(Rojahn et al., 2017)	Exploratory Factor Analysis Convergent; used Aggressive/Destruction subscale of BPI, correlations ranged from 0.33 to 0.86. Divergent; matrix of correlations between Problem scale and Provocation scale- ranged from -0.04 to 0.28 (evidencing different constructs). Diagnostic (congruent) validity tested – predicted DSM disorders significantly associated with A-SHARP. Confirmatory Factor Analysis (Rojahn et al., 2017)	NR	NR	Free to use (http://psychmed.osu.edu/)
BPI-01	Developed and revised over many years. Piloted. Items based on review of literature.	Predicted individuals with Pervasive Developmental Disorders to score higher on BPI-01, multivariate test was significant (Rojahn et al.,2001). Concurrent; BPI-01 subscales correlated with ICAP subscales, ranged from .66 to .11. (van Ingen et al., 2010)	Confirmatory Factor Analysis – Root Mean Square Error Approximation (RMSEA) to evaluate goodness of fit = .078 - considerable fit. Factor loading sig for all except 3 items. Item total correlations; SIB .39, Stereotyped .41, Aggressive/Destruct .59 (Rojahn et al.,2001). Frequency and Severity data correlated at .90. (considered dropping severity scale but argue has clinical importance). Convergent; BPI-01 and ASD-BPA significantly correlated. *r* = 0.89 (total frequency) and 0.66 (total severity) n=17, no ASD ppts.(Rojahn et al., 2010). Discriminant; ppts with ASD scored significantly higher on BPI-01 than those without ASD (Rojahn et al., 2010). Item Response Theory (Barnard-Brak et al., 2013)	NR	Translated into 11 different languages	Requires training Freely available by emailing author

Table 9 *Continued*

Measure	Validity			Responsiveness	Acceptability	Feasibility
	Content	Criterion (concurrent)	Construct (factor analysis, convergent, discriminant)			
BPI-S		NR	(Mascitelli et al., 2015) Confirmatory Factor Analysis (CFA) Frequency and Severity scores strongly correlated, r = 0.82 to 0.92 (Rojahn et al., 2012) CFA- confirms three factors Convergent and Discriminant; correlations with ABC, DASH-II, NCBRF. Correlations ranged from 0.00 (SIB with DASH-II Anxiety subscale) to 0.73(NCBRF conduct subscale with BPI-S aggression/destruction subscale). Item Response Theory (Barnard-Brak et al., 2013)	(Bowring et al., 2018) BPI-S shown to determine change in challenigng behaviour following service input or intervention. Normative data provided	Several incidences of missing data reported Bowring et al., 2018 -no missing data reported.	NR
CBI	Content validity assessed by comparing scores for each behaviour on specific items relating to relevant aspects of severity of impact that would be expected to differ based upon the topographies of the behaviour. Experts involved in development	Only reports concurrent validity using child sample – correlations with ABC ranged from 0.19 to 0.68.	NR	NR	Reported as being clear and easy to use	Copies of interview obtained freely from first author
MOAS	Based on the OAS	NR	NR	NR	NR	NR
(IBR-MOAS)	NR	NR	Factor analysis	NR	NR	NR
PBCL		Concurrent; correlated with MOAS	Factor analysis Convergent; PBCL and MOAS highly correlated	NR	Reports being simple, short and repeatable	Free to use for non-commercial purposes

ABC Aberrant Behaviour Checklist; *DASH-II* Diagnostic Assessment for the Severely Handicapped - II (Matson et al., 1991); *NCBRF* Nisonger Child Behavior Form (Aman et al., 1996); *OAS* Overt Aggression Scale; *SIB* Self Injurious Behaviour

Table 10
Strengths of psychometric properties for Challenging Behaviour Measures

Outcome Measure	Reliability			Validity	Responsiveness	Acceptability	Feasibility	Precision	Score
	Internal consistency	Test-retest	Inter-rater						
ABC	+	NR	NR	++	NR	NR	+	NR	7
A-SHARP	++	NR	+/++	++	NR	NR	+	NR	9.5
BPI-01	+	++	++	++	NR	+	+	NR	15
BPI-S	+/++	++	+	++	+	+	+	NR	16.5
CBI	NR	++	+	+	NR	+	+	NR	11
MOAS (IBR-MOAS)	- /+	++	++	-	NR	NR	NR	NR	8.5
PBCL	-	NR	++	+	NR	+	+	NR	10

++ = Excellent + = Good-Average, - = Fair, - - = Poor, NR = not reported

ABC Aberrant Behaviour Checklist; *A-SHARP* Adult Scale of Hostility and Aggression: Reactive/Proactive; *BPI-01* Behaviour Problems Inventory; *BPI-S* Behaviour Problems Inventory – Short; *CBI* Challenging Behaviour Interview; *MOAS* Modified Overt Aggression Scale; *IBR-MOAS (*Institute for Basic Research) Modified Overt Aggression Scale; *PBCL* Problem Behaviour Check List; *NR* Not Reported.

In evaluating psychometric properties, the BPI-S had the strongest properties out of all measures for challenging behaviour, followed by the BPI-01. The BPI outcome measure (both BPI-01 and BPI-S) also had the greatest number of published papers relating to its psychometric properties. These measures were followed by the CBI, PBCL and A-SHARP in order of psychometric strength. The MOAS and ABC rated lowest in terms of psychometric properties.

The BPI-S reports good to excellent internal consistency, inter-rater reliability, and excellent test-retest reliability. It has been shown to have excellent validity and evidences acceptability, feasibility and responsiveness. The BPI has been revised over many years and has been translated into 11 different languages. The length of time to complete the measure was not reported, however, with fewer items then the BPI-01, it will likely be quicker to administer. Despite the strong psychometric evidence for the BPI-S, the results should be interpreted with some caution – the BPI-S data reported by Rojahn et al., (2012) used the entire dataset of the BPI-01 and then manipulated the data to create scores for the BPI-S retroactively. Future studies will be required to explore the BPI-S independently of the BPI-01.

The CBI is a standardised interview providing in-depth information regarding the severity and frequency of behaviours and reports good reliability and validity. It has been developed by experts and used in both child and adult ID populations. However, concurrent validity was analysed with a child sample and not with an adult sample. The CBI has been reported to be acceptable and is freely accessible.

The PBCL is the shortest instrument (seven items) and quick to use as it is a checklist as opposed to a structured interview. It has excellent inter-rater reliability and fair internal consistency. The measure has shown to be valid, acceptable, and feasible.

The A-SHARP had excellent validity and internal consistency which was corroborated by independent reviewers and evaluated with large sample sizes. However, many psychometric features were not reported, including test-retest, acceptability and responsiveness. Further research is required to determine the clinical utility of the measure.

Due to methodological challenges it was not possible to evaluate the ABC fully. Three papers reporting the psychometric properties of the ABC were not accessible online (they were published in 1985,1987, 1995) and due to Covid-19 it was not possible to retrieve hard copies through inter-library loans. However, psychometric properties of the ABC have been reported elsewhere (see Flynn et al., 2017) and the ABC was often used to validate other outcome measures (e.g. CBI).

Two papers were identified reporting psychometric properties for the MOAS, however, only part of the IBR-MOAS was evaluated (the Aggression Scale) as the other aspects of this measure did not meet inclusion criteria. The MOAS was not designed specifically for adults with ID and is often used in autism specific populations. Furthermore, the MOAS has not been examined in clinical practice - it has only been assessed in a research context. Insufficient information has been provided to fairly evaluate the psychometric properties of the MOAS (responsiveness, acceptability, or feasibility have not been explicitly reported).

Discussion

This review identified and evaluated the psychometric properties of 21 outcome measures (14 QOL and seven related to challenging behaviour) that have been used for adults with ID. The outcome measures varied considerably in their psychometric properties - many did not comprehensively report details regarding various psychometric domains (reliability, validity, responsiveness, acceptability, feasibility and precision). Furthermore, the majority of the outcome measures appeared to have only been psychometrically tested by the authors of the measure and not replicated to confirm findings (with the exception of the BPI/BPI-S, A-SHARP and HONOS-LD). It is possible that lower rated measures could be psychometrically sound but due to a lack of published articles evaluating their psychometric properties it is not possible to evaluate these in detail. Further research and reporting of psychometric qualities is therefore required to advance understanding and improve decision making regarding measure selection for the evaluation of QOL and challenging behaviour outcomes within PBS based interventions.

Outcome measures not only need to be valid and reliable but also need to be simple to use, quick to complete, sensitive to change, and flexible (Unwin & Deb, 2014). The psychometric properties of the outcome measures assessed were wide-ranging and there will inevitably be a trade-off between these criteria and clinical judgement when measures are selected in clinical practice.

A variety of threats to reliability and validity can emerge depending on the type of outcome measure – self-report or informant/proxy. The type of scale used (e.g. Likert versus binary) and issues of acquiescence need to be carefully considered when designing and administering self-report questionnaires for individuals with ID. Research has examined the reliability and validity of Likert-type scales compared with binary (yes/no, either/or) or open-ended questions used in

outcome measures for adults and adolescents with ID (Hartley & MacLean., 2006). This concludes that Likert scales which include pictorial representations of response alternatives, brief response descriptors, and pre-tests are the most reliable and valid. Testing for acquiescence either in the form of a pre-test or incorporating it into the questionnaire are important factors in order to achieve higher levels of reliability and validity with adults with moderate to severe ID. Pre-tests help to decrease response bias and increase response rates by training individuals in how to use Likert scales (Hartley & MacLean, 2006). From our identified informant outcome measures, the mini-MANS-LD, Choice Questionnaire, Com-QOL-ID and LSS all test for acquiescence.

Informant-based measures can also result in threats to reliability and validity, depending on who is selected to complete the measure (e.g. support staff, family, psychologists). From information reported, the length of time and how well the informant knew the individual with an ID ranged significantly – from three months to five and a half years. The outcome measure itself may be psychometrically robust, however the information collected may not be if the informant does not know the individual very well. This may pose challenges within a service context where there is often high staff turnover (McKenkie et al., 2021) and it may not be possible to find an informant who knows an individual well enough to comprehensively complete the outcome measure. Furthermore, inconsistencies could be created when evaluating change over time if different informants complete the measure at different intervention phases. If using informant-based measures, it is recommended to have two informants to ensure reliability, however this may make the outcome measure less feasible due to not having enough resources.

Acceptability and feasibility are important considerations when deciding which outcome measure to use. The time required to complete an outcome measure is key in ensuring the

respondent and/or administrator do not feel burdened. If outcome measures are to be collected routinely, they need to be quick to complete and score. None of the challenging behaviour outcome measures explicitly reported time to complete - this may be due to the fact they are all informant based and mostly interview style measures. Of the QOL related outcome measures, those which did report length of time to complete ranged from five to six minutes (CC-QOL and mini-MANS-LD) to 45 minutes (PWI-ID). Andresen (2000) recommends measures for people with ID should preferably take less than 15 minutes to complete. Many of the outcome measures identified in this review would not meet this recommendation.

Consideration of the available modes of administration is also note-worthy for decision making regarding outcome measures. To our knowledge, all the outcome measures are paper and pen based. Many of the self-report outcome measures provided pictures and symbols which increases acceptability (CHANGE, 2016), however no measures reported computer-based options. This is particularly salient in the current context (Covid-19 pandemic), where many services are having to work remotely and are required to provide interventions through the use of Internet technology and web interfaces.

Recommendation for services

As discussed, there is no single measure most appropriate for evaluating PBS based interventions - there is not a 'gold standard'. From our analysis of the psychometric properties, services should consider using the following outcome measures:

1. HoNOS – LD
2. CC – QOL
3. BPI-S

4. Choice questionnaire

Limitations and Future Research

One limitation of the current review is the possibility of missing studies and outcome measures relevant to the review question. In particular, the review did not investigate how many research papers/ studies reported using the specific outcome measures (a huge task), but which may have also provided further information on a measure's psychometric properties. Other relevant studies may have been missed due to the search string used. Terms related to psychometric properties had to be included in the title or abstract and this may have missed papers with more interesting titles or articles which had multiple aims in addition to reporting on psychometric properties. Furthermore, the search terms used were not exhaustive and terms for ID did not include older terms such as 'mentally challenged' or 'moron' or 'imbecile' etc. Lastly, measures translated into different languages were not included and therefore the aspect of cross-cultural validity of measures was not assessed.

Of the measures identified, many did not report comprehensively on the multiple domains typically used to assess the psychometric strengths of a measure – few covered and evaluated all the dimensions of reliability, validity, responsiveness, acceptability, feasibility and precision, as recommended by Cahill et al., (2008) and Fitzpatrick et al., (1998). There still is no 'gold standard' outcome measure for measuring QOL or outcome of PBS based interventions in adults with IDs. Additionally, many of the measures only included a very small number of individuals with severe to profound disability and therefore do not represent the range of disability. Further research with larger and more representative samples is required to replicate findings of the preliminary psychometric properties for the promising outcome measures reported and discussed above.

Responsiveness (detection of change over time), and precision (norms and cut-offs) need increased investigation. Without providing benchmarks and/or cut-offs, it is difficult to identify clinically significant changes and to assess and compare the effectiveness of PBS based interventions, particularly when working with an individual client. However, this likely requires the establishment of large scale psychometric studies, and also some RCTs.

Conclusions

The aim of this review was to evaluate the psychometric properties of outcome measures to be used particularly for PBS based interventions. The focus of the review was to provide a comprehensive assessment of measures used to assess challenging behaviour and QOL in adults with IDs. Whereas previous work has evaluated only a limited range of measures, this review sought to include a comprehensive set of all measures currently available. Of the identified measures available, there was considerable variation in their psychometric properties. If outcome measures are not psychometrically robust, they are of little use. Outcome measures need to be meaningful to the individual, based on conceptual frameworks, valid and reliable, responsive to detecting change over time and feasible for implementation at a service level. This review has identified measures relevant to both challenging behaviour and QOL that show promise and in need of further research to realise this ambition fully.

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Service Improvement Project

Exploring Clinicians' Views on the Brain Health Centre Pilot Study – Recommendations for the Future

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Proposed Journal: Health Services and Delivery Research

This journal publishes evidence to improve the quality, accessibility and organisation of health services and to enhance the strategic focus on research that matters to the NHS.

Introduction

Project Background

The 'Prime Minister's challenge on dementia 2020' (Department of Health, 2015) sets out the UK's aim of being at the forefront of dementia care and support, providing the best environment for research into dementia and other neurodegenerative diseases by 2020. In line with this ambition and the Edinburgh consensus (Ritchie et al., 2018) which highlights the future for memory services, the National Institute for Health Research (NIHR) Oxford Health Biomedical Research Centre (BRC) was set up to establish an effective interface between translational research and clinical care. A key objective of the BRC was to set up the Brain Health Centre (BHC) to integrate research and clinical assessment, aiming to improve diagnosis and management for disorders of mental and cognitive health and in the long-term to provide improved diagnostic tools and new treatments. As part of a six-month pilot, patients who were referred to a local Memory Clinic (MC) to be assessed for dementia were seen at the BHC for an in-depth cognitive assessment (including an MRI scan) and were given the opportunity to consent to research.

Summary of relevant literature

Prevalence and Impact of Dementia

We are living with an ageing population, with dementia remaining a global challenge (World Health Organization, 2014) and a key priority outlined by NHS England and the government (Department of Health, 2015). The number of people with dementia in the UK is forecast to increase to over one million by 2025. According to local authority data, 8,468 people in Oxfordshire have dementia (Alzheimer's Society, 2014). Early diagnosis of dementia is advantageous as patients can access treatments to slow down the progression, support and advice can be provided, and it allows time to plan for the future (NICE, 2018). Getting care and timely support is cost-effective as

it can reduce the number and length of hospital admissions and delays moving into long-term residential care (National Audit Office, 2010). The Memory Services National Accreditation Programme (MSNAP; Royal College of Psychiatrists, 2015) aims to improve the diagnosis and care of people with dementia by providing timely and equal access to services, and evidence-based treatments.

Service Context and Need for Innovation

Our understanding of the brain has substantially increased in recent decades. However, despite advances in neuroscience research, there has been limited change in clinical assessments conducted in MCs across the UK. This gap in research and implementation limits patient access to high quality assessments and slows down the development of new treatments. Additionally, it has created inequality to healthcare as patients with other long-term conditions (e.g. cancer) are often offered advanced assessment and care which can be more readily available. Psychologists have a responsibility and skill set to help bridge the gap between research and practice in order to improve patient care.

The National Institute of Health and Care Excellence (NICE, 2007) recommends that in order to develop clinical guidance and successfully implement change, barriers need to be understood alongside an awareness and knowledge of what needs to change and why. The feasibility, costs versus benefits, skills and training requirements, and practicalities such as resources, personnel, and difficulties establishing service delivery are all important areas to evaluate. Furthermore, exploring clinicians' views is a key factor affecting implementation of health innovations (Chaudoir et al., 2013).

Aims and Scope

The project outlined below forms part of the Plan, Do, Study, Act cycle (PDSA, Langley et al., 2009) implemented to ensure quality improvement and assess whether the BHC should be extended and expanded in the long term. We aimed to explore factors recommended by clinicians that would improve the existing service and to evaluate the feasibility and practicality of offering an alternative approach to a routine service. Meetings were held with members of the BHC steering group, including the project manager, research coordinator and the Patient and Public Involvement (PPI) group to scope the project and identify key questions to be addressed (see Appendix B).

Methodology

Design and Participants

A two-part (pre- and mid-pilot) qualitative design, using individual semi-structured interviews and thematic analysis was implemented. This methodology was selected as it allows for exploration of clinicians' views and experiences of the BHC. A total of 11 interviews were conducted each lasting approximately 30-45 minutes. Audio recordings were transcribed verbatim with all identifiable information being removed at this stage. Semi-structured interview schedules were created collaboratively with the BHC steering group (including public and patient involvement) who helped generate questions. Questions were designed to be open-ended (e.g., "What are your expectations of the BHC?") and could be followed up with prompts to allow participants to expand on relevant or interesting responses. See Appendices C, D, E, and F for interview schedules, consent form and information sheets.

Recruitment emails were sent to each MC and nine clinicians (two male) self-selected to participate. Professions represented included psychiatry (n = 3), psychology (n=3), nursing (n=1),

occupational therapy (*n* =1) and team leader (*n* =1). All clinicians consented to taking part and to maintain confidentiality, each clinician was allocated an ascending number. The project was approved by the Oxford Health NHSFT audit committee.

Procedure

Phase 1: Pre-pilot interviews to obtain perspectives on current assessment process and expectations of the BHC pilot

Seven interviews were conducted (between October 2019 – January 2020) face to face prior to the pilot commencing; four clinicians were directly involved in the pilot and three clinicians were recruited from a wider geographical area within Oxford Health NHSFT. Pilot and non-pilot clinicians were included to gain a broader understanding of what clinicians' expectations of the BHC were and to help identify factors perceived as important for rolling out the pilot to other localities if delivery proved successful. Interviews focused on the clinician's report of the different aspects of the process related to referral, assessment, and feedback of findings.

Phase 2: Mid-pilot interviews to obtain perspectives on the BHC pilot in action

Phase two was significantly impacted due to the Covid-19 pandemic. The pilot was delayed and thus interviews were completed three months into the pilot as opposed to the end of the pilot. Four interviews with clinicians involved in the pilot were conducted digitally between November to December 2020.

Analysis

Braun and Clarke's (2006) inductive thematic analysis methodology was followed (see Appendix G). This is a dynamic process involving familiarising yourself with the data, generating codes, searching and reviewing for themes before interpreting and finally defining themes (Clarke

& Braun, 2013).. The author immersed themselves in the data by listening back to the interviews and reading and re-reading the transcripts whilst keeping a reflexive log. Seven transcripts were read by the internal supervisor and both author and supervisor created initial codes. Further coding and theme development across data was completed by the author and discussed with the supervisor until consensus was reached. Additionally, a third independent reviewer (Z.K) coded a selection of extracts to help reduce any bias.

Results

Phase 1: Pre-Pilot

Six themes were constructed from the pre-pilot analysis which combined results for those involved in the pilot and those not. Appendix H outlines themes and supporting quotes.

1. The Current Assessment Process

a. What is working well. Clinicians reported good links with other professionals, such as GPs, making the referral and patient pathway a smooth process. Clinicians described the current assessment process as "*quite a holistic approach*" (P3) with "*a lot of ground covered*" (P3).

b. Areas for potential improvement. Clinicians identified inconsistencies in the current referral process, with "*big variations in who gets referred for neuropsychological assessment*" (P4) and a "*gap in the number of diverse people coming through*" (P7). Referrals received were variable, "*the GPs have been using this new form…. which doesn't seem to encourage a very thorough referral*" (P6) and created additional work for clinicians during the triage stage.

The assessment process was identified as being the tip of an iceberg, "*just touching the surface of what could be offered"* (P2), and "*a bit bare bones.*" (P7).

Scan reports were described as "*vague*" (P7), "*very variable*" (P3) and "*often not that helpful*" (P1) because they are "*not reported with dementia in mind"* (P1). There was frustration from clinicians in all localities with delays in scans.

Some clinicians felt MCs were "*a bit old school" (P7) and* "*need quite an agile turnaround*" (P7) in order to enter the 21st century and match the advancements of other terminal conditions stating that,

> "*I'm not sure there's anywhere else where you go and get a terminal diagnosis where actually you get absolutely nothing out of it other than three months of tablets. It strikes me as quite a bizarre set-up that we have, really*." (P2)

Thus, the aims and ambitions of the BHC outlined above were welcomed by the clinicians.

2. The BHC

a. Hopes for the BHC. The notion of a 'one-stop shop' to provide an integrated and streamlined service was noted in several interviews,

> "*it will make our job more efficient because everything will be there ready and done*" (P1)

It was hoped that the BHC would "*upskill a little bit*" (P1) and clinicians could become specialists in the field, making it an attractive incentive for career progression.

b. Concerns about the BHC. Alongside the hopes and opportunities, there were worries over equity of service provision,

"*I envisage that the Brain Health Centre will almost cream off the easy patients"*(P2)

"*we might end up by having a two-tier system, that's a risk*" (P5)

3. Diagnosis – the good, the bad and the uncertain

a. What helps make a diagnosis?

There was agreement among clinicians that "*all strands of information...have got value*" (P3) and combining multiple sources of information is beneficial,

> "*scan results are always helpful, … information from a family member or something is always, well, it's vital really. Meeting the person face to face is pretty important. And then some kind of test results, some kind of quantitative testing.*" (P4)

Clinicians suggested access to a scan, specifically an MRI scan, was particularly important in instances where there was uncertainty and ambiguity around the diagnosis.

> " *it helps to confirm, particularly when you are on the fence about something and it helps you diagnose less obvious dementias*" (P1)

Whilst CT scans are the norm currently, most clinicians felt access to MRI scans would be advantageous and would overrule the possible limitations of an MRI being "*a bit more of a procedure for people to go through than a CT"* (P6) and being "*very loud, … long and loud*." (P2) Clinicians queried whether patients would be able to tolerate an MRI, however clinicians appeared to have more confidence in MRI scans as opposed to CT scans,

> *" I have a confidence if somebody's had an MRI in a way that with a CT, I'm more likely to be a little bit like, well, they've only had a CT scan*." (P7)

b. When to give a diagnosis? Clinicians described hesitating on when to give a diagnosis if there is uncertainty and/or complexity,

> "*if it's a complex diagnosis… you'll see people not wanting to give it the name until they're absolutely sure, which is sometimes many, many months and years down the line*." (P7)

Ethical dilemmas also factor into when to give a diagnosis, and there was no clear consensus about when or if there is a right time to diagnose,

> "*I think it depends on what's right for the patient at the time, you know, what's in their best interest. Is it to have a definite diagnosis of dementia, sometimes it is, sometimes it's not*?" (P4)

c. The process of giving and receiving a diagnosis. Before a diagnosis is given, it is vital that patients give informed consent to receive a diagnosis. Some concerns were raised regarding this process,

> "*they've hardly had a chance to think about it…I don't think people really very often make an informed decision of what they're putting themselves through*." (P5)

Clinicians felt their colleagues were *"very experienced at giving that news*" (P3) and showed compassion and sensitivity when giving a diagnosis. Despite this, clinicians commented that patients can understandably find receiving a diagnosis distressing describing it as a "*drop from the air diagnosis… it can come as a shock*" (P7).

