Glasgow Psychosis Screening Tool for use in Adults with Intellectual Disabilities (GPS-ID): Development and psychometric properties

and

Clinical Research Portfolio

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Chapter 1: Systematic Review
Psychosis in Adults with Intellectual Disabilities: A systematic review of prevalence and appraisal of study quality

Chapter word count: 6609

1. <u>Abstract</u>

Background   Psychotic disorders have been estimated to range between 0.8% and 5.0% in the Intellectual Disabilities (ID) population. This systematic review aims to provide the most accurate estimate of the prevalence of psychosis in the ID population, whilst appraising the quality of such literature.

Method   A systematic search was conducted of the electronic databases Medline, Embase, PsycINFO, and PubMed between commencement of each database and January 2016. Articles which investigated rates of psychosis in adults aged ≥16 years with a mild to profound ID were selected for quality analysis.

Results   Twelve articles met the predetermined criteria; five were rated as high quality and seven were rated as moderate quality. An overall prevalence of psychosis was calculated at 7.1% (95% CI = 3.9-10.3) with a range of 0.8-17.7%. Several methodological issues were identified as leading to both over- and under- estimates of psychosis in this population. A key issue is the level and distribution of ID included within samples, and the denominator used to calculate prevalence.

Conclusions   Existing evidence suggests that the prevalence of psychosis is likely to be higher than previously estimated; suggesting that policy makers and healthcare providers should consider how best to identify such individuals, so that they can access appropriate treatment.

2. <u>Background</u>

Psychotic illness has been estimated to range from 0.8-5.0% in the adult ID population (Lund, 1985; Deb *et al.* 2001; Bailey, 2007; Cooper *et al.* 2007a). Prevalence rates of psychosis have also varied in the adult general population, with estimates ranging from 0.4-1.2% (Jenkins *et al.* 1997; Brugha *et al.* 2005; Wittchen *et al.* 2011). Hence, psychosis is thought to occur at a higher rate in the ID population than the general population.

Existing literature on the prevalence of mental illness in the ID population is however known to be limited by methodological issues (see Smiley, 2005 for a review), making it difficult to generalise between studies. Prevalence rates can vary widely depending on the size and representativeness of the sample; the definition of ID; and the method of case ascertainment, such as the type of diagnostic criteria used to determine caseness. Specifically, general population nosology cannot accommodate the altered manifestation of mental illness caused by more severe levels of ID, leading to under-recognition of some psychiatric disorders in this population (Cooper *et al.* 2007a). For example, the prevalence of psychosis was found to vary across diagnostic criteria

applied to the same sample of adults with ID (Cooper *et al.* 2007b): 4.4% according to clinical diagnosis, 3.8% according to DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation), 3.4% according to the DMS-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, text revision), and 2.6% according to the ICD-10-DCR (International Classification of Diseases, 10th edition, Diagnostic Criteria for Research). Thus, any attempt at generalising findings must consider these methodological issues.

Furthermore, psychosis is a complex concept, particularly difficult to detect in the ID population. It is characterised by positive symptoms such as hallucinations, or delusions; and negative symptoms such as poverty of speech or avolition. Positive symptoms are internal experiences which can disrupt an individual's perception of the world around them. Hence, given the subjective nature of these experiences, they tend to be detected via self-report. However, they may be conceptually too complex for most individuals with ID to report (Smiley, 2005). Alternatively, language which is developmentally appropriate may be mistaken as thought disorder (Smiley, 2005). Negative symptoms can be easier to detect as they can be observed and reported by family members or carers. However, negative symptoms are relatively non-specific and may be caused by numerous other factors, such as positive symptoms, side-effects of medication, depression, environmental under-stimulation or demoralization (American Psychiatric Association, 2000). Negative symptoms may also be attributed to the individual's ID, and viewed by carers to be their 'normal' state. Such diagnostic overshadowing may be more likely in the ID population given that: 1) longitudinal general population research has demonstrated a lengthy prodromal phase of nonspecific symptoms and increasing functional impairment, before more diagnostically specific positive psychotic symptoms emerge (Bechdolf *et al.* 2012; Bora & Murray, 2014); and 2) ID support services often have a high turnover, resulting in workers having limited knowledge of the individual they support (Mencap, 2007). Hence, a multitude of factors can influence prevalence rates of psychosis.

3. Aim

The aim of this paper is to identify and systematically review studies that investigated the prevalence of psychosis in the adult ID population, with a view to 1) identifying the prevalence of psychosis within this population; and 2) appraising the quality of the studies.

4. <u>Methodology</u>

Where possible, the methodology followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) checklist (2009). The following eligibility criteria were applied to the search.

4.1 Eligibility

Inclusion criteria

1. Adults aged ≥16 years old with a mild to profound ID (as determined via researcher assessment or according to a learning disabilities service or register).
2. Studies investigating prevalence of psychosis, where rates are reported or can be calculated.
3. Studies where presence of psychosis is determined via clinical diagnosis, diagnostic criteria, screening measure or case-note review.
4. Peer reviewed articles.

Exclusion criteria

1. Review articles (original studies will be included).
2. General adult population studies (or mixed general and ID populations, where prevalence rates cannot be calculated for only those with ID).
3. Childhood studies (i.e. samples consisting exclusively of those aged ≤15 years old, or child and adult samples where prevalence rates cannot be calculated for only those aged ≥16 years old).
4. Studies with samples that consist exclusively of specific disorders of ID (e.g. Down's syndrome, Prader-Willi syndrome or Fragile X syndrome etc.).
5. Studies with samples that consist exclusively of ID populations with specific disorders (e.g. ASD, dementia or epilepsy etc.).
6. Studies consisting of only hospital/residential, specialist mental health or prison populations.
7. Studies not published in the English language.
8. Grey literature.

4.2 Information sources and search strategy

A systematic search was conducted on the electronic databases Medline, Embase, PsycINFO, and PubMed, from commencement of database until January 2016. MeSH headings and terms were identified and used to search for the following broad areas: 'intellectual disability', 'psychosis' and 'prevalence studies'. The results from these searches were combined with 'AND', in order to identify eligible studies. Each database was first reviewed for its use of MeSH headings and searches were made according to these. Terms that were not found under MeSH headings were searched as keywords in the title or abstract search fields. For example, the search terms used for the database Medline are detailed in Table 1. Further details of the search terms used are described in Appendix

2.1. The reference lists of eligible articles were then hand searched in order to identify any additional studies.

Table 1 Medline search strategy

Ovid MEDLINE(R) 1946 to Present		
Intellectual disability	MeSH search terms:	Intellectual Disability Mentally Disabled Persons
	Keyword search terms:	intellec* disab* or learning disab* or mental* retard* or learning impair* or mental* handicap*
Psychosis	MeSH search terms:	Psychosis Schizophrenia
	Keyword search terms:	psychotic disorders or psychosis or psychoses or psychotic* or psychos* or schizophrenia or schizo* or schizoaffective or schizoaffective disorder or delusional disorder*
Prevalence studies	MeSH search terms:	Prevalence studies
	Keyword search terms:	prevalence or prevalence rate$ or morbidity

4.3 Study selection

Following removal of duplicates, eligibility of the articles was determined systematically via screening titles, reading abstracts and reading remaining articles in full. Eligibility of all articles was determined in this manner, hence it was not necessary to contact authors for further information.

4.4 Data extraction and methodological quality

Each article was reviewed and the following information was sought: population characteristics; participant demographics; method of case ascertainment; and details of reported prevalence rates. A standardised appraisal of the quality of each study was conducted using an adapted rating tool designed to rate the quality of depression screening instruments for adults with ID (Hermans & Evenhuis, 2010). Hence, only slight amendments were required to make it fit for purpose (altering the focus from depression to psychosis). For the first criteria, a sample size of ≥30 should be less vulnerable to the influence of a non-standard distribution, and a sample of ≥100 should be powered to detect a significant effect (Field, 2013). The second and third criteria allow judgements to be made about sample representativeness. Population based-samples are most representative of the wider population as they attempt to identify all individuals meeting criteria within a geographical

location; whereas administrative samples use registers to identify participants thus excluding those who do not require such additional services. For the fourth criteria, the gold standard of assessment is considered to be a clinical diagnosis made by a psychiatrist or psychologist according to a standard diagnostic system (Hermans & Evenhuis, 2010; Nordgaard *et al.*, 2012). The fifth criteria require a confidence interval to be reported, thus allowing an estimate of precision. Criteria are listed for each domain and given a rating of 0, 1 or 2, allowing a total quality score ranging from 0 to 8 (Table 2). In line with Hermans and Evenhuis (2010) a score of ≤2 is consider to be low, 3–5 to be moderate, and a score of ≥6 to indicate high quality. Each included article was reviewed by the author (AM) and assigned ratings according to this tool. Low ratings reflect greater bias at the outcome level. Using the prevalence rates reported in the included studies, an overall mean prevalence was calculated for psychotic disorders within the adult ID population. In order to account for the risk of bias in this rate (i.e. from low quality studies), an overall mean prevalence of psychosis was also calculated using only the high quality articles (i.e. those scoring ≥6). A correlation was performed in order to investigate any possible relationship between study quality and prevalence rate.

Table 2 Quality rating criteria

Domain	Criteria	Rating
Sample size	>100	2
	30-100	1
	<30	0
Representativeness of sample	Population based	2
	Administrative	1
	All other	0
Reporting of level of ID	Distribution of ID reported	0/1
Method of assessment	Clinical diagnosis by a psychiatrist or psychologist based on standard diagnostic system	2
	Clinical diagnosis by a psychiatrist or psychologist	1
	Other psychosis screening instrument used	1
	All other	0
Report of precision estimate	Confidence interval is reported	0/1

5. <u>Results</u>

Figure 1 illustrates the literature search process utilised; 1544 initially identified articles were reduced to 1114 following removal of duplicates. Scanning the titles allowed a further 995 ineligible articles to be removed. The abstracts of 119 articles were read, and a further 81 records were excluded for not meeting the criteria. Thirty-eight papers were retrieved and read in full, allowing a further 26 articles to be excluded from the search (reasons for these exclusions are shown in Figure 1). A hand search of relevant reference lists identified one additional study, contributing to the total identification of 12 papers investigating the prevalence of psychosis in adults with ID. Further details of the 26 excluded papers are shown in Appendix 2.2. No systematic reviews were identified which investigated the rate of psychosis in the adult ID population, nor the quality of such studies. Study characteristics, prevalence rates and total quality ratings are detailed in Table 3.

5.1 Quality of included studies

Quality scores across the five domains are detailed for each study in Appendix 2.3. The average quality rating score for the 12 studies was 5.3 (SD=1.4) with a range of 4-8. Of the 12 studies, five were rated as high quality (Göstason, 1985; Lund, 1985; Cooper, 1997; Deb *et al.* 2001; Cooper *et al.* 2007b) and seven were rated as moderate quality (Salvador-Carulla *et al.*1998; Holden & Gitlesen, 2003, 2004; Taylor, *et al* 2004; Bailey, 2007; Nettelbladt *et al.* 2009; Sheehan *et al.* 2015). Only one study (Cooper *et al.* 2007b) received the maximum quality rating score of eight.

Figure 1 Flow chart of systematic literature search


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Identification

Records identified through          Additional records identified
database searching                  through other sources
(n = 1544)                          (n = 10)

                    Records after duplicates removed
                    (n =1114)

Screening

Records screened          →          Records excluded
(n =119)                             (n = 82)

