Review and update of the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD)

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Keywords:	Outcome Scales, Rating Scales, Intellectual Disability, HoNOS, Needs
Abstract:	Background: The Health of the Nation Outcomes Scales for people with Learning Disabilities (HoNOS-LD) is an eighteen-item measure which provides a structured and standardised approach to rating various clinical and psychosocial outcomes and has been in use nationally since 2002. Aims: To revise and improve the HoNOS-LD's utility in contemporary intellectual disability (ID) services whilst retaining its original objectives and five-point severity ratings. Method: ID clinicians were invited to complete an online survey, rating each item on the existing measure for being fit for purpose, identifying issues, and suggesting improvements based on their experience of using the HoNOS-LD in practice. Scales were then assessed and revised sequentially; survey responses were used to inform discussion and revisions to the HoNOS-LD by the Advisory Board. Results: A total of 75 individuals replied. Respondents had used HoNOS-LD for an average of 8.0yrs (S.D.5.28yrs) and 88% found the scale to be useful in their practice. On average, respondents used HoNOS-LD ratings to inform care 42.4% of the time (S.D. 33.5%). For each scale there was a significant negative correlation between the percentage of positive/very positive respondent ratings and the number of changes proposed. Common changes included simplifying terms, reducing ambiguity, and replacing anachronistic language. Conclusion: The changes outlined in this paper are based on the advisory group's expert consensus. These changes are intended to improve reliability and validity but now need empirical testing as well as review by service users.

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Short Title: Review and update of HoNOS-LD

Keywords: Outcome Scales, Rating Scales, Intellectual Disability, HoNOS, Needs

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Declaration of interest

All authors were members of the project's Expert Advisory Board

AR is the original developer of the HoNOS LD

RS has received institutional and research support from LivaNova, GW pharma, UCB, Eisai, Veriton pharma, Averelle and Destin outside the submitted work.

Funding

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Strengths and limitations of this study:

- Advisory Board members individually and collectively had a broad range of expertise in the use of the HoNOS LD.
- Participants represented a broad range of professions, working with PwID in a variety of settings, in two different countries.
- Survey responses were managed in a systematic and transparent manner through the application of a priori criteria that had been successfully applied in similar studies.
- Survey response rates are not known.
- The resulting measure is yet to be empirically tested and reviewed by service users.

Introduction

Intellectual Disability

Intellectual disability (ID) describes 'a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, including cognitive, language, motor and social abilities' (WHO, 2019). In the United Kingdom however, the term learning disability (LD) is the preferred term (Cluley, 2017) This article refers to clinical tools from the 1990s as well as contemporary clinical practice hence both terms are used interchangeably according to the timepoint in question.

The Health of the Nation Outcome Scales (HoNOS) and the HoNOS-LD

The HoNOS is a twelve-item outcome measure intended for use with adults of working age experiencing severe mental conditions (Wing et al, 1999). It was developed and refined through field tests with 2,706 patients and 492 clinicians (including psychologists, nurses, occupational therapists, psychiatrists, speech and language therapists and support workers) before the final version was validated with 197 psychiatric patients (Wing et al, 1998).

Testing of HoNOS with people with intellectual disabilities (PwID) found limitations in key clinical areas such as communication skills and movement disorders (Ashaye et al, 1997). This resulted in the development of the HoNOS-LD, an eighteen-item measure, which was tested against other established measures with 372 PwID. This was shown to have good reliability and validity, providing a structured and standardised approach to measure various clinical and psychosocial outcomes (Roy et al, 2002).

Like the HoNOS, the HoNOS-LD was intended to be holistic, suitable for routine use and hence acceptable to a range of professions in a variety of settings (Wing et al, 1998). It was also designed to have good reliability (both inter-rater and internal consistency), sensitivity to change over a three-month period, and have a positive correlation to more established scales such as the Aberrant Behaviour Checklist (Roy et al, 2002; Tenniij et al, 2009).