4. Post-Diagnostic Support

There was a strong sense that a diagnosis cannot be the end point of the patient journey and there needs to be a "*focus on living well with dementia,… the diagnosis isn't the end game, the diagnosis is the starting point*." (P7) The majority of clinicians all commented on the importance of post-diagnostic support yet talked about how they often are not commissioned to provide support,

> "*What's that, then? What post-diagnostic support? [sarcastic tone]…. the memory clinic people do their best but it's not properly funded and there's not very much of it*." (P4)

Yet, other MCs were able to offer some level of post-diagnostic support suggesting a postcode lottery approach to commissioning,

> "*we run our own post diagnostic sessions and CST sessions*" (P3)

There was a tension between excitement of what the BHC could offer in terms of improved diagnosis, but this was coupled with a concern about what happens to patients once they receive a diagnosis,

> "*We don't have very good treatments. So there's a lot at the moment which we're not offering people, and you're giving potentially people a bit of a false hope that we do all this fancy stuff, but at the end of it, at the moment we haven't got any further forward. And I do understand from a research point of view, this is great because this is how you develop it, but actually on an individual person's point of view it's … there's a risk there that's building up a lot of hype*." (P5)

5. Research

a. Positive views on research. Clinicians had positive views about patients participating in research, suggesting patients "*get more information about their disorder and prognosis*" (P5) and "*may feel they're doing something worthwhile"* (P5) which could improve their quality of life.

b. Concerns about research. Some patients are "*very reluctant to consider it at all*" (P5) and there were concerns about the uptake of research, "*we have a lot of people who don't want to take part in research*" (P5). The topic of trade-offs and who benefits, was also commented upon,

> "*I think whether it is fair to ask people to contribute more to research out of their own goodwill but let's not contribute more to their care; I think it's a bit of a mismatch*." (P7)

6. Patient Experience

A predominant theme that ran throughout all the previous themes was the patient's experience.

a. Emotional considerations. Clinicians reported patient care was a priority and can be done well, "*we deliver a really good service…we're a really caring team*" (P6). However, there was also a narrative that some patients had adverse experiences throughout all stages of their patient 'journey',

> "*They're generally very anxious; very fearful"* (P3)
>
> "*they sort of feel like they're abandoned by the health service after their diagnosis."* *(*P5)

b. Cognitive demands. Clinicians reflected on the fact that the assessment process could be cognitively demanding for patients

> *"I don't think you would put the person through any more than what we already do on that day,…, because I think an hour is, kind of, I do feel like, oh, we've put them through it now*" (P6)

c. Practical and environmental barriers. Transport and parking difficulties were highlighted in every interview, placing extra demands on patients before they even start the assessment process,

> "*Parking is rubbish… not ideal for patients at all in terms of just getting themselves to clinic*" (P2)

d. Patient care. Clinicians thought providing a detailed assessment improved patient's experiences - ensuring that individual experiences were not dismissed but seen as important and valued.

> "*I think having your concerns looked at carefully…, is so valuable. I think the worst thing for people is to feel that they're dismissed and that they're going to do a five-minute questionnaire on the basis of that they're going to make a diagnosis."* (P7)

Clinicians were hesitant about patient care not being at the centre of the BHC and the value to connecting and establishing a relationship with the patient could get lost,

> "*you have to have some really skilled people fronting it with very strong interpersonal skills, and managed very well, otherwise it could be a very stressful experience*." (P5)

Phase 2 : Mid-pilot

Six themes were created from the mid-pilot data analysis. See Appendix H for themes, codes and supporting quotes.

1. Impact of Covid-19 on service delivery

a. Impact on local MCs. Clinics were "*playing catch-up*" (P3) because routine clinics stopped for four months due to the pandemic. Post-diagnostic support was also halted due to many older adults facing barriers to accessing technology.

b. Impact on BHC pilot. The pandemic delayed the start of the pilot and reduced the number of patients seen. "*A phenomenal amount of work*" (P3) was required to "*make the place as safe as possible for patients and for people working there*" (P3). Training staff was more challenging, and the environment was viewed as "*formal*" (P9) as well as being "*clinical and fairly rigid*" (P3) due to the restrictions.

2. First impressions/Initial stages of BHC

a. ***Process of refinement.*** Clinicians described the pilot as "*still a work in progress*" (P3) and a process of ongoing learning from initial mistakes. The team were responsive and "*any issues seem to be ironed out on the day*" (P8).

An efficient service**?** Clinicians felt patients were "*being seen quicker than they would have been because of the turnaround on reporting the MRI*" (P3) and the feedback appointments were shorter because of the thoroughness of the BHC assessment. However, initial hopes that the BHC would act as a 'one-stop shop' had

yet to be fulfilled and there is still a need for two appointments. Whilst the local MC continued to run routine assessments concurrently with the pilot, there appeared to be a process of patients having multiple assessments, including cognitive testing, accompanied by a feeling that, *"we don't necessarily need to do everything again*." (P9)

3. What is working well?

a. ***Referral process***. Having an allocated person, with experience and enthusiasm, to take the lead on triaging and referrals was seen as a strength of the pilot. Whilst this required more work and was described as an intensive process, it was seen as valuable and reduced demands on the wider system.

b. ***Assessment process***. The collaborative report was described as being "*a useful tool and it can get a lot of information in quite a short amount of time*" (P3).

c. ***Feedback process***. Appointments for feedback and diagnosis have been streamlined, "*they're down to 45-minute appointments*" (P8) as opposed to 75-minute appointments, as medics are "*not sort of having to retread all the ground*" (P8). The BHC reports were described as being "*very useful*" (P9), "*standardised*" (P8) and a "*good length*" (P9).

4. Clinicians' experience

a. ***New learning opportunities.*** One clinician appreciated the opportunities of "*combining research in a clinical environment*" (P9), however, others felt the "*research training was quite a learning curve*" (P3), particularly around the consent processes.

b. ***Adapting to a different way of working***. Some clinicians had to change their working days to fit with the BHC and felt there were more demands on their time. Others felt their way of working was "*very similar*" (P9) and has "*not really changed anything specifically*" (P8).

c. ***Experienced staff working together to improve patient care***. Clinicians felt their colleagues were highly skilled, experienced, and able to contain patient emotions and anxieties.

5. Patient's experience

a. ***Positive experience of a high-quality service.*** Clinicians reported "*patients were very happy*" (P8) and the option to take part in research had gone well.

b. ***Resilient and accepting of the process***. Clinicians appeared surprised in patients' resilience in tolerating MRIs and the various assessment procedures,

> "*they just will get on, grit their teeth and just do it because, you know, that's what they need to do."* (P3)

c. ***Practical considerations***. Parking concerns appeared less of an issue than first anticipated, "*parking is fine*" (P3), "*really straightforward" (P8),* and free. However, transport was still a worry and may remain a barrier,

"*the problem which there will always be… it's a long way to travel*." (P2)

6. Looking ahead

a. ***Access to additional resources*.** Clinicians reflected on the BHC not having a CT scanner and how this may disrupt the patient journey for those unable to have an MRI scan but were aware this may not be feasible, "*in an ideal world the Brain Health Centre would have access to both*" (P2). On a practical level, clinicians requested "*having the actual paperwork, ACE[1] form, uploaded might also be useful*" (P8) and also talked about having "*more clinical support on the ground"* (P8).

Discussion

The aim of this project was to explore what factors clinicians thought were important to improve the existing memory assessment service and to evaluate the feasibility and practicality of offering an alternative assessment service which aimed to combine high quality assessment alongside research opportunities. The BHC high quality assessment included a comprehensive collaborative report, the ACE (Hsieh et al., 2013) as opposed to the Montreal Cognitive Assessment (MOCA; Nasreddine et al., 2005) and an MRI scan as opposed to a CT scan.

[1] ACE - Addenbrooke's Cognitive Examination (Hsieh et al., 2013). The ACE is a well validated cognitive screening tool often used in MCs

Factors important to improving current memory assessment services

Clinicians reflected on the process of current assessments conducted in MCs, although some areas worked well, there were areas for improvement. There was general consensus that MCs needed to be updated. Clinicians conveyed optimism and hope that the BHC would be a critical step in supporting this change, particularly around improving diagnosis for dementia. Throughout the data set, there was a strong narrative that patient centred care needs to remain at the core.

A number of themes from the pre-pilot analysis highlighted current barriers and areas for improvement. A need for consistent and thorough referrals from primary care was an area to be improved upon. Access to scans was one major barrier. Long waiting times to get a CT scan and receive the results was impacting the patient journey and the length of time it took to receive a diagnosis. Within the local MC, diagnosis targets had to be extended due to delays in getting CT scan results back. The implementation guide and resource pack for dementia care (National Collaborating Centre for Mental Health, 2018) propose a waiting time of no more than six weeks from referral to diagnosis. Reducing the timeline for scans and reports would be one way to help reach diagnosis targets. In addition to timely access, the reports received from the radiologists were reported to be extremely variable in quality and quantity of information and therefore clinicians were less reliant on CT scans when making a diagnostic decision. Furthermore, not having regular access to MRI scans was seen as disadvantageous particularly when making decisions where there was complexity and ambiguity.

Clinicians acknowledged that diagnosis is the beginning of the dementia journey and should be mapped onto post-diagnostic support which is adequately commissioned in order to support people to live well with dementia. Post diagnostic support in Oxfordshire is commissioned and

provided by the third sector not the health service. Some services continue to offer Cognitive Stimulation Therapy to meet MSNAP accreditation guidance because it is not yet provided elsewhere.

Transport and parking were other main barriers highlighted which needs careful consideration. Not having access to parking and not being located close to public transport links makes specialist services not accessible to some patients.

Evaluating the feasibility and practicality of the BHC

While this project aimed to evaluate a service improvement pilot, service delivery occurred in the context of a global pandemic. Covid-19 has significantly impacted the way routine health and care services were delivered, particularly within older adult services (Mueller et al., 2020). Covid-19 has negatively impacted dementia assessment and diagnosis with reports from Alzheimer's Society (2020) suggesting there has been a significant decrease in diagnosis rates and lengthy waiting times has impacted patient care. As described above, local MCs and the pilot were severely impacted and had to quickly adapt to new ways of working.

What did the BHC pilot deliver?

Clinicians raised a number of concerns about implementing an alternative assessment service, however from the mid-pilot analysis, many of these concerns had not materialised. Having an MRI scan was one of the main differences between the routine assessment process and the BHC assessment process. Whilst clinicians felt this was advantageous in terms of providing higher specificity and helpful in diagnosing the type of dementia, they were concerned whether patients would tolerate an MRI scan. However, despite the procedure being unpleasant, most patients

consented and proceeded with an MRI. Three factors appeared to contribute to patients opting for an MRI scan: having a medic taking the lead in referrals and triage - ensuring MRI criteria was met and speaking to patients to explain the process at point of referral, having experienced and skilled radiologists with strong interpersonal skills to contain any patient anxieties, and the individual patient's level of resilience to endure such a procedure.

Another concern about the BHC pilot was whether it would be too research focused and 'clinical', impacting on the patients' experiences and person-centred care. Although this project did not have the scope to evaluate the patients' experiences, reports from clinicians highlighted patients' positive experience of the BHC assessment and willingness to take part in research. All staff were experienced and showed they could manage patient distress and build therapeutic rapport. Having local MC clinicians at the BHC who were also present at the feedback appointment, provided continuity of care and was seen as a strength of the service. Research suggests continuity of care improves patient outcomes (e.g. Amjad et al., 2016; Van Walraven et al., 2010), thus continuing this process with clinicians acting as a point of contact for ongoing care would be valuable.

The BHC pilot succeeded in providing access to MRI scans and useful reports - a limitation in the routine MC assessment process. Clinicians shared the collaborative reports provided high quality information and were of a good length. The MRI reports were structured and standardised, reported with dementia in mind, and proved a useful resource both for informing a diagnosis and feeding back to the patient.

Clinicians hoped the BHC could act as a 'one-stop' shop and provide in-depth assessment while remaining streamlined and efficient. It is too soon to draw conclusions on whether the BHC

fulfils this ambition. The BHC was unable to remain open to patients for the entire 6-month pilot period due to a third national lockdown, and when they were open, they were only assessing two patients a day, one day a week. As they were unable to function at full capacity, it is unclear if they will be able to support local MCs to reduce their waiting times and improve diagnosis rates. From mid-pilot analysis, it appears the BHC has partially been able to streamline the process - patients were reported to have been seen quicker, with feedback appointment times 30 minutes shorter, freeing up time for clinicians. With that said, there appeared to be a dual assessment process occurring. Patients would attend their assessment day at the BHC and would be assessed again as part of the feedback appointment at the local MC, this included completing the MoCA with patients, despite already completing the ACE at the BHC. This is not an efficient use of clinicians' time and potentially not in the best interest of patients if it is not clinically warranted. When making the decision whether to continue the BHC service, this process should be reviewed and a single point of assessment could be considered.

Recommendations

The theme 'Looking Ahead' outlines further recommendations for the BHC pilot to consider taking forward and the main points are summarised below.

- Clinicians requested a copy of the ACE to be added to the main report as this can provide rich information about a patient's cognitive functioning and domains where they may have lost points or scored high in.
- To have a CT scanner on site. Clinicians felt that only offering an MRI may discriminate some patients who are unable to have an MRI and they would not receive the same equity of service. A cost-benefit analysis would be required and a clear patient pathway outlined for those who do not meet MRI criteria.

- To collaborate and link up with other local MCs in order to make it possible to roll out the BHC on a wider scale. Clinicians selected from the pilot MC clinic were invested in supporting the BHC. Building up strong working relationships with other MCs in the locality will be vital in order to progress. Reviewing and being transparent and clear about what clinicians are required to do would be helpful and senior management will need to factor supporting the BHC into job plans.

Limitations

The timescales of the pilot were significantly delayed due to Covid-19 and consequently we were unable to conduct post-pilot interviews. We were unable to explore what working at full capacity would have looked like and whether other implications may have arisen. However, the BHC pilot still met the requirements of a pilot – namely, to explore a novel and innovative service and to inform the feasibility, and identify any modifications required before rolling it out on a larger scale (Leon et al., 2011).

Another limitation of this project was recruitment. We were unable to recruit a non-pilot team manager for phase one and it may have been useful to interview research assistants as part of phase two – it is possible that different experiences were not captured. Similarly, it has been noted that in phase two, participant 2 had less 'voice' in the selected quotes and it was observed that they were unable to answer many questions because they were not directly involved in the day to day running of the pilot. Furthermore, it was not possible to analyse between professional group differences.

Conclusions

This report explored clinicians' views on current memory assessment processes and highlighted areas which could be improved upon. The results evaluated a new assessment process delivered by the BHC and findings suggest the new service is feasible and has potential to continue delivering high quality assessments alongside research opportunities.

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Main Research Project

An evaluation of the Psychometric Properties of the Adapted PHQ-9 and GAD-7 Outcome Measures for use with Adults with Intellectual Disabilities

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The Journal of Intellectual Disability Research is devoted exclusively to the scientific study of intellectual disability and publishes papers reporting original observations in this field.

Introduction

Background

Intellectual Disability and Mental Health

An estimated 1.4 million people in the UK have an Intellectual Disability (ID), of which 905,000 are adults (Department of Health, 2001). Individuals with ID have significant impairments of intellectual functioning and adaptive behaviour (everyday living skills and social functioning), with both impairments arising before adulthood (British Psychological Society, 2015). Hence, people with ID have difficulties with communication and require support in activities of daily living.

Adults with ID are more at risk of developing mental health difficulties due to multiple psychosocial predisposing factors. Adults with ID often have limited employment opportunities and can be less economically well off, resulting in fewer socially valued roles (Wolfensberger, 2000) and poorer quality of life (Eggleton et al., 1999) – factors that are associated with increased mental health problems (Paul & Moser, 2009). People with ID have fewer social relationships and are less likely to get married (Beart et al., 2005; Department of Health, 2001). Social deprivation and experiences of failure all contribute to an increased risk of developing mental health problems. Furthermore, the label “intellectual disability” is highly stigmatizing and can result in discrimination (MENCAP, 2018), which can increase the risk of developing poor self-esteem and increased vulnerability (Jahoda & Markova, 2004; Paterson et al., 2012). This can be exacerbated by the awareness of stigmatisation which can threaten identity and sense of well-being (Jahoda, & Markova, 2004). Cognitive Behaviour Theory proposes negative self-evaluations can contribute to the development of emotional problems (Beck, 2002). Additionally, people with ID are significantly more likely to experience adverse life events, and are more vulnerable to abuse and trauma than the

general population (Horner-Johnson & Drum, 2006). As well as external factors, internal factors can also contribute to mental health difficulties in people with ID. These include experiencing higher levels of anxiety, in particular intolerance of uncertainty, difficulties with recognising and regulating emotions, sensory sensitivities, and difficulties with executive functioning (e.g., Kiani & Miller, 2010; Sáez-Suanes et al., 2020).

Given the multiple predisposing factors and vulnerabilities, it is unsurprising that people with ID have a higher prevalence of mental health problems (approximately 40%) when compared to the general population, with depression and anxiety being most common (Cooper et al., 2007; Cooper et al., 2015). However, there are multiple challenges to identifying mental health problems within ID populations. Communication difficulties can make it harder for individuals to explain their experiences and for professionals to understand their problems – potentially preventing individuals from seeking help and accessing services. Detailed assessments by specialised professionals can be required, as mental health difficulties can present differently in people with ID. In many cases, there are comorbidities and physical health problems and/or sensory and cognitive difficulties which can mask mental health problems (Moss et al., 2000; NICE, 2016). Additionally, individuals with moderate to severe ID may present with challenging behaviours that can be attributed to their ID as opposed to a possible underlying mental health difficulty (Moss et al., 2000). Furthermore, there are limited clinical measures available to detect mental health difficulties in ID populations (Vlissides et al., 2016). These measures are not always accessible and may not have been developed with sufficient input from people with ID, raising questions about their acceptability. The National Institute of Health and Care Excellence (NICE, 2016) reported that there are no suitable tools for routine use in primary care settings that assist in identifying common mental health difficulties in ID populations.

Psychological Services, Reasonable Adjustments, and Outcome Measures

The Mental Health National Service Framework (Department of Health, 1999) adopts an inclusive approach and key policies (e.g. Valuing People; Department of Health, 2001 and The Greenlight Toolkit; NDTi, 2016) state that individuals with an ID should be able to access mainstream services. Psychological services (e.g. Improving Access to Psychological Therapies [IAPT]) have a legal responsibility to ensure people with protected characteristics, as outlined in the Equality Act, have equal access to care (HM Government, 2010). Services are required to provide 'reasonable adjustments' to ensure people with protected characteristics are not discriminated against. However, people with a disability (a protected characteristic) are under-represented in mainstream psychological services (Department of Health, 2012) and face a number of barriers to accessing psychological support. It is acknowledged that specialist services provided through Community Learning Disability Teams (CLDTs) are essential in providing mental health care for people with ID. However, the policy also states individuals with ID should use the same services, resources, and facilities as the rest of the general population (Department of Health, 2001). Individuals with ID who are able to access mainstream services, with some reasonable adjustments, should be supported to do so.

Outcome measures are routine in many psychological services, typically used to assess and monitor progress within treatment sessions and to evidence service delivery and effectiveness. The Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001), a self-report measure for depression, and the Generalised Anxiety Disorder scale (GAD-7; Spitzer et al., 2006) are mandatory outcome measures, which form part of the minimum data set, used in IAPT services (the main primary care psychological service). These measures are well validated for use with the general population, but

research suggests they may not be suitable for people with ID (Chinn et al., 2014) particularly those with communication difficulties, including difficulties in reading, writing, and comprehension. The absence of adapted versions of routine outcome measures (e.g. the PHQ-9 and GAD-7) to help accommodate communication difficulties is a barrier for people with ID accessing IAPT services and evidence-based interventions.

Current outcome measures available for people with ID

Measures to identify and monitor changes in mental health difficulties have been developed for individuals with ID, however, there is no "gold standard" consistently used across services. Having consistent clinical outcome measures are important to understand the efficacy of treatments provided by all services – at an individual, service and national level. Having valid and consistent measures will allow services to better track recovery rates for ID patients. Existing measures have predominantly been developed using small sample sizes and therefore, are not well validated (British Psychological Society, 2015; McGurk & Skelly, 2014). The lack of valid and reliable measures makes evaluating the effectiveness of psychological interventions for people with ID challenging.

Current measures used in specialist ID services include the Psychological Therapies Outcome Scale (PTOS-ID; Vlissides et al., 2017), the Clinical Outcome Routine Evaluation – Learning Disabilities (CORE-LD; Barrowcliff et al., 2018), the Glasgow Depression Scale (GDS-ID; Cuthill et al., 2003) and the Glasgow Anxiety Scale (GAS-ID; Mindham & Espie, 2003). The PTOS-ID aims to measure psychological distress and psychological well-being. It has been shown to have good reliability and good levels of construct and concurrent validity, however, further amendments and psychometric testing are required (Vlissides et al., 2017). The CORE-LD has a 30

or 14-item version and is recommended as a useful broad ranging measure of psychopathology. It has been shown to have good levels of internal consistency and convergent validity (Barrowcliff et al., 2018). The GDS-ID has specifically been created as a self-report measure of depressive symptoms for people with ID. The measure has been shown to have good internal consistency, test-retest reliability, and acceptable face and content validity (Cuthill et al., 2003). The GAS-ID (Mindham & Espie, 2003) has also been developed for use with ID populations to assess for anxiety problems and has shown to be psychometrically robust. The Glasgow scales are currently the most established measures to assess depression and anxiety in ID populations. However, these measures are not fully accessible, are time-consuming to complete and are not currently used in mainstream psychological services.

NICE (2016) and the Department of Health (2008) recommend adapting the minimum dataset used in IAPT services to ensure reasonable adjustments are provided to allow adults with ID equitable access to mainstream services providing evidence-based psychological therapies. Valid and reliable adapted outcome measures for individuals with ID will help with early intervention and likely provide better outcomes. Adapted versions of the PHQ-9 and GAD-7 have been designed specifically for individuals with ID, using a process of cognitive interviewing (Breen, 2017). These measures comply with easy read guidelines, using images and pictures in addition to text and fulfil the recommendations proposed in the Learning Disabilities Positive Practice IAPT Guidelines (Dagnan et al., 2015). The initial psychometric investigations proved encouraging, however, were limited in scope and further psychometric investigation of these measures is warranted before services adopt these measures (Breen, 2017).