Eligibility

                                     Full-text articles excluded, with
Full-text articles assessed          reasons
for eligibility           →          (n = 26)
(n = 37)                             Hospital/residential/specialist
                                     mental health samples (6)
                                     Review (5)
                                     Includes children (5)
                                     General population (5)
Included                             Includes borderline IQ (3)
                                     Data reported in other
Studies included in                  included study (1)
qualitative synthesis                Prevalence not reported (1)
(n = 12)
```
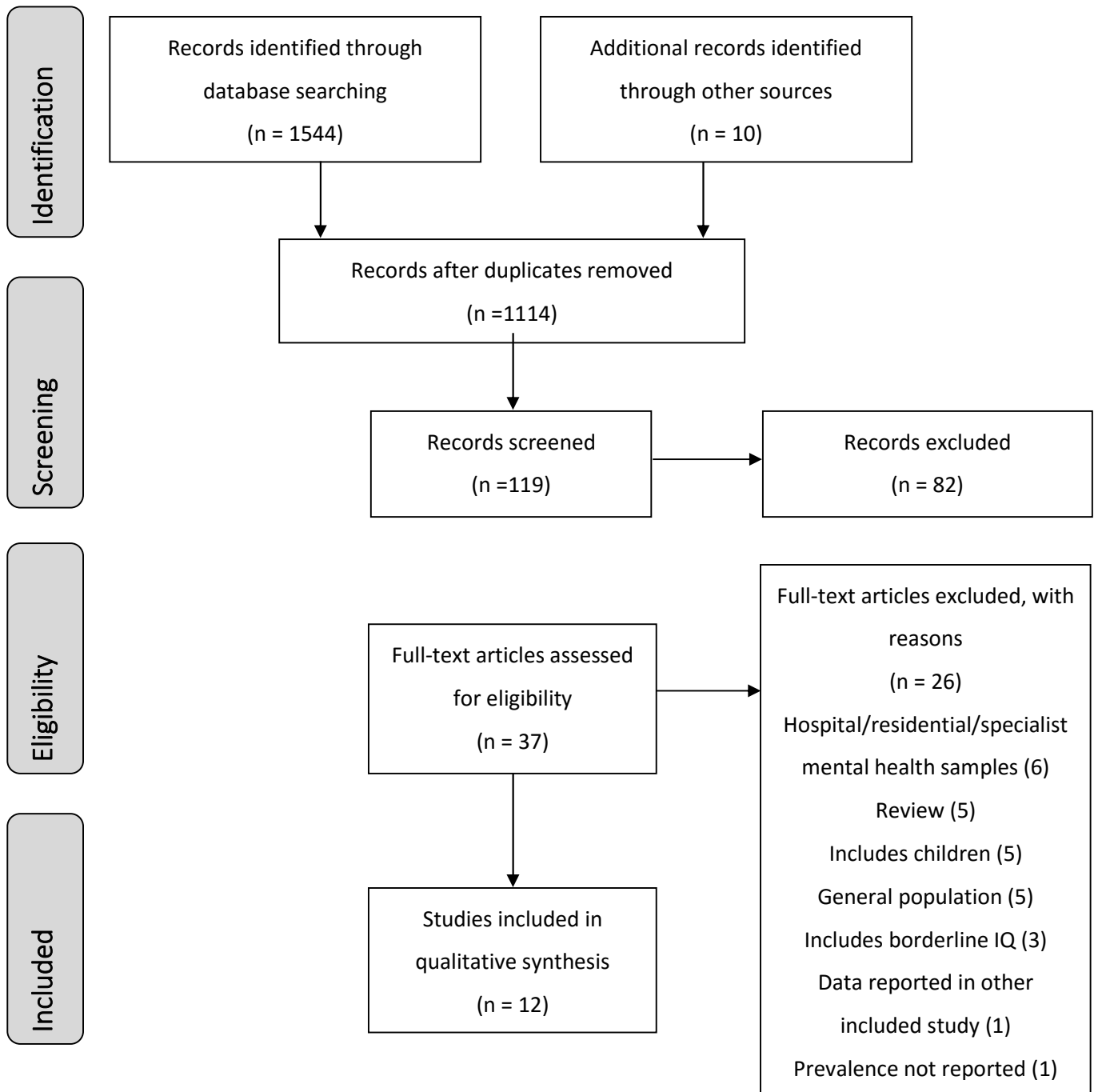
Table 3 Summary of study characteristics, prevalence rates and quality ratings

Study	Population characteristics	Participant demographics	Assessment method	Diagnostic tool	Diagnostic criteria	Rate of psychosis % (95% CI)	Quality rating (/8)
Göstason (1985)	N=132 (14,915) Stratified population based sample taken from census in Kopparberg County Sweden in July 1977	Age 20-60 Gender: males 59.1% Mild 56.8% Severe 43.2%	Psychiatric interview with participant and family or staff member	CPRS	DSM-III	Point-prevalence Schizophrenia, undifferentiated type 0.8% Schizophrenia, residual type 2.3% Total schizophrenic disorders 3.0%*	7
Lund (1985)	N=272 (302) Cluster sampling of adults registered on the Danish National Service for the Mentally Retarded (DNSMR) living in a county in Denmark	Age 20-65+ Gender reported for whole sample: males 56% IQ 67-52 (28.3%*) IQ 51-36 (31.3%*) IQ 35-20 (12.5%*) IQ 19-0 (9.2%*) Unclassified 51 (18.8%*)	Participants 'examined' and their parents or staff members interviewed	The MRC-HBC and a schedule of psychiatric symptoms, leading to computerized psychiatric diagnosis	DSM-III	Point-prevalence Schizophrenia 1.1%* Psychosis of uncertain type 5.5%* Total psychotic disorder 6.6%	6

Study	Population characteristics	Participant demographics	Assessment method	Diagnostic tool	Diagnostic criteria	Rate of psychosis % (95% CI)	Quality rating (/8)
Cooper (1997)	N=207 Population-based learning disabilities register in Leicestershire UK	Age 20-65 (m=39.2, SD=12.2) 65-94 (m=73.2, SD=6.48) Gender: males 52.7% Level of ID not reported	Clinical assessment with client and carer by psychiatrist & psychiatric case note review	PPS-LD	ICD-10	Point-prevalence Schizophrenia/delusional disorder 20-65yrs 2.7% 65+yrs 3.0% All ages 2.9%*	6
Salvador-Carulla *et al* (1998)	N=130 Adults working in a vocational centre during Apr-May 1992, Southern Spain	Age 18-65 (m=36.1, SD=10.5) Gender: males 70.8% Mild 63.8% Moderate 26.2% Severe/Profound 3.1% Unspecified 6.9%	Independent assessment using AIRP psychopathology section and psychiatric interview	AIRP	DSM-III-R	Point-prevalence Schizophrenia 7.69% Psychotic disorders not specified 9.23% Delusional disorder 0.77% Total psychotic disorders 17.7%	5

Study	Population characteristics	Participant demographics	Assessment method	Diagnostic tool	Diagnostic criteria	Rate of psychosis % (95% CI)	Quality rating (/8)
Deb *et al* (2001)	N=90 Social services case register in Vale of Glamorgan, UK	Age 16-64 (m=37.7, SD=13.5) Gender: males 52.2% Mild 53.3% Moderate 46.7%	Screening completed by psychiatrist with client and carer Semi-structured clinical interview with client and carer by psychiatrist	Mini PAS-ADD (for initial screening) Interview in line with full PAS-ADD interview	ICD-10 ICD-10	Point-prevalence Schizophrenia 7.8% Delusional disorder - Schizophrenia 4.4% (95% CI=0-8.4%) Delusional disorder 1.1% (95% CI=0-3.1%) Total psychotic disorder 5.5%*	6
Holden & Gitlesen (2003)	N=155 (165) Residents of local health authority's accommodation facilities and those who live with parents and receive respite in Hedmark, Norway	Age 18-46+ Gender: males 59% Mild 14% Moderate 27% Severe 35% Profound 23% Unknown 1%	Forms mailed to staff member judged by local management to be in best position to rate participant	PAS-ADD Checklist	ICD-10	Point-prevalence Psychosis 15.5%	4

Study	Population characteristics	Participant demographics	Assessment method	Diagnostic tool	Diagnostic criteria	Rate of psychosis % (95% CI)	Quality rating (/8)
Holden & Gitlesen (2004)	N=96 Administrative sample receiving care from local health authorities in Hedmark, Norway	Age ≥18 (m = 46.4) Gender: males 55.2% Moderate 35.4% Severe 32.3% Profound 32.3%	Telephone interview with informant staff member carried out by clinical psychologist	Items 6-49 of Mini PAS-ADD Interview	ICD-10	Psychosis 5.2%	4
Taylor *et al* (2004)	N=1155 Hospital and community residents living within a country district, North East England	Age 17-92 (m=43.8, SD=15.2) Gender 57.5% male Level of ID not reported	PAS-ADD Checklist completed by informants who had known participant for a median of 24 months	PAS-ADD Checklist	ICD-10	Point-prevalence Psychotic disorders 10.2%	4

Study	Population characteristics	Participant demographics	Assessment method	Diagnostic tool	Diagnostic criteria	Rate of psychosis % (95% CI)	Quality rating (/8)
Bailey (2007)	N=121 Random sample of adults using learning disability services in North Northamptonshire, England	Age 20-77 (m=38.5, SD=13) Gender 62% male Moderate to Profound (distributions not reported)	Clinical interview with client and/or carer by psychiatrist	PPS-LD	Clinical	Point-prevalence Schizophrenia 0.8% Delusional disorder 0% Schizoaffective disorder 0%	5
					DC-LD	Schizophrenia/delusional episode 0.8%	
					ICD-10-DCR	Schizophrenia 0.8% Persistent delusional disorder 0%	
					DSM-IV	Schizophrenia 0.8% Delusional disorder 0% Schizophreniform disorder 0%	
Cooper et al (2007b)	N=1023 Population-based sample of adults with ID in Greater Glasgow, UK between 2002 and 2004	Age 16-83 (m=43.9) Gender 54.9% male Mild 38.9% Moderate 24.2% Severe 18.9% Profound 18.0%	Clinical assessment with client and carer by psychiatrists	PAS-ADD Checklist (initial screening) PPS-LD		Point-prevalence All psychotic disorders including schizophrenia in remission:	8
					Clinical	4.4% (95% CI= 3.2–5.8)	
					DC-LD	3.8% (95% CI= 2.7–5.2)	
					ICD-10-DCR	2.6% (95% CI= 1.8–3.8)	
					DSM-IV-TR	3.4% (2.4–4.7)	

Study	Population characteristics	Participant demographics	Assessment method	Diagnostic tool	Diagnostic criteria	Rate of psychosis % (95% CI)	Quality rating (/8)
Nettelbladt *et al* (2009)	N=52 Prospective cohort following geographically defined community sample between 1947 and 1997, Sweden	Age 42-82 (median 61, range 42-82) Gender 63% male Mild 58% Moderate 27% Severe/Profound 13% Severity unspecified 2%	Retrospective application of DSM-IV criteria to information gathered during original psychiatrist examinations	None (original examinations conducted prior to development of diagnostic assessments)	DSM-IV	Period prevalence Schizophrenia and other psychotic disorders 7.7%*	4
Sheehan *et al* (2015)	N=33,016 Adults with ID drawn from The Health Improvement Network (THIN), a primary care database, UK.	Age 18-≥80 (m=36.6, SD=16.4) Gender 58% male Level of ID unknown	Electronic records for each person were examined	Unknown	Unknown	Point-prevalence Schizophrenia 4% Other psychosis 2% Total psychosis 5.8%*	4

* Not reported in paper, but calculated for purpose of review

Numbers in parentheses denotes total number in study; N denotes number included in prevalence calculation.

Interviewer characteristics (i.e. psychiatrist/psychologist) were only recorded if this information was reported in the study. AIRP = Assessment and Information Rating Profile; CGI = Clinical Global Impression; CPRS = Comprehensive Psychopathological Rating Scale; DC-LD = Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental

Retardation; DSM-III = Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition; DSM-III-R = Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition, text revision; DSM-IV = Diagnostic and Statistical Manual of Mental Disorders, 4th Edition; DSM-IV-TR = Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, text revision; ENCOR = Eastern Nebraska Community Office of Retardation; GAF = General Assessment of Functioning; ICD-10 -DCR= International Classification of Diseases, 10th edition, Diagnostic Criteria for Research; PAS-ADD Checklist = Psychiatric Assessment Schedule for use with Adults with Developmental Disabilities Checklist; PPS-LD = The Present Psychiatric State for Adults with Learning Disabilities; The MRC-HBC = The MRC Schedule of Handicaps, Behaviour, and Skills.

Nine studies consisted of samples of >100 participants (Göstason, 1985; Lund, 1985; Cooper, 1997; Salvador-Carulla *et al.* 1998; Holden & Gitlesen, 2003; Taylor *et al.* 2004; Bailey, 2007; Cooper *et al.* 2007b; Sheehan *et al.* 2015), and three had samples of between 30 and 100. Six studies used population-based sampling (Göstason, 1985; Lund, 1985; Cooper, 1997; Cooper, 2007b; Nettelbladt *et al.* 2009; Sheehan *et al.* 2015), five used administrative samples (Deb *et al.* 2001; Holden & Gitlesen, 2003, 2004; Taylor *et al.* 2004; Bailey, 2007), and one sampled adults working in a vocational centre (Salvador-Carulla *et al.* 1998). Three studies failed to report the level and distribution of ID within their samples (Cooper, 1997; Taylor *et al.* 2004; Sheehan *et al.* 2015) and one reported the levels of ID, but not the distribution across the sample (Bailey, 2007). However, these studies were included in the review as they identified their samples via learning disabilities services and registers. Only two studies diagnosed psychosis according to DC-LD criteria; in addition to using clinical, DSM and ICD criteria (Bailey, 2007; Cooper *et al.* 2007b). Five studies diagnosed according to ICD criteria (Cooper, 1997; Deb *et al.* 2001; Holden & Gitlesen, 2003, 2004; Taylor *et al.* 2004), four used DSM criteria (Göstason, 1985; Lund, 1985; Salvador-Carulla *et al.* 1998; Nettelbladt *et al.* 2009) and one did not report which criteria was used (Sheehan *et al.* 2015). Sheehan *et al.* (2015) reviewed existing electronic records, so it is likely that criteria will have varied according to the clinician and the year of assessment. Half of the studies met the gold standard assessment of diagnosing via clinician interviews and standard diagnostic systems (Göstason, 1985; Cooper, 1997; Salvador-Carulla *et al.* 1998; Deb *et al.* 2001; Bailey, 2007; Cooper *et al.* 2007b). Three made diagnoses according to informant completion of general psychopathology screening tools (Holden & Gitlesen, 2003, 2004; Taylor *et al.* 2004); one diagnosed according to a computerised system (Lund, 1985); one retrospectively applied DSM-IV criteria to information gathered during psychiatric examinations before diagnostic assessments were available (Nettelbladt *et al.* 2009); and one reviewed electronic records for existing diagnoses (Sheehan *et al.* 2015).

5.2 Prevalence of psychosis

Of the 12 studies, only one investigated the prevalence of psychosis as a primary outcome, albeit as part of a wider study into the prevalence of mental illness (Cooper *et al.* 2007b). The rates from all 12 studies were combined in order to calculate a mean prevalence of psychosis, which was found to be 7.1% (95% CI = 3.9-10.3) with a range of 0.8 to 17.7%. However, given the variation in study quality, this rate is likely to be subject to bias. In order to reduce the impact of bias, the average prevalence was calculated again using only the five studies rated as high quality (Göstason, 1985; Lund, 1985; Cooper, 1997; Deb *et al.* 2001; Cooper *et al.* 2007b). This resulted in a lower prevalence of psychosis, at a rate of 4.5% (95% CI = 2.5-6.5) with a range of 2.9 to 6.6%. A correlation (Pearson's

r as data were found to be parametric) revealed no significant association between study quality and prevalence rate (r= -0.421., p=0.18).

6. Discussion

The prevalence of psychosis in adults with ID was found to occur at a rate of 7.1% (95% CI = 3.9-10.3), which is higher than previously suggested rates ranging between 0.8% and 5% (Smiley, 2005). This rate is based on a wide range of scores (0.8-17.7%) reported by studies varying in methodology and consequently, quality. High quality studies reported a lower range of prevalence (between 2.9% and 6.6%) which is more in keeping with previous estimates. This suggests that the rates reported at the extremes of the range are the result of greater methodological limitations. These limitations include sample size and composition, method of assessing psychosis, type of diagnostic criteria and type of psychosis that was reported.

For example, the highest prevalence rate of 17.7% was found in a vocational sample, the majority of whom were referred from psychiatric institutions (Salvador-Carulla *et al.* 1998). Hence mental illness was likely to be more prevalent, and the authors suggested it was not representative of other occupational centres in Spain. Second, 90% of the sample comprised people with mild and moderate ID, with only 3.1% having severe and profound ID (6.9% were 'unspecified'). Given the difficulties of diagnosing psychosis in people with more severe ID (Smiley, 2005), it is to be expected that predominantly mild/moderate samples would report higher rates of psychosis than those with a higher proportion of less able people. For example, the lowest prevalence rate of 0.8% was reported by Bailey (2007) who recruited a comparable sample to Salvador-Carulla *et al.* (1998) in terms of size (N=121 vs. 120), age (m=38.5vs. 36.1), gender (male 62% vs. 70.8%), assessment (both psychiatric interview) and diagnostic criteria (DSM-IV vs. DSM-III-R), respectively. The main difference between the samples was the level of ID, with Bailey's (2007) sample consisting exclusively of people with moderate to profound ID (distribution not reported). Therefore, it is likely that the different rates found between the two samples can in part be attributed to the included levels of ID. Third, the rates reported could be impacted by cultural differences, with Salvador-Carulla *et al.* (1998) investigating a Spanish sample; however, no other Spanish samples were included so it is not possible to determine whether a true cultural difference exists. Fourth, it is possible that the high proportion of males (70.8%) in this sample contributed to the higher rate of psychosis. Although Bailey's (2007) sample also consisted of a high proportion of males (62%), this would be somewhat inconsequential if the majority had more severe ID and communication impairment (meaning that psychosis could not be accurately diagnosed). Taylor *et al.* (2004) and Cooper *et al.* (2007b) were

the only studies to investigate the possible relationship between psychosis prevalence and gender, with both reporting no significant associations. However, a general population review has shown incidence and relapse of psychotic illness to be lower in females than males (Ochoa *et al.* 2012); but no real conclusions can be made without further investigation within ID populations.

High rates of psychosis were also reported by Holden & Gitlesen (2003) and Taylor *et al.* (2004), i.e. 15.5% and 10.2% respectively. Both studies used informant completion of the Psychiatric Assessment Schedule for use with Adults with Developmental Disabilities (PAS-ADD) Checklist. It is likely that use of the PAS-ADD Checklist and the lack of clinical interview contributed to the higher rates. For example, Holden and Gitlesen (2003) dichotomised symptoms as present or absent, rather than using the original 4-point scale designed for the PAS-ADD Checklist. Using a dichotomous scale could lead to higher scores, given that symptoms which were present but had 'not been a problem' would be scored as '1' rather than '0'. However, the authors did not report amending the cut-off threshold for psychotic disorders in order to counterbalance this change. Hence, it is unsurprising that a high proportion of the sample scored above the threshold of '2' for a psychotic disorder. Although Taylor *et al.* (2004) used the original 4-point scale, their high psychosis rate may be attributable to their sample consisting of both hospital and community residents.

The lower range of prevalence rates are also likely to be influenced by methodological differences. As previously stated, the lowest rate of 0.8% reported by Bailey (2007) may be due to the sample consisting exclusively of adults with moderate to profound ID. Given the subjective nature of psychosis, diagnoses tend to rely upon self-reports. Consequently, it is not currently possible to diagnose psychosis in those with more profound difficulties who cannot communicate (Cooper et al, 2007b). Hence, it would be expected that lower rates of psychosis would be reported in samples consisting of less able people. Low rates of 2.9% and 3% were also reported by Cooper (1997) and Göstason (1985), respectively. Göstason's (1985) sample consisted of adults with mild and severe ID (57% vs. 43%, respectively) and it is likely that this distribution contributed to the lower rate. Göstason (1985) reported that schizophrenic disorders could not be demonstrated with any degree of certainty in those with severe ID. However, the whole sample was used as the denominator to calculate the overall rate of 3%. Hence, this is likely to be an underestimate of the true prevalence of psychosis. Cooper (1997) did not report the level or distribution of ID included in their sample, so it is not possible to conclude whether the low prevalence rate reported may also be explained in this way.

This calculation limitation is not restricted to the studies reporting lower prevalence rates of psychosis. Cooper *et al.* (2007b) highlighted that they used the entire ID population as the denominator for calculating the prevalence rate, despite not being able to diagnose psychosis in

those with more severe impairments.   Hence, they reported that their rates were likely to be an undercount of the true prevalence of psychosis. A further seven of the 10 studies that reported level of ID included people with profound disabilities. Their calculations were based on the total population and so are also likely to have underestimated the rate of psychosis (Lund, 1985; Salvador-Carulla *et al.* 1998; Holden & Gitlesen, 2003, 2004; Bailey, 2007; Nettelbladt *et al.* 2009). Thus, the higher the proportion of severe and profound ID in a sample, the greater the underestimate is likely to be.

Another possible cause of underestimating prevalence of psychosis is the type of diagnostic criteria used. Despite known limitations of using general population criteria in people with ID (Cooper *et al.* 2007a), only two of the seven studies carried out after publication of the DC-LD used this ID specific criteria (Bailey, 2007; Cooper *et al.* 2007b). Given that 10 studies included in this review used general population criteria, it is likely that the calculated rate of 7.1% is actually an underestimate of the true prevalence of psychosis in the ID population.

However, it is also likely that the seven studies including adults with mild ID in their samples (Göstason *et al.* 1985; Lund, 1985; Salvador-Carulla *et al.* 1998; Deb *et al.* 2001; Holden & Gitlesen, 2003; Cooper *et al.* 2007; Netteldbladt *et al*. 2009) will have over-estimated the prevalence of psychosis in the wider ID population. Despite four of these studies recruiting population-based samples (Göstason *et al.* 1985; Lund, 1985; Cooper *et al.* 2007; Netteldbladt *et al*. 2009), it is unlikely that they were able to fully identify all adults with mild ID within their specified geographical area. Whilst good ascertainment rates of people with moderate to profound ID can be achieved via case registers, learning disabilities services, or specific social funding etc., these methods are less successful at identifying those with mild ID (Smiley, 2005). In fact, many adults with mild ID are not known to learning disabilities services, unless they have additional needs requiring support (such as psychiatric illness). Therefore, those adults with mild ID identified via case registers and learning disabilities services etc. are likely to have more needs and hence result in a biased sample. Thus, those studies including adults with mild ID may have over-estimated the prevalence of psychosis within the ID population.

Of the 12 studies included, only one received the highest possible quality rating score (Cooper *et al.* 2007b). The authors investigated a large population-based sample, and employed psychiatric interviews according to clinical, ID and general population criteria. As noted by the authors, the rate of 4.4% may be an underestimate due to the method of calculation. The authors also used the PAS-ADD Checklist to screen for participants requiring psychiatric interview. The PAS-ADD Checklist, although designed for the ID population, is derived from general population criteria.

When used in a sample of adults with mild to severe ID, it failed to recognise 25% of those with a clinical diagnosis of schizophrenia (Moss *et al.* 1996). Hence, it may not be the most appropriate screening tool for a study investigating the prevalence of psychosis. However, Cooper *et al*. (2007b) addressed this issue by adding items relating to psychosis to the checklist, and lowering the threshold for psychotic disorders. Interestingly, of the psychopathology tools used by 10 of the studies as part of their assessment (Göstason, 1985; Cooper, 1997; Salvador-Carulla *et al.* 1998; Cooper *et al.* 2007b) or for diagnostic purposes (Lund, 1985; Deb *et al.* 2001; Holden & Gitlesen, 2003, 2004; Taylor *et al.* 2004; Bailey, 2007), none were designed specifically to detect psychosis in the ID population.

6.1 Limitations

Strict adherence to the predetermined criteria prevented the inclusion of some studies reporting rates of psychosis in ID populations. For example, Morgan *et al.* (2008) investigated schizophrenia in 13, 295 adults identified through cross-linkage of the Western Australian population-based psychiatric register and the intellectual disability register from 1983 onwards. They reported rates of schizophrenia to be 3.6% and lifetime prevalence of psychosis to be 8.4%. However, adults with borderline intellectual functioning were included in this study, and it was not possible to calculate the prevalence rate of only those with mild to profound ID. Similarly, the investigation of mental illness carried out by White *et al.* (2005) could not be included because their sample consisted of 15-64 year olds; it was not possible to calculate the prevalence rate of those aged ≥16 years old. The authors used the Australian national 'Disability, Ageing and Carers Survey, 1998' to carry out secondary analysis of data collected on 42, 664 people. They reported prevalence of psychotic disorders to be 1.3%, which is lower than the majority of rates reported in this review. Finally, literature search and selection, and quality appraisal was conducted by the first author (AM) only; reliability could have been enhanced through an additional independent scorer.

6.2 Future research

Although numerous factors were identified as contributing to both the over- and under-estimation of prevalence, it is likely that the true rate of psychosis in the ID population is higher than previously estimated. Despite five of the studies being rated as high quality, future research into the prevalence of psychosis is still needed. Only one study investigated psychosis as a primary outcome, and this was as part of a wider study into the prevalence of mental ill-health (Cooper *et al.* 2007b). Given that it is currently not possible to diagnose psychosis in people who cannot communicate,

future research should exclude such individuals from their calculations of prevalence. They should also be clear about the levels and distribution of ID in their samples; use clinical or DC-LD criteria and if an initial screening phase is used, a tool should be developed specifically for screening psychosis in the ID population.

Future research should also seek to determine why adults with ID are more vulnerable to psychosis than the general population. Of the studies included in this review, only five investigated factors associated with psychosis (Cooper, 2007b; Holden & Gitlesen, 2003, 2004; Taylor *et al.* 2004; Cooper *et al.* 2007b), but with the exception of the Cooper *et al.* (2007b) study, these tended to be restricted to the relationship between psychosis and basic demographics. Finally, efforts must be made to accurately identify those with psychosis so that they can receive appropriate support and treatment. To this end, a psychosis screening tool designed specifically for the ID population would be of clinical value.

7. Conclusions

The prevalence of psychosis in adults with ID was found to be 7.1%, and limitations in the literature leading to both under- and over- estimates of psychosis have been highlighted. There is a paucity of research with the primary aim of identifying the prevalence of psychosis in the ID population, which may partially explain the moderate quality of over half of the studies. Hence, there is a need for future research to investigate the rate of psychosis within the ID population, preferably through the use of psychosis screening tools and diagnostic criteria designed specifically for this population. Policy makers and Healthcare providers should consider that there are likely to be more people with ID affected by psychotic disorders than previously thought; consideration needs to be given to how best to accurately identify such individuals and ensure they receive access to appropriate treatment.

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Chapter 2: Major Research Project

Glasgow Psychosis Screening Tool for use in Adults with Intellectual Disabilities (GPS-ID): Development and psychometric properties