Since its development, the HoNOS-LD has been translated into other languages including French (Straccia, 2021) and Spanish (Esteba-Castillo et al, 2018). It is used in clinical practice in England, where it forms part of outcome data collected nationally (NHSDigital, 2022) and New Zealand, where its use is mandated (Ministry of Health, 2011; Te Pou, 2021). It has shown to be useful in measuring outcomes and guiding treatment in a range of settings (Hillier et al, 2010).

The aim of this study was to review and improve the HoNOS-LD's utility in contemporary intellectual disability services whilst retaining its original objectives and five-point severity ratings. This paper outlines the scope, process, issues identified, and resulting revisions (subsequently renamed HoNOS-Intellectual Disabilities or HoNOS-ID)

Method

Study design:

An Advisory Board (chaired by the RCPsych's National HoNOS Advisor) was convened by canvassing professional networks for representatives from England and New Zealand with extensive experience in either: HoNOS-LD staff training; its use in clinical practice; using aggregated HoNOS-LD data for service, professional or governmental level oversight. The eight Board members represented psychiatry, psychology, mental health and ID nursing, nurse educators and information analysts from England and New Zealand (see supplementary information 1).

Members of this board oversaw the development of an online survey tool and identified relevant professional stakeholder networks (including the UK's: Royal College of Psychiatrists, the British Psychological Society, Learning Disability Senate, Intellectual Disability Research Network and New Zealand's: Programme for the Integration of Mental Health Data and the HoNOS Trainer's Group), where the survey link was subsequently circulated. Finally, Board member JP collated and analysed the survey responses before using them to inform the Board's revisions to the HoNOS-LD.

Measures:

With reference to the project's aims and objectives, the bespoke questionnaire was developed using Qualtrics (Qualtrics, 2022), an online survey platform. The international membership of the working group ensured the phrasing of questions was generalisable to clinicians working both in the UK and New Zealand where different terminology is used. The final version of the survey was estimated to take approximately 30 minutes to complete which was deemed the optimum time to balance response engagement and gain the minimum required information to draw meaningful conclusions.

The online cross-sectional survey used an exponential and non-discriminatory snowballing technique (Etikan et al, 2016). This involved commencing with key contacts in professional organisations of the authors in different participating countries and requesting they forward the request and link within their own professional networks. This should be considered non-probability sampling.

The introductory section specified that the survey was aimed at clinicians working primarily with PwID before gathering some generic information about the respondents. Subsequent sections guided participating healthcare professionals to reflect on their experience of using the HoNOS-LD in routine practice, to identify issues, and to suggest any revisions they felt the Advisory Board should consider making. Finally, for the overarching HoNOS-LD instruction

page, and each of the subsequent 18 scales, the original text was presented followed by four questions:

i) What could be changed to simplify this part of the tool?
ii) What could be changed to reduce ambiguity in this part of the tool?
iii) Is there any language in this section that is now outdated in the context of contemporary practice?
iv) Overall, this section is fit for purpose (a five-point Likert scale from 'strongly disagree' – 'strongly agree').

The survey was available online throughout July and August 2020 with a reminder to encourage participation sent at the midpoint. The survey template is provided in supplementary information 2.

Process:

To ensure consistency with the previous reviews of HoNOS (James, Painter, Buckingham et al, 2018) and HoNOS65+ (James, Buckingham, Cheung, et al, 2018), the same criteria were used to judge the survey responses. These were that, for a change to be supported, it needed to result in a tangible improvement (for example simplification / clarification / removal of anachronisms) and:

- maintain the original instrument's integrity as far as possible.
- maximise comparability with existing individual and aggregated data.
- support the use of HoNOS-LD as a summary of clinical assessment(s).
- adhere to the HoNOS-LD 'core rules':
    - each item is a behaviourally anchored 5-point scale.
    - items are sequentially rated (1-18).
    - all available information is used to make a rating.
    - information already rated in an earlier item is disregarded.
    - the most severe problem/worst manifestation from the preceding four weeks is rated.
    - problems are rated according to the degree of distress caused and/or its impact on behaviour.
    - must be rated by a mental health professional trained in clinical assessment.
    - problems are rated regardless of cause.