Aims

This study aimed to investigate the psychometric properties of the adapted PHQ-9 and GAD-7. Specifically, we aimed to evaluate the measures' internal consistency and test-retest reliability. We aimed to test for concurrent validity through comparisons with the Glasgow depression and anxiety measures and to test for divergent validity. We aimed to test for discriminant validity by comparing scores on the measures between a clinical and non-clinical (community) sample, predicting that the clinical group would score significantly higher on the measures than the community group.

Method

Design

A quantitative evaluation of the psychometric properties of the adapted PHQ-9 and GAD-7 was conducted using a cross-sectional design and between group analyses to test for discriminant validity. Concurrent and divergent validity was tested using a correlational design. Opportunity sampling was used to recruit participants to either the clinical or community group. Questionnaires were completed at a single time point for participants in the clinical group. In the community group, the adapted PHQ-9 and GAD-7 were repeated at a second time point to assess test-retest reliability.

Participants

Participants were all adults (aged 18+) with a mild to moderate ID with capacity to consent to research. The clinical group were patients of Community Teams for People with Learning Disabilities (CTPLDs) accessing support from services for a mental health difficulty and were recruited from five NHS Trusts across England. The community group included participants who were not currently accessing any mental health services, and were recruited by attending various

virtual advocacy groups, day centres, colleges, and supported living services, and through emailing colleagues and sharing social media posts and adverts. Due to Covid-19, all recruitment took place remotely, therefore access to video conferencing platforms (with support if required) became an inclusion criterion. Anyone unable to speak English or communicate verbally, or who had a diagnosis of dementia was excluded.

Forty-eight adults completed questionnaires between October 2020 and June 2021. One participant was excluded (see below for details) making a total of 47 participants. They had a mean age of 35.15 years (*SD* = 10.52) with a range of 20 – 60 years. There were 25 males, 21 females and one participant identified as 'Other'. There were 21 participants in the clinical group and 26 in the community group. The groups did not differ significantly in age, ethnicity, or gender distribution. Table 1 presents demographic characteristics.

Out of the 31 participants the main author completed the questionnaires with, 15 required additional support from family members or carers to access the study and the technology required. Many participants self-reported on the demographic questionnaire comorbidities and other health difficulties. This included Autism Spectrum Disorders (*n* = 11 in community group, *n*= 5 in clinical group), ADHD (*n* =1 in community group, *n* =3 in clinical), Downs Syndrome (*n* = 3 in community group, *n* = 1 in clinical). In the community group a diagnosis of Dandy-Waller Syndrome, Williams Syndrome, and Cerebral Palsy were reported. Epilepsy (*n* = 2 in community group, *n* = 1 in clinical group) and heart problems (*n*= 2 in community group, *n* = 2 in clinical group) were also reported.

Table 1

Demographic characteristics of participants

		Group		
		Clinical	Community	Total (%)
Gender				
	Male	9	16	25 (53.2)
	Female	12	9	21 (44.7)
	Other	0	1	1 (2.1)
Ethnicity				
	White	18	22	40 (85.1)
	Black	1	2	3 (6.4)
	Asian	1	1	2 (4.3)
	Other	1	1	2 (4.2)
Age				
	20-29	10	8	18 (38.3)
	30-39	2	12	14 (29.7)
	40-49	4	4	8 (17.1)
	50-60	5	2	7 (14.9)
Total		21	26	47

Measures

Glasgow Depression Scale (GDS-ID; Cuthill et al., 2003)

The GDS-ID is a self-report measure of depression specifically developed for adults with mild to moderate ID. It takes 15 minutes to administer and consists of 20 items that are rated on a three-point Likert scale, ‘never’, ‘sometimes’, ‘always’. The suggested clinical cut-off is a score of 13 or more. Five items are reverse scored, before adding up individual scores to give a total score (out of 40). It is reported to be a sensitive measure, with good internal consistency (Cronbach’s alpha .9) and good test-retest reliability (r =.97) (Cuthill et al., 2003).

Glasgow Anxiety Scale (GAS-ID; Mindham & Espie, 2003)

This is a self-report measure of anxiety specifically developed for adult ID populations and takes five to 10 minutes to complete. Items are rated on the same Likert scale as the GDS-ID, with a

clinical cut off of 13. One item is reverse scored, and individual scores are added together to give a total score out of 54. It consists of 27 items divided into questions about ‘worries’, ‘specific fears’ and ‘physiological symptoms’. The GAS-ID has good internal consistency (Cronbach’s alpha .96) and good test-retest reliability (r = .95).

Adapted PHQ-9 (Breen, 2017)

The adapted PHQ-9 is a 9-item self-report measure of depression for adults with ID. It has a four-point Likert scale, with the following responses, ‘no days’, ‘some days’, ‘a lot of days’, ‘nearly every day’. The measure has been adapted from the PHQ-9 (Kroenke et al., 2001) by a process of cognitive interviewing to ensure the measure is more accessible for adults with ID. The measure has been adapted by including pictures with easy-to-read English, prompts for the facilitator and rewording of the scale. It has been estimated to take between five to 10 minutes to complete (Breen, 2017). Individual item scores are summed to give an overall score (out of 27) with higher scores indicating more severe symptoms of depression.

Adapted GAD-7 (Breen, 2017)

This is a 7-item self-report measure of anxiety for adults with ID. It has the same four-point Likert scale as the adapted PHQ-9 and has been adapted from the GAD-7 (Spitzer et al., 2006) by a process of cognitive interviewing with adults with ID and has a similar format to the adapted PHQ-9. It takes an average of five minutes to complete (Breen, 2017). Individual item scores are summed to give an overall score (out of 21) with higher scores indicating higher levels of generalised anxiety.

Procedure

Easy read information sheets were designed, with support from service users, to explain what the research was about and what it involved. Participants gave verbal informed consent (due to the study being conducted via video conferencing) and received electronic copies of their consent form. All participants in the community sample completed questionnaires via video conferencing with the main author. Participants in the clinical group completed questionnaires with a suitably qualified clinician in their service (n =16) or with the main author (n=5). Questionnaires were all administered in the same order (demographic questionnaire, adapted PHQ-9, adapted GAD-7, GDS-ID, GAS-ID) as no order effects were expected. Participants were informed it was not a test and there were no right or wrong answers. Participants were informed they would be asked questions relating to their feelings in the past week, and the rating scale was explained to them. Questions were read out verbatim and the 'share screen' function was used to show each question visually. Participants in the community sample attended a second meeting around a week later to complete the adapted PHQ-9 and GAD-7 again. Verbal informed consent was obtained again at the second visit. Participants were debriefed and were offered a certificate of participation, thanking them for their contribution. See Appendices K, L, and M for all participant facing documents.

Ethical review

Ethical approval for the study was received from the Surrey Research Ethics Committee and the NHS Health Research Authority (see Appendix N). Local approvals to conduct the research in five NHS sites across England were granted.

Statistical analysis

The data were analysed using SPSS 27.0. Parametric test assumptions were checked prior to conducting analysis. Cronbach's alpha was used to measure the internal consistency of each outcome measure. Test-retest reliability was assessed through intraclass correlation coefficients (ICC) as it provides the degree of correlation and agreement between measurements (Koo & Li, 2016). Independent t-tests were computed to test for discriminant validity, to see if there were any significant differences between clinical and community group scores on the measures. Concurrent validity was tested by correlating the adapted PHQ-9 with the GDS-ID and the adapted GAD-7 with the GAS-ID. Divergent validity was tested by correlating the questionnaires with age and gender. One participant from the clinical sample was excluded from analysis as they answered 'zero' on every single item of each questionnaire. It was assumed the participant did not understand the measures as it was reported they were accessing weekly psychology sessions due to anxiety and panic attacks. There was one missing value on the GAS-ID (question 10) for one of the clinical group participants – this participants' total score on the GAS-ID was not included in the discriminant validity analysis and only total sub-scale scores were calculated for the 'Specific fears' and 'Physiological symptoms' and not the 'Worry' subscale for this participant. No other data was missing from the sample.

Results

Histograms, normal Q-Q plots and box plots were visually inspected for the entire sample and the questionnaire scores appeared to be normally distributed (Appendix O displays histograms). When the data was split into the clinical and community groups, the adapted PHQ-9, GAD-7, and GDS-ID appeared slightly positively skewed, however analysis of skewness and kurtosis indicated

that the measures were within the normal limits (z-values were between -1.96 and +1.96) thus the data was suitable for parametric testing.

Reliability

Internal consistency

Cronbach's alpha for the adapted PHQ-9 (*n*= 47) was .84, suggesting good internal consistency (Kline, 2000). The range in internal consistency for the total scale, measured by alpha if item deleted was between .81 and .85. The item total correlations ranged from .30 to .74.

Cronbach's alpha was .86 for the adapted GAD-7 (*n*= 47), with the range in internal consistency, as measured by alpha if item deleted, being .82 to .85. The item total correlations ranged from .53 to .73. The measure thus showed good internal consistency (Kline, 2000).

Cronbach's alpha for the GDS-ID (*n* = 47) was .91 and for the GAS-ID (*n* = 46) was also .91. Both Glasgow measures showed excellent reliability (Kline, 2000).

Test-retest reliability

Data on 24 test-retest sets were available. The mean time taken between each administration of the adapted PHQ-9 and GAD-7 was nine days (*SD* = 2.82; range 7-17 days). Two-way mixed intraclass correlations (ICC) with absolute agreement were calculated for test-retest reliability. An ICC estimate of .40 is poor, .40-.59 is fair, .60-.74 is good and .75-1.0 suggests excellent reliability (Cicchetti, 1994). An ICC estimate of 1 indicates perfect agreement and 0 indicates random agreement. An excellent degree of test-retest reliability was found for the adapted PHQ-9 (ICC =.91, 95% CI .80-.96, p <.001) and for the adapted GAD-7 (ICC =.77, 95% CI .55-.90, p <.001).

Validity

Discriminant validity

The ability of the adapted PHQ-9 and GAD-7 measures to discriminate between the clinical group and the community group was investigated by conducting independent t-tests. Table 2 reports group means and standard deviations for each measure.

On average, the clinical group scored higher on the adapted PHQ-9 (M = 10.38, SD = 5.80, n= 21) than the community group (M = 6.62, SD = 5.47, n= 26). There was a significant difference in depression scores between groups, t (45) = -2.28, p = .03, 95% CI [-7.09, -.45]. According to Cohen's (1988) conventions the effect size was medium to large (Cohen's d =.65).

The clinical group also scored higher on the adapted GAD-7 (M = 10.00, SD = 4.73, n= 21) than the community group (M = 5.27, SD = 4.47, n= 26). There was a significant difference in anxiety scores between groups, t (45) = -3.52, p = .001, 95% CI [-7.44, -2.02]. The effect size was large (Cohen's d = 1.03).

We also tested the Glasgow measures ability to discriminate between the clinical and community groups. The clinical group scored higher on the GDS-ID (M = 16.14, SD = 7.38, n= 21) than the community group (M = 10.38, SD = 8.61, n= 26) and there was a significant difference between the two groups, t (45) = -2.43, p = .019, 95% CI [-10.54, -.98], d = .72.

The clinical group also scored higher on the adapted GAS-ID (M = 24.50, SD = 11.02, n= 20) than the community group (M = 15.31, SD = 8.97, n= 26). There was a significant difference in anxiety scores between groups, t (44) = -3.12, p = .003, 95% CI [-15.13, -3.25], d = .91.

Table 2

Mean total scores and standard deviations

	Group		
Measure	Clinical	Community	Total Groups
Adapted PHQ-9	10.38 (5.80)	6.62 (5.47)	8.30 (5.87)
Adapted GAD-7	10.00 (4.73)	5.27 (4.47)	7.38 (5.12)
GDS-ID	16.14 (7.38)	10.38 (8.61)	12.96 (8.51)
GAS-ID	24.50 (11.02)	15.31 (8.97)	19.30 (10.83)

Concurrent validity

The clinical and community groups were combined (n= 47) for the correlational analysis. Concurrent validity, whereby a new measure is administered at the same time as a pre-existing measure and the two are correlated, was assessed using scatter plots (see Appendix P) and Pearson's product moment correlation. The adapted PHQ-9 total score was correlated with the GDS-ID total score. A significant positive relationship was found, r (47) = .86, p < .001.

The adapted GAD-7 total score was positively correlated with the GAS-ID total score, r (46) = .77, p < .001. The adapted GAD-7 total score was also positively correlated with the GAS-ID 'Worry' subscale (r (46) = .75, p < .001), the 'Specific fears' subscale (r (47) = .52, p < .001), and 'Physiological symptoms' subscale (r (47) = .69, p < .001).

Table 3

Means, standard deviations, and correlations

Measure	*M*	*SD*	PHQ-9	GDS-ID	GAD-7	GAS-ID	GAS-ID Worries	GAS-ID Specific fears	GAD-ID Physiological symptoms
PHQ-9	8.30	5.87	1						
GDS-ID	12.96	8.51	.86**	1					
GAD-7	7.38	5.12	.77**	.81**	1				
GAS-ID	19.30	10.83	.80**	.82**	.77**	1			
GAS-ID Worries	8.54	4.90	.74**	.80**	.75**	.89**	1		
GAS-ID Specific fears	5.30	3.86	.51**	.46**	.52**	.82**	.57*	1	
GAS-ID Physiological symptoms	5.51	3.82	.78**	.81**	.67**	.85**	.65**	.56**	1

Note. M and *SD* used to represent mean and standard deviation respectively.
**. Correlation is significant at the 0.01 level (2-tailed).

Divergent validity

To test that constructs that should have no relationship do, in fact, not have any relationship we correlated total scores for the adapted PHQ-9 and GAD-7 with age. As expected, there were no significant correlations, providing evidence for divergent validity. The adapted PHQ-9 total score was slightly positively correlated with age, r (47) = .03, p = .85. The adapted GAD-7 total score was not correlated with age, r (47) = -.01, p = .97. There were no significant correlations between age, r (47) = -.06, p = .68, , with the GDS-ID or with the GAS-ID., r (46) = .07 p = .63

We conducted independent t-tests between gender and total scores on the adapted PHQ-9 and GAD-7 to further test for divergent validity. Females scored slightly higher on the adapted PHQ-9 (M = 8.71, SD =6.64, n =21) than males (M = 7.96, SD = 5.39, n =25) but there was no significant difference in total scores on the adapted PHQ-9 between males and females, t (44) = .43, p = .67, 95% *CI* [-2.82, 4.33].

Females also scored higher on the adapted GAD-7 (M = 8.90, SD =5.96, n =21) than males (M = 6.12, SD = 4.13, n =25) but there was no significant difference in total scores on the adapted GAD-7 between males and females, t (34.68) = 1.81, p = .08, 95% CI [-.34, 5.91].

Discussion

The aim of this study was to further evaluate the psychometric properties of the adapted PHQ-9 and GAD-7 for use with adults with ID. The results suggest both measures appear reliable and valid and thus clinically useful. Previous initial investigations by Breen (2017) reported the validity of the adapted PHQ-9 and GAD-7 as inadequate as only one validity test was computed. To account for this previous limitation, we aimed to compute three validity tests, namely discriminant validity, concurrent validity, and divergent validity. Regarding reliability, Breen (2017) reported internal consistency, but no other reliability tests were conducted. We computed test-retest reliability in addition to testing for internal consistency to further evaluate the measure's reliability. Despite challenges with recruitment due to Covid-19 we were able to recruit a respectable sample size and compute parametric statistical analysis. Our sample size was comparable to the psychometric investigations for the Glasgow measures (n = 38 for the GDS-ID, n = 54 for the GAS-ID) and larger than Breen's initial testing (n =32).

In relation to reliability, both the adapted PHQ-9 and GAD-7 measures were rated as having good internal consistency and excellent test-retest reliability based on conventional criteria proposed by Kline (2000) and Cicchetti (1994). However, Koo and Li, (2016) suggest confidence intervals should be used and not the ICC estimate itself when evaluating the level of test-retest reliability. Therefore, the adapted PHQ-9 is considered to have a good to excellent level of test-

retest reliability whereas the adapted GAD-7 has a moderate to excellent level of test-retest reliability. Overall, the findings suggest stability in measurement.

The adapted PHQ-9 and GAD-7 measures are deemed to be valid. As hypothesised, the measures were able to discriminate between the clinical and community sample in terms of the total score on the depression and anxiety measures. Participants in the clinical sample scored significantly higher on the adapted PHQ-9 and GAD-7 than participants in the community sample who were not currently accessing mental health services. Divergent validity was evidenced by the measures not being significantly correlated with age or gender. Concurrent validity was evidenced by the adapted PHQ-9 and GAD-7 measures being significantly correlated with the more established Glasgow measures. As expected, the adapted GAD-7 was more strongly correlated with the GAS-ID 'worries' subscale compared to the 'specific fears' and 'physiological symptoms' subscales. Hinkle et al., (2003) provide interpretation guidance for correlation coefficients, suggesting .90 to 1.00 is very highly correlated, .70-.90 is high, .50 to .70 moderate and .30 to .50 is low. Using these guidelines, both the adapted PHQ-9 and GAD-7 were highly correlated with the Glasgow measures. Anastasi and Urbina (1997) comment that "correlations should be moderately high but not too high. If the new test correlates too highly with an already available test, without such added advantages as brevity or ease of administration, then the new test represents needless duplication" (pg.127). However, the adapted PHQ-9 and GAD-7 are much quicker to administer than the Glasgow measures and participants informally commented they found them much easier to complete. Thus, it appears the adapted measures have added advantages and could be an alternative to the Glasgow measures, particularly in busy clinical settings.

Additionally, the adapted PHQ-9 and GAD-7 measures provide a reasonable adjustment to the minimum dataset that must be routinely collected in IAPT services. Having psychometrically robust routine outcome measures that are compatible with the minimum dataset and acceptable and accessible for people with ID will help reduce discrimination and be one less barrier to receiving equal access to mainstream psychological services. The adapted measures formalise the recommendations laid out in NICE (2016) and the Learning Disabilities Positive Practice IAPT Guidelines (Dagnan et al., 2015). Implementing the adapted measures would ensure clinicians across IAPT services in the UK were administering measures in a consistent way as opposed to each service making up individual 'reasonable adjustments'. Furthermore, without the consistent use of outcome measures suitable for people with ID, improved tracking of intervention efficacy for ID populations will not occur. This poses challenges to improving the evidence base by conducting randomised controlled trials (RCTs) within this population, which is warranted considering the high prevalence of mental health difficulties in this population.

Limitations

A limitation of this study was the small sample size and thus some caution is required when interpreting findings as there is the risk results are biased, consequently impacting on validity. Additionally, as it was a convenience sample, it may not be representative of the population, thus issues with generalisability arise. However, the sample was larger than the sample sizes used to evaluate the GDS-ID and GAS-ID and other self-report measures used in ID studies (e.g. mini-MANS-LD; Raczka et al., 2018).

Due to the scope of this study, we only reported on reliability and validity. Fitzpatrick et al., (1998) advise investigating the feasibility, acceptability, and responsiveness of measures in addition

to reliability and validity when assessing the psychometric quality of outcome measures. From anecdotal evidence collected by the first author, the measures were quick and easy to administer. Participants understood the rating scale and questions, it was rare that the supplementary material to provide prompts for the questions or to explain a question was required. From this, and previous reports from Breen (2017) it suggests the measures are acceptable and feasible. However, future research is required to replicate our findings and further evaluate if the measures can detect change over time (responsiveness) and to investigate possible clinical cut-offs. Additionally, due to many services offering digital/online assessments and interventions due to the Covid-19 pandemic, it could be valuable to produce electronic versions of the measures. Again anecdotally, our study suggests it is feasible to complete these measures remotely via video call using the 'share screen' function. It was easy to enlarge the text and show one question at a time on the screen.

Conclusions

The present study has evaluated the psychometric properties of the adapted PHQ-9 and GAD-7 for use with adults with ID. The measures have shown to be reliable and valid. They provide a reasonable adjustment for the minimum dataset used in IAPT services and can be easily administered in routine clinical practice.

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Executive Summary for Main Research Project

Why did we do the research?

People with Intellectual Disabilities (ID) often have more mental health problems than the general population, yet they are underrepresented in mainstream psychological services. They face many barriers to getting help for problems such as feeling sad (depression) and feeling worried (anxiety). One barrier is the lack of adapted materials, like questionnaires, for helping people with ID. Questionnaires are often used in services that help people with mental health problems to assess if they have problems with feeling sad or worried and the questionnaires help to check if people are getting better. Psychological services (e.g. Improving Access to Psychological Therapies) have a legal responsibility to ensure people with protected characteristics, as outlined in the Equality Act, have equal access to care. Services are required to provide 'reasonable adjustments' to ensure people with protected characteristics are not discriminated against.

Adapted measures for depression (adapted PHQ-9) and anxiety (adapted GAD-7) have been made for people with ID providing a reasonable adjustment. The questionnaires are accessible and easy to complete by adults with ID. The current study aimed to make sure the questionnaires were reliable and measured what they were supposed to measure (that they were valid).

What did we do?

Forty-seven adults with ID were recruited and completed a set of four questionnaires. These were the adapted PHQ-9 (measure of depression), the adapted GAD-7 (measure of anxiety) and the Glasgow Depression and Anxiety Scales (GDS-ID, GAS-ID). We recruited a clinical group (accessing mental health services) and a community group (not accessing mental health services) to test if the measures could distinguish between the two groups (discriminant validity). We tested for

concurrent validity (when a new measure is administered at the same time as a pre-existing measure and the two are correlated) by correlating the adapted PHQ-9 with the GDS-ID and the GAD-7 with the GAS-ID. We tested for divergent validity (to test that constructs that should have no relationship do, in fact, not have any relationship) by correlating the measures with age and gender. We tested the reliability (consistency) of the adapted PHQ-9 and GAD-7 measures by internal consistency analysis. The community sample completed the adapted PHQ-9 and GAD-7 measures on two occasions (approximately one week apart) to assess for test-retest reliability.

What did we find out?

The adapted PHQ-9 and GAD-7 measures have shown to be valid and reliable. There were significant differences in total scores on the adapted PHQ-9 and GAD-7 between the clinical and the community groups, evidencing good discriminant validity. The adapted PHQ-9 was significantly positively correlated with the GDS-ID and the adapted GAD-7 was also significantly positively correlated with the GAS-ID, suggesting good concurrent validity. There were no significant correlations between the measures and age or gender, providing evidence for divergent validity. The adapted PHQ-9 and GAD-7 measures had good internal consistency and good test-retest reliability.

The adapted PHQ-9 and GAD-7 appear valid and reliable measures to use in routine clinical practice. The measures provide a reasonable adjustment to the minimum dataset that must be routinely collected in IAPT services and will help contribute to providing adults with ID equal access to mainstream psychological services.

We want to thank everyone who helped with the research. We plan to share our findings with mental health services and with researchers and hope the questionnaires will be regularly used in mental health services.

Connecting Narrative

Main Research Project

After my initial project fell through, Olivia Hewitt suggested a project within the field of Intellectual Disabilities (ID). Olivia kindly put me in contact with Kate Theodore and the three of us shaped the current project – evaluating the psychometric properties of adapted questionnaires for adults with ID. I had little experience of working with this population but thought it would be a good opportunity to gain experience and stretch myself. I was aware of the importance of outcome measures in clinical settings from my previous role as a psychological wellbeing practitioner. Having a project that aligned with my interests of reducing discrimination and improving accessibility to psychological services was important to me, I knew this would keep me going when challenges inevitably would come. When Olivia went on maternity leave, Myra Cooper kindly offered to be my internal supervisor. I felt well supported by having supervisors with a wealth of research experience and speciality in ID.