Prepared in accordance with requirements for submission to the

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(Appendix 1)

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Title

Glasgow Psychosis Screening Tool for use in Adults with Intellectual Disabilities (GPS-ID): Development and psychometric properties

Background

Psychosis occurs at a higher rate in people with intellectual disabilities (ID) than in the general population. Despite this, there are no psychosis screening measures that have been developed specifically for people with ID. Some psychosis screening tools developed for the general population have been used with people with ID. However, there is evidence to suggest that these general population measures may not be the best tools to detect psychosis in people with ID.

Aims

To develop a psychosis screening tool that can be used with people with mild and moderate ID.

Methods

Participants

Two groups of participants were recruited: a focus group and a testing group.

Inclusion criteria

    Focus groups

- Adults aged 16 or older with an ID who have psychosis
- Family or paid carers of adults with an ID who have psychosis

    Testing group

- Adults aged 16 or older with an ID who have a diagnosis of psychosis

- Adults aged 16 or older with an ID, who do not have psychosis

Exclusion criteria

- Adults with autism

- Adults with dementia

- Adults with severe and profound levels of ID

Recruitment

Information about the study was given to community and inpatient mental health services. People who met the study criteria were told about the study by a clinician they knew (such as their nurse). If they were interested in finding out more, they were given information sheets, allowing them to indicate their interest in the study.

Consent

A trainee clinical psychologist spoke to everyone interested in the study and answered their questions. Those who wanted to take part were asked for their consent, and/or the consent of their welfare guardian.

Design of study and data collection

The focus group helped inform the new scale by discussing their experiences of psychosis. The testing group were interviewed with both the final scale, and an existing psychosis scale developed for the general population (Hatton *et al.* 2005). They were also given the opportunity to provide any feedback they had on the new tool.

Main findings and Conclusions

A new psychosis screening tool was developed for adults with ID. It was able to distinguish between ID adults with psychosis, and those without psychosis. Further investigation is needed to test how well the tool works.

Practical applications and Dissemination

The tool can be used to help identify people with ID who might have psychosis, and need further assessment.

The study will be submitted for publication in a scientific journal.

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Hatton, C., Haddock, G., Taylor, J. L., Coldwell, J., Crossley, R., & Peckham, N. (2005). The reliability and validity of general psychotic rating scales with people with mild and moderate intellectual disabilities: an empirical investigation. *Journal of Intellectual Disability Research, 49*(7), 490-500. doi: 10.1111/j.1365-2788.2005.00696.x

1. <u>Abstract</u>

Background

Prevalence of psychosis is known to be higher in adults with intellectual disabilities (ID) than in the general adult population. However, there have been no attempts to develop a psychosis screening tool specifically for the adult ID population. The present study describes the development and preliminary evaluation of a new measure, the Glasgow Psychosis Screening tool for use in Adults with Intellectual Disabilities (GPS-ID).

Method

An item pool was generated following: 1) focus groups with adults with ID and psychosis, and their carers and/or workers; 2) expert input from clinicians. A draft scale was compiled and refined following expert feedback. The new scale, along with the Psychotic Symptom Rating Scales was administered to 20 adults with ID (10 with and 10 without psychosis) and their relative or carers.

Results

The GPS-ID total score, self-report subscale and informant rating-subscale differentiated psychosis and non-psychosis groups. The tool had good internal consistency (Cronbach's α=0.91), and a cut-off score ≥4 yielded high sensitivity (90%) and specificity (100%). The method of tool development supports face and content validity. Criterion validity was not supported.

Conclusions

Preliminary investigation of the tool's psychometric properties is positive, although further investigation is required. The tool is accessible to adults with mild to moderate ID and can be completed in 15-30 minutes. The GPS-ID is not a diagnostic tool, therefore any adult exceeding the cut-off score of ≥4 should receive further assessment.

2. <u>Background</u>

The point prevalence of psychosis in adults with ID has been estimated to range between 0.8% and 5.0% (Bailey, 2007; Lund, 1985, respectively). Prevalence of psychosis in the general adult population has been estimated at a lower rate, ranging between 0.4% and 1.2% (Jenkins *et al.* 1997; Brugha *et al.* 2005; Wittchen *et al.* 2011); suggesting psychosis is twice as prevalent in the adult ID population. Psychopathology tools are regularly used in clinical practice to both screen for, and monitor symptomatology. However, despite the higher prevalence of psychosis in adults with ID, there is currently no psychosis screening tool developed for this population.

Some general psychopathology screening tools developed for the ID population contain items or subscales that screen for psychosis, such as the Psychiatric Assessment Schedule for use in Adults with Developmental Disabilities Checklist (PAS-ADD Checklist; Moss *et al.* 1998). However, there are limitations associated with using these screening tools to detect psychosis. They are derived from general population criteria (i.e. the ICD or DSM), and can lead to under-recognition of some psychiatric disorders when used in adults with ID. For example, in a sample of 1023 adults with mild to profound ID, psychosis was found to vary between 2.6% and 4.4% according to type of diagnostic criteria (Cooper *et al.* 2007). Rates were lowest for general population criteria ICD-10-DCR (the International Classification of Diseases, 10th edition, Diagnostic Criteria for Research) and DMS-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, text revision) and highest according to ID criteria, the DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation and clinical diagnosis) and clinical diagnosis. It is likely that the latter criteria would allow a more accurate rate of psychosis to be determined, given that the DC-LD was developed specifically for the ID population (Royal College of Psychiatry, 2001), and clinical criteria has more flexibility to accommodate the pathoplastic effects of ID.

The limitations of using general diagnostic criteria are evident in research investigating the validity of the PAS-ADD Checklist to detect schizophrenia (Moss *et al.* 1996a). The PAS-ADD Checklist is an informant-rating measure, designed to screen for psychopathology in adults with ID. It uses 29 items to screen experiences occurring within the past four weeks, and employs the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) algorithm (WHO, 1994), which assigns diagnoses according to strict application of ICD-10 research criteria. Ninety-eight participants with mild to severe ID and a range of psychiatric diagnoses were screened by trained interviewers using the PAS-ADD Checklist. Interviewers were blind to participant's diagnosis, as determined by their psychiatrist. The PAS-ADD Checklist failed to recognise 25% of those participants determined by their psychiatrists as having active symptoms of schizophrenia. Auditory hallucinations were the only first rank symptom that could be detected with any frequency. Despite delusions being noted frequently, participants and informants could not provide a 'sufficiently unequivocal' account to fulfil the SCAN algorithm, and hence did not meet the PAS-ADD Checklist threshold for an ICD-10 diagnosis. This has been an area of contention, with some suggesting that people with ID may present with an atypical profile of psychosis; therefore, the use of standard psychiatric diagnostic criteria may fail to recognise people with mild ID and distressing psychotic symptoms (Hatton *et al*. 2005).

Researchers have addressed some of the aforementioned issues by developing screening tools for specific psychiatric disorders in the ID population. For example, the Glasgow Depression

Scale for people with a Learning Disability (GDS-LD; Cuthill et al. 2003) and the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID; Mindham & Espie, 2003) considered symptomatology included in both the ICD-10 and the DC-LD. Both studies employed focus groups of adults with ID to inform item selection, and developed screening tools with good psychometric properties (Appendix 3.1). The tools screen symptoms occurring within the past week, and both are designed to be administered to individuals with ID. Neither is intended as a diagnostic tool; however, both purport to be useful for clinical and research practice, allowing screening and monitoring of symptoms (Mindham & Espie, 2003; Cuthill *et al.* 2003). As of yet, no similar attempt has been made to develop a screening tool for psychosis. Given the high prevalence of psychosis in the ID population, and the limitations associated with existing measures, there is a need for a tool that is sensitive to the manifestation of psychosis in this population, and accessible to these individuals and their families or carers. Such a tool would be useful to both detect illness and monitor treatment related changes.

More recently, researchers have investigated the utility of using psychosis screening tools developed for the general population, such as the PSYRATS (Haddock *et al.* 1999) and the Positive and Negative Syndrome Scales (PANSS; Kay *et al.* 1989) with the ID population (Hatton *et al.* 2005). The PSYRATS consists of an auditory hallucinations and delusions subscale, and the PANSS consists of positive symptoms, negative symptoms and general symptoms subscales. The PSYRATS requires respondents to make complex ratings about their experiences, whereas the PANSS requires respondents to describe their symptoms in sufficient detail to allow the interviewer to rate them accordingly.

Hatton *et al.* (2005) used the PSYRATS and the PANSS to interview 62 adults with mild ID. The participants were identified as having psychosis by either psychiatrist clinical judgement according to ICD-10 criteria, or PAS-ADD Checklist screening. A range of adequate psychometric properties were reported for both tools (Appendix 3.2). However, the authors suggested that further investigation was necessary, particularly regarding applicability of items concerning negative symptoms and delusions. It should be considered that the authors used general population diagnostic criteria to both select their sample and diagnose psychosis. Therefore, it is possible that individuals presenting with an atypical profile would not have been identified as having psychosis, and hence would have been ineligible for the study.

In addition to these issues, tools developed for the general adult population do not take into account the language and comprehension needs of people with ID. For example, the PSYRATS depends upon self-report judgements of complex constructs (e.g. frequency, duration, intensity etc.) regarding abstract concepts. Questions about time or requiring a judgment of frequency or degree

have been found to be problematic for many people with ID, as have questions about abstract concepts. If the answer is not known, the question is too long or the structure is too complex, people with ID are more likely to acquiesce (Finlay and Lyons, 2001). Hence, despite the PSYRATS having adequate psychometric properties, it may not be the most accessible screening tool for adults with ID.

Finally, some researchers have suggested that self-report of psychotic symptoms (rather than informant-report) can be crucial for detecting psychosis in people with ID (Moss *et al.* 1996b). In the interest of both increasing sensitivity and equality, adults with ID should have the opportunity to self-report their symptoms, and amendments should be made to support this wherever possible. Given that adults with ID are more vulnerable to psychotic illness than the general population, and self-report may be fundamental to detecting psychosis, it seems imperative that there is an appropriate psychosis screening tool which is accessible to the adult ID population.

3. Aims

To develop and evaluate a psychosis screening tool that is appropriate for use in the mild to moderate adult ID population.

4. Method

4.1 Ethical approval

A research proposal was developed (see Appendix 4) and ethical approval was sought and obtained from Scotland A REC, NHS Greater Glasgow & Clyde R&D and NHS Ayrshire & Arran R&D (see Appendices 6.1-6.3. Following a substantial (Appendix 6.4) and non-substantial (Appendix 6.7) amendment to the original study design, further approval was sought and obtained (see Appendices 6.5-6.9).

4.2 Study strategy

First, the literature was reviewed in order to inform the research methodology, and to develop a suitable interview schedule for focus groups. Next, focus groups were consulted in order to inform appropriate item selection for the screening tool. Experts in the field were also consulted in order to further supplement item selection. A draft tool was then developed and reviewed by an expert panel. It was refined according to expert feedback, and used to interview adults with ID, with and without psychosis. Finally, the psychometric properties of the screening tool were tested.

4.3 Review of literature

First, in view of both the importance of self-reports in detecting psychosis (Moss *et al.* 1996b), and the limitations associated with relying upon self-reports regarding complex concepts in this population (Finlay and Lyons, 2001), it was decided that information would be sought from several sources: individuals with ID and psychosis, their carers/workers and experts in the field. This is in line with recommendations for scale development by Steiner *et al.* (2015), who highlight that while "*clinicians may be the best observers of the outward manifestation of a trait or disorder, only those who have it can report on the more subjective elements*" (pp. 20). Second, given the limitations associated with using general population criteria, it was deemed prudent to base the item pool on ID criteria, the DC-LD for 'Schizophrenic/delusional episode' (Royal College of Psychiatrists, 2001; Appendix 5.1). An interview schedule was subsequently developed, whereby each DC-LD criterion was paired with prompt questions to elicit those specific experiences (see Appendix 7.1).

4.4 Recruitment procedure

Health and Social Care workers within NHS Greater Glasgow & Clyde were provided with information sheets, and asked to invite people meeting the following criteria to participate in the study:

Inclusion criteria

Focus groups

- Adults aged ≥16 with a mild to moderate ID who have reasonable verbal communication i.e. are able to express themselves, and a diagnosis of psychosis.
- Relatives or workers of adults with mild to moderate ID who have a diagnosis of psychosis and wish to take part in the focus group.

Field test groups

- Adults aged ≥16 with a mild to moderate ID, who have reasonable verbal communication and a diagnosis of psychosis, with active symptoms.
- Adults aged ≥16 with a mild to moderate ID, who have reasonable verbal communication, and do not have a diagnosis of psychosis.

Exclusion criteria

- Adults with a diagnosis of autism.
- Adults with a diagnosis of dementia.
- Adults with severe and profound ID.

First, potential participants were identified by members of their health care team between March-June 2016. They were given information sheets containing reply slips to indicate their interest in participating. Consent was sought in accordance with the Adults with Incapacity (Scotland) Act): it was given by those who had capacity to consent to take part in research, and by the nearest relative or welfare guardian/attorney for those who wanted to participate but did not have capacity to consent. Next, individuals and their relative or worker participated in the focus groups. Following development of the new tool, participants and their relative or worker were interviewed using the GPS-ID and the PSYRATS. Finally, Health and Social Care workers were contacted and asked to provide participant's age, gender, level of ID and diagnosis.

4.5 Focus groups and expert input

It was intended that two focus groups would be recruited, totalling six to 10 people with ID and their relative or worker. Similar numbers were found to be appropriate in the development of previous ID screening tools (Mindham & Espie, 2003; Cuthill *et al.* 2003). The aim was to elicit the language people with ID and their relative or worker use to describe experiences of psychosis. The first focus group lasted approximately 60 minutes and consisted of two adults with ID and their support workers. The second focus group lasted approximately 85 minutes and consisted of one adult with ID, her mother and her Community Learning Disability Nurse.   All three participants were female aged 50-56 (mean 54 years); one had a borderline level of ID, and two had a mild ID. All three had a diagnosis of schizophrenia, two of which had active symptoms. Both groups were audiotape-recorded and then transcribed. No one used the word 'psychosis', nor did they report any word to encompass their experiences. Instead, those with ID talked about their specific experiences, for example "*Och, they* [the voices] *were calling me Cows an that, whore, uh, umpteen things*"; while their relative or worker talked about the behaviours they would notice, for example "*we would maybe see* [client] *withdraw. She likes to stay in her room regardless but, you could physically see her withdrawing into herself or she would think we were talking about her or you know different things like that and complain to outside agencies that we were drugging her or whatever, things like that*" (see Appendix 7.2 for further excerpts).

Next, expert input was sought from three adult inpatient Learning Disability Nurses who reported their observations of adults with ID experiencing psychosis. They talked about behavioural observations (e.g. patients gaze shifting as if in response to something unseen), and gave examples of things patients might say when experiencing psychosis (e.g. "I'm a spy"). This discussion lasted for two hours and the content was recorded by hand (Appendix 7.3).

4.6 Drafting the tool and expert feedback

Given that focus group members did not use specific words to describe their experiences, but could nonetheless report their experiences; it was decided that an accessible screening tool would facilitate people to describe their own experiences of psychosis. A draft tool with clinician instructions for administration was compiled, comprising two sections screening experiences and behaviours. The first section consisted of three self-report questions regarding auditory hallucinations, visual hallucinations and delusional beliefs. Each question included several prompts and examples. The examples were constructed from the focus groups and expert input. It was hoped that these examples would 1) facilitate participants' understanding of the complex concepts being discussed; and 2) help normalise psychosis and hence encourage participants to describe their own experiences. Participants were then asked to rate whether their experience had made them feel 'ok/a little upset' (1) or 'very upset' (2). If no evidence of a psychotic experience was described, experiences were rated as 'no' (0). Readability of each self-report question was assessed using the 'Flesch-Kincaid readability tests' tool (Table 1) within Microsoft Word. A higher Flesch Reading Ease score (ranging 0-100) and a lower Flesch-Kincaid Grade level score indicates easier reading material.

Table 1 Readability of self-report questions

Self-report Question	Flesch Reading Ease	Flesch-Kincaid Grade level
A1	89.8	3.3
A2	85.6	4.2
A3	81.8	4.5

The second section was designed to be completed by an informant who knew the person well. It consisted of items regarding behavioural observations (taken from the focus groups and expert input). In keeping with GAS-ID and GDS-LD response formats, informants were asked to rate whether behaviours had occurred 'no/never' (0), 'sometimes' (1) or 'always/a lot' (2).

Next, the draft tool was reviewed by an expert panel, consisting of two Psychiatrists, one Psychologist and one Speech and Language Therapist, all specialising in adults with ID. It was decided that a negative symptoms self-report question would not be included, given that focus group participants with ID did not describe such symptoms; both psychiatrists supported this decision. Feedback was provided regarding the time period over which symptoms are screened; the format, content and language of questions; the response format; and the instructions for administration (see Appendix 7.4). The tool was subsequently refined according to feedback. For example, the time scale was increased from two weeks to four weeks; the instructions

recommended establishing an 'anchor' event for this time period; general questions asking how the individual had been feeling were included in the first section, before more specific prompts were added; and a visual aid was provided to help individuals rate their level of distress. Similarly, more general questions about the individual's wellbeing were added to the second section, one item was removed from the list of questions and three additional questions were included. The resulting screening tool consisted of three self-report items and 20 informant-report items concerning symptoms during the past four weeks. Thus, the GPS-ID (Appendix 8) yields a total score for the screening tool (0-46), as well as subtotals for the self-report scale (0-6) and the informant scale (0-40). The self-report scale is further divided into a hallucinations subscale (0-4) and a delusions subscale (0-2).

4.7 Materials

Participants were interviewed with the GPS-ID and the PSYRATS (Appendices 8 and 9). The PSYRATS consists of an auditory hallucinations scale (11 items) and a delusional beliefs scale (6 items). All items relate to experiences occurring within the past week and are rated according to a five-point scale ranging from 0-4.

4.8 Analysis

First, descriptive statistics were used to investigate the spread of the data. Next, the following psychometric properties of the GPS-ID were investigated:

- Content validity "is the degree to which elements of an assessment instrument are relevant to and representative of the targeted construct for a particular assessment purpose" (Haynes *et al.* 1995, pp. 238). It is determined via expert judgement.
- Criterion validity refers to the extent to which the GPS-ID scores correlate with the PSYRATS scores for the psychosis group. A correlation coefficient of ±.3 represents a medium effect and ±.5 represents a large effect (Field, 2013).
- Discriminant validity refers to the ability of the GPS-ID to discriminate between the psychosis and non-psychosis groups. A Mann-Whitney test was used to investigate the discriminant validity of the GPS-ID total scores, self-report subscale and informant-rating subscale.
- Internal consistency refers to how well the items on the GPS-ID measure the construct of psychosis. It was tested using Cronbach's α. An alpha of >.9 indicates 'excellent' internal consistency, and an alpha of 0.8-.09 indicates 'good' internal consistency (George & Mallery, 2003).

- Sensitivity refers to the ability of the GPS-ID to correctly identify the psychosis group as having psychosis; and specificity refers to the ability of the GPS-ID to correctly identify the non-psychosis group as not having psychosis. Sensitivity and specificity were investigated using Receiver Operator Characteristic (ROC) curve analysis. Values closer to 100% represent greater sensitivity and specificity.

4.9 Sample size and power calculation

A sample size of 12 participants per group are recommended for a pilot study (Julious, 2005). The statistical software 'G*Power 3.0.10' was used to perform a sensitivity analysis for testing between group differences on the GPS-ID. The parameters: α err prob (0.05), power 1-β err prob (0.8), sample size group 1 (12), sample size group 2 (12) produced an effect size of 1.0, indicating that recruiting 12 participants per group would have an 80% chance of detecting a large effect.

5. Results

5.1 Participants

The psychosis and non-psychosis group each consisted of 10 participants. Two psychosis group participants were described as having mild-moderate ID. Due to the small numbers per group, they were re-classified as 'moderate' in order to allow Chi Squared analysis to be conducted. Demographics of each group are described in Table 2, which shows there were no significant differences in terms of age, gender and level of ID.

Table 2 Comparisons of characteristic between psychosis and non-psychosis group

Characteristics	Psychosis group (n=10)	Non-psychosis group (n=10)	Test statistic	*P*
Age: mean (SD)	38.5 (12.7)	39.8 (12.9)	$t=.227$	.823
Gender: n (%)				
Male	6 (60%)	4 (40%)	$x^2=.800$	.656
Female	4 (40%)	6 (60%)		
Level of ID: n (%)				
Borderline	1 (50%)	1 (50%)	$x^2=.000$	1.000
Mild	5 (50%)	5 (50%)		
Moderate	4 (50%)	4 (50%)		

Mental health diagnoses within the two groups are displayed in Table 3. The total number of diagnoses exceed the total sample size due to some participants having multiple diagnoses.