For the methodology and design of the project, I enjoyed creating participant facing documents in Easy read to ensure they were accessible and acceptable to people with ID. Having service user involvement to provide feedback on the documents was valuable. It was encouraging to know service users thought the project was important and were keen to help in any way they could.

I had never applied for full ethics approval before, and perhaps naïvely thought it would not be a problem due to my strengths in time management, organisation and methodically approaching research. However, the ethics process took longer than anticipated. Unfortunately, at the time I was ready to submit to ethics, the Covid-19 pandemic hit. I decided to change my methodology to ensure we could conduct the project remotely. This was the right decision, however, I was slightly

concerned that this would impact recruitment and limit how accessible the project would be. I was proud of getting ethical approval and R&D approval from five NHS Trusts across the country. I submitted two minor amendments (to open up eligibility criteria and to add another NHS site) to improve recruitment numbers. Being Chief Investigator has provided many opportunities to hone in on my research skills, ensuring rigour, and reminding me of the importance of working collaboratively - these are skills I will carry with me as I continue my career.

Recruitment was significantly impacted by Covid-19, particularly recruiting the clinical sample - many services stopped routine work, prioritising those in crisis. Thus, supporting my project was not a priority at the time. Many hours attending advocacy and community group Zoom calls, giving presentations and networking with local and national services, advertising on social media sites and communicating regularly with NHS Trusts all contributed to boosting recruitment numbers. My determination, perseverance, and creativity ensured we recruited a large enough sample for the statistical analysis, comparable to other similar research studies. It was an absolute privilege to meet many of the participants. Although the questionnaires asked about low mood and anxiety, all participants I met with were willing to talk about their emotions and experiences, with all reporting that they were glad to have taken part and found it a validating and even enjoyable process.

The results provided evidence that the adapted PHQ-9 and GAD-7 measures are psychometrically robust. This is likely to have significant clinical implications as these measures can be used in clinical settings and could potentially be rolled out for use in IAPT services, in particular, to provide reasonable adjustments for adults with ID accessing mainstream psychological services.

Critical Review of the Literature

From an initial review of the literature, discussions with Olivia and Kate, and realising there were no 'gold standard' outcome measures for people with ID, my systematic literature review on evaluating the psychometric properties of outcome measures for PBS based interventions for challenging behaviour in adults with ID was developed.

At the time of conducting my literature review, I still had minimal experience of working in ID settings and did not feel confident in my knowledge about PBS or psychometric properties. I also had never conducted a systematic literature review before. I felt slightly overwhelmed by the prospect and wondered if I had bitten off more than I could chew! Despite experiencing imposter syndrome frequently, I persevered knowing it could contribute to service delivery and improve patient outcomes. I am grateful to Emily Gray who screened a proportion of the papers to ensure reliability.

I was encouraged by my supervisors to submit my review for publication. This was an exciting prospect and another new learning experience. My first submission was rejected and some of the reviewer comments were hard to swallow. However, this process taught me the importance of critically appraising research and spurred me on to make further amendments to my review. I am hoping to soon disseminate my findings so it can contribute to clinical practice.

Service Improvement Project

Training provided me with the opportunity to conduct both quantitative and qualitative research. I used the later methodology for my SIP. I enjoyed collaborating with researchers from Oxford University, Clinical Leads in Oxford Health NHSFT, and people with lived experience of

dementia. I found it exciting to be involved in a pilot aiming to provide a joint clinical-research service to improve the assessment and treatment of dementia. I enjoyed learning about the process of thematic analysis and developing themes from the rich data provided by conducting semi-structured interviews. Support from my internal supervisor, Reena Vohora was invaluable in reviewing extracts and reaching consensus on themes. Positive feedback was received from the service regarding the report and recommendations. There has since been national interest in the findings, and I am in the process of preparing a submission for publication.

Following this work, I feel more confident conducting quantitative and qualitative research and I am keen to implement my learning in conducting service development projects in my new role. In the future, I hope to supervise trainee research projects to continue contributing to clinical research.

Acknowledgements

I want to extend my gratitude to all project supervisors who have supported me from start to finish with my research projects. I want to say a huge thank you to Myra Cooper, Kate Theodore, Olivia Hewitt, Reena Vohora, Candy Stone, and Jane Fossey. I also want to thank my course tutor Matthew Knight who offered advice, support, and helped me to build my confidence throughout the three years of training.

I am incredibly grateful for all the clinical staff who were willing to be interviewed for my service improvement project and for all the adults with intellectual disabilities who helped me with my main research project. I was overwhelmed with people's generosity in their time, willingness to support my research and passion for making a difference to service accessibility. Thank you to all the community and advocacy groups, supported living and day centre services, and colleges who helped with recruitment. I am also indebted to Jon Codd, Gemma Gray, Helen Fletcher, Kate Theodore, Chris Hutchinson, and all the other staff working in the various NHS Trusts who helped recruit the clinical group during a pandemic – this was no easy task but thank you for persevering.

I want to thank friends and family who supported me throughout this rollercoaster journey, who stuck with me in the highs and lows and kept me going. Thank you to all the girls I trained with – I could always turn to you for support, encouragement, and offloading, knowing you would 'just get it'. Lastly, I want to thank my husband, Andy. Thank you for continuing to believe in me, reminding me of the bigger picture, making sure I had many giggles and memories along the way, and always making sure I had my morning coffee!

APPENDICES

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Appendix A: CRL - Search String

“Intellectual* disab*” OR “learning disab*” OR “developmental* disab*” OR “mental* retard*” OR “mental* disab*” OR “Intellect* Development Disorder” OR “mental* handicap*” OR “disabled person*” OR “intellect* impair*” OR “learning disorder”

AND

“Outcome measure*” OR outcome* OR measure* OR questionnaire* OR assessment* OR screen* OR tool* OR “self-report*” OR “self report*” OR “informant measure*” OR “treatment outcome*” OR scale* OR subscale* OR instrument* OR interview* OR inventor* OR survey OR rating* OR “treatment outcome” OR “client outcome” OR checklist OR schedule OR “PROM” OR “patient reported outcome measure”

AND

“Challenging behav*” OR “self-injur*” OR “self injur*” OR aggressi* OR anger OR “inappropriate behav*” OR “inappropriate sex* behav?” OR violen* OR “problem behav*” OR “Quality of life” OR “client satisfaction” OR “happiness index” OR “subjective wellbeing” OR “objective wellbeing” OR “emotional wellbeing” OR “physical wellbeing” OR “community participation” OR “social inclusion” OR “positive behave* support” OR “Behav* intervention*” OR “Social validity”

AND

Valid* OR reliab* OR psychometric OR sensitive* OR specific* OR feasibility OR standardi?* OR accura* OR predictab*

Appendix B : SIP - Scoping and Aims

The broad questions to be addressed were as follows:

- What are clinicians' expectations of the BHC?
- What factors do clinicians think are important in making improvements to the existing service?
- Will the BHC impact services and clinicians' job roles?
- Does clinicians' confidence in diagnosing dementia improve with access to MRI results?

Appendix C: SIP - Interview Schedules

Interview schedules were co-created with the BHC steering group, consisting of the project manager, research co-ordiantor, the Head of Older Adult Services and the Associate Director of Psychological Services for Oxford Health NHS FT and PPI members. The steering group helped to generate questions and reviewed the wording to ensure questions were open ended. Supervisors reviewed the final schedule.

Brain Health Centre
Biomedical Research Centre
Semi-Structure Interview Schedule – Script Guide

Pre-Pilot Interview Schedule

Before Interview (10 minutes)

- Introductions
- Thank clinician for meeting
- Confirm that the session will last no longer than 1 hour
- Check clinicians have an information sheet and whether there are any more questions. Remind clinicians that the interview will be recorded, but all data will be anonymised and kept confidential.
- Signing consent forms
- Confirm clinician is ready to start the interview

- What is your understanding of the BHC?

  Prompts:
  - *How involved have you been in the set-up of the BHC?*

- Are there areas of routine service that you think work well?

  Prompts:
  - *Referral process?*
  - *Assessment process?*
  - *Feedback process?*

- Are there areas of the routine service that you think could be improved?

  Prompts:
  - *Do you feel there is anything currently missing?*
  - *Is there anything regarding the referral process and waiting times which you think could be improved?*
  - *Do you think the assessment process could be improved?*

        - *What about cognitive assessments?*
        - *Access to brain scans? MRI vs. CT scans?*
    - *Are there any aspects of the feedback process that you think could be improved?*
    - *Post diagnostic support information?*
    - *Practicalities? Location? Parking? Building environment?*

***Provide BHC information sheet** (on the next page)*

- What are your expectations of the BHC?

  Prompts:
    - *Have you got any hopes?*
    - *Have you got any worries or concerns?*
    - *Can you see any foreseeable challenges?*
    - *What do you think the screening tools (MOCA, ACE-III) and MRI scans will contribute to the assessment process?*
    - *How do you feel about the opportunities to engage in research?*

- Do you think the BHC could have an impact on clinicians?

  Prompts:
    - *How do you think it could affect your job role and the range of work that you do?*
    - *How do you foresee feedback and communication between the BHC and local clinic to work?*
    - *Do you perceive any negative or positive impact?*

- Do you think the implementation of the BHC could have an impact on patients?

  Prompts:
    - *How do you think patients might feel about attending the BHC?*
    - *Do you think patients care pathway will change?*
    - *Do you perceive any negative or positive impact?*

- What are your thoughts on the new assessment service (the BHC) taking place away from the local memory clinic?

  Prompts:
    - *Any concerns related to patients? Carers?*
    - *Changes for clinicians?*
    - *Access to clinical information?*

- From your experience, what information has been useful in helping to make a diagnosis?

  Prompts:
    - *Type of cognitive screen used?*

- *Scans?*
- *In what circumstances are MRI scans requested if this is not routinely offered?*
- *What other information might be helpful, but you don't currently have access to?*

- In your opinion, what is the role of an MRI scan in diagnosing dementia?

  Prompts:
  - *What factors do you think help to make a diagnosis?*
  - *Would access to MRI results change how you feel about making a diagnosis? (for psychiatrist only)*

- I would like to ask you what hopes have you got for the development of new cognitive assessments and research going forward? What do you think about possible opportunities to develop collaborative research projects with Oxford University?

- Is there anything else you would like to say about the BHC pilot that has not been covered?

Brain Health Centre
Biomedical Research Centre
Semi-Structure Interview Schedule – Script Guide

Semi-Structured Mid-Pilot Interview Schedule (for clinicians directly involved in the BHC)

Before Interview (10 minutes)

- Introductions
- Thank clinician for meeting
- Confirm that the session will last no longer than 1 hour
- Check clinicians have an information sheet and whether there are any more questions. Remind clinicians that the interview will be recorded, but all data will be anonymised (as much as possible, considering there will only be 4 post-interviews and people know who have been directly involved) and kept confidential.
- Signing consent forms
- Confirm clinician is ready to start the interview

Acknowledge that Covid-19 has impacted on the pilot commencing but also the process of it. Things might be different to what was originally planned but still helpful to evaluate the BHC, particularly looking at clinicians' experiences.

1. Has the first few months of the BHC pilot been impacted in any way by Covid-19?
    a. *What was your experience of the changes?*

2. Can you tell me about your experience of:
    a. *The referral process?*
    b. *The assessment process?*
    c. *The feedback process?*
        i. *The quality of information provided – including the BHC clinical report*
        ii. *Giving a diagnosis (F2F in clinic)*
        iii. *How has this process worked for you?*

    (pick up on both positives and possible challenges/barriers)

3. Can you tell me a bit about your ways of working/practice since the implementation of the BHC?
    a. *Were there changes to your practice?*
        i. *Use of the scans?*
            a. *What are your thoughts about the radiology report?*
            b. *Access to images?*
        ii. *Cognitive assessments?*
        iii. *Feedback?*

    b. What, if any, impact has the BHC clinical report had on the memory clinic appointment?
        i. *Format?*
        ii. *Length?*

4. Can you tell me about the type of screening/assessment tools the BHC were using?
    a. *What did the ACE-III bring to the assessment?*
    b. *Are there other screening tools which you think would be helpful as part of the assessment (e.g. anxiety, depression, or other cognitive of ADL measures)?*

5. Do you think the role of [enter profession] will change if this new service continues and is rolled out to other services?

6. Where there any gaps in the team/workforce?

7. What are your thoughts about the BHC and the patient journey?

    a. *Do you think it benefited patients in any way?*
    b. *Do you have any concerns regarding patient care/patient safety?*

   c. *Was everyone referred able to access the service?*
      i. *Parking? Building environment?*
      ii. *Do you feel assessments were offered at a time and environment acceptable to all parties?*
      iii. *Was information clearly given to patients regarding the referral, assessment and feedback process?*
   d. *What was the impact on waiting times? Were people assessed and given a diagnosis within 6 weeks from referral?*
   e. *Do you think the new service changed the diagnosis rate?*

8. What has your experience been of having access to MRI scans as part of the process?
   a. *Has access to MRI results changed how you feel about making a diagnosis? (for psychiatrist only)*

9. Would you suggest any changes?
   a. *Suggested changes for the pilot?*
   b. *Suggestions for future additions/directions/expansion of the BHC?*

10. Is there anything else you would like to say about the BHC pilot that has not been covered?

Appendix D: SIP - BHC Information Sheet

The Oxford Brain Health Centre (BHC) is an **ambitious and innovative joint clinical-research service** that aims to **bring NHS memory services into the 21st century** by addressing gaps between clinical practice and research advances into dementia, and preparing the health system for the future of dementia diagnosis and treatment (Ritchie et al., 2018; ARUK 2018, Thinking Differently). The BHC is the result of a **strong collaboration** between the University of Oxford and Oxford Health NHS Foundation Trust, underpinned by **partnership with public contributors** with lived experience of dementia who are actively involved in the project at all stages.

The BHC will **improve assessments available to patients with memory problems** by providing access to high-quality assessments not routinely available in clinical practice, e.g. MRI rather than CT, and by developing novel diagnostic tools sensitive to earlier pathological changes. Enhanced information will be fed into clinical notes, **improving the quality of information available to clinicians** when making diagnoses in the memory clinic. Thus the BHC will **empower clinicians** to make more confident and accurate timely diagnoses, essential to give patients access to appropriate treatment and support, and to prepare the health service for future life changing treatments, which will be more effective in early stages (Ritchie et al., 2018).

The BHC will also **increase opportunities for patients and their families to participate in research** studies and trials by **embedding dementia research in the NHS service**. As part of routine care, every patient will be able to take part in research, either by consenting to the use of clinical data for research, by completing additional research assessments, and/or choosing to be contacted about future research opportunities. This equality of access to research participation will **empower patients** to take part in research, and enable researchers to test novel diagnostic, treatment and prevention strategies. With this approach, we intend to exceed the target of the Prime Minister's Challenge on Dementia to have 10% of dementia patients involved in research by 2020 (Department of Health, 2015).

The BHC will **actively encourage collaborative and transparent research by making all research data freely available** to the scientific community through the BHC Research Database. Shared data can be used in research to increase understanding of diseases that lead to dementia, as well as to improve diagnostics, prognostics, prevention and treatments available for dementia. Crucially, the BHC will provide a **translational interface**, enabling new advances in diagnosis and treatment to be rapidly implemented in clinical practice to provide better care for patients.

A six-month pilot of approximately 150 patients from a single memory clinic will launch in Autumn 2019 to demonstrate feasibility and refine procedures, before expanding to other memory clinics across Oxfordshire and Buckinghamshire. The Oxford Brain Health Centre will be **the first of its kind**, developing **the model for a specialist dementia unit** that can be adopted and implemented throughout the NHS.

Appendix E: SIP Consent Form

NIHR | Oxford Biomedical Research Centre

NHS
Oxford Health
NHS Foundation Trust

CONSENT FORM

Exploring clinicians' views on the Brain Health Centre pilot study – recommendations for the future

Name of Researcher: Hannah Jenkins

If you agree, please initial box

1. I confirm that I have read the information sheet for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason prior to data being analysed.	
3. I understand that the interview will be audio recorded and I agree to this.	
4. I understand that anonymised quotes may be used in research reports and/or publications.	
5. I understand that the research may also be presented at a conference.	
6. I agree to take part in this study.	

_____	_____	_____
Name of Participant	*Date*	*Signature*
_____	_____	_____
Name of Person taking Consent	*Date*	*Signature*

Appendix F: SIP Participant Information Sheets

Pilot Clinicians:

NIHR | Oxford Biomedical Research Centre

NHS
Oxford Health
NHS Foundation Trust

PARTICIPANT INFORMATION SHEET

Exploring clinicians' views on the Brain Health Centre (BHC) pilot study – recommendations for the future

We would like to invite you to take part in our evaluation of a pilot project. Before you decide, it is important you understand why the project is being conducted and what it would involve for you. Information is provided below and if there is anything that is not clear or you would like further information, please don't hesitate to ask.

What is the purpose of the study?

The Brain Health Centre (BHC) has been set up to offer high quality assessments to patients and increase access to research opportunities in order to improve diagnosis and management of cognitive and mental disorders.

The BHC is running a 6-month pilot and the purpose of this project is to evaluate the pilot and explore clinician's views on the new assessment process offered by the BHC. More specifically, we aim to explore clinician's expectations of the BHC, what factors clinicians think are important to making improvements, and whether the BHC impacts services and clinician's job roles.

Why have I been invited?

You have been invited as you have been identified as being a clinician working in a memory clinic within Oxfordshire and employed by Oxford Health NHS FT. We would like to hear your views about the BHC pilot as someone directly involved in the pilot. We intend to interview four clinicians of various professions (e.g. psychologist, psychiatrist, service lead, dementia nurse) at two time points; before the pilot starts and at the end of the pilot.

Do I have to take part?

No. Taking part is entirely voluntary and you can withdraw at any time prior to data being analysed, without having to give a reason.
If you would like to take part, please email hannah.jenkins@hmc.ox.ac.uk.

What will happen to me if I decide to take part?

You will be contacted to arrange a convenient time for a one-to-one semi-structured interview with Hannah Jenkins (trainee clinical psychologist). The interview will take approximately 45 minutes and can be held at a convenient location for you (e.g. your workplace, Warneford site etc.). Interviews will be analysed using thematic analysis to look at broad themes and recommendations for the future.

What about confidentiality and data protection?

All information you share will remain confidential. Confidentiality will only be broken in the event of the disclosure of information regarding professional practice or any risk issues which warrants reporting.

Interviews will be recorded on an encrypted Dictaphone and stored on an encrypted Oxford Health NHSFT computer until transcribed. Audio files will be deleted once transcribed and data will be de-identified. Responsible members of the Oxford Health NHS Foundation Trust may be given access to data for monitoring to ensure that the project is complying with applicable regulations. We will follow all privacy rules.

Will I be reimbursed for taking part?

As a thank you for your time and participation, you can vote for a chosen charity. A total of £50 will be donated.

What will happen to the results of this project?

Findings will be published and shared with the Biomedical Research Centre (funding the BHC) and no identifiable information will be included in the report. The project being undertaken will also contribute to the fulfilment of a doctoral thesis.

What if there is a problem?

If you wish to complain about any aspect of the way in which you have been approached or treated, or how your information is handled during the course of this study, you should contact Hannah Jenkins (hannah.jenkins@hmc.ox.ac.uk) or you may contact Hannah's supervisors (Dr Reena Vohora, reena.vohora@hmc.ox.ac.uk or Dr Candy Stone, candy.stone@oxfordhealth.nhs.uk). Alternatively, you can contact Dr Lola Martos, Associate Clinical Director (Lola.Martos@oxfordhealth.nhs.uk).

Further information and contact details:

Please don't hesitate to contact Hannah Jenkins by email on Hannah.jenkins@hmc.ox.ac.uk or call 07821361896 for further information and to register your interest in this project.

Thank you for considering taking part.

I look forward to receiving an email from you if you would like to take part.

Non-Pilot Clinicians

NIHR | Oxford Biomedical Research Centre

NHS

Oxford Health
NHS Foundation Trust

PARTICIPANT INFORMATION SHEET

Exploring clinicians' views on the Brain Health Centre (BHC) pilot study – recommendations for the future

We would like to invite you to take part in our evaluation of a pilot project. Before you decide, it is important you understand why the project is being conducted and what it would involve for you. Information is provided below and if there is anything that is not clear or you would like further information, please don't hesitate to ask.

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The BHC is running a 6-month pilot and the purpose of this project is to evaluate the pilot and explore clinician's views on the new assessment process offered by the BHC. More specifically, we aim to explore clinician's expectations of the BHC, what factors clinicians think are important to making improvements, and whether the BHC impacts services and clinician's job roles.

Why have I been invited?

You have been invited as you have been identified as being a clinician working in a memory clinic within Oxfordshire and Buckinghamshire localities and employed by Oxford Health NHS FT. We would like to hear your views about the BHC pilot as someone not directly involved in the pilot and what your thoughts are regarding the possible rolling out of the pilot to your localities. We intend to interview four clinicians of various professions (e.g. psychologist, psychiatrist, service lead, dementia nurse) to cover a broad perspective.

Do I have to take part?

No. Taking part is entirely voluntary and you can withdraw at any time prior to data being analysed, without having to give a reason.
If you would like to take part, please email hannah.jenkins@hmc.ox.ac.uk.

What will happen to me if I decide to take part?

You will be contacted to arrange a convenient time for a one-to-one semi-structured interview with Hannah Jenkins (trainee clinical psychologist). The interview will take approximately 45 minutes and can be held at a convenient location for you (e.g. your workplace, Warneford site etc.). Interviews will be analysed using thematic analysis to look at broad themes and recommendations for the future.

What about confidentiality and data protection?

All information you share will remain confidential. Confidentiality will only be broken in the event of the disclosure of information regarding professional practice or any risk issues which warrants reporting.
Interviews will be recorded on an encrypted Dictaphone and stored on an encrypted Oxford Health NHSFT computer until transcribed. Audio files will be deleted once transcribed and data will be de-identified. Responsible members of the Oxford Health NHS Foundation Trust may be given access to data for monitoring to ensure that the project is complying with applicable regulations. We will follow all privacy rules.

Will I be reimbursed for taking part?

As a thank you for your time and participation, you can vote for a chosen charity. A total of £50 will be donated.

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What if there is a problem?

If you wish to complain about any aspect of the way in which you have been approached or treated, or how your information is handled during the course of this study, you should contact Hannah Jenkins (hannah.jenkins@hmc.ox.ac.uk) or you may contact Hannah's supervisors (Dr Reena Vohora, reena.vohora@hmc.ox.ac.uk or Dr Candy Stone, candy.stone@oxfordhealth.nhs.uk). Alternatively, you can contact Dr Lola Martos, Associate Clinical Director (Lola.Martos@oxfordhealth.nhs.uk).

Further information and contact details:

Please don't hesitate to contact Hannah Jenkins by email on **hannah.jenkins@hmc.ox.ac.uk** or call 07821361896 for further information and to register your interest in this project.

Thank you for considering taking part.

I look forward to receiving an email from you if you would like to take part.

Appendix G: SIP - Phases of Thematic Analysis

Braun and Clarke's (2006) approach to thematic analysis, using a six phase process was flowed and described below.