Table 3 Mental health diagnoses within psychosis and non-psychosis group

Psychiatric diagnosis	Psychosis Group (n=10)
Psychosis	4
Schizophrenia	2
Schizophrenia affective disorder	3
Delusional disorder	1
Depression	1
	Non-psychosis Group (n=10)
Complex trauma	2
Depression	2
None	7

5.2 Distribution of GPS-ID and PSYRATS scores

Total GPS-ID scores ranged from 0-27, with a median of 2 and an interquartile range of 13.75. Total PSYRATS scores ranged from 0-41, with a median of 0 and an interquartile range of 0. Plotted data indicated a non-normal distribution, which was confirmed by Kolmogorov-Smirnov's test of normality. Total GPS-ID scores $D(20) =.293$, $p=.004$, and total PSYRATS scores $D(19) =.468$, $p=.000$ significantly deviated from a normal distribution. Hence, non-parametric analyses were used for all inferential statistics.

5.3 Validity

Content Validity

The method used to create the GPS-ID supports the face and content validity of the screening tool. Twelve of the 23 items received a score of '0' for over half of the psychosis group participants, suggesting that item content did not describe their experiences of psychosis. However, all items received a score of '1' or '2' for at least one psychosis group participant; suggesting that the GPS-ID screens for a wide range of behaviours indicative of psychotic experience.

Criterion validity

To investigate criterion validity, total GPS-ID scores were correlated with total PSYRATS scores for nine psychosis group participants (PSYRATS scores were incomplete for one participant). The data were analysed using Spearman's correlation coefficient (which excludes missing cases), yielding *rho*=.456, *p*=.217. Although non-significant, the *rho of .456 indicates that there may be a small to moderate relationship between GPS-ID and PSYRATS total scores.*

Discriminant validity

Figure 1 illustrates the ability of the GPS-ID to discriminate between the psychosis and non-psychosis groups. Mann-Whitney tests revealed that GPS-ID total scores, self-report subscale scores and informant-report subscale scores were all significantly higher in the psychosis group than the non-psychosis group (Table 4).

Table 4 Differences between psychosis and non-psychosis GPS-ID scores

GPS-ID scores	*Mdn* (IQR)		U	z	p	Effect
	Psychosis	**Non-psychosis**			*value*	size (*r*)
GPS-ID total scores	13.00 (12)	0.5 (2)	1.5	-3.710	.000	-0.83
Self-report subscale scores	1.5 (3)	0 (0)	20.00	-2.799	.005	-0.63
Informant-rating subscale scores	11.5 (10)	0.5 (2)	1.5	-3.710	.000	-0.83

Internal consistency

The GPS-ID total score was found to have excellent internal consistency when administered to both groups (α=0.91, n=20); with a range for the total scale, as measured by alpha if item-deleted, between 0.897 and 0.915. When administered to only the psychosis group, internal consistency remained satisfactory (α=0.81, n=10); with a range for the total scale, as measured by alpha if item-deleted, between 0.784 and 0.836.

Sensitivity and Specificity

A total GPS-ID score of ≥4 yielded high sensitivity (90%) and specificity (100%). Sensitivity and specificity was found to be the same for the informant rating subscale with a cut-off of ≥4 yielding 90% sensitivity and 100% specificity. The self-report subscale was also investigated, and a cut-off score of ≥1 yielded a sensitivity of 60% and a specificity of 100% (Figure 3).

5.4 Reliability

Inter-test reliability between the self-report subscale and the informant-rating subscale was found to be high for both groups together (rho=.780, p=.000) and the psychosis group (rho=.824, p=.003).

Figure 1 Comparison of GPS-ID total scores (mean ±SE) for psychosis and non-psychosis groups
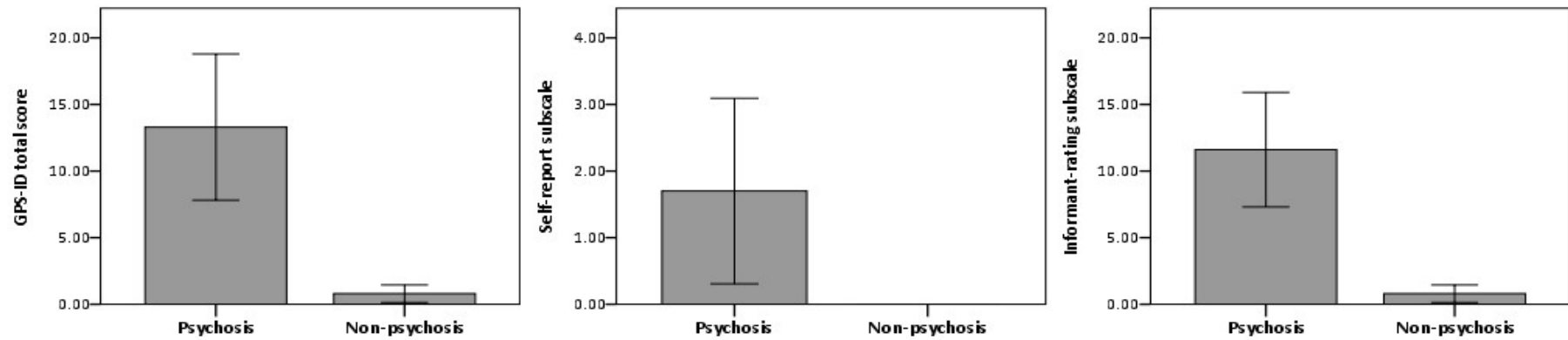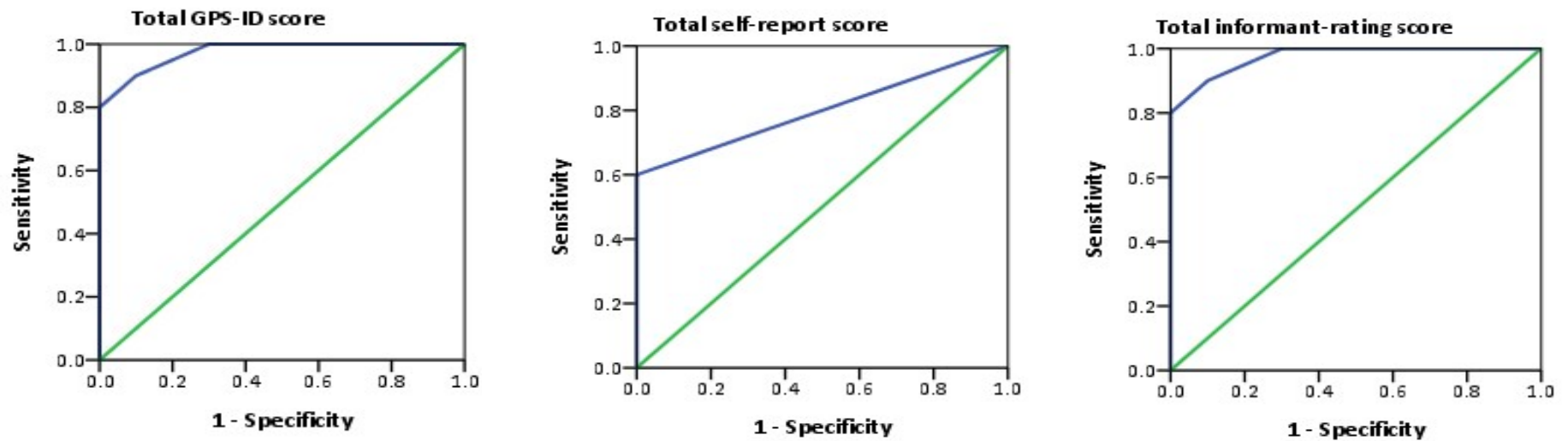

Figure 2 ROC curves for total GPS-ID score, self-report subscale and informant-rating subscale

6. Discussion

There is a clear need for a psychosis screening tool that has been developed specifically for the mild to moderate adult ID population. Preliminary evidence suggests the GPS-ID may fulfil this need, although further testing is required. The GPS-ID was found to have satisfactory psychometrics, in terms of face/content validity; discriminant validity; internal consistency ($\alpha=0.91$); and sensitivity (90%) and specificity (90%). Criterion validity was not supported, and test-retest reliability was not investigated.

The methodology employed supports the validity of this measure. However, it was noted that 12 items scored '0' for over half the psychosis group. This could suggest the item content did not appropriately describe participant's experiences. However, it was not expected that all participants would score on all items. Furthermore, not all psychosis group participants were experiencing psychotic symptoms at interview, despite having a psychotic illness and being referred into the study as having active symptoms. Considering the small sample size (n=10), it is unlikely that all items would receive a positive score for all participants. Moreover, none of the 23 items scored '0' for every psychosis group participant, suggesting that the tool describes a wide range of experiences that can manifest in adults with ID and psychosis. Further investigation with a larger sample size is required in order to make more conclusive judgements about the content validity of the GPS-ID.

Investigation into the criterion validity of the GPS-ID yielded a small to moderate, albeit non-significant relationship between the GPS-ID and PSYRATS total scores. However, the lack of significant correlation may be attributable to other factors, rather than indicating a true lack of criterion validity. First, the GPS-ID scores symptoms occurring within the past four weeks, whereas the PSYRATS scores only symptoms present during the past week. Therefore, a participant experiencing symptoms during the past month but not the past week, would score on the GPS-ID, but not the PSYRATS. Second, the GPS-ID screens for a range of psychotic experiences including visual hallucinations and negative symptoms; whereas the PSYRATS scores only auditory hallucinations and delusions. Therefore, someone experiencing negative symptoms would score on the GPS-ID, but not the PSYRATS. In retrospect, the PSYRATS may not have been an optimum comparator; however, in the initial planning of the study it was deemed the best choice of the only two general population psychosis screening tools that have been tested in the ID population. Third, given that the majority of the non-psychosis group did not have additional mental health problems, it is possible that the GPS-ID detected emotional distress rather than psychotic symptoms, which could account for the lack of significant relationship between the GPS-ID and the PSYRATS total scores. Finally, the lack of

correlation between the two tools may be due to the small sample size. Further investigation with a larger sample size and a control group of adults with ID and other mental health problems would allow for more conclusive judgements to be made.

High levels of discriminant validity were demonstrated for the GPS-ID. However, the majority of participants in the non-psychosis group did not have a mental health problem. Future research is needed to determine whether the GPS-ID can discriminate between adults with ID and psychosis, and adults with ID and other mental health problems, particularly affective disorders. This is important given the high prevalence of mental health problems in this population (Cooper *et al.* 2007)

Internal consistency was found to be high when calculated for both groups together and the psychosis group alone, suggesting that the items are measuring the same construct. Investigations into the sensitivity and specificity of the GPS-ID suggest that the tool may be used flexibly, according to clinical need. Sensitivity and specificity were found to be high for both the GPS-ID total score and the informant-rating subscale (with a cut-off score of ≥4 yielding 90% sensitivity and 100% specificity). Similarly, specificity remained high at 100% for the self-report subscale, but sensitivity reduced to 60% (for a cut-off score of ≥1). Therefore, the self-report scale can also be used as a standalone screen to exclude those without psychosis. When employing cut-off scores achieving 100% specificity, it is recommended that participants scoring above the thresholds receive further assessment.

In comparison with the PSYRATS and the PANSS (Hatton *et al.* 2005), the GPS-ID appears to perform well. It shows similar rates of internal consistency to the PSYRATS, and higher rates than the PANSS. The PSYRATS and PANSS showed discriminant validity for the auditory hallucinations subscale and positive symptoms subscale, respectively. However, the PSYRATS delusions subscale and the PANSS negative symptoms subscale failed to discriminate between the psychosis, other mental health and no psychosis groups. None of the psychosis group participants scored on the PSYRATS delusions subscale, despite some reporting delusional beliefs during the initial PAS-ADD Checklist screening. This suggests that the PSYRATS may not be accessible to individuals with ID. Rates of sensitivity and specificity were not reported for the PSYRATS and the PANSS, preventing further comparison.

The GPS-ID took on average 15-30 minutes to administer, varying with participants' ability and severity of symptoms. Generally, participants had no difficulties answering the self-report questions. However, some psychosis group participants required prompting from their carers to describe their symptoms. One such individual found it less distressing to shake or nod their head, rather than verbally acknowledging auditory hallucinations. One psychosis participant with a moderate ID was able to complete

the self-report questions (using the visual aid) but was unable to complete the PSYRATS. This suggests that the GPS-ID may be more accessible to those with more severe ID and psychosis than the PSYRATS. However, further testing with a larger sample would be required to determine this supposition. For the non-psychosis group, some participants described non-psychotic experiences in relation to self-report questions. For example, one participant reported auditory hallucinations, but further investigation revealed that they were referring to traffic noise. When asked 'Has anyone been picking on you or getting at you', several participants talked about being bullied. This may be a common response given that most adults with ID experience bullying during their childhood (Mencap, 2007). However, it was quickly established that participants were not describing psychotic experiences. Similarly, carers had no difficulties responding to the informant-rating subscale. Several in the non-psychosis group reported that participants had 'been talking to themselves', but further investigation revealed that this was often soliloquy or self-reassurance. Given that responses often require further investigation, it is recommended that the GPS-ID is administered only by clinicians with a knowledge of psychosis in this population, and in strict adherence to the instructions for use.

Despite the high rates of sensitivity and specificity found for a cut-off score of ≥4, caution should be taken when interpreting scores as the GPS-ID is not a diagnostic tool, and. It is imperative that all adults meeting or exceeding the cut-off score of ≥4 receive further assessment, to avoid any unnecessary and potentially harmful treatment. Furthermore, it is possible that this cut-off score can be met without any positive scoring on the self-report scale. Although some individuals with psychosis will be unwilling or unable to report their symptoms, it is difficult to accurately detect psychosis without such a self-report of internal experience. It is therefore suggested that scores meeting the cut-off without a positive self-report score are viewed with caution, and clinicians should consider other possible causes of the observed behaviours. It is recommended that the informant-rating subscale may have more utility in the monitoring of symptoms in those already known to have a diagnosis of psychosis. Equally, given the abstract nature of the self-report questions, some adults may report experiences which appear to be, but are not in fact psychotic in nature. Hence, care must be taken to fully understand the experience that is being reported, so as not to increase the likelihood of false-positives.

6.1 Limitations

First, only three adults with ID participated in the focus groups, along with four relatives/workers. Original intentions were to recruit a total of six to 10 people for the focus groups. However, recruitment proved challenging, with Health and Social workers concerned that potential participants were either too unwell or lacking the necessary communication skills to attend focus groups. Given the small number who participated, the experiences reported may not be representative of the wider population of adults with ID and psychosis. Some attempt was made to counteract this limitation, through obtaining clinical input from inpatient Learning Disability Nurses with several years' experience working with people with ID and psychosis. Given that psychosis is estimated to be less prevalent than affective disorders in the ID population (4.4% vs. 6.6%; Cooper *et al.* 2007), this may explain why it was not possible to recruit numbers equivalent to those reported by the GAS-ID and GDS-LD studies. Second, due to the small sample size, it was not possible to show criterion validity of the GPS-ID; and as previously noted, not all psychosis group participants had active psychotic symptoms at interview. It was originally intended that adults without ID and psychosis would be recruited to test criterion validity; however, due to time constraints this step was omitted. Third, it was originally intended that following expert feedback, a draft GPS-ID would be piloted with people with ID and psychosis, allowing one final iteration of refinement. However, time constraints prevented this step, which would likely have increased the face validity of the tool. Instead, participants were asked for their views after interview; however, their responses were limited, and perhaps less informative than if a more structured approach had been taken. Fourth, the interviewer was not blinded to participant groups, and this may have impacted completion of the questionnaires. Fifth, due to time constraints, test-retest reliability of the GPS-ID could not be investigated. Finally, two adults with a borderline level of ID participated in the study. They were invited by health care workers, who later reported that they had borderline ID. These participants were not subsequently excluded because they were not from the same group (and hence their abilities were matched between groups); and it was viewed as unethical to exclude them after they had given up their time to participate.

6.2 Future research

Initial findings of the utility of the GPS-ID are promising, however future research is needed to both replicate and further investigate its psychometric properties. Such studies should recruit a larger sample of adults with ID and psychosis, so that content validity can be further investigated. Structured feedback from

participants and their carers regarding the tool would also be beneficial. Construct validity could also be further tested with a larger sample, and researchers may consider recruiting general population adults with psychosis for this purpose. Future studies should recruit a comparison group of adults with ID and a range of affective disorders in order to further assess the discriminant properties of the tool. It may also be beneficial to consider a different tool for comparison purposes such as the PANSS (Kay *et al.* 1989) which may share more constructs with the GPS-ID than the PSYRATS.   Furthermore, interviewers should be blinded to participant's mental health, and test-retest reliability should be investigated.

6.3 Clinical implications

Preliminary investigations suggest the GPS-ID is accessible for adults with mild to moderate ID and psychosis. High levels of sensitivity and specificity were found for the total score, self-report and informant-rating subscales, suggesting that the tool can be used flexibly. It takes 15-30 minutes to complete and can exclude those without psychosis and identify those likely to have psychosis, and thus requiring further assessment. It also fulfils a clinical need, given that no other psychosis screening tool has been developed specifically for the adult ID population.

7. <u>Conclusions</u>

The GPS-ID was found to have a range of acceptable psychometric properties, including face/content validity, discriminant validity, internal consistency and sensitivity and specificity. Further research is needed to replicate the reported psychometric properties, and to investigate those which could not be fully assessed due to sample size and time constraints.

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Chapter 3: Appendices

Appendix 1 – Author guidelines

Journal of Intellectual Disability Research

ETHICAL GUIDELINES

The Journal of Intellectual Disability Research adheres to the ethical guidelines for publication and research summarised below.

Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research.

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It is a requirement that all authors have been accredited as appropriate upon submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study

and any potential conflict of interests if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

Ethical Approvals

Experimental Subjects: experimentation involving human subjects will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net/e/policy/b3.htm) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. Editors reserve the right to reject papers if there are doubts as to whether appropriate procedures have been used.

All studies using human participants or animal subjects should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

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Original Research Article The main text should proceed through sections of Abstract, Background, Methods, Results, and Discussion. Reports of up to 4,500 words are suitable for major studies and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions. Please note that articles exceeding 4,500 words will be unsubmitted immediately from the review process and the authors will be asked to reduce the length of the article.
Authors submitting articles should be guided by the following checklists prior to submission:

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For diagnostic studies: (<u>http://www.stard-statement.org/checklist_maintext.htm</u>)

Systematic Reviews of up to 4,500 words are suitable for submission. Authors submitting a systematic review are encouraged to assess the quality of their article against the PRISMA checklist prior to submission (<u>http://www.prisma-statement.org/2.1.2%20-</u> <u>%20PRISMA%202009%20Checklist.pdf</u>) or MOOSE guideline (insert link to MOOSE PdF). Further details on systematic reviews can be obtained from Prof. Richard Hastings (Editor); email: R.Hastings@warwick.ac.uk

MANUSCRIPT FORMAT AND STRUCTURE
5.1. Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp . All services are paid for and arranged by the author and use of one of these services does not guarantee acceptance or preference for publication.

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It is important that the term 'intellectual disabilities' is used when preparing manuscripts. Please note that 'intellectual disability', as used in the journal, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some counties. The term 'person', 'people' or 'participant(s)' should be used as opposed to 'patient(s)'.

A high proportion of papers are submitted with the term 'behavior' as opposed to 'behaviour'; please use 'behaviour'.

Where applicable the journal standard is to use words ending in –ise as opposed to –ize. For example, use 'analyse' 'standardise' as opposed to 'analyze' and 'standardize'

5.2. Structure

All manuscripts submitted to *The Journal of Intellectual Disability Research* should include: Title, Keywords, structured Abstract, Main Text (divided by appropriate sub headings) and References.

Title Page: Please remember that **peer-review is double-blind**, so that neither authors nor reviewers know each others' identity. Therefore, **no identifying details of the authors or their institutions must appear in the submitted manuscript; author details should be entered as part of the online submission process**. However, a 'Title Page' must be submitted as part of the

submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

Keywords: The author should also provide up to six keywords to aid indexing. Please think carefully about the keywords you choose as this will impact on the likelihood of your article being located during literature searches (https://authorservices.wiley.com/bauthor/seo.asp).

Abstracts: For full and brief reports, and reviews, a structured summary should be included at the beginning of each article, incorporating the following headings: Background, Method, Results, and Conclusions. These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

References

The Journal follows the Harvard reference style. References in text with more than two authors should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic Markers in Human Blood.
- Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* **24**, 137- 41.
- Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: *Life Course Perspectives on Adulthood and Old Age* (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

Where more than six authors are listed for a reference please use the first six then 'et al.'

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here: www.endnote.com/support/enstyles.asp Reference Manager reference styles can be searched for here:www.refman.com/support/rmstyles.asp

5.4. Tables, Figures

Tables: Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, Table 2, etc., and give a short caption.

Figures: All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. All symbols and abbreviations should be clearly explained. Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

Figure Legends: In the full-text online edition of the Journal, figure

Appendix 2 – Systematic review searches and quality ratings

Appendix 2.1 Search strategy according to database

Table 1 Ovid Medline search strategy

Search number	Search terms	Search results
1	exp Intellectual Disability/	86342
2	(intellec* disab* or learning disab* or mental* retard* or learning impair* or mental* handicap*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	80358
3	exp Mentally Disabled Persons/	2310
4	1 or 2 or 3	114219
5	exp Psychosis/	41277
6	exp schizophrenia/	91673
7	(psychotic disorders or psychosis or psychoses or psychotic$ or psychos$ or schizophrenia or schizo$ or schizoaffective or schizoaffective disorder or delusional disorder$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	285640
8	5 or 6 or 7	285790
9	exp prevalence studies/	212306
10	prevalence.mp. or Prevalence/ (prevalence or prevalence rate$ or morbidity).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	781927
11	9 or 10	931796

12	4 and 8 and 11	473

Table 2 Ovid Embase search strategy

Search number	Search terms	Search results
1	exp mental deficiency/	139767
2	limit 1 to abstracts	96356
3	(intellec* disab* or learning disab* or mental* retard* or learning impair* or mental* handicap*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	73092
4	limit 3 to abstracts	62901
5	2 or 4	122718
6	exp Psychosis/	256972
7	(psychotic disorders or psychosis or psychoses or psychotic$ or psychos$ or schizophrenia or schizo$ or schizoaffective or schizoaffective disorder or delusional disorder$).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	437871
8	6 or 7	463014
9	(prevalence or prevalence rate$ or morbidity).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	1149878
10	5 and 8 and 9	920

Table 3 PSYCInfo search strategy

Search number	Search terms	Search options	Search results

1	DE "Intellectual Development Disorder" OR DE "Learning Disabilities"	Search modes - Boolean/Phrase	58951
2	DE "Schizophrenia" OR DE "Schizophrenia (Disorganized Type)" OR DE "Acute Psychosis" OR DE "Paranoid Schizophrenia" OR DE "Fragmentation (Schizophrenia)" OR DE "Catatonic Schizophrenia" OR DE "Acute Schizophrenia" OR DE "Psychosis" OR DE "Paranoia (Psychosis)" OR DE "Schizoaffective Disorder"	Search modes - Boolean/Phrase	95570
3	TX prevalence or prevalence rate$ or morbidity	Search modes - Boolean/Phrase	105082
4	S1 AND S2 AND S3	Search modes - Boolean/Phrase	46

Table 4 PubMed search strategy

Search number	Search terms	Search results
1	Search intellectual disability[MeSH Terms]	84517
2	Search psychosis[MeSH Terms]	44216
3	Search schizophrenia[MeSH Terms] Sort by: Author	90117
4	Search (schizophrenia[MeSH Terms]) OR psychosis[MeSH Terms] Sort by: Author	124018
5	Search (intellectual disability[MeSH Terms]) AND ((schizophrenia[MeSH Terms]) OR psychosis[MeSH Terms])	1622
6	Search (prevalence[Text Word] OR prevalence rate$[Text Word] OR morbidity[Text Word])	769931
7	Search (((intellectual disability[MeSH Terms]) AND ((schizophrenia[MeSH Terms]) OR psychosis[MeSH Terms]))) AND ((prevalence[Text Word] OR prevalence rate$[Text Word] OR morbidity[Text Word])) Sort by: Author	105

Appendix 2.2 Excluded papers

Table 5 Details of excluded papers

Excluded studies	Author	Reason for exclusion
1.	Heaton-Ward (1977)	Hospital sample
2.	Monfils & Menolascino (1983)	Sample of patients using specialist psychiatric services for people with ID
3.	Reid (1994)	Hospital sample