Phase	Description of the process
Phase 1: Familiarising yourself with the data	The author conducted all the semi-structured interviews and transcribed two interviews. Remaining interviews were transcribed professionally. Transcripts were read and re-read, highlighting parts of the transcripts and making a note of initial ideas.
Phase 2: Generating initial codes	Each transcript was analysed separately, coding interesting features of the data. An inductive, data-driven, approach was utilised. Open coding was used – we did not have pre-set codes, rather developed and modified the codes as we worked through the coding process. Seven transcripts were re-read and coded by the internal supervisor. Few differences were found and any disagreements were discussed and a consensus reached. Another trainee clinical psychologist (not involved in the project) also coded 4 segments of randomly selected transcripts.
Phase 3: Searching for themes	Codes were collated into potential themes, across transcripts for pre- and mid analysis. Initial themes were created on the frequency and codes which fitted together, but also by significance. Themes were reviewed with the internal supervisor and any different ideas discussed and agreement was found.
Phase 4: Reviewing themes	Themes were revised to ensure they made sense in relation to the entire data set. Any overlapping themes were then collapsed into one and some themes were dropped at this stage.
Phase 5: Defining and naming themes	Final refinement of themes was carried out. Quotes were checked to ensure they were congruent with the themes.
Phase 6: Producing the report	Writing up findings commenced, making multiple revisions and including verbatim quotes within the write-up.

Appendix H: SIP Themes and Supporting Quotes

Table 1
Themes, subthemes, and example quotes from pre-pilot interviews (non-pilot clinicians; pilot-clinicians)

Theme	Subthemes/Codes	Example Quotes
The current assessment process	What is working well with the current process	*"I guess we have a close relationship with the GPs,... they know who we are, we know who they are, and I guess that might make some parts of communication easier."P5*
	Referral and pathway	*"It's fairly local. The clinicians that are working in the memory clinic are sitting in the CMHTs at the moment, so we have that integral link in with the CMHT" P3* *"there are sometimes people who come to the CMHT and then we see that actually clearly this is a memory impairment so they will go into the memory clinic. There's a flow both ways." P2*
	Assessment process	*"It's quite detailed, there's a lot, so at the moment there's quite a lot of ground covered." "five-pronged approach at the moment.... the information they give us before they come. We've got obviously the scanning and the technology, which I guess is where things will change more dramatically. We've got the interview process, the informants process, and we've got the memory testing." P3* *"We can spend quite a lot of time with people, really, an hour to an hour and a half, and, you know, you can cover quite a lot in that time."* *"I think we're quite thorough... we get a real good history of that person's life and what their life is like at the moment." P6* *"I think we're getting better with some of the more cross cultural, bilingual language assessments, so maybe thinking a little bit carefully about things that aren't so language heavy or culture heavy."P7* *"I suppose it's fairly streamlined in some ways in that, you know, there is a pathway for it. And based on that it works well if people then get a diagnosis and they are offered some treatment and then they'll follow up." P2* *"I think we're pretty efficient in terms of knowing what we're doing in that, albeit that it's a model that seems a bit blunt because it's a one-stop shop, I think it's got all the key components in it." P7* *"Well, we now have assistant psychologists working, and I think that's been quite a success... they both take a responsible role in doing the assessments with the person with dementia. They do the MoCAs and so on. And that does seem to work well. That works very well, actually." P4* *"the clinic itself, I think they are run fairly efficiently" P1*
	Areas for potential improvement	*"it would be good to have a bit more consistency" P4* *"I mean I think GPs aren't great at referral details" P2*
	Inconsistencies in referral process	*"the GPs have been using this new form.... Which doesn't seem to encourage a very thorough referral... I've noticed it's just, yes, not quite as detailed. So then the triage process is just longer" P6* *"we've probably got a gap in the number of diverse people coming through." P7* *"it is a pathway and it happens, and it's very clinical, it's very medical and very clinical." P2* *"I think we're basic in terms of what we offer other than a medical diagnosis and treatment, really basic." P2*
	A basic assessment	*"in the clinic we do basic ones, so we usually do a MoCA, we also do an Addenbrooke's." P5* *"I think we could probably be using more, just have different tools at least to use." P6* *"doing the more sort of complicated means assessments of some people's functions kind of, that would be really helpful, and we don't really have access to that". P5* *"there's quite a big range of variation in the kind of assessment that people get" P4* *"We don't have access to speech and language therapy or speech and language therapy assessments."P5*

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
The BHC	Hopes for the BHC	*"perhaps doing it all in one might be really helpful for people because, you know, there's just less waiting involved." P6*
	A one-stop shop	*"if it does make things more joined up rather than less joined up then that will be good." P4* *"having that as a package for memory clinic I think is gonna be useful because we will have better information, so we will be able to make more accurate diagnosis, and that means we will be able to prescribe more appropriately and sign post more appropriately" P1* *"the aim is to integrate part of the memory clinic assessment process with research and perhaps then give people access to more sophisticated imaging but also to have easy access to people who are taking part in research."P5* *"if you're having all in one place that's a definite benefit for the person, like a one-stop shop." P6*
	Upskilling clinicians	*"you learn from each other, really. So, I think that is a positive. And then it improves people's quality of life and their job as well. And then it can be quite an attractive thing for trainees to be in that clinic, and medical students, I mean it could be quite a nice thing." P5* *"I hope that as clinicians we'd get more information, … and it kind of can be spread more broadly, I think that's often a frustration is that feeling that you know there's little bits going on but you don't get to hear about it" P7* *"for training and for inter-speciality sort of education, I mean yes, so, you know, geriatricians and the neurologists and the psychiatrists, you know, they all are involved in it. I think if we met centrally, I think that's good for everyone really." P5* *"I think it will upskill a little bit because, although we might become less practiced at doing routine cognitive assessments, …I think we will get better at discriminating between the various types of dementia and then better at tailoring the management plan to the individual." P1*
	Concerns about the BHC	*"And then those people that, for whatever reason, whether it's their own physical or mental health barriers to accessing all of that, what will they get? What will happen to those patients who can't get in?" P3*
	Equity of service provision	*"I suppose I also almost envisage that the Brain Health Centre will almost cream off the easy patients so we might still be running a memory clinic here with the patients who it's more difficult to get to Oxford, it's more difficult to get to a MRI, or they don't get to a scan at all, or they have got massive social care issues, or, you know, [unintelligible 00:24:54], they're all going to still be with us here" P2* *"I'm also not sure about the, um, the criteria. I mean are we, are we saying all patients that would have gone to the memory clinic will go here or is there a subset and are we gonna discriminate in some way by choosing patients who might be at an earlier stage in their dementia so might benefit more from research" P1* *"I would hope that there'll be a way of managing the people who can't do the MRI, that they don't then not get the Brain Health Centre service." P2* *"I suppose from my point of view if there could be a hub that would seem to be fairer for people who don't live in Oxford, really, because otherwise you privilege again people who are generally more privileged." P5* *"So there would be a question about whether or not that will be there for a two-tier sort of assessment process, so people that can get in [to Oxford] and can park and do all this and get a very high quality access to, you know, all of it. And then those people that, for whatever reason, whether it's their own physical or mental health barriers to accessing all of that, what will they get? What will happen to those patients who can't get in?" P3*

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
The current assessment process	Areas for potential improvement	*"So at the moment our waiting times are affected by CT scans." P2*
	Scan waiting times and scan reports	*"And we've got a bit of issue in terms of when we get that information back. So there's lots of delays to the ... so there's delays to when they're done, there's a variation in the kinds of reports we get" P7*
		"it is frustrating if you want a MRI, we have to justify massively to get a MRI, and then there's a really long waiting list, often."P5
		"the reporting is very variable and I'm not an expert but, again, the reports that we get, you know, you can get two lines," P3
		"We have a lot of patients where the CT might not be ideal, if you can't see the right structures in as much depth, and it is not reported well. They are often reported quite generically, umm...you know perhaps commenting on the general level of brain atrophy and if there is some small vessel disease which is often ok if you have a fairly good clinical head on and you do some cognitive testing and you get a good history but sometimes it's not quite enough, you know if you are discerning between two different diagnoses or more then it can be, you need a bit more detail."P1
		"I'm less reliant on the imaging at the moment because you can often predict kinda what it is gonna say and it is often not that helpful."P1
		"I am always frustrated if they come back and say nothing of note, which does happen, or, in keeping with age, which is frustrating, or, unremarkable, something like that. So there's a bit of frustration there."P7
		"there is an issue with getting scans done timely... and we only have at the moment the option to have the CT scan. We are very much bound to waiting for the scan, so yes, the fact that we don't have access to scanning, to timely scans, does cause problems." P3
	Demands on clinician's time	*"It is sorta thought that ok you know you see your 3 patients and you are done but it's actually, what we know is there's work to do in-between, you know, making onward referrals, liaising with social care where necessary, signposting, you know, prescribing, doing the follow-up prescribing, you know feedback from neuropsychs. There is a lot of other things other than the hour and 15 minutes and that's not really factored in so we have to try and book it in, in times where we are supposed to be doing other things. So that can be difficult. So timing is not very good"P1*
		"it can be quite frustrating in terms of thinking about leave, in terms of like study leave or annual leave... The memory clinics are booked up that far in advance that it is difficult to get them re-arranged if you need to"P1
	A call to update MCs	*"memory clinics are old enough now to be a bit old school and they need to get a bit more up to date, dare I say it." P7*

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
Diagnosis – the good, the bad and the uncertain	What helps make a diagnosis?	
	Piecing together information	*"I think all of the strands of information that we're getting have got value, so whether it's the past information they give us, the history, whether it's how they talk to us in a face to face, I think, for me, it's how people conduct themselves in their assessment that's the most integral part"P3* *"we take a full history, most of that is relevant to the diagnosis" "That coupled with the cognitive test, gives you a really good idea as to the type of dementia" P1* *"So history, probably doing the memory testing, a part of it, and obviously getting results. And the informant history. I mean, quite frankly, you know, that is often enough but, clearly, you want to make sure you back up with something so it's nice to see a scan as well." P5*
	Role of scans	*"And in the grey area, it's the MCI and grey area it becomes much more crucial, the scans. And also differentiating between different dementias can be quite difficult without a scan, the better the scan, obviously, the more helpful." P5* *"the scan can give you some really useful information, and if that scanning information that we get, if the imaging access improves for us obviously that could be quite an integral part to us being able to tell people what kind of dementia they've got." P3* *"having a good MRI is a really, really helpful addition."P7* *"I think it's essential and I can't imagine why you would want to have that diagnosis made without somebody having looked at your brain structure and ruled out other potential diagnoses."P2* *"the thing is, you know, even with Alzheimer's, early changes aren't very pronounced on imaging so you often can't see anything on CT so having an MRI that can particularly, you know, measure um, the size of medial temporal lobe structures, can give you a sorta better predictive accuracy for dementia and couple with a decent cognitive assessment, you, you, you're home and dry really." P1*
	CT vs. MRI	*"I think in general I have a confidence if somebody's had a MRI in a way that with a CT I'm more likely to be a little bit like, well, they've only had a CT scan." P7* *"MRI are just amazing, being more clear and defined than a CT, so I can understand from a diagnostic point of view that actually it's much clearer to have a MRI."P2* *"People perfectly well make diagnoses without them [MRI scan]. So I'm not sure it's going to make very much difference. It's going to give me a bit more information but it's not actually going to make a difference to what I say about test results." P4* *"I mean CT scans are very quick to do and people who don't like the idea of a scan are more likely to be able to tolerate a CT than MRI"P4* *"It's [CT scan] quicker and less daunting for people."P6* *"MRI are just amazing, being more clear and defined than a CT, so I can understand from a diagnostic point of view that actually it's much clearer to have a MRI."P2*

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
Diagnosis – the good, the bad and the uncertain	What helps make a diagnosis?	*"Just MRI is a bit more of a procedure for people to go through than a CT, I just wonder if that's necessarily for a lot of people."P6*
	Necessity of a scan	*"So I'm not sure it's going to make very much difference. It's going to give me a bit more information but it's not actually going to make a difference to what I say about test results." P4* *"People perfectly well make diagnoses without them [MRI scan]." P4* *"the scan can give you some really useful information, and if that scanning information that we get, if the imaging access improves for us obviously that could be quite an integral part to us being able to tell people what kind of dementia they've got."P3* *"I can imagine people who are at very early stages of dementia being able to tolerate the MRI but I couldn't imagine that people who are further down their dementia journey" P2* *"Whether patients can tolerate an MRI I think will be an interesting one, we'll see but er, that might be an issue and don't know whether they'll have a backup CT or something" P1*
	Role of clinicians' confidence	*"there's uncertainty about the diagnosis and we're usually pretty good at giving diagnosis, but I think most clinicians would agree that we don't have enough access to more scientific routes for diagnosis and we would like more to be able to be much more confident in our diagnosis."P3* *"I find it tricky as a clinician, to give someone a really life-changing diagnosis and I haven't done any of the testing, because I think you can get quite a different feel for what's actually going on when you do the testing yourself."P5* *I have definitely had people referred for neuro because the psychiatrist who's originally seen them is a bit inexperienced.... it's not that they're reluctant to say they've got dementia but they feel less confident about it, so they ask for a neuro opinion." P4* *"Improving the quality of information available to clinicians who are making diagnoses in the memory clinic, empower clinicians to make more confident and accurate and timely diagnoses. That's very laudable and that's some of what I was talking about" P4* *"I think there's a lot, if you look at it, of vagueness. I think there's a lot of times that we sent reports back which are, mm, it doesn't look like this at the moment, and I don't know if we're all just skirting the issue or we're just not sure."P7*
	When to give a diagnosis?	*"But I wonder whether we also just ought to have a tighter definition, when do you tell someone they've got dementia? Because different people have different views on that." P4* *"there isn't a consensus on how and when you diagnose dementia." P4* *"I think people are rightly hesitant sometimes, but I think you get into the gap in some memory services where that means that people are passed from pillar to post, so something that's a bit more decisive can probably be useful"P7*
	Uncertainty and ambiguity	

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
Diagnosis – the good, the bad and the uncertain	When to give a diagnosis?	
	Ethical considerations	*"there's the very blurred borderline between MCI and dementia, and different people have different ideas about when you cross over from one to the other. And to some extent, I think it depends on what's right for the patient at the time, you know, what's in their best interest. Is it to have a definite diagnosis of dementia, sometimes it is, sometimes it's not? But it ought to depend more on the benefit to the patient rather than the habits and experience of whoever they're seeing, the professional" P4*
		"But I think that depends very much on what stage people are at at the point they come for diagnosis, because, you know, there's a question of whether we're diagnosing people early enough anyway, isn't it? You know, you get a lot of people who come, who are referred to the memory clinic, who are significantly impaired by the time they come to clinic." P2
		But I always have a slight concern at the moment because we have very little actually to prevent things yet. It's just how we phrase this in the wider world because, you know, MCI, it's going to get earlier and earlier and all this stuff about biomarkers, and we'll be able to tell if someone's likely to develop Alzheimer's Disease so early, but we'll have no idea how quickly, probably, for a lot of people. And even if we did, you know, who wants to know 15 years before you start getting any cognitive problems that will affect your daily living that you might have those risk factors?" P5
		"But then I suppose the whole question is about what the benefit in early diagnosis is. It's great if there were treatments that were going to help you and delay that, ... but, equally, there is also the question, isn't there, of how much difference is going to make to you if actually there isn't a medication that's going to help you and you are going to deteriorate, and actually do you want to know early on" P2
	The process of giving and receiving a diagnosis	*"I think it's really important they're always asking the question of whether that person wants to know at the beginning, just in a couple of occasions sometimes that isn't happening" P6*
	Informed consent	*"whereas actually the way it works now, I don't think people really very often make an informed decision of what they're putting themselves through."P5*
		"We do these whole clinics where people come not really understanding what they're always letting themselves in for." P5
		"the clinicians and the medics are all very good and very experienced at giving that news." P3
	Compassionate delivery	*"I mean most of it is the art of communication in terms of giving feedback for patients"P1*
		"I think we've got really compassionate psychiatrists who are giving diagnoses quite well" P7
		"I think we're very sensitive in the way that we report back and we allow people to take that diagnosis in." P3
		"most of the time it's done very, very well, very sensitively, I think. I think what they tend to do is just, you just, because you do your full assessment first and you gauge an idea of what that person's thinking and feeling, and how certain words might have an impact on that person, on their family. And I think there are ways you can explain it a tiny bit nicer and, you know, being a bit more positive about it and not saying it as if it's the end of the world, really." P6
	Patients response to the diagnosis	*And they're anxious that they're going to be told that they've got dementia, because that's, you know, that's the significant diagnosis to have."P3*
		"And I think if we don't get the pre-diagnostic stuff right and we don't get the process in right, then it can, like anything, it can come as a shock"P7 "mild cognitive impairment isn't mild, for some people it's massive" P7
		"you can't really give people a chance to anticipate that they may be getting a diagnosis and then give it after a period of time, and I think that's quite difficult. But that's difficult for the diagnosis but also for the driving aspects, people often you have tell them about the driving issues and they're not happy, and so those things; it's not really a very humane way of doing things." P 5

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
Post-Diagnostic Support	Commissioning/ lack of funding	*What's that, then? What post-diagnostic support? [sarcastic tone]…. the memory clinic people do their best but it's not properly funded and there's not very much of it. And, again, there's a big lack of consistency across the localities so here in the South we manage to do CST, which they're not as, they don't, it doesn't happen nearly as regularly in the North or the City"* *"In the North they do some post-diagnostic couples work and coming to terms with your diagnosis kind of stuff, but the rest of us aren't in the habit of doing that." P4* *"So the memory clinic team here offer post-diagnostics support, I think it's a one-off group. And again, that's something that actually we're not, you know, our clinic isn't focused majorly on the post-diagnostic stuff other than offering medication." P2* *"We have at hand all the post diagnostic information that we can give, and obviously we're working with our dementia service as well to make sure that there's a fairly smooth transitional option, and we have a post diagnostic … we run our own post diagnostic sessions and CST sessions, so the flow through to those post diagnostic options is fairly good at the moment."P3* *"they do have a CST group that they have embedded in the system, even though I think there's some commissioning gaps in that they're not really paid to do anything" P7* *"we have CST running but we're not commissioned to run CSTs" P2* *"it's just been a bit of an issue for us in our team, is CST, because it's, you know, an evidence based intervention that we're supposed to be offering as part of MSNAP, but we're just struggling with the resources to actually do it regularly." P6* *"There's a gap in knowledge of what a post-diagnostic intervention looks like …. I think it's easy to blame commissioning and I think flexibility and time to change are probably quite difficult things as well."P7* *"the commissioning process has emphasised diagnosis over a flow and a journey." P7*
Post-Diagnostic Support	Provisions after a diagnosis	*"But I suppose I'd also hope that it isn't just going to be about diagnosis and medical treatment, because I would hope that actually it's also going to be of the health of the person post-diagnosis, which would be my aspiration for memory clinics." P2* *So I think it's the support mechanisms post-diagnosis and medication treatment, it's all that stuff and how the Brain Health Centre will link into that. How it will look into the evidence for other stuff, so not just CST but cognitive rehab, brain training, all that stuff, you know, actually is it going to have the ability to investigate some of the non-medical advances in dementia or evidence base for non-medical occupational therapy, carer research, you know, all that stuff, CBT for carers, all that stuff."P2* *"So you feel as if you need the Brain Health Centre to link up with a psychological intervention centre, which then links up with a living well. So I guess it's got to link, hasn't it, to the kind of health strategy, but I'd be concerned that this becomes too much of a focus, that it's at the front end." P7* *"But I suppose I'd also hope that it isn't just going to be about diagnosis and medical treatment, because I would hope that actually it's also going to be of the health of the person post-diagnosis, which would be my aspiration for memory clinics." P2* *"I guess the more local a service is the idea is the more awareness they might have of what's available in that area" P6*

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
Research	Positive views on research	*"for patients, I mean, clearly, if it's easy for them to sign on the dotted line there and then, then they're more likely to do it, and that's great. I mean if it improves the opportunities for clinicians to take part in research that would be good too, yes."P4* *"I've always been excited about using research in clinical settings, so it fits in very much from a personal point of view, I think it's very exciting."P3* *"being involved in research tends to mean patients get better care anyway, cuz they tend to get more face to face contact, with various clinicians" P1* *"But I actually think people get a lot out of taking part in research, that there's lots of hidden benefits."P5* *"A patient might just see people more often and get more information about their disorder and prognosis" P5*
	Concerns about research	*"I think whether it is fair to ask people to contribute more to research out of their own goodwill but let's not contribute more to their care; I think it's a bit of a mismatch." P7* *"we have a lot of people who don't want to take part in research."P5* *"I think people are often very, very reluctant to consider it at all."P5*
	Future of dementia research	*"there haven't been breakthroughs in dementia for a long time. Despite, you know, research happening on it. So I think changing the focus to you know early detection, erm, getting big cohorts of patients, putting together decent imaging and decent assessment tools, ermm.. I think is the best focus, you know, rather than just, let's try and find another drug" P1* *" I think development of new cognitive tests is good, I think getting computer based ones might be helpful… because it will allow people to do, although they have to be IT fluent, I think you will get more people who are IT fluent in the years ahead. But you know, if they can do stuff on the computer, then it will give, there will be more different types of testing that they will be able to do I think, you know, reaction time type tests and various things" P1* *"So, for example, we use something, you know, line judgement task on the RBANS, and I think, you know, really? In this day and age knowing full well that you can measure eye movement on an iPad, or you can measure people's ability to scan something across a pad with their hand and follow a line and really have all of that stuff measured, I think we are way behind on that." P7*

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
Patient Experience	Emotional/psychological considerations	*"so the people that come to me mostly find that they have been treated with respect and they generally have had a good experience." P4*
	Feeling cared for	*"feedback tends to be very good and sometimes … and that it's a very supportive system. They felt very supported" P2*
	Negative experiences	*"when we say we're discharging them sometimes that can be a bit of a shock to them" P6* *"I hope they never feel like they're left on their own, they can ring me for advice if they need it."P6* *"a one and a quarter hour assessment and you take the whole history, examination, give them a diagnosis, signpost them, and potentially never see them again. And I think that's not great." P5* *"the patient was upset for example about the driving, they weren't so upset about the diagnosis, it was about the driving funnily enough" P1*
	Cognitive demands	*"you know memory clinic is very time pressured, people need to be there on time, they need to be able to give a history or have someone there to give a history, they need to be able to engage to some extent with cognitive testing and all within an hour, and kinda get feedback as well, so there is lots to do and so they need to be relatively fit and able to do that" P1* *"I know some places have a one-stop shop, well I think that would be a bit much for someone to do everything in one day. I would be worried about somebody's concentration and fatigue." P4* *"in the hour and 15 minutes slot, we are giving a lot of information that's not gonna be retained, and that's not particular to them and their diagnosis, it is just the nature of medical consultations that most information isn't retained" P1*
	Practical and environmental barriers	*"Parking… really it's quite bad" P6* *"People don't like driving to Oxford, especially a lot of the elderly patients; they worry very much about where to park." P5*
	Parking and transport	*"but maybe some of the other problems will still exist, which are patients who don't turn up for their scan, patients with transport problems to their scan."P2* *"transport is often an issue…. we don't think you should be driving, by the way we have this post diagnostic information session coming up that is run here in Abingdon. And they say, the next question is, well how do I get there you've just told me I can't drive and then that just winds people up." P1* *"I think people in Banbury wouldn't want to go to Oxford, I don't think. Well, that's a generalisation, I think some would if they found out they could do it all in one day, perhaps they would, a lot of them might opt for that. But I know an awful lot of people that we see that would find that too far to get to." P6*
	Waiting times	*"We don't get the sense that people are sort of fed up with waiting. But…they do wait for the appointment and then they wait for the scan as well" P6* *"There is quite a long wait" P5* *"some of them might think that there are too many different appointments to come to, and some of them might think they've had to wait a bit for their appointment." P4*

Table 1
Continued

Theme	Subthemes/Codes	Example Quotes
Patient Experience	Patient care	
	Hopes for improved care	*"Anything that's going to make access time to information quicker for the person, the results, I know that plays on a lot of patients minds." P6* *"it will probably have a feel of more, more, modern medicine…… more of a feeling of ,right, they are taking my memory problems seriously, this is the best care, best treatment available, and this is really good."P1* *"… I think their experience might be better, I mean in terms of enthusiasm for a new service, it is always there, so, staff are gonna be enthusiastic, I'd imagine you know that the infrastructure is gonna be fairly new and modern and it will be good and you know I think patients like that rather than turning up to a sort of dusty old crumbly place. Er.. you know, being seen perhaps by staff who have done this a billon times before, so they are less than enthusiastic. I'm making assumptions, that, that might not be accurate. But I know that enthusiasm, I hope would be good." P1*
	Concerns about losing connection	*"I'd hope it wouldn't lose the relational bit that you have in clinics with nurses who are really experienced and are kind of set up, you know, you don't want it to be too diagnostic and complicated." P7* *"If they're in a process where things are happening regardless, you know, I'd hate to think they were going to be more overwhelmed or find the process too challenging. I hope that those, you know, those aspects are going to be equally sensitively managed at the Brain Health Centre, even though it's going to be much smarter in a clinical sort of way." P3* *"I think that would be a concern is that older people across the age range, the oldest old, maybe have a different approach to certain services, they'd be a bit concerned if they were a bit too researchy, a bit too academic."P7*

Table 2
Themes, subthemes, and example quotes from mid-pilot interviews

Theme	Subthemes/ Codes	Example Quotes
Impact on Covid-19 service delivery	Impact on local MCs	"one of the trickiest things for us in Memory Clinic was that scanning stopped so we had a big backlog of people that actually we couldn't see and we couldn't diagnose because actually we haven't got the relevant information even if we'd been able to run clinics going throughout, there is a percentage of people that we cannot diagnose without a scan." P2
	Playing 'catch up'	"In terms of routine Memory Clinics, we have a massive backlog so we're still playing catch-up really, trying to fit them in. So hopefully the Brain Health Centres help that, because part of the problem was not getting CTs." P3
	Impact on post-diagnostic support	"Cognitive stimulation groups…information sessions just aren't happening" P9 "so not everyone has access to technology, well most people don't, so it's really hard to kind of implement any virtual groups and to have enough people to be able to join that and feel kind of, providing kind of equal access to opportunities because – it's not really fair to say, "We're offering virtual groups but you can't participate because you don't have the internet"." P9
	Impact on BHC pilot	"you're not necessarily working to your capacity because, you can't, you know, you've got to plan everything, you've got to air everything, and you've got to clean everything" P2
	Delays and reduced capacity	"I mean the whole thing stopped dead at a point at which we were about to arrange to take our first patients in, so yeah, it had a massive impact." P3 "I think obviously the number of patients we've had through the service or the Brain Health Centre has been fewer than we would have expected in time" P8
	Delivering a Covid safe clinic	"a phenomenal amount of work to make the clinic Covid ready. So they have and they're still working to make the place as safe as possible for patients and for people working there, so a massive amount of work they've had to do really." P3 "It also made, I guess, shadowing quite challenging because you can't just kind of go anywhere with anyone, you have to make sure there's enough kind of, the room they're in is appropriate and things like that." P9
First impressions/Initial stages of BHC	Process of refinement	"So it's adapting as we go along and it feels like they're happy to listen to feedback as we go along and make some changes as needed." P8 "We've recently changed the procedure a little bit so that now the MRI scan comes first and then they do the ACE which I think works a lot more smoothly." P9
	Learning as we go	"it's been refined over the few months that we've been set up now, and I feel like that process has become a lot slicker and a lot smoother" P8 "It's still a work in progress and I think because we're only having two kind of patients a day we've got plenty of time and sometimes that's happened really quickly and sometimes patients are taking a long, long time" P3
	An efficient service?	"If people have had a Brain Health MRI, and we can get that back fairly quickly, then yeah, they are being seen quicker. Though I think I am aware that there are people that are being seen a lot, lot quicker than had they been waiting for a scan. So I think that's possibly, and I can't say that in terms of, you know, absolute data, but my belief is, is that people are being seen quicker than they would have been because of the turnaround on reporting the MRI back." P3 "Well I suppose at the moment what it hasn't done is stop the need for two appointments because I suppose my initial understanding of the Brain Health Centre was it was a bit of one stop shop, but it isn't because actually the scans done, still need to be reported, so they still need to come here and have the outcome of a scan and a cognitive assessment, etc, with the doctor here. So we haven't reduced that need to go to two appointments." P2 But I think in the long term, when it's more established, the plan is then to like cut down that time because obviously we don't necessarily need to do everything again. "P9 "if we had the ACE form … I don't see the reason why we still have to do the MoCA or something similar." P9

Table 2
Continued

Theme	Subthemes/ Codes	Example Quotes
What is working well	Referral process	"one of our worries was that it was going to impact the triage staff and they really don't need to be doing this as well, you know, for them at the moment it is very, very difficult, they are very, very pressured and very busy from the CMHT side. So I was always a little bit wary of adding this onto them. So [clinicians name] has sort of just taken, he's taken that and run with it, so yeah, I think that's why it's working." P3 "so it takes more time, it is more intensive, it is, you know, I think it's valuable doing that." P8
	Assessment process Collaborative report	"it's a collaborative report, it isn't the patient's own view, so we have to be mindful of that. But it's giving the – so it's a lot more than we would normally be getting possibly from the consultee." P3 "in terms of the actual kind of assessment process, it's like structured enough to kind of give you – because they only do the interviews that are structured enough to kind of give you an idea of what to ask. At the same time it allows you enough freedom to kind of have a conversation with the person to make it more comfortable for them." P9
	Risk management and teamwork	"So we had a few participants where concerns had been raised about things on some of the assessment questionnaires about mood and suicidality. And again that felt, even though the clinicians were quite anxious, so seeing that come through and then the process, you know, calling one of, you know, escalating to a senior or calling the clinic, you know, over here [in the local MC] to discuss about that. …That sort of process occurred and it happened and it seemed to go relatively well as well, so I think without our clinical support directly on the ground, it seems that there's a process that's smooth and able to be followed." P8
	Feedback process Streamlined	"having that collateral information through does make the follow-up a bit slicker. You know, the fact that you, they've already had a bit of a chat with the relative and gathered some of the information means that you're not sort of having to retread all the ground." P8
	BHC and MRI reports	"I think there's a bit of a standardisation that's quite useful and you get sort of the same information coming through from all the reports and it's quite useful" P8 "in terms of the actual report, like kind of the kind of qualitative information that the Research Assistant provides and then also the informant kind of summary is very, very useful." P9 "we're having particular Radiologists report the scan, because there's only a few of them doing it, and you know, we're recording it to a template which means that it's then structured and standardised which is generally helpful." P8
Clinicians' experience	New learning opportunities	"Just all in all I really like the idea of kind of combining research in a clinical environment ... And it's definitely, like in terms of my role as like an aspiring Psychologist, it's made me more aware of the importance of kind of incorporating research into my role and making people aware of research." P9 "there was a whole load of new learning research. So I think the – I was surprised, I thought that the clinicians, we were just going to go in and see, do the collaborative report, so I was quite surprised that actually we were quite involved in the consent side of things. So we had to do a whole load of new research training which was quite a learning curve." P3
	Adapting to a different way of working	"I've had to change what I do. I mean I'm now cramming it all into three days a week, so from a practical point of view, it's quite hard" P3 "it's not really changing anything specifically. I suppose, the one bit I would say with the triaging processes, that's a slight addition of work for, you know, making sure people can tolerate an MRI. It has added a bit more time to that part of the process" P8 "I don't think it's massively changed the way I work really because I still find that with the – because even the ways we assess in Memory Clinics, we have like a pro forma that we follow, so it's quite similar" P9 "if you're kind of either wearing kind of normal clothes or whatever, or not wearing a mask, you seem a lot more friendly and there's like, the kind of, the PPE makes us an additional barrier which sometimes makes it a bit harder to kind of form more like therapeutic relationships I suppose." P9

Table 2
Continued

Theme	Subthemes/ Codes	Example Quotes
Clinicians' experience	Experienced staff	"the ones [research assistants] that we've got are very well able to take on board the anxieties and worries of patients" P3 "The Radiologists seem to be amazing at keeping people grounded and safe and feeling safe and reassured." P3
Patient's experience	Positive experience of a high-quality service	"I think the thoroughness of the scan and possibly there being more time in the Brain Health Centre for people to be assessed and for the family member to be, you know, it's just good, I think that can only be a positive really for the patient's journey at the specialist centre," P2 "no one's had a negative experience I don't think, although I've been told, and actually they said, you know, "It was very nice", it was you know, they felt supported through the assessment there, that you know, they've had relatively quick follow-ups from the clinic here which has been, you know, relatively joined up working, you know, we've not had big gaps where patients have been waiting ages." P8 "So, I think that's really positive because I do find that some people who have memory difficulty actually really want to kind of contribute to finding say new treatments or just learning more about dementia and memory difficulties in general. So I think that's a really positive experience and, as I said, the team is really friendly so their experience automatically would be positive I think, I hope." P9
	Patients being resilient and accepting of the process	"So it says a lot about peoples' resilience and that, you know, that they will do what they – they would go and have them do something despite how uncomfortable it makes them feel and how frightened they are, they will do it anyway." P3
	Tolerating MRI	"I'm astounded that people will – because they know that they need it, but also because they know, you know, it's been part of the research…, or whether it's just that people are stoic and they just will get on, grit their teeth and just do it because, you know, that's what they need to do. I don't know, but I think it's been, from my point of view, I think it's been a higher uptake than I would have anticipated which is great." P3
	Practical considerations	"Parking is fine at the moment because patients can park outside. So as far as I'm aware, there aren't any issues around access or parking, certainly once patients are in, you know, it's all one level, the facilities are very, very good, yeah, definitely compliant with disability and with Covid" P3
	Parking and transport	"The issues have been around patients who can't drive or can't have a relative drive them, so there's some we've had to decline on the basis they would be coming on public transport and there's a higher Covid risk and things with that, so we unfortunately had to say no to those." P8
Looking ahead	Access to additional resources	"I did suggest that they had a permanent clinician in" P3 "I get the sense that maybe more clinical support on the ground… So, if there's scope for training up someone who is a, you know, a nurse or somebody a bit clinical, that could offer a bit of support to the non-clinical members of staff who were doing some of the assessments," P8 "It's probably still nice for some people to have access to a CT scan because obviously some people might not tolerate kind of the confined space and the noise" P9
	Improve links/collaboration with other local MCs	"There's been a real problem getting people released from other localities, hence I think we are the only team still and that's, you know, that's a big shame that we haven't been able to expand. Obviously they've made it available and certainly the north locality are meant to be having Tuesdays but they just haven't been able to release people because of the pressure of their work." P3 "I'm much more invested in making it work than maybe the other teams who obviously can see the benefits of it but at the same time, are thinking "We just can't deal with this right now", you know, and they can't. So it might be we need to go back to the, you know, to the consulting board about making it easier for clinicians to come on board with it possibly" P3

Appendix I: SIP Lay Summary

What was the project about?

The Brain Health Centre (BHC; part of the Biomedical Research Centre based in Oxford) ran a 6-month pilot project. The BHC pilot aimed to combine high quality clinical assessment and opportunities to participate in research to patients who would normally be referred (by their GP) to a memory clinic (often for a diagnosis of dementia). Clinical assessments in memory clinics have not changed for many years and new research is required to provide better tools to improve diagnosis and treatment.

Collecting feedback from staff and patients who access the new service is important to help evaluate the pilot project and to decide if it will continue to provide a service to patients in the longer term and be adopted by other local areas. This service improvement project aimed to interview the staff's views on the BHC pilot project and to explore what things, if any, need to be improved upon before service expansion is considered.

What did we want to find out?

- What were staff's expectations of the BHC pilot? What were their hopes for the pilot? Did they have any concerns about the pilot?
- What factors do staff think are important in making improvements to the current assessment service?
- Will the BHC impact on staff job roles?

How did we do it?

We interviewed nine staff to explore their views about the BHC pilot. Before the pilot started, we interviewed four staff who were directly involved in the BHC pilot and three staff who were based in other memory assessment services within Oxford Health NHS FT who were not directly involved in the pilot. This ensured we got a broad range of views. Once the pilot started, we then interviewed four staff directly involved to see if initial expectations were met or not, and to evaluate how the BHC pilot was going. The project got delayed due to Covid-19.

What did we find?

Part 1 – Before the pilot started

Staff talked about the need for memory assessment services to be updated and were hopeful that the BHC pilot would offer this alongside improving diagnosis. From the staff interviewed, there was mixed findings of the current assessment process – some reported it as being thorough and others felt the assessment process was quite basic. Getting scans completed and receiving the scan report was an area all staff felt needed to be improved upon. Staff shared that getting a dementia diagnosis is important however, this is the start of a journey and there is a need for more post-diagnostic support which is adequately commissioned.

Staff were hopeful that the BHC pilot would help streamline the assessment process and felt combining research opportunities with the clinical assessment would provide benefits for patients. Staff raised concerns that the BHC pilot might discriminate against some people who may not meet their criteria for an assessment and there were concerns about transport and parking. They also had concerns whether patients would be able to tolerate having an MRI scan.

Part 2 – During the pilot

Staff talked about the negative impact Covid-19 had on services and on the BHC pilot – there were many delays and staff had to work extremely hard to get the pilot up and running safely. Staff felt that the BHC was responsive and learnt from mistakes, regularly reviewing and refining the process as they went along. Staff reported that scan reports received were useful and standardised and the feedback process of giving a diagnosis was quicker due to the comprehensive BHC assessment reports that staff received. Some staff were surprised how well the patients tolerated the MRI scan and parking and transport did not appear to be an issue.

What are the implications and recommendations?

From these initial findings, it appears that the BHC pilot is offering a high quality assessment service and it seems feasible to continue running. Consideration would need to be taken to have other local memory assessment services on board if it is to be rolled out throughout Oxford Health NHS FT and to ensure they offer an equitable service.

Appendix J: SIP Service Response and Feedback

Written feedback was provided by the BHC Service Lead and Research Co-ordinators. Their responses are summarised below.

General comments

- We are preparing for the next phase of the BHC and your results contribute some really important elements to our case for sustained support. For me one of the stand-out results is the mismatch between the expectation that patients wouldn't manage an MRI scan and would find it all too much, and the outcome which demonstrates that this is not the case for most of the patients who attended.
- It's a really fantastic piece of work and I'm so impressed/grateful that you were able to conduct this analysis in the crazy pandemic months!
- I think the issue about a 2-tier system is real and one that we will have to address.
- I have to say that your report is absolutely fantastic. I'm so grateful to you for all the work you've done on this. It's not been the most straightforward project for you, with lots of delays and uncertainties, but I know your report is going to be incredibly helpful for making the case for the BHC, as well as giving us things to work on and improve.
- It was a very interesting read particularly as I joined the team after the initial interviews but prior to the BHC opening; it was very interesting to see how opinion of the BHC changed.

What is your initial reaction to the report and the results?

- It was fantastic to hear the enthusiasm and interest the clinicians had for the BHC, and even better to hear they thought the pilot was going well, was of value, and their concerns about the pilot were largely not born out. It was really useful to see the limitations of the current MC model described in clinicians own words, and reassuring that this matched our perception (as non-clinicians) of the issues with the current service.
- The content on the hesitance of giving diagnosis particularly when unsure or there is complexity was really interesting. With the enhanced assessments, even if this cannot lead to a clear diagnosis, there is potential in future for clinicians to recommend personalised interventions to patients – this is something we're currently discussing incorporating into the BHC in future. Just because a diagnosis cannot be given doesn't necessarily mean nothing can be done, although there is no scope for this in the current MC model, given the lack of provision for post-diagnostic (post-assessment?) support.
- In the mid pilot feedback, I agree that the BHC has been responsive to develop and improve the service, but I would disagree that this has been in response to 'mistakes'. The purpose of the pilot is to learn and adapt to things that aren't working as well as could be, but I think that's different to making mistakes.
- It was fantastic to hear that the clinical report the BHC produces is useful and a good length, as this has been a source of concern for BHC staff.

Did any of the themes surprise you?

- The description of the MRI being an ordeal and having to grit your teeth etc was a bit of a surprise. Whilst MRIs are more involved than CTs, they really aren't that bad. They aren't invasive, and patients have earplugs that really minimise the noise (many patients have hearing aids, which are removed for the scan). We've recently started collecting patient feedback on the MRI, as we expect the experience is not as bad as people expect it to be. Out of 60 scans, we've probably only had 1 patient who was not able to complete the scan due to discomfort at the experience of the scan.
- The negative views of research, particularly patients lack of willingness to be involved in research, was interesting. Before starting the pilot, we too weren't sure if patient update would be low or extremely high – and thankfully it has been the latter. It would be interesting to compare the way research opportunities are presented to patients in different settings to explore this difference in uptake.
- The concern about patient care not being at the core of the BHC was interesting, and a very valid concern. We've always been mindful that the patient experience should be at the heart of everything done at the BHC, so have had extensive PPI input right from the start. Thankfully this has led to really high patient experience, as captured on our feedback questionnaires. This is also testament to our amazing team that deliver the service – our staff are the most frequently commented on aspect of the BHC in the feedback, highlighting how comfortable they made patients feel, that they were kind and reassuring, both before and during appointments. I think the length of BHC appointments actually helps form a rapport between staff and patients/relatives, and we have ensured patients have one member of staff with them throughout their appointment to ensure continuity of care on the day.
- The recurrence of the one-stop-shop model is interesting – this was never the plan for the pilot, and has always been a longer term plan for the BHC. The level of clinician interest and motivation for this model is useful to capture to inform future plans.
- The point about MC clinicians being at BHC to provide continuity of care was interesting. This is something that has been difficult to achieve, in great part due to the pandemic, but I agree is vitally important, so great to hear this from clinicians. This is something we intend to continue.
- I was surprised to hear the m/c still complete the MOCA at appointments; as you say this seems unnecessary and I think there should be evaluation of this to prevent duplicated work. If the ACE is not useful for clinicians perhaps there can be training for memory clinic staff/a review of the neuropsych included in the BHC.

Would you consider changing anything about the BHC?

- The discussion of potentially duplicative assessments, e.g. cognitive assessments, at BHC and MC is interesting. In planning the BHC, clinicians had concerns that the quality of the cognitive assessments conducted at the BHC would not be sufficient, so it was decided to keep assessments at both BHC and MC. Based on the feedback in your report, we will review this and see how clinicians feel about dropping the MoCA at the MC appointment for the more comprehensive ACE that there is time for at the BHC.
- The concerns about the distance to travel are valid. Patient feedback questionnaires have largely shown patients are happy to travel to the BHC and I think patients are happy to travel for what they see to be enhanced assessment. In the evaluation of the pilot, we will look at which patients are benefitting most from the MRI, to refine triage process and only require those that will benefit most from MRI > CT to travel.

- The potential expansion of the BHC will likely involve making enhanced non-imaging assessments available at the MCs, meaning patients can benefit from the BHC without having to travel outside their routine care area (this hopefully will also avoid a two-tier system that was mentioned as a concern).
- I agree it would be useful to have a CT scanner onsite, although it is unlikely we will purchase one. We could look into our options for re-referring patients to CT whilst at the BHC and sending them over to JR for a scan, saving them another trip on another day.
- The upload of the ACE docs is something we're working on fixing. More clinical support on the ground is something that has improved over the course of the pilot and we are working on options for sustaining this.

How (if at all) has this project helped with evaluating the pilot?

- Definitely this project has helped in the evaluation of the pilot.
- In the evaluation, we want to capture the feasibility of the service – your project captures clinicians views around a number of aspects of BHC feasibility, and having pre-pilot concerns that we can show were not issues in the end is valuable.
- We want to capture practicability of the service – your project highlights a number of areas we can look at to improve practicality, e.g. evaluating the MoCA/ACE scores to see if both are useful, and if not remove unnecessary duplication.
- An intended outcome of the pilot was to demonstrate clinician thought the clinical service was as good as previous, and the clinical assessment was better than previous – your project provides evidence towards both points and gives us topics to include in a further survey evaluation.
- It also highlights several areas for evaluation beyond the scope of your report, e.g patient feedback, demonstrating the MRIs are valuable, impact on waiting times etc – these are important areas as they clearly matter to the clinicians.

Appendix K : MRP - Participant Information Sheets

Chief Investigator: Hannah Jenkins
hannah.jenkins@hmc.ox.ac.uk

EASY READ PARTICIPANT INFORMATION SHEET

COMMUNITY GROUP

Study Title: Do Adapted Questionnaires Work for People with Learning Disabilities?

	My name is Hannah.
	I am doing some research at the University of Oxford. Research is when we talk to people and ask questions to find out new information. This research study involves completing some questionnaires.
	Would you like to help me? You don't have to take part in this research study. It's your choice. You can also change your mind at any time.

What is this research study about?

Questionnaires are used by psychology services to help us understand how people feel.

Services want to check if these questionnaires are easy for people with learning disabilities to understand.

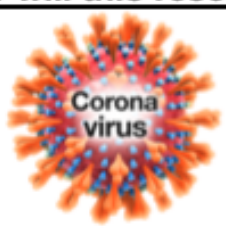
This research study wants to make sure the questionnaires measure what they are supposed to measure (they need to be valid and reliable).

This research is looking at questionnaires that are used with people with learning disabilities:

- 2 questionnaires about how sad people feel,
- 2 questionnaires about how worried people feel.

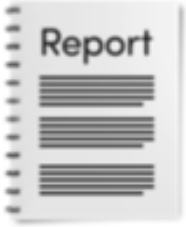
This research study has been checked and approved by an independent group of people called the Research Ethics Committee.

Who can take part?	
	People who • Have a learning disability • Are aged 18 or over • Can understand what it means to take part in the research study

How will this research study be conducted?	
	There will be 2 options: 1. If it is safe to do so, Hannah will meet with you face to face to help you complete the questionnaires OR
	2. We will use video calls to help you complete the questionnaires. A weblink will be emailed to you. You can ask for support from someone you know to access this.

What will happen if I take part in the research?	
 	You will sign a consent form. You will complete a questionnaire about yourself with support from Hannah. You will fill out 4 questionnaires with support from Hannah. • 2 questionnaires will be about how sad you feel, • 2 questionnaires will be about how worried you feel.
	It will take about 1 hour to complete the questionnaires during your first research study visit. 1 week later, Hannah will meet with you again and support you to fill out the questionnaires again.

Is taking part in the research private?	
	Yes. What you tell us will be kept: • Private • In a safe place • And it will not have your name on it Information will only be shared with your carer or GP if we are very worried about you or someone else's safety. Oxford University will also monitor the study to make sure it is all done correctly and is confidential. We will not tell people that you took part in the research or give away information about you like your name.
	We will keep all information about you safe and secure. This information will include your name, contact details, GP, and emergency contact number.
	You can stop taking part at any time and you do not need to give a reason. We will only keep information about you that you have already agreed for us to use. If we think you are no longer able to take part in the study, we will stop and not ask you anymore questions. If that happens, we will remove you from the study. Then we would only use information you had already agreed for us to use.