4.	Cherry *et al.* (1997)	Residential sample
5.	Tsakanikos *et al.* (2006)	Sample of patients using specialist psychiatric services for people with ID
6.	Bhaumik *et al.* (2008)	Sample of patients using specialist psychiatric services for people with ID
7.	Reid (1989)	Review paper
8.	Campbell & Malone (1991)	Review paper
9.	Vitiello & Behar (1992)	Review paper
10.	Reid (1993)	Review paper
11.	Azam *et al.* (2009)	Review paper
12.	Dyggve & Kodahl (1979)	Included children ≤15 years – not possible to calculate results for those aged ≥16 years
13.	Kishore *et al.* (2004)	Included children ≤15 years – not possible to calculate results for those aged ≥16 years
14.	Kishore *et al.* (2005)	Included children ≤15 years – not possible to calculate results for those aged ≥16 years
15.	White *et al.* (2005)	Included children ≤15 years – not possible to calculate results for those aged ≥16 years
16.	Myrbakk & von Tetzchner (2008)	Included children ≤15 years – not possible to calculate results for those aged ≥16 years
17.	Pasamanick (1961)	General population

18.	Astrup (1989)	General population
19.	Hagnell *et al.* (1994)	General population – results of ID population reported in Nettelbladt *et al.* (2009)
20.	Noorbala *et al.* (2004)	General population
21.	Patel *et al* (2007)	General population
22.	Chaplin *et al.* (1996)	Included adults with borderline ID – not possible to calculate results for those with mild to profound ID.
23.	Hassiotis *et al.* (2008)	Included adults with borderline ID – not possible to calculate results for those with mild to profound ID.
24.	Morgan *et al.* (2008).	Included adults with borderline ID – not possible to calculate results for those with mild to profound ID.
25.	Salvador-Carulla *et al.* (2000)	Same data reported in other included study - Salvador-Carulla *et al.* (1998)
26.	Kozlowski *et al.* (2011)	Prevalence of psychosis not reported

Appendix 2.3 Quality ratings

Table 6 Quality rating criteria

Domain	Criteria	Rating
Sample size	>100	2
	30-100	1
	<30	0
Representativeness of sample	Population based	2
	Administrative	1
	All other	0
Reporting of level of ID	Distribution of ID reported	0/1
Method of assessment	Clinical diagnosis by a psychiatrist or psychologist based on standard diagnostic system	2
	Clinical diagnosis by a psychiatrist or psychologist	1

		Other psychosis screening instrument used	1
		All other	0
Report of precision estimate		Confidence interval is reported	0/1

Table 7 Quality ratings for included studies

Study	Sample size	Representativeness of sample	Reporting of level of ID	Method of assessment	Report on measure of variability	Total score
Göstason (1985)	2	2	1	2	0	7
Lund (1985)	2	2	1	1	0	6
Cooper (1997)	2	2	0	2	0	6
Salvador-Carulla *et al* (1998)	2	0	1	2	0	5
Deb *et al* (2001)	1	1	1	2	1	6
Holden & Gitlesen (2003)	2	1	1	0	0	4
Holden & Gitlesen (2004)	1	1	1	1	0	4
Taylor *et al* (2004)	2	1	0	0	1	4
Bailey (2007)	2	1	0	2	0	5
Cooper *et al* (2007)	2	2	1	2	1	8
Nettelbladt *et al* (2009)	1	2	1	0	0	4
Sheehan *et al* (2015)	2	2	0	0	0	4

Appendix 3 – Psychometric properties of existing measures

Appendix 3.1 Psychometric properties of ID screening tools

Table 8 Psychometric properties of depression and anxiety screening tools developed for the ID population

Study/measure	Psychometric property	Value/evidence
Cuthill *et al.* (2003) GDS-LD Three groups of participants: ID depression = 19 ID no depression = 19 Non-ID depression = 27	Face/content validity	Method employed; no items scored 0 for >half of depression group
	Criterion validity (n=27)	*r*=0.94, *p*<.001
	Discriminant validity (n=65)	Significant difference between group scores where *p*<.05
	Internal consistency (n=38) (n=19)	α=0.90 α=0.81
	Test-retest reliability (n=38) (n=19)	*r*=0.97, *p<.001* *r*=0.94, *p*<.001
	Sensitivity (n=38)	96%
	Specificity (n=38)	90%
Mindham & Espie (2003) GAS-ID Three groups of participants: ID anxiety = 19 ID no anxiety = 16 Non-ID anxiety = 19	Face/content validity	Method employed
	Criterion validity (n=19)	ρ=0.75, *p*<.001
	Discriminant validity (n=54)	Significant difference between group scores where *p*<.05
	Internal consistency (n=35)	α=0.96
	Test-retest reliability (n=17)	*r*=0.95, *p*<.0001
	Sensitivity (n=36)	100%
	Specificity (n=36)	100%

Appendix 3.2 Psychometric properties of ID screening tools

Table 9 Psychometric properties of psychosis screening tools developed for the general population

Study/measure	Psychometric property	Value/evidence
Hatton *et al.* (2005)	Face/content validity	Not relevant to study
PSYRATS	Criterion validity (n=62)	PSYRATS auditory hallucinations subscale correlated with PANSS positive symptoms *r*=0.45, *p*<.001
Three groups of ID participants:		
Psychosis n=11	Discriminant validity (n=62)	No significant difference between groups on delusions subscale where *p*=.52
Other mental health n=14		Significant difference between groups on
No mental health n=37		auditory hallucinations subscale where *p*<.001
	Internal consistency (n=62)	Delusions subscale - α=0.94 Auditory hallucinations subscale - α=0.88
	Test-retest reliability (n=10)	Delusions subscale – not tested Auditory hallucinations subscale - *rho*=0.99, *p*=.001
	Sensitivity	Not reported
	Specificity	Not reported
Hatton *et al.* (2005)	Face/content validity	Not relevant to study
PANSS	Criterion validity (n=62)	PSYRATS auditory hallucinations subscale correlated with PANSS positive symptoms *r*=0.45, *p*<.001
Three groups of ID participants:		
Psychosis n=11	Discriminant validity (n=62)	Significant difference between groups on positive symptoms subscale where *p*=.001
Other mental health n=14		No significant difference between groups on
No mental health n=37		negative symptoms subscale where *p*=.55
		Significant difference between groups on general symptoms subscale where *p*=.03
	Internal consistency (n=62)	Positive symptoms - α=0.62 Negative symptoms - α=0.68 General symptoms - α=0.70
	Test-retest reliability (n=10)	Positive symptoms - *rho*=0.89, *p*=.001 Negative symptoms - *rho* =0.92, *p*=.001 General symptoms - *rho* =0.47, *p*=.18

	Sensitivity	Not reported
	Specificity	Not reported

Appendix 4 – Major research proposal

Development of a psychosis screening tool for use in adults with intellectual disabilities

Abstract

Background

Psychosis has been found to have a higher prevalence in the intellectually disabled population than the general population. However, there are currently no screening measures which have been developed specifically for use in the intellectually disabled population. Some general population screening tools have been found to have adequate reliability in the ID population, but there is some evidence suggesting such tools may have poor sensitivity.

Aims

To develop a measure for screening psychosis that is appropriate for use in the mild to moderate ID population.

Methods

Items will be pooled from existing measures and diagnostic criteria, and presented to focus groups of adults with ID and psychosis and their carers. Items will be refined according to focus group input and a draft scale will be compiled. The measure will then be used to interview two groups of participants: adults with ID and active psychosis, and adults with ID without psychosis. All participants will also be interviewed with The Psychotic Symptom Rating Scales PSYRATS. The psychometric properties of the measure will then be investigated. Should they wish to do so, adults with ID and psychosis will then be given the opportunity to provide any feedback they may have on the new tool.

Applications

The resulting measure may help with the identification, diagnosis and trajectory of psychotic illness in people with intellectual disabilities.

Introduction

Research has found the point prevalence of psychosis in adults with intellectual disability (ID) to range from 0.8-5.0% (Lund, 1985; Deb *et al*. 2001; Bailey, 2007; Cooper *et al*. 2007). Prevalence rates of psychosis have also varied in the general population, with estimates ranging from 0.4-1.2%

(Jenkins *et* al, 1997; Brugha *et al*. 2005; Wittchen *et al*. 2011). Thus it appears that the prevalence of psychosis is much higher in the ID population than the general population. Given this higher prevalence, it is surprising that there is currently no psychosis screening tool designed specifically for use within the ID population.

Several general psychopathology screening tools have been developed specifically for use in the ID population, some of which comprise items or subscales that screen for psychosis (for example, the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson *et al*. 1984) and the Psychiatric Assessment Schedule for use in Adults with Developmental Disabilities (PAS-ADD; Moss *et al*. 1998). However, the use of psychopathology screening tools in identifying psychosis is problematic. These scales were derived from general population criteria, such as the *Diagnostic and Statistical Manual of Mental Disorders 3rd Edition* (DSM-III; American Psychiatric Association, 1980) and *The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research* (ICD-10; World Health Organization, 1993). Such general population nosology have been shown by some researchers to be unable to accommodate the pathoplastic effects of ID, and thus their application result in under-recognition of psychiatric illness in people with ID (S.-A. Cooper et al., 2007). This under-recognition has been shown specifically in relation to diagnosis of psychosis when using the PAS-ADD Checklist. The PAS-ADD Checklist employs the Schedules for Clinical Assessment in Neuropsychiatry (SCAN; WHO, 1994) algorithm, which assigns diagnoses according to strict application of ICD-10 research criteria. Moss et al (1996) investigated the validity of diagnosing schizophrenia according to the PAS-ADD Checklist, and found that it failed to recognise 25% of people with a clinical diagnosis of schizophrenia. The researchers noted that although the PAS-ADD Checklist scores did not translate to an ICD-10 diagnosis, the participants exhibited clear psychotic symptoms.

More recently, researchers have attempted to develop scales for specific psychiatric disorders in the ID population which address the aforementioned issue. For example, the Glasgow Depression Scale for people with a Learning Disability (GDS-LD) considered symptomatology included in both general population criteria (the ICD-10) and criteria designed specifically for use in the ID population (the diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation (DC-LD); Royal College of Psychiatrists, 2001). Focus groups of adults with ID were also consulted, and the resulting 20-item screen was found to have good test-retest reliability (r=0.97) and internal consistency (Cronbach's α=0.90), with high sensitivity (96%) and specificity (90%) (Cuthill, Espie, & Cooper, 2003).

Currently, there have been no such attempts to develop specific psychosis scales according to DC-LD criteria. There have however been investigations into the use of general psychotic rating scales. For

example, the Positive and Negative Syndrome Scale (PANSS; Kay, Opler, & Lindenmayer, 1989) and the Psychotic Symptom Rating Scales (PSYRATS; Haddock, McCarron, Tarrier, & Faragher, 1999) have been reported to show adequate reliability and validity within a sample of 62 adults with mild ID (Hatton et al., 2005). The participants in this study were recruited from two sites: in one site, specialist psychiatrists selected potential participants based on clinical judgement according to ICD-10 criteria; in the other site, potential participants were selected on the basis of a large scale PAS-ADD Checklist population screening. Although the researchers reported adequate psychometric properties, they suggested that further investigation was necessary, particularly regarding applicability of items concerning negative symptoms and delusions. This has been an area for contention, with some suggestion that the profile of psychotic disorders may be different in people with ID than the general population (Hatton et al., 2005). The Hatton et al study (2005) used general population diagnostic criteria to both select their sample and diagnose psychosis. Therefore, it is possible that individuals presenting with an atypical profile would not have been identified as having psychosis.

Hence, the use of both general population psychosis screening tools and ID psychopathology screening tools may lead to under recognition of psychosis in people with ID. This seems counterintuitive to current Scottish policy regarding ID, which aims include "ensuring that services are fully tailored to individual needs" (COSLA foreword; The Scottish Government, 2013). Thus, it seems there is a need to develop a psychosis rating scale for use in the ID population.

Aims and hypotheses

Aims

To develop a screening measure for psychosis that is appropriate for use in the mild to moderate ID population.

Hypotheses

The resulting scale will have acceptable psychometric properties which are similar to those of existing screening measures developed for use with the ID population (such as the GDS-LD (Cuthill et al., 2003) and the GAS-ID (Mindham & Espie, 2003)).

- discriminant validity: effect size f=0.4

- criterion validity: $r \geq 0.75$

- test re-test reliability: $r \geq 0.70$

- internal consistency: $\alpha \geq 0.70$

- sensitivity: $\geq 70\%$

- specificity: ≥ 70%

Plan of Investigation

Participants

Focus groups

Participants will include adults with ID who are accessing learning disability community mental health services, and their paid or family carers. If they prefer, the adults with ID may attend the focus group without a paid or family carer. Only paid or family carers of a person who wishes to take part in the focus group and wants their paid or family carer to go with them will be invited.

Field test groups

Participants will include adults who are accessing learning disability community or inpatient mental health services.

Participants who attend the focus group may also take part in the field test groups.

Inclusion and Exclusion Criteria

Inclusion criteria

Focus groups

- Adults aged ≥16 with a mild to moderate ID who have reasonable verbal communication i.e. are able to express themselves, and diagnosis of psychosis.
- Family or paid carers of adults with mild to moderate ID who have a diagnosis of psychosis and wish to take part in the focus group.

Field test groups

- Adults aged ≥16 with a mild to moderate ID, who have reasonable verbal communication, a diagnosis of psychosis, and are currently experiencing psychosis.
- Adults aged ≥16 with a mild to moderate ID, who have reasonable verbal communication, and do not have a diagnosis of psychosis.

Exclusion criteria

- Adults with a diagnosis of autism.
- Adults with a diagnosis of dementia.
- Adults with severe and profound ID.

Recruitment Procedures

Recruitment will be conducted in two waves: focus group, then field test participants. Participants will be recruited from learning disability community and inpatient mental health services. Information regarding the purpose of the study and inclusion/exclusion criteria will be provided to

the aforementioned mental health services. Potential participants will be told about the study by a familiar clinician (for example, their community psychiatric/learning disability nurse) and should they be interested, provided with a participant information sheet. Information sheets will be specific to the focus and field test groups, and will be available for participants and welfare guardians. Focus group information sheets will invite the person with ID and their paid or family carers to participate in focus groups. Contact information and reply slips with freepost envelops will be provided with information sheets, allowing potential participants to notify their interest in the study. In accordance with the Adults with Incapacity (Scotland) Act), consent will be taken from those who have capacity to consent to take part in research and wish to participate in the study. For those who wish to participate but do not have such capacity, consent will be sought from their nearest relative or welfare guardian/attorney. Information sheets will be provided to the participant's nearest relative or welfare guardian/attorney detailing the purpose of the study and what participant would entail. Following consent, information regarding participant level of ID and current psychosis status will be sought from appropriate clinicians.

Measures

Psychotic Symptom Rating Scales (PSYRATS; Haddock et al., 1999)

- The PSYRATS consists of an auditory hallucinations scale comprising of 10 items, and a delusions scale comprising of six items. Probing questions are provided for each item, which is scored on a 0-4 point scale. Individual scoring criteria are provided for each item. See Appendix 9 for PSYRATS Interview Schedule.

Psychosis screen for adults with ID

Design

A between groups design will be employed, with the above scales administered to each group.

Research Procedures

An item pool will be generated from existing psychosis screens and diagnostic criteria (see Appendices 5 and 9). It will then be discussed by two focus groups; consisting of a mix of adults with ID and their family member or support worker. At least half of the people in each group will have an ID. The focus group will be facilitated by the trainee clinical psychologist, with additional support provided by another trainee or member of the clinical team. The facilitator will help the groups reach consensus of relevant items and concepts. The focus groups will last up to two hours and will inform refinement of the items, ensuring they are accessible to people with ID. A draft scale will then be developed and reviewed by experts in the field (i.e. clinicians and researchers of psychosis in ID). The resulting schedule, along with the PSYRATS, will then be administered to the field test group, along with their family member or support worker, in a one-to-one interview with the trainee

clinical psychologist. Those with an ID and psychosis from the field test group will then be interviewed with the new scale on a second occasion one to two weeks later (to allow examination of test re-test reliability). Analysis of the psychometric properties of the resulting schedule will then be conducted.

Data Analysis

Descriptive statistics will be used to investigate the spread of the data. If the data is parametric, discriminant validity will be tested using an independent t-test. If the data is non-parametric, discriminant validity will be tested using a Mann-Whitney test. Criterion validity will be tested by correlating scores of the new scale with scores of the PSYRATS for the non-psychosis group. Test re-test reliability will be examined by correlating scores of the new scale from two time points. If the data is parametric, Pearson's correlation coefficient will be used. If the data is non-parametric, Spearman's correlation coefficient will be used. Internal consistency of the psychosis screen for adults with ID will be examined using Cronbach's α (or Cohen's Kappa). Sensitivity and specificity will be examined through determining threshold scores for the psychosis screen for adults with ID which correctly identify those with and without a diagnosis of psychosis.

Justification of sample size

Six to ten people in total will be recruited for the focus groups. A minimum of 12 people will be recruited for each psychosis and non-psychosis group. This sample size has been informed by clinicians working with people with ID and psychosis in Greater Glasgow & Clyde, who have estimated that there will be approximately 20 people with ID and active psychosis over the recruitment period (which will last up to seven months).   Similar numbers have been found to be sufficient for the development of a depression screening tool for use in adults with ID (Cuthill et al., 2003) which is now routinely used, and thus should also be adequate for a psychosis screening tool.

Power calculation

In order to provide further justification of the proposed sample size and to determine whether the results will be indicative of a true clinical difference, the statistical software 'G*Power 3.0.10' was used to perform a sensitivity analysis. G*Power requires information to be input regarding the type of test conducted and parameter values from that test. In this case, selections were: 't tests', ' Means: Difference between two independent means (two groups)', and 'Sensitivity: Compute required effect size – given α, power, and sample size'. A power of 0.8 or more provides an 80% chance of detecting an effect if one genuinely exists. Therefore, a power of ≥0.8 will be used to signify a clinically relevant finding.

For a pilot study, it is recommended that a sample size of 12 participants per group is employed (Julious, 2005). Therefore, for difference in psychosis scores between the two groups, the

parameters: α err prob (0.05), power 1-β err prob (0.8), sample size group 1 (12), sample size group 2 (12) were entered into G*Power, and an effect size was calculated to be 1.0. Therefore, recruiting a sample of 12 participants per group will yield a large effect size of 0.6.

Settings and Equipment

A private, quiet room will be required to conduct focus groups and interviews. Necessary equipment includes the aforementioned screening measures and stationary for the focus groups.

Health and Safety Issues

Researcher Safety Issues

Due to the nature of psychosis, the behaviour of participants may be unpredictable, with the potential for outbursts of distress or aggression directed toward the researcher. All interviews will be conducted within a day centre or NHS clinical areas, ensuring that support can be obtained quickly from other members of staff. Furthermore, those individuals most likely to become impulsive are likely to be residing in inpatient care, where their interviews would take place. As such, staff would be able to advise on the individual's ability to participate and would be able to provide additional support if required. Such clinical areas will be equipped with alarms and the researcher will adhere to local GG&C guidelines.   An additional trainee clinical psychologist or member of the clinical team will attend the focus groups, providing the researcher with additional support, should it be required. For further details, see Appendix 4.1.

Participant Safety Issues

It is possible that participants may become upset when discussing distressing psychotic experiences. However, both focus groups and interviews will be conducted by a trainee clinical psychologist who is experienced in working in clinical settings with patients who at times become distressed. The interviewer will therefore be able to use their skills to risk assess and contain any such distress. The additional trainee clinical psychologist or member of the clinical team attending the focus groups will ensure that should a participant become upset or wish to take a break, one person will be available to support them while the other can continue to facilitate the group. For further details, see Appendix 4.1.

Ethical Issues

There are two pertinent ethical issues that may arise within this study. Firstly, due to the nature of both ID and psychosis, it is possible that potential participants may not have capacity to consent to participate. In order to ensure that only those who have capacity and wish to participate are recruited, the trainee clinical psychologist will assess capacity to consent, in accordance with the Adults with Incapacity (Scotland) Act. Secondly, it is possible that participants may become

distressed while discussing the nature of their illness. In order to insure participants are fully informed, it will be made clear during the consent process that: i) participants may become upset; ii) participants are free to withdraw from the study at any point; and iii) withdrawing will have no effect on the care they receive. If a participant becomes overly distressed but does not ask to end their participation, the trainee clinical psychologist may choose to do so if it is deemed to be in the best interests of the participant. In such scenarios, the interviewer will use their clinical training to alleviate participant distress. For further details, see Appendix 4.1.

Ethical approval will be sought from a research ethics committee specialising in learning disability (e.g. Scotland A REC).

Financial Issues

- Freepost envelopes and paper for participant information sheets and consent forms
- Stationary for focus groups: flip chart, pens, paper.
- Refreshments for focus groups: tea/coffee, juice, biscuits.

See Research Costs form in Appendix 4.2.

Timetable

Task	Estimated length of time to completion	Estimated start date	Estimated completion date
Draft proposal			16/03/15
Final proposal			17/0715
Research and Development submission	Up to 4 weeks	Mar 2015	Apr 2015
Ethics Submission	2-3 months	Apr/May 2015	June/July 2015
Generate items list	3 weeks	July 2015	July 2015
Recruit and run focus group	Up to 6 weeks	Aug 2015	Sep 2015
Make scale/ expert review	Up to 6 weeks	Sep 2015	Oct 2015
Final refinement	Up to 3 weeks	Jan 2016	Jan/Feb 2016
Recruit and field test	Up to 4 months	Feb 2016	May 2016
Test psychometric properties	Up to 2 months	May 2016	June 2016

Practical Applications

The resulting screening measure may help with the identification of psychotic symptoms in adults with ID, potentially aiding diagnoses and allowing changes in the severity of illness to be measured.

The results of the study will be written in the trainee clinical psychologist's thesis. The results will also be published in scientific journals and presented at meetings and conferences. Results of the study will also be disseminated to the participants who are interested in receiving them.

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Appendix 4.1

WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW

DOCTORATE IN CLINICAL PSYCHOLOGY

HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Development of a psychosis screening tool for use in adults with intellectual disabilities
2. Trainee	Dr Amanda Muir
3. University Supervisor	Dr Alison Jackson
4. Other Supervisor(s)	Dr Moira Phillips
5. Local Lead Clinician	Dr Moira Phillips
6. Participants: (age, group or sub-group, pre- or post-treatment, etc.)	Adults aged ≥16 with intellectual disability and a diagnosis of psychosis, not currently in episode. Paid or family carers of adults aged ≥16 with intellectual disability and a diagnosis of psychosis. Adults aged ≥16 with intellectual disability without a diagnosis of psychosis. Adults aged ≥16 with intellectual disability and a diagnosis of psychosis, currently in episode.
7. Procedures to be applied (e.g., questionnaire, interview, etc.)	Two separate focus groups will be conducted. Questionnaires will be administered to the ID group with active psychosis on two occasions (between one to two weeks apart).
8. Setting (where will procedures be carried out?) General	Focus groups will be carried out at an NHS location, such as a hospital, resource centre or day centre. Interviews will be carried out at NHS inpatient units, resource centres or day centres. If day centres are not

	NHS buildings, local health and safety policies will be checked and discussed with the study supervisor prior to arranging focus groups. This will ensure health and safety procedures are equivalent to NHS procedures.
ii) Are home visits involved	No
9. Potential Risk Factors Identified (see chart)	1) It is possible that participants of the focus group may be upset while discussing symptoms that they find distressing. 2) It is possible that participants who are completing questionnaires may become upset by discussing symptoms that they find distressing. 3) Furthermore, for those participants experiencing psychosis, they may as a result present with impulsive, irrational or unpredictable behaviour, and/or have poor emotional control.
10. Actions to minimise risk (refer to 9)	Firstly, with regards to each point, it is reasonable to expect that some individuals may become upset whilst discussing a topic which they find distressing. However, it is not expected that the nature of the topics would produce distress of a significant level. In order to minimise any possible distress, participants would be made aware that: Participation is of a voluntary nature, and they can withdraw from the study at any time. Participants can take as many breaks as necessary Participants can choose to be accompanied by a carer or support worker with whom they feel safe. Participants are under no obligation to discuss anything that they do not wish to disclose

The interviewer is a trainee clinical psychologist who has experience with adults with mental ill health, both with and without intellectual disability. The interviewer also has experience of working with adults with intellectual disabilities both in individual and group settings, with and without their carers. The interviewer is experienced in working with people who are or have become upset, distressed or angry. As such, the interviewer is able to identify risk and determine the best course of action, for example, acknowledging the distress and allowing space for the individual, using breaks where necessary, containing or minimising distress, and where necessary ending sessions. An additional trainee clinical psychologist or member of the clinical team will attend the focus groups. This will allow one person to provide one-to-one support to any individual if they become distressed, while the facilitator can remain with the rest of the group.

Furthermore, it is probable that the individuals most likely to become impulsive, irrational or distressed will be those currently experiencing psychosis to an extent which has necessitated their stay in inpatient care. As such, staff/nurses would be able to advise whether the individual is well enough to participate on a given day, will be in the vicinity if the individual becomes distressed (to a level requiring their assistance). Within such inpatient settings, personal alarms or panic buttons will be available should they be required, and the interviewer will be aware of the process, according to local NHS health and safety policy.

	For any participants who become distressed, the trainee clinical psychologist will seek their consent to inform their carer/relative/nurse of their distress.

Trainee signature: Date: 13/07/15

University supervisor signature: Date:

Appendix 4.2

University of Glasgow | College of Medical, Veterinary & Life Sciences

RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

Trainee …Amanda Muir……………………………………………………………………

Year of Course Second…………………………….. **Intake Year**…2013…………..

Please refer to latest stationary costs list (available from student support team)

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary	1 x box of labels at £3.17 1x box of A4 Envelopes at £9.01 1x box of A5 Envelopes at £8.52 500x B&W Print 1 sheet at £0.05	Subtotal: £45.70
Postage	100X Freepost costs per letter at £0.62	Subtotal: £62.00
Photocopying and Laser Printing (**includes cost of white paper**)		Subtotal: £0.00
Equipment and Software	Flip chart	Subtotal: £0.00
Measures	PSYRATS	Subtotal: £0.00
Miscellaneous	Refreshments for focus groups (tea, coffee, water, juice, biscuits)	

	Pens	
		Subtotal: £20.00
Total		£127.70

For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:

Trainee Signature…………………………………… …   Date………………………

Supervisor's Signature ………………………………...   Date ………………………

Appendix 5 – DC-LD Diagnostic criteria

IIB3. 1*X* Schizophrenic/delusional episode

A   The symptoms/signs must not be a direct consequence of other psychiatric disorders (e.g. dementia, delirium, depressive episode, manic episode, mixed affective episode), prescribed or illegal drugs or alcohol or physical disorders such as thyroid dysfunction.

B   The criteria for schizoaffective episode are not met. (Hierarchically, schizoaffective episode takes precedence over schizophrenic/delusional episode.)

C   One of item groups 1, 2 *or* 3 must be present:

1   One of the following symptoms must be present on **most days for at least two weeks:**

   a   Third person auditory hallucinations (hallucinatory voices discussing the person among themselves)

   b   Hallucinatory voices from some part of the body

   c   Impossible/fantastic delusions (delusions are culturally inappropriate and completely impossible, for example, being able to communicate with aliens)

   d   Thought insertion *or* withdrawal *or* broadcasting; *or* thought echo; *or* delusions of control, influence or passivity (clearly referred to body or limb movements or specific thoughts, actions or sensations); *or* delusional perception; *or* hallucinatory voices giving a running commentary.

2   One of the following symptoms is present for **most of the time during a one-month period, or some time every day for at least one month** (a longer timescale, in view of the lesser diagnostic significance of these symptoms):

   a   Delusions are not mood congruent (delusions cannot be explained by the person's religious, cultural and environmental background)

   b   Hallucinations that are not mood congruent – these may occur in any sensory modality.

3   Two of the following symptoms must be present **on most days for at least two weeks,** although may change in intensity and type from day to day:

a   Delusions, that are not mood congruent (delusions cannot be explained by the person's religious, cultural and environmental background)

b   Hallucinations that are not mood congruent – these may occur in any sensory modality.

c   Catatonic symptoms, for example stupor, posturing, waxy flexibility, negativism

d   'Negative' symptoms, where there is definitive evidence that these are a change from the individual's premorbid state/baseline functioning, for example apathy, loss of adaptive skills, impairment of goal-directed behaviour, flattening or incongruity of emotional responses

e   Disordered form of thought, where there is definitive evidence that this is a change from the individual's premorbid state.

Appendix 6 – Ethical approval and amendments

Appendix 6.1 Scotland A REC approval

Scotland A REC
2nd Floor Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG

Telephone: 0131-465-5679

19 February 2016

Dr Alison Jackson
Mental Health & Wellbeing, University of Glasgow
Gartnavel Royal Hopital
1055 Great Western Road, Glasgow
G12 0XH

Dear Dr Jackson,

Study title: **Development of a psychosis screening tool for use in adults with intellectual disabilities**

REC reference: 16/SS/0004

IRAS project ID: 187473

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

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Manx Neill, manx.neill@nhslothian.scot.nhs.uk.

Confirmation of ethical opinion

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

Adults with Incapacity (Scotland) Act 2000

I confirm that the Committee has approved this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee is satisfied that the requirements of section 51 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

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

<u>Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

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

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

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

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

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

<u>Registration of Clinical Trials</u>

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

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

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

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

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study.   The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

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

Document	Version	Date
Covering letter on headed paper [Cover letter]		11 February 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Glasgow Insurance Indemnity]		
GP/consultant information sheets or letters [Recruitment information for GG&C community and inpatient LD teams]	3	03 February 2016
GP/consultant information sheets or letters [GP letter]	1	08 February 2016
Interview schedules or topic guides for participants [Focus group interview schedule]	1	25 January 2016
Participant consent form [Consent Form 1 for Participants – Learning disability focus group]	3	08 February 2016
Participant consent form [Consent Form 2 for Participants – Family member/support worker focus group]	2	03 February 2016
Participant consent form [Consent Form 3 for Participants – Pilot group]	4	08 February 2016
Participant consent form [Consent Form 4 for Participants – Learning disability psychosis field test group]	5	08 February 2016
Participant consent form [Consent Form 5 for Participants – Learning disability non-psychosis field test group]	3	08 February 2016
Participant consent form [Consent Form 6 for Participants – General population field test group]	4	08 February 2016
Participant consent form [Focus group consent form 1 for nearest relative/guardian or welfare attorney]	2	08 February 2016
Participant consent form [Pilot group consent form 1 for nearest relative/guardian or welfare attorney]	2	08 February 2016
Participant consent form [Learning disability field test group consent form 1 for nearest relative/guardian or welfare attorney]	2	08 February 2016
Participant consent form [General population field test group consent form 1 for nearest relative/guardian or welfare attorney]	2	08 February 2016
Participant information sheet (PIS) [General population field test group information sheet 4 for nearest relative/guardian or welfare attorney]	2	
Participant information sheet (PIS) [Participant information sheet 1 –	5	12 February 2016

Learning disability focus group]		
Participant information sheet (PIS) [Participant information sheet 2 – Family member/support worker focus group]	5	11 February 2016
Participant information sheet (PIS) [Participant information sheet 3 - Pilot Group]	5	03 February 2016
Participant information sheet (PIS) [Participant information sheet 4 – Learning disability psychosis field test group]	5	03 February 2016
Participant information sheet (PIS) [Participant information sheet 5 – Learning disability non-psychosis field test group]	4	
Participant information sheet (PIS) [Participant information sheet 6 – General population psychosis field test group]	4	
Participant information sheet (PIS) [Focus group information sheet 1 for nearest relative/welfare guardian]	3	03 February 2016
Participant information sheet (PIS) [Pilot group information sheet 2 for nearest relative/guardian or welfare attorney]	3	03 February 2016
Participant information sheet (PIS) [Learning disability field test group information sheet 3 for nearest relative/guardian or welfare attorney]	3	03 February 2016
REC Application Form [REC_Form_01122015]		01 December 2015
Research protocol or project proposal [Development of a psychosis screening tool for use in adults with intellectual disabilities]	8	06 November 2015
Summary CV for Chief Investigator (CI) [Dr Alison Jackson CV]		
Summary CV for student [Dr Amanda Muir CV]		
Summary CV for supervisor (student research) [Dr Alison Jackson CV]		
Validated questionnaire [Psychotic Symptom Rating Scales]		

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

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

HRA Training

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

16/SS/0004	Please quote this number on all correspondence

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

Yours sincerely

Dr Ian Zealley
Chair

Email:manx.neill@nhslothian.scot.nhs.uk

Tel: 0131-465-5680

Enclosures:	"After ethical review – guidance for researchers" *[SL-AR2]*
Copy to:	*Ms Emma Jane Gault*
	Ms Elaine O'Neill, NHS Greater Glasgow and Clyde

Appendix 6.2 NHS GG&C R&D approval

NHS
Greater Glasgow and Clyde

Administrator: Mrs Elaine O'Neill
Telephone Number: 0141 232 1815
E-Mail: elaine.o'neill2@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
West Glasgow ACH
Dalnair Street
Glasgow G3 8SW

10 March 2016

Dr Amanda Muir
Mental Health & Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Dr A Muir,

Study Title:	**Development of a psychosis screening tool for use in adults with intellectual disabilities**
Principal Investigator:	**Dr Amanda Muir**
GG&C HB site	**Community Learning Disabilities and Adult Mental Health Teams**
Sponsor	**NHS Greater Glasgow and Clyde**
R&D reference:	**GN15CP484**
REC reference:	**16/SS/0004**
Protocol no:	**V8; 06/11/15**

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004

    a. During the life span of the study GGHB requires the following information relating to this site
        i. Notification of any potential serious breaches.
        ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
    a. Recruitment Numbers on a monthly basis
    b. Any change of staff named on the original SSI form
    c. Any amendments – Substantial or Non Substantial
    d. Notification of Trial/study end including final recruitment figures
    e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

E O'Neill

Mrs Elaine O'Neill
Senior Research Administrator

Appendix 6.3 Ayrshire & Arran R&D approval

NHS Ayrshire & Arran

Research & Development
58 Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Dr Amanda Muir
Trainee Clinical Psychologist
Mental Health & Wellbeing
University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XN

Date	11 March 2016	
Your Ref		
Our Ref	AG/KLB/AMK 2015AA077	
Enquiries to	Karen Bell	
Extension	25850	
Direct line	01563 825850	
Fax	01563 825806	
Email	Karen.bell@aaaht.scot.nhs.uk	

Dear Dr Muir

Development of a psychosis screening tool for use in adults with intellectual disabilities

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

Documents received:

Document	Version	Date
IRAS R&D Form	5.2	1 December 2015
IRAS SSI Form	5.2.1	25 February 2016
Protocol	8.0	6 November 2015
Participant Information Sheet 1 – Focus Group	5.0	12 February 2016
Participant Information Sheet 2 – Family Member or Support Worker Focus Group	5.0	11 February 2016
Participant Information Sheet 3 - Pilot Group	5.0	3 February 2016
Participant Information Sheet 4 – Field Test ID Psychosis Group	5.0	3 February 2016
Participant Information Sheet 5 – Field Test ID non-psychosis group	4.0	3 February 2016
Participant Information Sheet 6 – General	4.0	3 February 2016

Population Psychosis Field test Group		
WGNR Participant Information Sheet 1 – Focus Group	3.0	3 February 2016
WGNR Participant Information Sheet 2 – Pilot Group	3.0	3 February 2016
WGNR Participant Information Sheet 3 – LD Field Test Group	3.0	3 February 2016
WGNR Participant Information Sheet 4 – non LD field test group	3.0	3 February 2016
Consent Form 1 – LD Focus Group	3.0	8 February 2016
Consent Form 2 – Family Member or Support worker	2.0	3 February 2016
Consent Form 3 – Pilot Group	4.0	8 February 2016
Consent Form 4 – LD Psychosis Field Test Group	5.0	8 February 2016
Consent Form 5 – LD non-psychosis field test group	3.0	8 February 2016
Consent Form 6 – General Population Field Test Group	4.0	8 February 2016
WGNR Focus Group Consent Form	2.0	8 February 2016
WGNR Pilot Group Consent Form	2.0	8 February 2016
WGNR General Population Field test Group Consent Form	2.0	8 February 2016
WGNR LD Field test Group Consent from	2.0	8 February 2016
Focus Group Interview Schedule	1.0	25 January 2016
Recruitment Information for Health Care Team	3.0	3 February 2016
GP Letter	1.0	8 February 2016
Psychotic Symptom Rating Scales Questionnaire	/	/

The terms of approval state that the investigator authorised to undertake this study within NHS Ayrshire & Arran is: -

- Dr Amanda Muir, University of Glasgow

With no additional investigators

The sponsors for this study are NHS Greater Glasgow and Clyde.

This approval letter is valid until 11 December 2016.

Regular reports of the study require to be submitted. Your first report should be submitted to Dr K Bell, Research & Development Manager in 12 months time and subsequently at yearly intervals until the work is completed.

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS R&D staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

- All research activity must comply with the standards detailed in the Research Governance Framework for Health and Community Care www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEdTwo.pdf and appropriate statutory legislation. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek further advice if you are unsure.

- Recruitment figures must be submitted to R&D on a monthly basis. If recruitment figures are not received timeously you will be contacted by a member of the R&D team to provide this data.

- You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at www.ich.org/LOB/media/MEDIA482.pdf), Ethics Guidelines, Health & Safety Act 1999 and Data Protection Act 1998.

- If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.

- The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.

- The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the R&D Department must be copied into this correspondence.

- The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.

www.nhsaaa.net

- As custodian of the information collated during this research project you are responsible at all times for ensuring the security of all personal information collated in line with NHS Scotland policies on information assurance and security, until the secure destruction of these data. The retention time periods for such data should comply with the requirements of the Scottish Government Records Management: NHS Code Of Practice. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and guidance please contact the Information Governance Team based at University Hospital Crosshouse 01563 825831 or 826813).

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely

Dr Alison Graham
Medical Director

c.c.   Emma Jane Gault, NHS Greater Glasgow & Clyde (sponsor contact)
Lesley Douglas, Finance, Ailsa Hospital
Information Governance, Ailsa Hospital
Helen Lynn, NHS Ayrshire & Arran
Derek Barron, NHS Ayrshire & Arran
Dr Alison Jackson, University of Glasgow (Academic Supervisor)
Dr Moira Philips, University of Glasgow (Academic Supervisor)
Professor Andrew Gumley, University of Glasgow (Academic Supervisor)

Appendix 6.4 Details of substantial amendment

The original study proposal consisted of three stages as shown below. However, due to time constraints a substantial amendment was made to the methodology, whereby two steps were omitted (shown in boxed italics).

Inclusion criteria

Focus groups

- Adults aged ≥16 with a mild to moderate ID who have reasonable verbal communication i.e. are able to express themselves, and diagnosis of psychosis.
- Family or paid carers of adults with mild to moderate ID who have a diagnosis of psychosis and wish to take part in the focus group.

> ***Pilot group***
>
> - *Adults aged ≥16 with a mild to moderate ID, who have reasonable verbal communication, a diagnosis of psychosis, and are currently experiencing psychosis.*

Field test groups

- Adults aged ≥16 with a mild to moderate ID, who have reasonable verbal communication, a diagnosis of psychosis, and are currently experiencing psychosis.
- Adults aged ≥16 with a mild to moderate ID, who have reasonable verbal communication, and do not have a diagnosis of psychosis.

> - *Adults aged ≥16 without ID, who have reasonable verbal communication, a diagnosis of psychosis, and are currently experiencing psychosis.*

Appendix 6.5 NHS GG&C approval of substantial amendment

Dear Dr A. Muir,

R&D Ref: GN15CP484   **Ethics Ref**: 16/SS/0004

Investigator: Dr Amanda Muir

Project Title: Development of a psychosis screening tool for use in adults with intellectual disabilities

Protocol Number: V10; 18/03/16

Amendment: Substantial Amendment 1 (07/04/16)

Sponsor: NHS Greater Glasgow and Clyde

I am pleased to inform you that R&D have reviewed the above

study's Amendment 1 (07/04/16) and can confirm that Management Approval is still valid for this study.

Reviewed Documents:	Version	Dated
Ethics Approval Letter		04/05/16
Notice of Substantial Amendment Form		0704/16
GP Letter	3	21/03/16
Proposal	10	18/03/16
PIS-4 Field Test ID psychosis group	7	18/03/16
Recruitment Information for Health Care Team	5	21/03/16
WGNR LD Field Test Group Consent Form	4	18/03/16
WGNR PIS-3 LD field Test Group	5	18/03/16

I wish you every success with this research project.

Kind regards

NHS GG&C R&D
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow G3 8SW

Tel: +44 (0)141 232 1815
Generic email for PR team: RandD.PRTeam@ggc.scot.nhs.uk

Web: www.nhsggc.org.uk/r&d

Please note that R&D operates a paperlite electronic record system. Please submit study documents via email.

Appendix 6.6 NHS A&A approval of substantial amendment

NHS
Ayrshire & Arran

Research & Development Office
58 Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Dr Amanda Muir
Trainee Clinical Psychologist
Mental Health & Wellbeing
University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XN

Date	9th May 2016
Our Ref	AG/KLB/NM R&D 2015AA077
Enquiries to	Karen Bell
Extension	25850
Direct line	01563 825850
Fax	01563 825806
Email	Karen.bell@aaaht.scot.nhs.uk

Dear Dr Muir

***Development of a psychosis screening tool for use in adults with intellectual disabilities –
Substantial Amendment 01***

I have received the undernoted documentation, relating to proposed changes to the above study:

- REC Favourable opinion of a substantial amendment letter sent 04/05/16
- Amendment Form – signed 07/04/16
- GP letter v3 21/03/16
- MRP proposal v10 18/03/16
- PIS4 Field test ID psychosis group v7 18/03/16
- Recruitment information for health care team v5 21/03/16
- WGNR LD field test group consent v4 18/03/16
- WGNR PIS3 LD field test group v5 18/03/16

I can confirm that the above amendment has been approved.

Please contact the R&D Office if you have any queries. On behalf of the department, I wish you
every success with the project.

Yours sincerely

Dr Alison Graham
Medical Director

c.c.   Elaine O'Neill, Senior Research Administrator - PR Team, R&D, NHS GG&C
        Derek Barron, NHS Ayrshire & Arran
        Helen Lynn, NHS Ayrshire & Arran

Appendix 6.7 Details of non-substantial amendment

Dr Moira Phillips and Dr Fiona Cuthill were added to the list of investigators, allowing them to

conduct interviews.

Appendix 6.8 NHS GG&C approval of non-substantial amendment

Dear Dr A. Muir,

R&D Ref: GN15CP484   **Ethics Ref**: 16/SS/0004
Chief Investigator: Dr Alison Jackson
Project Title: Development of a psychosis screening tool for use in adults with intellectual disabilities
Protocol Number: V10; 18/03/16
Amendment: Minor Amendment (20/05/2016)
Sponsor: NHS Greater Glasgow and Clyde

I am pleased to inform you that R&D have reviewed the above study's Amendment and can confirm that Management Approval is still valid for this study.

Reviewed Documents:	Version	Dated	Rec'd
Notification of minor amendment	---	20/05/16	30/05/2016
Participant information sheet 4 (learning disability psychosis field test group)	8	20/05/16	30/05/2016
Participant information sheet 5 (learning disability non-psychosis field test group)	5	20/05/16	30/05/2016
Participant information sheet 3 (nearest relative /guardian or welfare attorney)	6	20/05/16	30/05/2016

The Amendment includes also an addition of two researchers: Dr Moira Phillips and Dr Fiona Cuthill, who will be carrying out some of the interviews.

I wish you every success with this research project.

Kind regards
NHS GG&C R&D
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow G3 8SW

Tel: +44 (0)141 232 1815