What will happen to the results of the research?	
	Hannah will write a report about the research. The report will be written in a way that no-one can work out that you took part in the study. You can contact Hannah if you would like a copy of the report.
UNIVERSITY OF OXFORD	The results of this study will be sent to Oxford University and shared with other researchers and might be published. No personal information will be included in the publication.

Can I talk to someone about the research?	
	Yes. You can ask Hannah questions. You can also talk to your family, friends, carer, GP for advice or if you have any questions.
	You can call and leave a message for Hannah Jenkins on **07312095703** Hannah will call you back.
	You can email Hannah at: Hannah.jenkins@hmc.ox.ac.uk

	You can talk to Hannah's supervisors Myra Cooper (myra.cooper@hmc.ox.ac.uk) or Kate Theodore (kate.theodore@rhul.ac.uk) if you are unhappy with anything about the research. Or you can contact the University of Oxford on 01865 616480, or email ctrg@admin.ox.ac.uk. You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/

Thank you for reading this information sheet.

Chief Investigator: Hannah Jenkins
hannah.jenkins@hmc.ox.ac.uk

Please insert your NHS Trust loge here

EASY READ PARTICIPANT INFORMATION SHEET

CLINICAL GROUP

Study Title: Do Adapted Questionnaires Work for People with Learning Disabilities?

	My name is Hannah.
 	I am doing some research at the University of Oxford. Research is when we talk to people and ask questions to find out new information. This research study involves completing some questionnaires.
	Would you like to help me? You don't have to take part in this research study. It's your choice. You can also change your mind at any time.

	If you don't want to take part, that's ok. It will not affect the treatment you receive from your Learning Disability Team.

What is this research study about?

Questionnaires are used by psychology services to help us understand how people feel.

Services want to check if these questionnaires are easy for people with learning disabilities to understand.

This research study wants to find out if the questionnaires measure what they are supposed to measure (they need to be valid and reliable).

This research is looking at questionnaires that are used with people with learning disabilities:

- 2 questionnaires about how sad people feel,
- 2 questionnaires about how worried people feel.

This research study has been checked and approved by an independent group of people called the Research Ethics Committee.

Who can take part?

People who

- Have a learning disability
- Are aged 18 or over
- Can understand what it means to take part in the research study

How will this research study be conducted?

There will be 2 options:

1. If it is safe to do so, a staff member from the Learning Disability service will meet with you face to face to help you complete the questionnaires

   OR

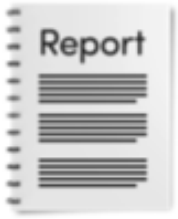
2. We will use video calls to help you complete the questionnaires.

   A weblink will be emailed to you.

   You can ask for support from someone you know to access this.

What will happen if I take part in the research?	
	You will sign a consent form. You will complete a questionnaire about yourself with support from your psychologist or Hannah. You will fill out 4 questionnaires with support from your psychologist or Hannah. • 2 questionnaires will be about how sad you feel, • 2 questionnaires will be about how worried you feel.
	It will take about 1 hour to take part in this research study.
	What you tell us will be kept: • Private • In a safe place • And it will not have your name on it

Is taking part in the research private?	
  	Yes. Information will only be shared if we are very worried about you or someone else's safety. Only if we need to, we may share information with someone who can help, like your GP or the Learning Disability Team. Oxford University will monitor the study to make sure it is all done correctly and is confidential. We will not tell people that you took part in the research or give away information about you like your name. We will keep all information about you safe and secure. This information will include your name, contact details, GP, and emergency contact number.
	You can stop taking part at any time and you do not need to give a reason. We will only keep information about you that you have already agreed for us to use. If we think you are no longer able to take part in the study, we will stop and not ask you anymore questions. If that happens, we will remove you from the study. Then we would only use information you had already agreed for us to use.

What will happen to the results of the research?	
	Hannah will write a report about the research. The report will be written in a way that no-one can work out that you took part in the study. You can contact Hannah if you would like a copy of the report.
UNIVERSITY OF OXFORD	The results of this study will be sent to Oxford University and shared with other researchers and might be published. No personal information will be included in the publication.

Can I talk to someone about this research study?	
	Yes. You can talk to your psychologist, family, friends, carer, or GP if you have any questions or want advice.
	You can call and leave a message for Hannah Jenkins on **07312095703** Hannah will call you back.

	You can email Hannah at: hannah.jenkins@hmc.ox.ac.uk
	You can talk to Hannah's supervisors Myra Cooper (myra.cooper@hmc.ox.ac.uk) or Kate Theodore (kate.theodore@rhul.ac.uk) if you are unhappy with anything about the research. Or you can contact the University of Oxford on 01865 616480, or email ctrg@admin.ox.ac.uk. You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/

Thank you for reading this information sheet.

Appendix L: MRP Verbal Consent Form

Chief Investigator: Hannah Jenkins
hannah.jenkins@hmc.ox.ac.uk

Study Code:		*Site ID Code:*		*Participant identification number:*				
L	D	0	0					

VERBAL CONSENT FORM – COMMUNITY GROUP

Study Title: Do Adapted Questionnaires Work for People with Learning Disabilities?

Researcher to seek and record informed verbal consent, after participant has had sufficient time to think about whether they want to take part.

Please check the boxes to record that the question has been asked by the researcher via telephone or video call and that the participant has responded by saying yes:

		√
	I have read the Participant Information Sheet.	
	Someone has checked if I have any questions about the research.	

	I understand that my information will be kept: • Private • In a safe place • And it will not have my name on it	
	I know that it is my choice to take part in this research and I can change my mind at any time.	
	I agree to share my contact details, my carer's details and my GP contact details for emergency use only.	
	I would like to take part in the research study.	

 	My contact details are: Telephone: _____ Email: _____ Address: _____ _____

Name of Participant

_____

Name of Researcher taking consent Date Signature

_____ _____ _____

**1 copy for participant (e.g. emailed securely to participant); 1 copy for researcher site file*

Appendix M: MRP Questionnaire Pack

Chief Investigator: Hannah Jenkins
hannah.jenkins@hmc.ox.ac.uk

Study Title: Do Adapted Questionnaires Work for People with Learning Disabilities?

DEMOGRAPHIC QUESTIONNAIRE

Study Code:		*Site ID Code:*		*Participant identification number:*				
L	D	0	0					

Questions about you…

(To be completed with support from the study clinician or researcher)

How old are you?	_____ years
Are you…	 Man (male) ☐  Woman (female) ☐ Other ☐ Prefer not to say ☐
Which of the following best describes your ethnic background?	☐ Asian or Asian British ☐ Black or Black British ☐ White ☐ Mixed ☐ Other ☐ Would rather not say

What services do you access currently?	LD Services ☐ Mental health services ☐ Advocacy ☐ Health services ☐ Day services ☐ Other? _____ Type of contact with professionals (e.g. psychology review once a month): _____ _____
Have you got a Learning Disability?	Yes ☐ No ☐ Not sure ☐
Have you got any other health or mental health difficulties?	Yes ☐ No ☐ Not sure ☐ If yes, what do you have? (e.g. Autism Spectrum Disorder, depression, anxiety?) _____

Study Code:		Site ID Code:		Participant identification number:					
L	D	0	0						

ADAPTED PHQ-9 & GAD-7 QUESTIONNAIRES

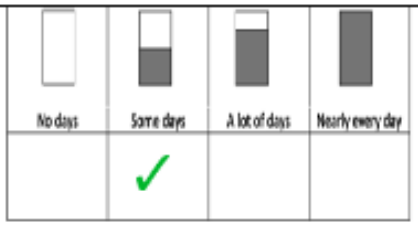
How to fill in these questionnaires:

<table>
<tr>
<td> 
 
 
  </td>
<td>These questionnaires are used by psychology services to help us understand how people feel.

• One questionnaire measures how sad people feel.

• One questionnaire measures how worried people feel.

Questionnaires also help us see if people feel better after they see us.</td>
</tr>
<tr>
<td> 
</td>
<td>These questionnaires ask you about how you have been feeling in the past week.

It might help you to think about something that you did 1 week ago to answer these questions</td>
</tr>
<tr>
<td> 
</td>
<td>For each question, tick one of the boxes to show how you have been feeling in the past week.
This is not a test, there are no right or wrong answers.</td>
</tr>
<tr>
<td> 
</td>
<td>If you need help or have questions, you can talk to your therapist.</td>
</tr>
</table>

1 FEELING SAD (PHQ-9)

Have you felt less interested in doing things?

 No days	 Some days	 A lot of days	 Nearly every day

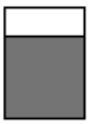
2

Have you felt sad?

 No days	 Some days	 A lot of days	 Nearly every day

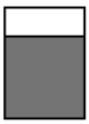
3

Have you had problems with your sleep?

			
No days	Some days	A lot of days	Nearly every day

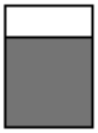
4

Have you been feeling tired?

			
No days	Some days	A lot of days	Nearly every day

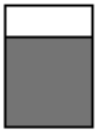
5

Have you been more or less hungry than normal?

			
No days	Some days	A lot of days	Nearly every day

6

Have you been feeling like you have let yourself down or let other people down?

			
No days	Some days	A lot of days	Nearly every day

7

Has it been hard to concentrate on things?

			
No days	Some days	A lot of days	Nearly every day

8

Have you been

- moving or speaking more slowly?

OR

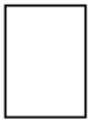
- moving or speaking a lot faster?

			
No days	Some days	A lot of days	Nearly every day

9

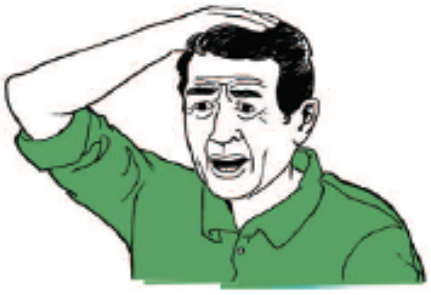
Have you had thoughts about:

- Hurting yourself on purpose?
- Killing yourself?

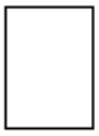
			
No days	Some days	A lot of days	Nearly every day

PHQ-9 TOTAL	

1 FEELING WORRIED (GAD-7)

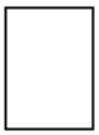
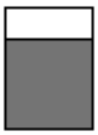


Have you been feeling worried?

			
No days	Some days	A lot of days	Nearly every day

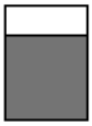
2

Has it been hard to stop worrying?

			
No days	Some days	A lot of days	Nearly every day

3

Have you been worrying about lots of different things?

			
No days	Some days	A lot of days	Nearly every day

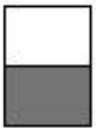
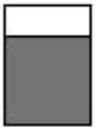
4

Has it been hard to relax?

			
No days	Some days	A lot of days	Nearly every day

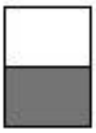
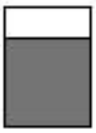
5

Has it been hard to sit still?

			
No days	Some days	A lot of days	Nearly every day

6

Have you felt angry?

			
No days	Some days	A lot of days	Nearly every day

7			
 Have you felt scared?			
 No days	 Some days	 A lot of days	 Nearly every day

GAD-7 TOTAL	

Is there anything you want to tell us about your answers?

.....

.....

.....

.....

.....

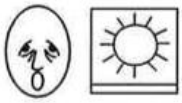
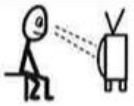
.....

.....

Thank you!

Glasgow Depression Scale

(score of 13 or over indicates depression).

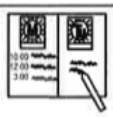
In the last week...		Prompts	no	some times	a lot
1. 	Have you felt sad?	Have you felt upset, depressed, miserable, fed up, low?	0	1	2
2. 	Have you been in a bad mood?	Have you felt bad tempered, wanted to shout at people?	0	1	2
3. 	Have you enjoyed doing things?	Have you had fun?	2	1	0
4. 	Have you enjoyed talking and being with people?	Have you liked having people around?	2	1	0
5. 	Have you had a bath/shower and changed your clothes?	Have you taken care of the way you look / appearance?	2	1	0
6. 	Have you felt tired during the day?	Have you gone to sleep during the day, found it hard to stay awake?	0	1	2
7. 	Have you cried?	What made you cry?	0	1	2
8. 	Have you felt people don't like you?	Have you felt you are a horrible person?	0	1	2
9. 	Have you been able to concentrate, such as watch TV?	What is your favourite TV programme? Are you able to watch it all?	2	1	0
10. 	Have you found it hard to choose things?	Have you found it hard to decide what to wear, eat or do?	0	1	2

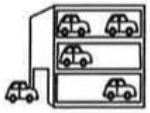
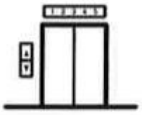
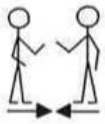
In the last week...		Prompts.	no	some times	a lot
11.	Have you found it hard to sit still?	Have you fidgeted, moved around a lot more?	0	1	2
12.	Have you eaten less? Have you eaten more?	Have people said you should eat more or less?	0	1	2
13.	Have you found it hard to get a good night's sleep?	Have you found it hard to fall asleep, woken up a lot or too early?	0	1	2
14.	Have you wished you were dead?	Have you wanted to stop living?	0	1	2
15.	Have you felt everything is your fault?	Have you felt people blame you for things?	0	1	2
16.	Have you felt people are looking at you, talking about you?	Have you worried about what other people think of you?	0	1	2
17.	Have you been upset if people say you have done something wrong?	Do you feel sad, or feel like crying if someone tells you off?	0	1	2
18.	Have you felt worried?	Have you felt nervous, tense, wound up or on edge?	0	1	2
19.	Have you thought that bad things will happen to you?	Have you felt nothing nice happens to you?	0	1	2
20.	Have you felt happy when something good happens?	What makes you feel happy?	2	1	0

Cuthill, F. M., Espie, C. A. , Cooper, S (2003) Development and psychometric properties of the Glasgow Depression Scale for people with a learning disability: Individual and carer supplement versions. The British Journal of Psychiatry 182:347-353. Adapted by MK, GB, GW, DHCFT 2008.

Glasgow Anxiety Scale.

(score of 15 or above indicates anxiety).

		Prompts	no	some times	a lot
1.	 Do you worry a lot?	Feel wound up, get worked up	0	1	2
2.	 Do you have lots of thoughts in your head?	Can't stop thinking, can't keep thoughts away.	0	1	2
3.	 Do you worry about your familiy or friends?	Think something bad will happen.	0	1	2
4.	 Do you worry about the future?	Link prompt to individual.	0	1	2
5.	 Do you worry that something bad will happen?		0	1	2
6.	 Do you worry about being ill?	If you feel poorly.	0	1	2
7.	Do you worry about doing something new?	Afraid to try new things.	0	1	2
8.	 Do you worry about what you are doing tomorrow?		0	1	2
9.	 Can you stop yourself worrying?	Make yourself think about something else.	2	1	0
10.	 Do you worry about dying?		0	1	2

		Prompts.	no	some times	a lot
11. 	Are you scared of the dark?	Do you turn the lights off at night.	0	1	2
12. 	Do you feel scared when you are high up?	Do you like multi storey car parks.	0	1	2
13. 	Do you feel scared in lifts?	Would you get in one.	0	1	2
14. 	Are you scared of dogs?	Would you stroke one.	0	1	2
15. 	Are you scared of spiders?	Would you touch one.	0	1	2
16. 	Are you scared of going to the Doctor or Dentist?	Would you go if you needed to.	0	1	2
17. 	Are you scared of meeting new people?	Are you shy.	0	1	2
18. 	Are you scared in busy places or crowds?	Such as Westfield or Supermarkets.	0	1	2
19. 	Are you scared of open spaces?	Where there is nothing around you.	0	1	2

		Prompts.	no	some times	a lot
20	 Do you get hot and sweaty?	All hot and bothered.	0	1	2
21	 Does your heart beat fast?	Feel your heart is thumping.	0	1	2
22	 Do your hands and legs shake?		0	1	2
23	Do you get butterflies in your stomach?	Knots in your stomach, fluttering.	0	1	2
24	 Do you find it hard to breath?	Are you out of breath a lot.	0	1	2
25	 Do you have to wee more often?		0	1	2
26	 Is it difficult to sit still?	Feel you can't relax.	0	1	2
27	Do you panic?	Get in a panic or a state.	0	1	2

Mindham,J,. Espie,C.A(2003) Glasgow Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disabilities. **Journal of Intellectual Disabilities** 47 (Pt 1):22-30.
Adapted by Marsha Kerrigan and Gill Baker DHCFT 2013.

Appendix N : MRP Ethical Approval Letter

Mrs Hannah Jenkins
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
The Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre, Warenford Hospital
Oxford
OX3 7JX

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

24 September 2020

Dear Mrs Jenkins

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**An evaluation of the psychometric properties of the adapted PHQ-9 and GAD-7 outcome measures for use with adults with intellectual disabilities.**
IRAS project ID:	**274545**
Protocol number:	**000000**
REC reference:	**20/PR/0291**
Sponsor	**University of Oxford / Clinical Trials and Research Governance**

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

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

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

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

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

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

What are my notification responsibilities during the study?

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

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

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

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

Your IRAS project ID is **274545**. Please quote this on all correspondence.

Yours sincerely,
Nicole Curtis

Approvals Specialist

Email: approvals@hra.nhs.uk

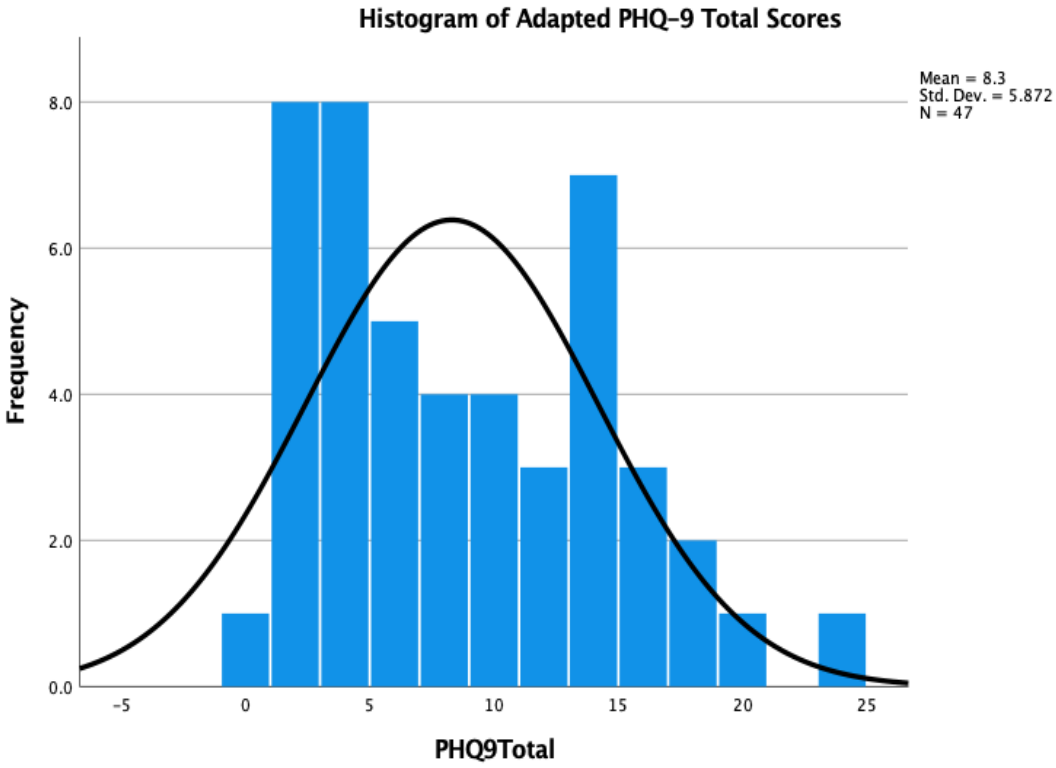
Copy to: *N/A N/A CTRG*

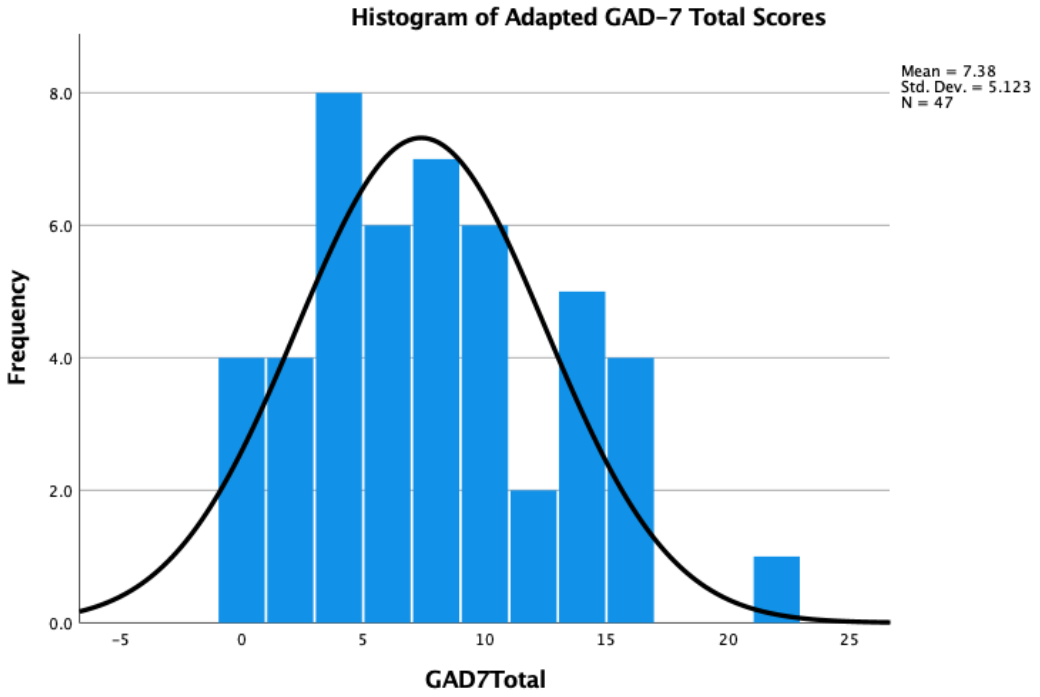
List of Documents

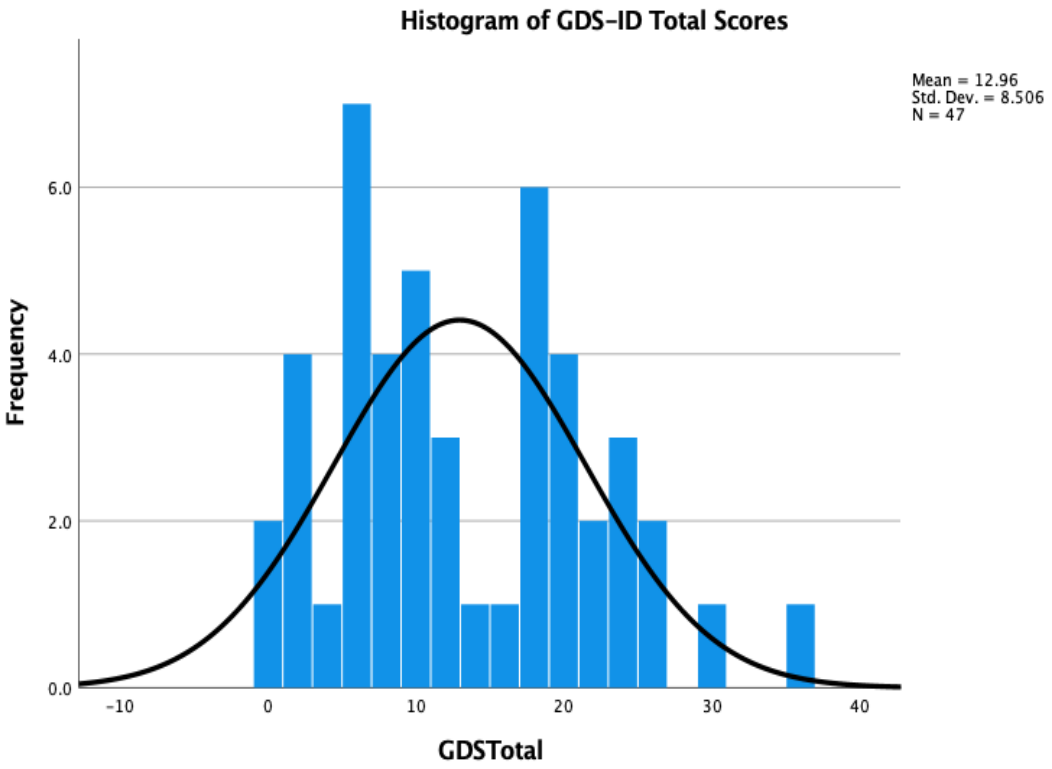
The final document set assessed and approved by HRA and HCRW Approval is listed below.