Generic email for PR team: RandD.PRTeam@ggc.scot.nhs.uk

Please note that NHS GG&C R&D now operates an electronic record system and that only electronic submissions are now accepted

Appendix 6.9 NHS A&A approval of non-substantial amendment

NHS
Ayrshire & Arran

Research & Development Office
58 Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Dr Amanda Muir	Date	6 June 2016
Trainee Clinical Psychologist	Your Ref	
College of Medical, Veterinary & Life Sciences	Our Ref	AG/KLB/NM R&D 2015AA077
University of Glasgow		
Institute of Mental Health & Wellbeing	Enquiries to	Karen Bell
Gartnavel Royal Hospital	Extension	25850
1055 Great Western Road	Direct line	01563 825850
Glasgow	Fax	01563 825806
G12 0XH	Email	Karen.bell@aaaht.scot.nhs.uk

Dear Dr Muir

***Development of a psychosis screening tool for use in adults with intellectual
disabilities (NSA 20/05/16)***

I have received the undernoted documentation, relating to proposed changes to the above
study:

- • Notification of non-substantial/minor amendments
- • PIS4 Field test ID psychosis group v8 20-05-16
- • PIS5 Field test ID non-psychosis group v5 20-05-16
- • WGNR PIS3 LD field test group v6 20-05-16

I can confirm that the above amendment has been approved.

Please contact the R&D Office if you have any queries. On behalf of the department, I
wish you every success with the project.

Yours sincerely

Dr Alison Graham
Medical Director

www.nhsaaa.net

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Appendix 7 – Development of GPS-ID

Appendix 7.1. Focus group interview schedule

This interview schedule sets out a broad structure and additional questions will be asked depending on the direction of the conversation.

1. Introduction and thanks for coming

    a. Go over consent

    b. Lay out plan for group i.e. ice breaker, important info

2. Ice breaker – ask to introduce the person they have brought with them (or person next to them if they did not bring a carer/relative)

3. Important info

    a. Confidentiality (and audio recording)

    b. What to do if upset/not needing to disclose what you don't want others to know

    c. Breaks/toilets

    d. Fire exits

4. Group rules

    a. Confidentiality (again)

    b. Respecting others/not talking over each other

    c. What rules the group want to add?

5. Introducing the topic

    a. Psychosis describes lots of different symptoms and experiences. Some common experiences that people with psychosis have are: hearing voices that other people cannot hear; seeing things that other people cannot see; feeling worried that other people are trying to harm them; believing things that other people say are impossible. Some people also find it much harder to do the things they can normally do,

like going out with friends or doing their housework. Some people can find it hard to think properly, and can feel very confused. This can make it hard for them to talk to other people.

b. I'm interested in finding out about your experiences. Maybe we can start by making a list of the experiences you have had, then we can talk about them all a bit more. Has anybody had any of the experiences I just mentioned? Which ones? Additional prompt: what do you think is the hardest experience to cope with? Use prompts from table below to query symptoms that have not been mentioned.

c. After constructing list, group words into symptom clusters (based on focus group response) and discuss each group i.e. this group describes hearing voices, can you tell me a bit more about what that is like? How does it make you feel? What do you do when it happens? How might people know this is happening to you? What makes these experiences worse? What helps you cope with these experiences?

   i. **To carers:** What do notice in person you support?

   ii. **Specifically, for voices**: What are the voices like? Do you know what they are saying? Do they say nasty things? Are the voices ever nice? Do you ever talk to them? What is that like? Do other people notice when you talk to the voices? What would they think? Do you ever try to ignore the voices? What happens when you try this? How do the voices make you feel? Do you feel scared of the voices? If you can hear the voices, and your family or carer is trying to speak to you, what does this feel like? What do carers/family notice?

d. Repeat c. for each group identified and refer to prompts in table

e. You've told me about lots of different experiences, like i.e. hearing voices or thinking other people are talking about you. I've used the word 'psychosis' to describe these symptoms. Have you heard of the word 'psychosis'? What do you think it means? Do you use it? What other words do you use to describe all of these experiences? What words do carers use? [make list of suggested words]

f. Overall, how do/have these experiences affect your life? How would your life be different if you no longer had/have these experiences?

Symptom	Prompt questions
1. Present most days for at least 2 weeks	
A Third person auditory hallucinations (hallucinatory voices discussing the person among themselves)	Do you hear voices that other people can't hear? Do you hear someone talking to you when no-one is there? (Clarify this is not the TV, radio or people walking past etc.).
B Hallucinatory voices from some part of the body	We've talked about hearing voices, where do you think the voices are coming from? Have you ever thought that the voice was coming from a part of your body (other than inside your head)?
C Impossible/fantastic delusions (delusions are culturally inappropriate and completely impossible, for example, being able to communicate with aliens)	Do you ever think you can do things that other people say are impossible? For example, thinking you have super powers? Or thinking you can talk to aliens? Or thinking you have the power to make people do anything you want?
D Thought insertion	Do you worry that other people are putting thoughts in to your head? Do you worry that your thoughts are not your own? Do you ever feel like your thoughts don't belong to you?
or withdrawal	Do you ever worry that someone has taken your thoughts out of your head? Have you felt like someone has stolen your thoughts/ideas/what you have been thinking?
or broadcasting;	Do you worry that other people can hear your thoughts and you don't want them to? Do you worry that people can read your mind? Do you worry that people know what you are thinking?
or thought echo;	Do you ever hear your thoughts being repeated out loud?

	Have you heard another voice repeat your thoughts?
	Do you feel like there is an echo in your head?
or delusions of control, influence or passivity (clearly referred to body or limb movements or specific thoughts, actions or sensations);	Have you ever felt that someone else is controlling you/your feelings, your thoughts/ how you are behaving? Have you thought that your thoughts, feelings and behaviours have not been your own?
or delusional perception;	Some people have an experience where something normal happens, but they think it has a special meaning, or is a special sign. For example, someone notices that it has started raining, and they think this is a sign that they need to save the world; or they see a green traffic light and think that this means they are the king
or hallucinatory voices giving a running commentary	Do you hear a voice/s that talks about everything you do while you are doing it? Do you hear a voice constantly talking about what you are doing?
2. One of the following symptoms is present for most of the time during a one-month period, or some time everyday for at least one month (a longer timescale, in view of the lesser diagnostic significance of these symptoms).	
A Delusions are not mood congruent (delusions cannot be explained by the person's religious, cultural and environmental background)	See **1.C**
B Hallucinations that are not mood congruent – these may occur in any sensory modality.	Do you ever see things that other people can't see? What kind of things have you seen? Did you know that other people couldn't see them? How did seeing them make you feel?

3. Two of the following symptoms must be present on most days for at least two weeks, although may change in intensity and type from day to day:	
A Delusions, that are not mood congruent (delusions cannot be explained by the person's religious, cultural and environmental background)	See **1.C**
B Hallucinations that are not mood congruent – these may occur in any sensory modality.	See **2.B**
C Catatonic symptoms, for example stupor, posturing, waxy flexibility, negativism	Have you felt that you have slowed down/that you are moving much more slowly than usual, or even staying in the same place and not moving at all, even when other people ask you to move?
D 'Negative' symptoms, where there is definitive evidence that these are a change from the individual's premorbid state/baseline functioning, for example apathy, loss of adaptive skills, impairment of goal-directed behaviour, flattening or incongruity of emotional responses	Do you ever notice a change in the things you can normally do? So, not being able to do things as well as normal, or not being able to do them at all? For example, not being able to do the daily activities you can normally do, like going for a shower, making your breakfast, cleaning your house or doing your food shopping? Do you ever notice a change in your motivation/wanting to do things you normally want to do? For example, not wanting to go to work/college/day centre, or to meet up with friends? Do you notice a change in the way you normally feel? For example, feeling like you don't care about things? Feeling a bit numb? Maybe not feeling as happy/excited/angry/upset as you normally would about things?
E Disordered form of thought, where there is definitive evidence that this is a	Have you felt like your thoughts were all mixed up so that when you spoke, you didn't make sense to people?

change from the individual's premorbid state.	Have there been times you have felt like you've had lots of ideas going around in your head?
	Have other people felt like it's been hard to understand, because you've switched between different topics/talking about different things?
	Have there been times when you've spoke really fast, without stopping? Did other people notice this was different from how you usually speak?
	Have there been times when people that know you well have not been able to understand what you are talking about (and this has been unusual)?

Appendix 7.2 Focus group excerpts

One Participant described being kept awake at night by voices that she thought were coming from vans driving past her house at night. She described sleeping in her wardrobe to try to block out the noise.

Participant 1: Haha, I know it sounds daft but… but, eh, naw… ah, cos, it was during the night and whenever bugging me, it was going roon aboot and I was trying to shut it off. So that's what I was trying to dae, but.

Support worker 1: Because you could hear the, the voices in the vans didn't you?

Participant 1: Oh huh

Interviewer: The voices in the vans?

Support worker 1: White vans I think, if I can recall from (nurse)

Interviewer: Can you tell me a bit more about what the voices in the vans were?

Participant 1: Uh

Support worker 1: They were talking about you weren't they?

Participant 1: Och, they were calling me Cows an that, whore, uh, umpteen things but.

Another participant seemed to have ambivalent feelings about hearing voices. Later in the conversation, the participant began to experience auditory hallucinations telling her not to talk to the group.

Interviewer: So when you, when you heard the voice telling you what to do… it sounds like from what [Support worker 2] is saying, sometimes you would get annoyed by it?

Participant 2: Yes

Interviewer: But you said before that sometimes it made you happy… so… was there someone else, were they nice to you sometimes?

Participant 2: Yeah

Interviewer: Yeah? Can you remember what kind of nice things they used to say?

Participant 2: How you keeping

Interviewer: Ok, they'd ask how you're keeping?

Participant 2: Yeah

……

Support worker 2: Do you hear anything [Participant 2], in your head?

Participant 2: Aye

Support worker 2: What's it saying? Can you tell us?

Participant 2: Just keep quiet

Interviewer: Ok, so it's telling you not to talk about it?

Participant 2: Uhuh. Keep it quiet

Interviewer: Just now?

Participant 2: Uhuh.

Participant 3's mother and Community Learning Disabilities Nurse (CLDN) talked about how she would not recognise her mother when she was unwell.

Interviewer: And who does she think you are?

Mother: She thinks I'm either an aunty or I've kidnapped her, one of the two

CLDN: She's made comments before about "your face has melted". That was a long time ago, remember when in [inpatient unit] she was saying things like that. You canny be ma mum your face has melted, ma mums face has'ne.

Participant 3 talked about voices which she believed were interfering with her body at night and stopping her from breathing. She frequently used a word (possibly a neologism) which she was unable to define 'cirtle'. Later in the conversation, her mother pointed out that her eyes were shifting when she did not believe what her mother was saying.

Participant 3: They're just quiet and they're tucked away interfering with my throat and I feel my neck sore and everything an they're piercing doon at the top but it's still interferring. Somebody's still interfering. Doing things to my human self eh body.

Interviewer: Ok

Participant 3: And my human self body is my body, my neck, my neck at the back and my throat at the front and they're breathing's cutting air, dead, into death, they're putting a big heavy, heavy heavy lasting, it's in my chest and it's sitting. This heavy weight on top of my chest

Interviewer: So it's like a heavy weight on top of your chest?

Participant 3: Aye.

Interviewer: And it's hard to breath?

Participant 3: It's no breathing

……….

Mother: If I wasn'e breathing I wouldn't be here [Participant 3] and neither would you {says to Interviewer watch the (Participant 3's) eyes] aye they wouldn'e be. That's when she's no believing you, did you see the eyes?

Interviewer: Mhmm

Mother: Mhmm. Shifty.

Appendix 7.3 Expert input

The expert panel stated that most people do not report what they are experiencing. They described the observations they have made of people with ID and psychosis while working in a Specialist Learning Disabilities inpatient unit.

Behaviours

Distracted, person doesn't seem to be in the moment

Person turns their head as if responding to something unseen i.e. nurse is talking to patient and patients is looking above nurses head or to the side

Sudden agitation and no obvious stimulation

Complaining about excessive noise (when there is none)

Starting to cry or becoming distressed – spontaneous, no noticeable trigger or cause – appears to be responding to a hallucination

Person becomes distressed when watching t.v. – thinks that a t.v. programme is based on their life

Person shows no facial expression - distress is only apparent through their disjointed conversation

Not sleeping – I'm not tired

Throwing shoes and personal objects at the wall → stating that there is someone in the wall

Talking to staff then looking away and laughing at something else

Person wears excessive make-up – change from usual

Gorging on food (continuous eating/not chewing) but only when food placed in front of them, do not seek it out

Requiring help with eating and drinking

Shadow boxing

Eye blinking/twitching head

Self-care neglect → requiring more prompts than usual

Standing motionless in shower or stripping and standing motionless

 Not taking usual cues e.g. in shower but does not start to wash self

Putting t-shirt on back to front

Listening to music/t.v./headphones more often to drown out auditory hallucinations

Talking to phone, talking to self

reacting to normal sights and sounds oddly, such as changes in light or noises from pipes

Standing in the shower for a very long time → possibly to block out sensations and sounds

---

Strange beliefs/delusions

Person makes odd statements e.g. 'I've won Britain's got talent'; 'I'm in the CIA'; 'I've won a car'; 'If I come out of my bedroom the cutting machines are going to get me'

Delusions based on events in the news

Beliefs about having a job in the inpatient unit after helping out with a chore

Patient might not present at distressed but narrative is deluded

Rocking back and forwards, restless pacing

Focus on famous/infamous people

Delusion of being covered in wasps

Believing that they themselves are the devil

Being taunted – hearing voices calling them names

Believing people are watching or staring at them

Reporting that they cannot sleep because bugs are biting them

Suspicious behaviour/statements

'You're writing lies'

Worrying that telling other people about their experience will put those people in danger

Not feeling safe because others will try to harm them

Believing insects are in food or medication

Visual hallucinations

Person states seeing unusual things e.g. Sir Lancelot, mounted police, woman in the wall, man standing outside, little boy etc.

Seeing animals when there are none

Change in personality

Unusual personality traits

Labile mood: hysterical laughing → crying → aggressive → quiet → sad

Unusually aggressive, disproportionate responses with no triggers

Stripping, running around naked, destructive behaviour

Impulsive behaviour

Violent behaviour – linked to delusional beliefs

Change in personality from good manners to inappropriate

Overly sexualised behaviour and speech content

Appendix 7.4 Expert feedback

Comments on self-report subscale

- Start by asking more open questions about how the person is feeling, before asking more specific questions that are scored, e.g. "Has anything been bothering or worrying you recently?".

- Use more open questions and prompts to elicit responses before providing the examples, e.g. "Has anyone been picking on you or getting at you?". Using the examples first might close the person down, or they might response with the example they have just heard.

- Auditory hallucination examples - voices talking to each other about the person are probably the most common type of hallucination, and voices giving commands are also common in psychosis, as is a voice giving a running commentary on what the person is doing.

- Questions and examples are complex and a lot to remember – recommend asking a specific question after the example, e.g. "Have you ever heard noises or voices when there is nobody around?".

- Too many examples for each question.

- Delusion question – do not think this describes what a delusion is and may lead to confusion.

- Perhaps more focus on the erroneous or absurd aspects of this experience.

- Recommend not using a screening item for negative symptoms.

- Consider whether people will understand the word "experience" – perhaps use the word feel/felt/thing, e.g. "Everyone with psychosis feels different", and "The first thing I want to ask you about is…".

- Good idea to give examples – in the first section, the easiest examples to understand (in terms of complexity of language) are provided first and increase in difficulty. Recommend following easy→difficult example order for all three questions. Person more likely to understand shortest/most concrete examples first.

- The scale of distress - 'How much' is a difficult concept. Recommend using a visual aid to support the person to answer these questions.

Comments of informant rating-subscale

- Start by asking more open questions/prompts about how the person, e.g. "Any strange experiences like hearing voices or seeing things that other people don't?".

- Add to list of questions – Is the person suspicious of other people?

- In the questions, as well as the TV, consider including phone and radio. And add in these objects referring to the person, giving messages, giving instructions

- Person talking to self - need to distinguish from soliloquy, rehearsing things, repeating nice things.

- Question re change in person's sexual behaviour - this is a mania question rather than schizophrenia. To capture mania, other more common items would be needed. Recommend removing this question.

- Too many items - most of them are not specific to psychosis which may lead to high numbers of false positives.

- Consider providing a reminder that questions 14-18 refer to changes that do not need to have taken place in only the past two weeks.

- Question 13 re switching topic in conversation - the ability to appropriately signal a topic shift, is like the ability to undertake conversational repair, a higher level language skill. And even people with a mild LD have some level of communication difficulty, most likely in this sort of area. So in this client group, the question may have less validity.

General comments on administration of tool

- Two weeks is a short period of time and could miss active symptoms of psychosis – recommend increasing to 4 weeks.

- Recommend developing a glossary of items to facilitate administration.

- Make clear who would administer the scale – consider that concepts and language are abstract so would need to determine that the person can operate at this level.

- Time scale - even people with mild LD tend to struggle with time concepts. Recommend that the clinician uses an event to anchor the time frame over which symptoms are being asked about.

- Provide a simple explanation of what psychosis is.

Appendix 8 – GPS-ID

Glasgow Psychosis Screening Tool (GPS-ID)

Section A – self-report

I would like to ask you/and your relative/ worker some questions about how you have been feeling over the last four weeks. The questions I'm going to ask are about something called psychosis. Everyone's experience of psychosis is different, but there are a few problems that most people experience, like seeing or hearing things that other people can't see and hear. There are no right or wrong answers to these questions, I just want to find out how you have been feeling. If you like, your relative/worker can help you answer.

Prompts:

- *Can you tell me how have you been feeling recently?*
- *Has anything been bothering or worrying you?*
- *Has anything strange or unusual happened to you recently?*
- *Has anything happened that you've found difficult to talk about or understand?*

---

1. Do you hear voices or sounds that only you can hear? Other people like your relative/ worker can't hear them. This is not about hearing your own voice when you are speaking or when you are thinking.

Has anything like this happened to you? Can you tell me about it? Your relative/ worker can help you if you like.

Prompts:
- *Can you think clearly?*
- *Has anyone been reading your mind?*
- *Has anyone been picking on you or getting to you?*
- *Has the T.V., radio or phone been bothering you?*

If you'd like, I can give you some examples of things that have happened to other people? Remember that everyone's experiences are different
Examples:
- *Jane hears voices in her head that talk about her; sometimes they call her nasty names.*
- *Mark hears a voice in his head that tells him what to do; sometimes it tells him not to speak to his support workers.*
- *Alice hears voices shouting at her from outside, but no one is there.*
- *Thomas hears a voice in his head that talks to him, sometimes it is nice and asks him how he is feeling.*
- *Claire hears a voice that talks about what she is doing; for example, it will say "Claire is washing the dishes".*
- *John hears a voice in his head telling him that other people are talking about him; it tells him not to trust them.*

How upsetting has this been for you in the last four weeks?

………..

………..

………..

………..

Evidence of an auditory hallucination		
No	**Yes,**	**Yes,**
=0	**little or no distress=1**	**very distressing =2**

---

2. Now I'd like to ask if you see things that only you can see? Other people like your relative/ worker can't see them.

Has anything like this happened to you? Can you tell me about it? Your relative/ worker can help you if you like.

Prompts:
- *Has anyone been watching you?*
- *Have you seen anything that has scared you?*

If you'd like, I can give you some examples of things that have happened to other people? Remember that everyone's experiences are different

Examples:
- *Jane sees a man standing outside her house watching her, but no one else can see the man.*
- *Mark sometimes sees a little boy and an old woman in his house, but no one else can see them.*
- *Alice sometimes sees people that look like zombies walking around; she feels really scared when this happens.*
- *Thomas sometimes thinks he can see a man following him, this happens more when it's dark.*
- *Claire sometimes sees her granddad waving at her; she knows that he died a long time ago but she feels happy when she sees him.*
- *John sometimes sees animals like cats and dogs, but his family say they can't see them.*

How upsetting has this been for you in the last four weeks?

………..

………..

………..

………..

Evidence of a visual hallucination		
No	**Yes,**	**Yes,**
=0	**little or no distress=1**	**very distressing =2**

---

3. Do you believe or think things that your family/ worker say can't be true?

Has anything like this happened to you? Can you tell me about it? Your relative/ worker can help you if you like.

Prompts:
- *How do other people behave to you?*
- *Are you suspicious of anyone?*

If you'd like, I can give you some examples of things that have happened to other people? Remember that everyone's experiences are different

Examples:
- *Jane sometimes thinks that aliens have stolen her brain.*
- *Mark sometimes thinks he is a spy, like James Bond.*
- *Alice sometimes thinks that things happening on a T.V. programme or in the news are about her.*