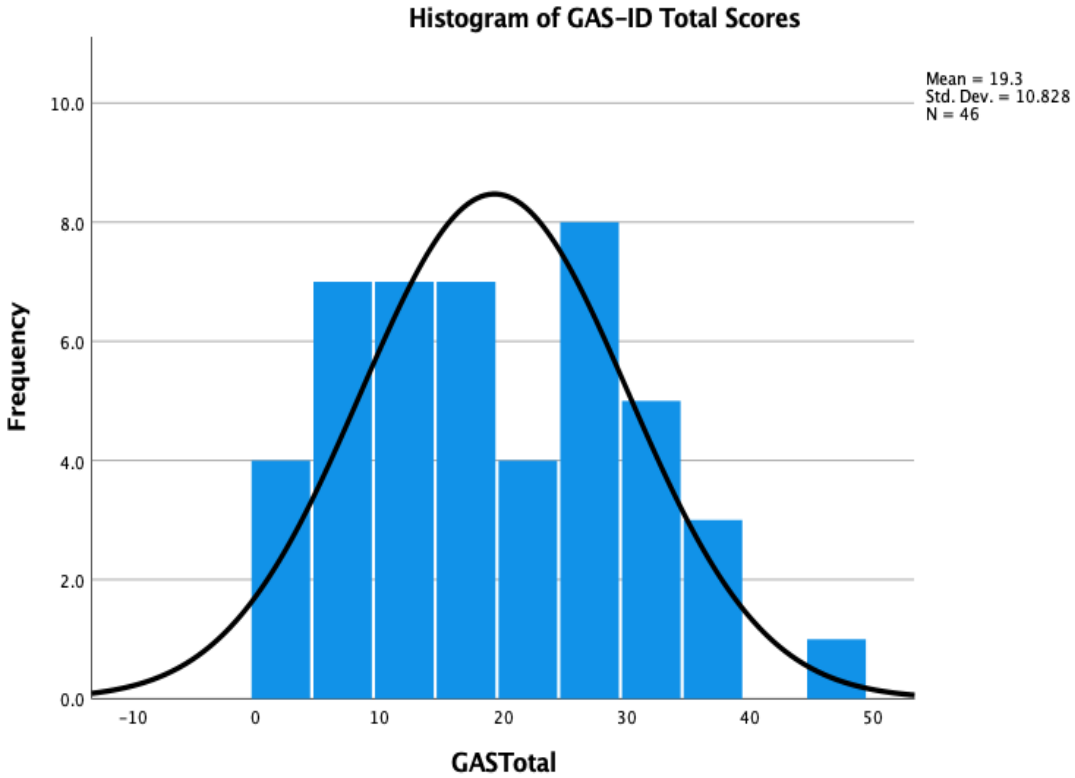
Document	*Version*	*Date*
Copies of advertisement materials for research participants [Social media post]	v.1.0	09 June 2020
Copies of advertisement materials for research participants [Advertisement poster]	v.1.0	09 June 2020
IRAS Application Form [IRAS_Form_22072020]		22 July 2020
Letter from funder [Funding letter]		10 December 2019
Letter from sponsor [Sponsorship letter]		14 July 2020
Letters of invitation to participant [Invitation letter]	v.1.0	09 June 2020
Non-validated questionnaire [Demographic questionnaire]	v.1.0	09 June 2020
Organisation Information Document [OID]	v.1.0	14 July 2020
Other [Insurance cover letter]		24 July 2020
Other [Insurance certificate]		01 August 2020
Other [Debrief]	v.1.0	22 February 2020
Other [Certificate]	v.1.0	09 June 2020
Other [Email template for weblink]	v.1.0	09 June 2020
Participant consent form [ICF clinical]	v.2.0	17 September 2020
Participant consent form [Verbal ICF clinical]	v.2.0	17 September 2020
Participant consent form [Verbal ICF community]	v.2.0	17 September 2020
Participant consent form [Verbal consent script]	v.2.0	17 September 2020
Participant consent form [ICF community]	v.2.0	17 September 2020
Participant information sheet (PIS) [PIS clinical]	v.2.0	17 September 2020
Participant information sheet (PIS) [PIS community]	v.2.0	17 September 2020
Research protocol or project proposal [Protocol]	v.1.0	09 June 2020
Schedule of Events or SoECAT [Schedule of Events (HRA Assessed)]	1	05 August 2020
Summary CV for Chief Investigator (CI) [CI CV]		26 January 2020
Summary CV for student		26 January 2020
Summary CV for supervisor (student research) [Supervisor CV - MC]		02 March 2020
Summary CV for supervisor (student research) [Supervisor CV - KT]		09 January 2020
Validated questionnaire [Adapted PHQ-9 & GAD-7]		
Validated questionnaire [PHQ-9 original]		
Validated questionnaire [GAD-7 original]		
Validated questionnaire [GDS-ID & GAS-ID]		

Appendix O: MRP Histograms

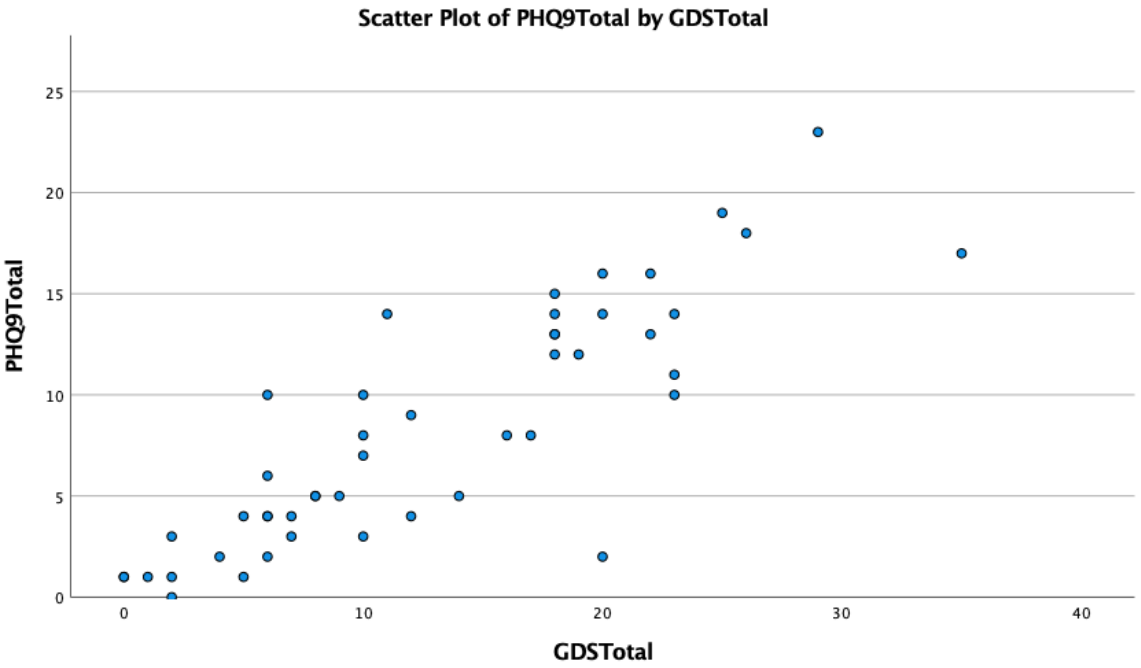


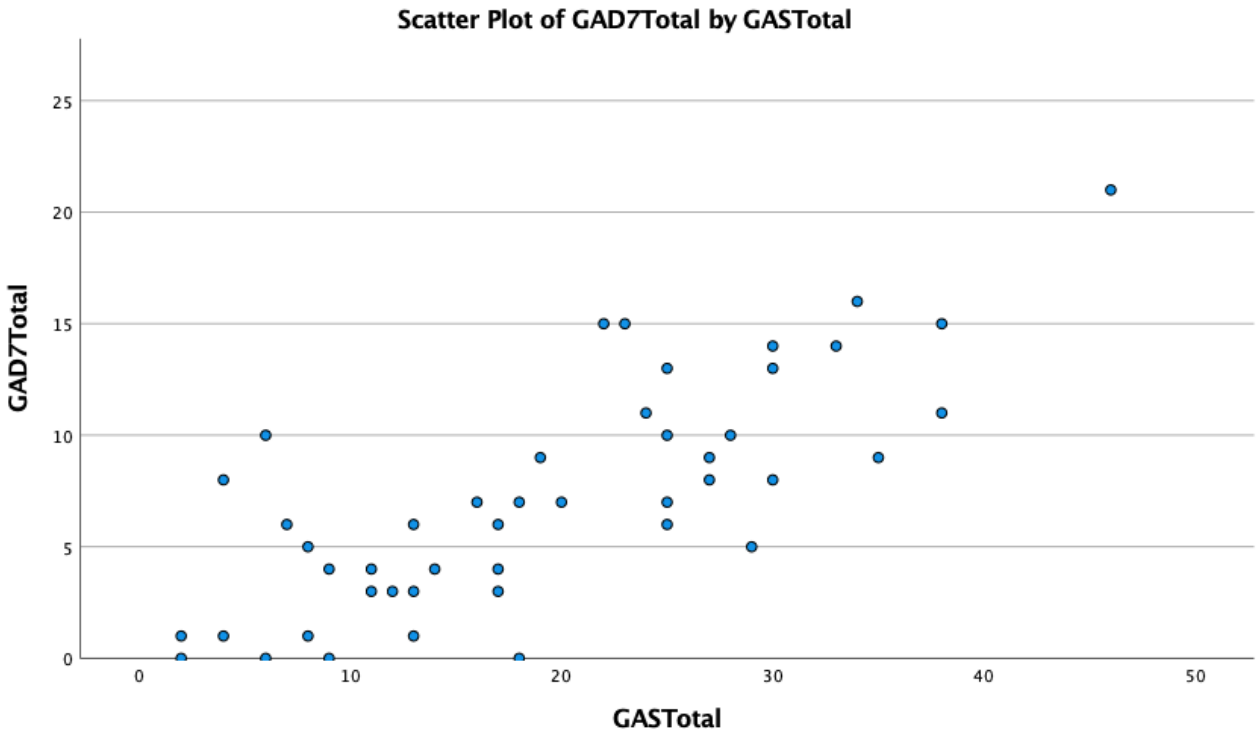


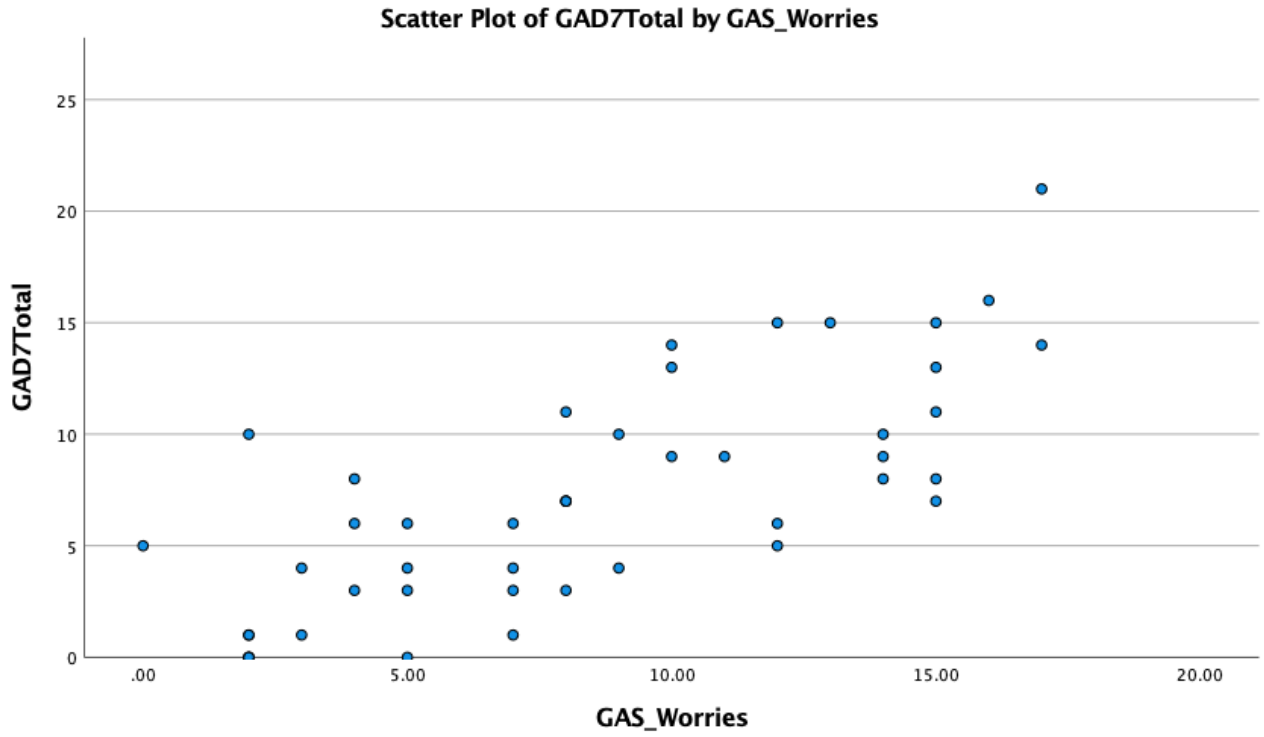

Histogram of GDS-ID Total Scores
Mean = 12.96
Std. Dev. = 8.506
N = 47
Frequency
6.0
4.0
2.0
0.0
-10
0
10
20
30
40
GDSTotal

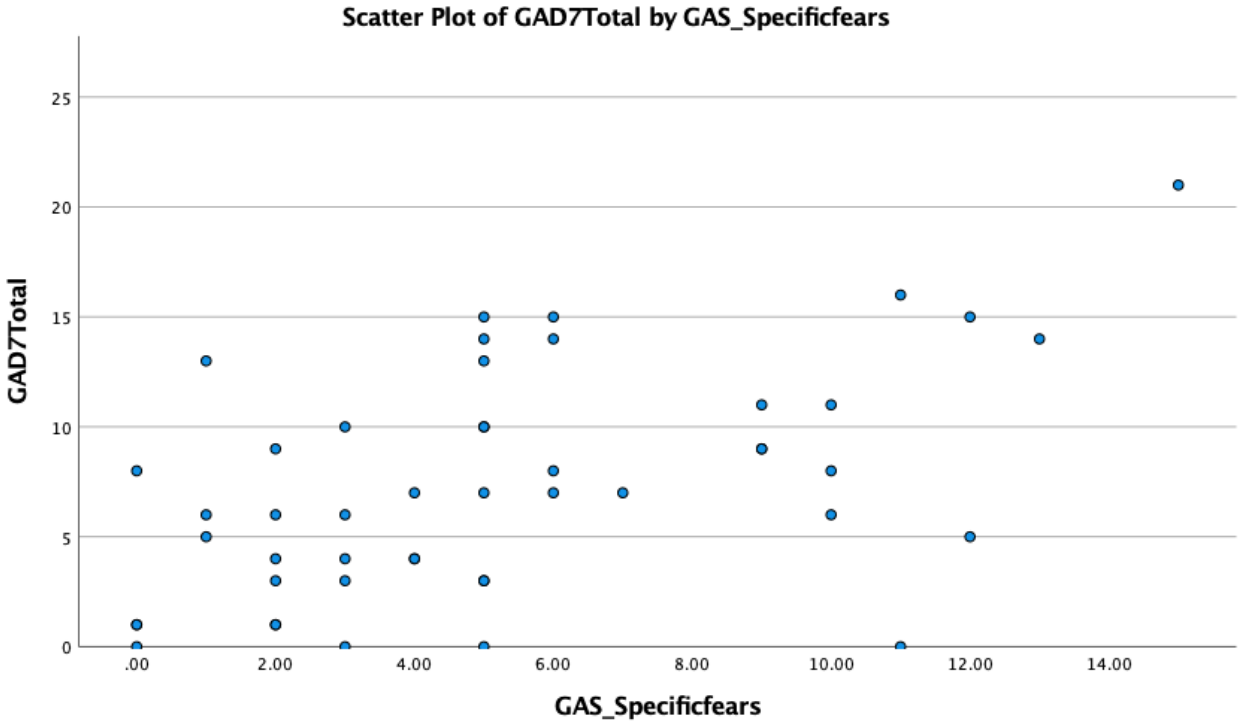

Histogram of GAS-ID Total Scores
Mean = 19.3
Std. Dev. = 10.828
N = 46
Frequency
10.0
8.0
6.0
4.0
2.0
0.0
-10
0
10
20
30
40
50
GASTotal

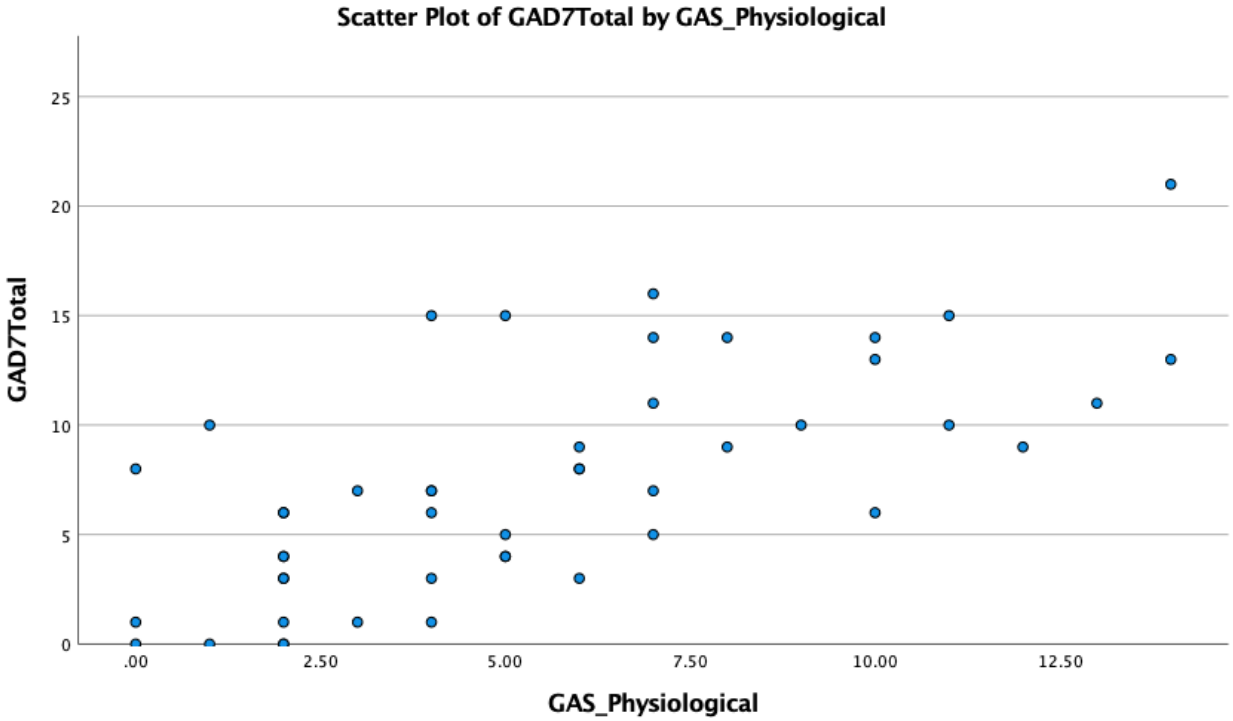
Appendix P: MRP Scatter Plots






Scatter Plot of GAD7Total by GAS_Worries
GAD7Total
25
20
15
10
5
0
.00
5.00
10.00
15.00
20.00
GAS_Worries


Scatter Plot of GAD7Total by GAS_Specificfears
GAD7Total
25
20
15
10
5
0
.00
2.00
4.00
6.00
8.00
10.00
12.00
14.00
GAS_Specificfears


Scatter Plot of GAD7Total by GAS_Physiological
GAD7Total
25
20
15
10
5
0
.00
2.50
5.00
7.50
10.00
12.50
GAS_Physiological

Appendix Q: MRP Easy Read Executive Summary

Chief Investigator: Hannah Jenkins
hannah.jenkins@hmc.ox.ac.uk

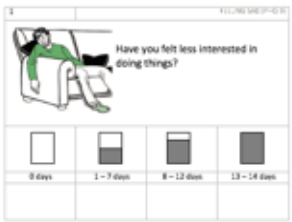
EASY READ RESEARCH SUMMARY

Study Title: Do Adapted Questionnaires Work for People with Learning Disabilities?

Why did we do the research?	
	Questionnaires are used by psychology services to help us understand how people feel. Two easy read questionnaires had been made for people with learning disabilities.
	One questionnaire asks about how sad people feel. One questionnaire asks about how worried people feel.
	This research wanted to check if the questionnaires were valid and reliable. This means that the questionnaires measured what they were supposed to measure and were a high quality.

What did we do?	
	We asked adults with learning disabilities to complete questionnaires about feeling sad and feeling worried. 47 people completed the questionnaires.
 	There were two groups: ● Adults with learning disabilities getting help from Learning Disability NHS Services for their mental health problems ● Adults with learning disabilities in the community not currently getting help for any mental health problems
What did we find out?	
	The questionnaires are a high quality and can be used with adults with learning disabilities.
	The questionnaires measure sad and worried feelings. This means they are valid – they measure what they are supposed to measure.

	The questionnaires are reliable. This is good because they are consistent – they measure the same thing over time.

What happens next?	
	We want to let people know about the research findings. We will talk about the research at conferences and share our findings with therapists and mental health services.
	We will write up a report. The results of this study will be sent to Oxford University and shared with other researchers and might be published.
 	We hope the questionnaires will be regularly used in mental health services. This will provide a 'reasonable adjustment' to support people with learning disabilities to be included and get the help they need from mental health services.

<table>
<tr><td> 
</td><td>We want to say thank you to everyone who helped with the research.</td></tr>
<tr><td colspan="2">Questions?</td></tr>
<tr><td>  </td><td>Hannah Jenkins was the researcher.</td></tr>
<tr><td>   </td><td>Kate Theodore and Myra Cooper were the research supervisors.</td></tr>
<tr><td> 

 </td><td>You can email Hannah at:

Hannah.jenkins@hmc.ox.ac.uk

Or you can call and leave a message on:

07312095703

Hannah will call you back.</td></tr>
</table>