- *Thomas tells people that he has a new job working in a shop, but his support workers tell him this isn't true. Thomas gets really upset about this.*
- *Claire sometimes thinks that someone is trying to kill her; she worries that if she tells her family they will be in danger too.*
- *John sometimes believes that his family is not really his family; he will tell people 'that's not my mum'.*

How upsetting has this been for you in the last four weeks?

……
……
……
……

Evidence of a visual hallucination		
No **=0**	**Yes,** **little or no distress=1**	**Yes,** **very distressing =2**

Section B – carer observations

Now I'd like to ask your relative/ worker some questions about how you have been over the past

four weeks.

- Have you noticed any changes in the person's usual behaviour?
- Have you noticed any odd or unusual behaviour that you couldn't understand?
  - ➢ Can you tell more about this?
- Has the person developed any strange or new beliefs, unusual for them?
  - ➢ Can you tell me about these?
- Has the person had any strange experiences like hearing voices or seeing things that other people do not?

During the last four weeks…	No/ Never	Sometimes	Always / A lot
1. Has the person appeared distracted or as though they were listening to something others could not see?	0	1	2
2. Has the person reacted oddly to sights and sounds they would normally tolerate? For example, have they been scared when lighting in the room has changed or they have heard water	0	1	2

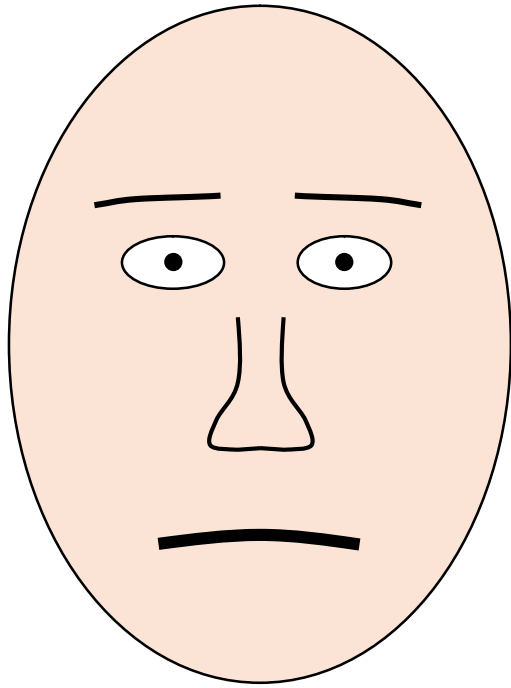|				
	trickling in the radiators?			
3.	Have you noticed the person turning up the T.V. or radio really loud or spending a long time in the shower as though trying to block out other sensations?	0	1	2
4.	Have you noticed the person becoming withdrawn? Perhaps asking for quiet time or talking to people less?	0	1	2
5.	Have you noticed the person becoming distressed, agitated, scared or upset when there has been no observable reason for this?	0	1	2
6.	Have you noticed the person becoming distressed, agitated, scared or upset when in a noisy environment or when watching the T.V., listening to the radio, or when holding their phone (but not making a call)? (Clarify T.V./radio content was not upsetting).	0	1	2
7.	Has the person thought that the T.V., radio or phone are referring to them, giving them messages or giving them instructions?	0	1	2
8.	Has the person been talking to themselves?	0	1	2
9.	Have you noticed the person talking to someone who isn't there, or talking to the T.V. or, radio or to their phone when they haven't made or received a call?	0	1	2
10.	Has the person said anything strange or impossible? For example, that they have stopped breathing, they have been kidnapped, or that aliens are listening to their thoughts?	0	1	2
11.	Has the person said something plausible that you know is untrue? For example, that they have just had an operation or that their purse has been stolen?	0	1	2
12.	When the person is talking to you, have you noticed that sometimes they are not making any sense?	0	1	2
13.	When the person is talking to you, have they switched between different topics so that it is hard to follow what they are talking about?	0	1	2
14.	When you are talking to the person, have you noticed their eyes shifting to the side or their head twitching?	0	1	2
15.	Has the person been suspicious of other people?	0	1	2
16.	Has the person had problems sleeping? For example, have they complained of not being able to sleep because of hearing voices or feeling things on their skin, such as bugs crawling on them or biting them?	0	1	2
17.	Have you noticed a change in the person's self-care skills? For example, have they been less able to wash themselves as well as they normally would? Have they put their clothes on back to front? Have they worn much more or much less make-up or hair gel than usual? Have they needed more self-care prompts?	0	1	2
18.	Have you noticed a change in how the person usually eats and drinks? For example, have they gorged on food, gulping it down without chewing it properly? Have they seemed distracted and eaten less than usual? Have they needed more help with eating and drinking than usual?	0	1	2
19.	Have you noticed a change in the person's personality? For example, have they been more aggressive, irritable, upset, distressed or quiet than usual? Have they appeared to do things	0	1	2

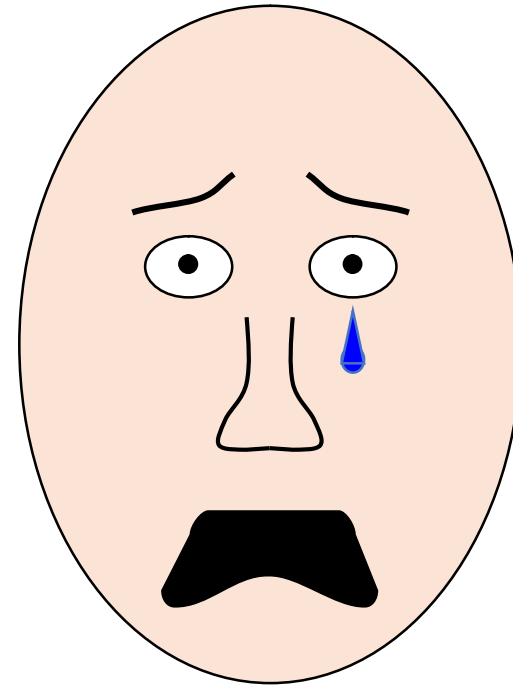|			
more slowly than usual?			
20. Have you noticed any other change causing concern?...	0	1	2

Scoring system

Subscale	Score
Section A – Self-report	
Hallucinations subscale = question 1 + question 2	
Delusions subscale = question 3	
Total self-report = question 1 + question 2 + question 3 (range 0-6)	
Section B – Informant ratings	
Total informant rating = Sum of questions 1-20 (range 0-40)	
Total score = section A + section B (range 0- 46)	

A total score of ≥4 yields a sensitivity of 90% and specificity of 100%

The GPS-ID is not a diagnostic tool. Any Individual meeting or exceeding this score should receive further assessment. It is possible that the cut-off score can be met without a positive score on the self-report scale – it is imperative that such scores be interpreted with caution and individuals receive further assessment to rule out other possible causes of the observed behaviours.

OK or a little upset

Very Upset

GPS-ID: interviewer instructions for use

The GPS-ID is not a diagnostic tool. Any individual meeting or exceeding the cut-off score of ≥4 should receive further assessment.

This screening tool is designed to be completed by a clinician competent in the assessment of mental health difficulties, e.g. a psychologist or a psychiatrist. It should be completed with both the individual and a relative or worker who knows them well, and has observed their behaviour over the past four weeks. Section A is designed to encourage the individual to report their experiences, with help from their relative/worker if necessary. Section B asks their relative/ worker to rate how often the individual has displayed a range of behaviours.

Section A (questions 1-3)

This section is designed to encourage the individual to self-report any symptoms they have been experiencing over the past four weeks. To help the individual think about this time-frame, try to establish an anchor event that occurred four weeks ago (for example going to a birthday party) and ask them to think about how they have felt since then. All writing in plain text should be read aloud to the individual, substituting 'person' and 'relative' etc. for the appropriate name, e.g. "I'd like to ask you and your mum some questions…". Use the first list of prompts to encourage the individual to talk about how they have been feeling, before moving on to the specific questions 1-3. For questions 1-3, an initial question is followed by several prompt questions. Although the prompts in questions 1 and 2 are designed to elicit reporting of hallucinatory experiences, it is possible they may cause the person to discuss experiences of delusions, and vice versa, with the prompts in question 3. If this occurs, use the information the individual supplies to complete the relevant question. It is not necessary to ask all the prompt questions the assessor should use clinical judgement to guide them. If the individual is struggling to understand the question and prompts, move on to the examples. It is not necessary to read through every example, but they should be read in the order in which they appear. After each example ask "Has anything like that happened to you?".   Always ask the initial question and prompts before reading the examples.

For reports of hallucinations, check that these cannot be explained by other sources, for example hearing a neighbours' T.V. or someone walking past outside. For reports of delusions, check that these are not developmentally appropriate beliefs, such as having imaginary friends. Record the person's hallucination and/or delusional experiences and ask how upsetting they have found these to be, using the visual aid to help them answer. Clinical judgement should be used to decide

whether there is evidence of true hallucinatory or delusional experience, and rate according to level of distress reported by the person and their relative/ worker.

Section B (questions 1-20)

This section is designed to help the relative/worker report behaviours they have witnessed over that past four weeks that may be indicative of psychosis. The initial prompts should be used to encourage the relative/worker to speak more broadly about any unusual behaviour or changes they have noticed, before asking them to rate the specific questions. The relative/ worker is asked to rate how often the behaviours outlined in questions 1-17 have been present during the past four weeks. Questions 17-20 refer specifically to any **changes** that the carer has noticed in the individual's behaviour. These changes do not have to have occurred in the past four weeks, and may have been noticeable over the last few months. If the carer has noticed changes but these are known to be due to a physical illness they should be rated as 'No/Never'.

Glossary of terms and instructions for use

For all items, do not rate if they can be explained by other psychiatric disorders, drug or alcohol use, physical illness or sensory impairments.

1. **Appearing distracted/listening to something others could not see**
   The person struggles to concentrate on those around them and may appear to focus on empty space as though listening to some unseen entity speaking to them.

2. **Reacting oddly to sights and sounds they would normally tolerate**
   Does the person appear scared or agitated by sights or sounds that usually have no effect? Ensure not due to sensory issues.

3. **Blocking out other sensations**
   Check that person is not turning up the T.V. or radio to drown out noise from other objective sources. Do not rate if they have a known hearing impairment.

4. **Becoming withdrawn**
   Is there evidence that this is a change from the individual's usual functioning, for example apathy, loss of adaptive skills, impairment of goal-directed behaviour, flattening or incongruity of emotional responses. Rate as '2' if present for most days for at least two weeks. Do not rate if there is a clear explanation, such as a life event precipitating low mood.

5. **Distressed, agitated, scared or upset when there has been no observable reason**
   Check that there is no obvious reason for distress, or whether it may be a delayed reaction to another event. Did it seem as though the person was responding to something that others could not see or hear.

6. **Distressed, agitated, scared or upset due to noisy environment/T.V./radio/phone**
   Clarify that T.V./radio content was not distressing. Check whether person understands T.V. shows/characters are not real e.g. do they think that a character actually died or that another character is an actual murderer.

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7. **Concern that the T.V., radio or phone are referring to them**
As above, ensure that person understands T.V. programmes are not real. Probe to ascertain if there is a logical reason as to why the individual thinks the T.V. was referring to them, e.g. they share a similarity with a character or the show is set in the city they live in.

8. **Person has been talking to themselves**
If this is the person saying their thoughts out loud, rehearsing things or repeating nice things to themselves it should be scored as '0'.

9. **Talking to someone who isn't there, or to the T.V., radio or phone**

10. **Saying strange or impossible things**
Check the person's level of conviction, do they continue to believe these things despite evidence to the contrary. Do not rate if they can be explained by the person's religious, cultural and environmental background.

11. **Saying something plausible that is untrue**
Check there is not a rational reason for why the individual thinks this. If it has been a misunderstanding rate as 0. If the individual believes it to be true despite there being no misunderstanding or no evidence, rate as 1 or 2.

12. **Person is not making sense when talking**
Is there evidence that this is different from the person's usual level of functioning? Rate if there is evidence of making up new words, breaks, adding in information, or being tangential in the train of thought.

13. **Person switching between different topics when talking**
As above.

14. **Person's eyes shifting to the side or their head twitching**
Rate as '0' if this is known to be due to a visual or other sensory impairment.

15. **Suspicious of other people**
Only rate this symptom as present if there are no rational grounds for the person's suspicions. It is important to consider that people with learning disabilities can be vulnerable to bullying and abuse.

16. **Problems sleeping**
If the person reports being kept awake by voices or noise, check these are not from neighbours or outside etc. If the person has been observed to have problems sleeping but has not reported why, check they have not experienced any recent physical illness or pain that might account for this problem.

17. **Changes in the person's self-care skills**
Rate as 0 if due to physical ill health.

18. **Change in how the person usually eats and drinks**
Rate as 0 if due to physical ill health.

19. **Change in the person's personality**

Check that changes cannot be explained by physical ill health or pain.

20. **Other change in behaviour**
Rate behaviour which is a change from the person's usual behaviour and cannot be explained by a rational cause, or physical illness.

The Psychotic Symptom Rating Scales

Interview Schedule

Gillian Haddock

Version 2009

AUDITORY HALLUCINATIONS

1. **Frequency**

Probing questions

How often have you heard your voices over the last week?
Thinking about the last week, what has it been like?" e.g. every day, all day long etc."

Scoring criteria:

0   Voices not present or present less than once a week (specify frequency if present)
1   Voices occur for at least once a week
2   Voices occur at least once a day
3   Voices occur at least once an hour
4   Voices occur continuously or almost continuously i.e., stop for only a few seconds or minutes

2. **Duration**

Probing questions

When you have heard your voices over the last week, how long have they lasted?
Have they lasted for a few seconds, minutes, hours, all day long for example....?"

Scoring criteria:

0   Voices not present
1   Voices last for a few seconds, fleeting voices
2   Voices last for several minutes
3   Voices last for at least one hour
4   Voices last for hours at a time

3. **Location**

Probing questions

When you have heard your voices over the last week, where did they sound like they were happening?

Did they sound like they were inside your head and/or outside your head? Whereabouts do your voices sound like they are coming from?

Scoring criteria:

0   No voices present

1	Voices sound like they are inside head only
2	Voices outside the head, but close to ears or head. Voices inside the head may also be present.
3	Voices sound like they are inside or close to ears and outside head away from ears
4	Voices sound like they are from outside the head only

4. Loudness

Probing questions

How loud are your voices?
Are they louder than my voice, about the same loudness, quieter or just a whisper?

Scoring criteria:

0	Voices not present
1	Quieter than own voice, whispers.
2	About same loudness as own voice
3	Louder than own voice
4	Extremely loud, shouting

5. Beliefs regarding the origin of voices

Probing questions

What do you think has caused your voices?
Are the voices caused by factors related to you, or due to other people or factors?
Are your voices caused by your mental health problems or illness?

How much do you believe that your voices are caused by (add interviewee's contribution) on a scale from 0-100 with 100 being that you are totally convinced, have no doubts and 0 being that it is completely untrue?

Scoring criteria:

0	Voices not present
1	Believes voices to be solely internally generated and related to self
2	Holds a less than 50% conviction that voices originate from external causes
3	Holds 50% or more conviction (but less than 100%) that voices originate from external causes
4	Believes voices are solely due to external causes (100% conviction)

6. Amount of negative content of voices

Probing questions

Do you think that your voices have said unpleasant things or negative things over the last week?
How much of the time do the voices say these types of unpleasant or negative items?

Scoring criteria:

0   No unpleasant content
1   Occasional unpleasant content
2   Minority of voice content is unpleasant or negative (less than 50%)
3   Majority of voice content is unpleasant or negative (50% or more)
4   All of voice content is unpleasant or negative

7. **Degree of negative content**

Probing questions

Can you tell me a bit about what you have heard your voices saying over the last week?
Can you give me some examples of the things you have heard this week?

Scoring criteria:

0   Not unpleasant or negative
1   Some degree of negative content, but not personal comments relating to self or family e.g. swear words or comments not directed to self, e.g. "the milkman's ugly"
2   Personal verbal abuse, comments on behaviour e.g. "shouldn't do that or say that"
3   Personal verbal abuse relating to self-concept e.g. "you're lazy, ugly, mad, perverted"
4   Personal threats to self e.g. threats to harm self or family, extreme instructions or commands to harm self or others and personal verbal abuse as in (3)

8. **Amount of distress**

Probing questions

Have you found your voices to be distressing over the last week?
How much of the time have they caused you distress over the last week?

Scoring criteria:

0   Voices not distressing at all
1   Voices occasionally distressing, majority not distressing (<10%)

2   Minority of voices distressing (<50%)

3   Majority of voices distressing, minority not distressing (≥ 50%)

4   Voices always distressing

9. **Intensity of distress**

Probing questions

Over the last week when your voices have been distressing, how distressing has that been? Thinking about the worst distress you could feel, over the last week, how have your voices compared to that? For example, has it been slightly, moderately distressing etc.?

Scoring criteria:

0   Voices not distressing at all

1   Voices slightly distressing

2   Voices are distressing to a moderate degree

3   Voices are very distressing, although interviewee could feel worse

4   Voices are extremely distressing, feel the worst he/she could possibly feel

10. **Disruption to life caused by voices**

Probing questions

How much disruption have the voices caused to your life over the last week?
Can you tell me how the voices stopped you from working or doing any other daytime activity that you wanted to do?
How much have they interfered with your relationships with friends and/or family?
How much have they prevented you from looking after yourself, e.g. bathing, changing clothes, etc.?

Scoring criteria:

0   No disruption to life, able to maintain social and family relationships (if present)

1   Voices cause minimal amount of disruption to life e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support.

2   Voices cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The interviewee is not in hospital although may live in supported accommodation or receive additional help with daily living skills.

3   Voices cause severe disruption to life so that hospitalisation is usually necessary. The interviewee is able to maintain some daily activities, self-care and relationships whilst in hospital. The interviewee may also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships.

4   Voices cause complete disruption of daily life requiring hospitalisation. The interviewee is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

11. <u>**Controllability of voices**</u>

Probing questions

What control had you had over your voices over the last week?

How much control have you had over your voices when they happened over the last week?

Can you get rid of, dismiss or bring on your voices?"

Scoring criteria:

0   Interviewee believes they can have control over the voices and can always bring on or dismiss them at will

1   Interviewee believes they can have some control over the voices on the majority of occasions

2   Interviewee believes they can have some control over their voices approximately half of the time

3   Interviewee believes they can have some control over their voices but only occasionally. The majority of the time the interviewee experiences voices which are uncontrollable

4   Interviewee has no control over when the voices occur and cannot dismiss or bring them on at all.

DELUSIONAL BELIEFS

1. <u>Amount of preoccupation with delusions</u>

Probing questions

*Over the last week, how much time have you spent thinking about your beliefs about ……
[insert client's beliefs]?*

Scoring criteria:

0   No delusions, or delusions which the interviewee thinks about less than once a week.

1   Interviewee thinks about beliefs at least once a week.

2   Interviewee thinks about beliefs at least once a day.

3   Interviewee thinks about beliefs at least once an hour.

4   Interviewee thinks about delusions continuously or almost continuously.

2. <u>Duration of preoccupation with delusions</u>

Probing questions

*When you have thought about any of your beliefs (i.e. [insert interviewee's beliefs] …) over
the last week, how long do they tend to stay in your mind? - Few seconds/minutes/hours,
etc.?*

Scoring criteria:

0   No delusions

1   Thoughts about beliefs last for a few seconds, fleeting thoughts

2   Thoughts about delusions last for several minutes

3   Thoughts about delusions last for at least one hour

4   Thoughts about delusions usually last for hours at a time

3. <u>Conviction</u>

Probing questions

*At the moment, do you have any doubts about any of your beliefs, for example do you
sometimes wonder whether they are real or not? (Go through each belief in turn).*

*How much do you believe in…[insert belief/beliefs]? Can you estimate this on a scale from 0
– 100, where 100 means that you are totally convinced by your beliefs and 0 being that you
are not convinced at all?*

Scoring criteria:

0   No conviction at all
1   Very little conviction in reality of beliefs, less than 10%
2   Some doubts relating to conviction in beliefs, between 10-49%
3   Conviction in belief is very strong, between 50 – 99%
4   Conviction is 100%

4. **Amount of Distress**

Probing questions

Have your beliefs about [insert interviewee's beliefs] caused you distress over the last week? How much of the time have they caused you distress over the last week?

Scoring criteria:

0   Beliefs never cause distress
1   Beliefs cause distress on the minority of occasions.
2   Beliefs cause distress on less than 50 % of occasions
3   Beliefs cause distress on the majority of occasions when they occur between 51-99% of time
4   Beliefs always cause distress when they occur

5. **Intensity of Distress**

Probing questions

Over the last week, when you have felt distressed by your beliefs about [insert interviewee's beliefs] how severe does this feel?" Have you felt slightly, distressed, moderately distressed etc..

Scoring criteria:

0   No distress
1   Beliefs cause slight distress
2   Beliefs cause moderate distress
3   Beliefs cause marked distress
4   Beliefs cause extreme distress, couldn't be worse

6. **Disruption to life caused by beliefs**

Probing questions

In what way have your beliefs caused disruption for you over the last week?
In what way have they stopped you working or carrying out a day-time activity?
In what way have they interfered with your relationships with family or friends?
In what way have they interfered with your ability to look after yourself, e.g. washing, changing clothes, etc.?

Scoring criteria:

0   No disruption to life, able to maintain independent living with no problems in daily living skills. Able to maintain social and family relationships (if present)

1   Beliefs cause minimal amount of disruption to life, e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support.

2   Beliefs cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The interviewee is not in hospital although may live in supported accommodation or receive additional help with daily living skills.

3   Beliefs cause severe disruption to life so that hospitalisation is usually necessary. The interviewee is able to maintain some daily activities, self-care and relationships whilst in hospital. The interviewee may also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships.

4   Beliefs cause complete disruption of daily life requiring hospitalisation. The interviewee is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

AUDITORY HALLUCINATIONS RATING SCALE SCORE SHEET

Briefly describe experiences for rating:

1.   FREQUENCY……………………………………………….. |___|

2.   DURATION…………………………………………………. |___|

3.   LOCATION………………………………………………… |___|

4.   LOUDNESS……………………………………………….. |___|

5.   BELIEFS RE-ORIGIN OF VOICES……………………………… |___|

6.   AMOUNT OF NEGATIVE CONTENT OF VOICES………… |___|

7.   DEGREE OF NEGATIVE CONTENT……………………….. |___|

8.   AMOUNT OF DISTRESS………………………………………… |___|

9.   INTENSITY OF DISTRESS…………………………………….. |___|

10.   DISRUPTION…………………………………………………… |___|

11.   CONTROL………………………………………………………… |___|

TOTAL AUDITORY HALLUCINATIONS SCORE |___|

DELUSIONS RATING SCALE SCORE SHEET

Briefly describe experiences for rating:

1.   AMOUNT OF PREOCCUPATION…………………………………   ☐

2.   DURATION OF PREOCCUPATION……………………………..   ☐

3.   CONVICTION……………………………………………………….   ☐

4.   AMOUNT OF DISTRESS…………………………………………   ☐

5.   INTENSITY OF DISTRESS………………………………………..   ☐

6.   DISRUPTION………………………………………………………   ☐

TOTAL DELUSIONS SCORE   ☐