Ethics and governance:

All participants were advised at the start of the study that participation was voluntary, that no participant identifiable data would be collected, and their replies would be anonymised and pooled prior to analysis. Further, it was specified that informed consent from these healthcare professionals would be presumed if participants submitted the survey. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant

national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. *All procedures involving human subjects/patients were* ethically approved by Sheffield Hallam University (Review ID: ER21994638).

Analysis:

Anonymised responses to the survey were downloaded into Microsoft Excel for data cleaning and analysis. Fixed-response variables were categorical or ordinal, thus analysis consisted of frequencies and cross tabulations. A Spearman's rank correlation was calculated to assess the relationship between the percentage of positive/very positive fitness-for-purpose ratings and the number of changes proposed for each scale.

Free-text replies were grouped for analysis by author (MM) before authors (JP and MJ) applied the agreed criteria to categorise each suggestion as potentially in/out of scope according to the magnitude and significance of the change that would be required. In conjunction with the Likert scale ratings for each HoNOS-LD scale (table 2), this helped to structure the Advisory Board's monthly online meetings. Scales were assessed and revised sequentially before the revised tool was reviewed in its entirety to ensure:

- No changes had breached the a priori project criteria.
- Consistency of language.
- The gradation of severity ratings remained in keeping with the original scales.
- All survey responses had either been actioned or rejected with the group's decision recorded for transparency.

Upon completion of their discussions, the Board agreed the final draft of the revised tool which is presented in this paper.

Results

The 75 respondents that completed the survey had worked in the field of ID for an average of 16.8yrs (S.D. 10.1yrs) and used HoNOS-LD for an average of 8.0yrs (S.D.5.28yrs). Further participant details can be seen in Table 1.

Respondents	
Country of practice	
United Kingdom	n=65
New Zealand	n=10
Clinical Setting	
Exclusively inpatient	n=7
Exclusively community/outpatient	n=43
Both inpatient & community	n=25
Nature of usage	
In clinical practice	n=70
HoNOS LD trainers	n=9
Macro level (e.g., service evaluation)	n=9
Research	n=5
Other	n=2
Profession	
Nurse	n=37
Psychiatrist	n=11
Psychologist	n=9
Speech & language therapist	n=8
Occupational Therapist	n=6
Physiotherapist	n=2
Behavioural specialist	n=2
Confidence in ability to provide helpful insights	
Very Confident	n=10
Confident	n=38
Somewhat confident	n=24
Not confident	n=3

Table 1 Participant attributes

Nine survey respondents (12%) reportedly found HoNOS-LD extremely/very useful in their practice, 57 (76%) found it moderately/slightly useful, and nine (12%) did not find it useful. On average, respondents used HoNOS-LD ratings to inform care 42.4% of the time one was completed (S.D. 33.5%). Their fitness for purpose ratings can be seen below in Table 2 where scale 10 (Problems with sleeping) and 13 (Seizures) were rated most favourably and scales 3 (Other mental and behavioural problems) and 15 (Activities of daily living outside the home)

rated notably lower than the remainder. For each scale there was a significant negative correlation between the percentage of positive/very positive respondent ratings and the number of changes they proposed (r(17) = -.57, p = .016). However, there was no association between fitness for purpose and the actual number of changes made. In part this is due to the varying proportions of these suggestions that were deemed to be out of scope changes.

HoNOS-LD section	Responses to survey question: iv) Overall, this section is fit for purpose								Responses, by HoNOS-LD item to survey questions: i) What could be changed to simplify this part of the tool? ii) What could be changed to reduce ambiguity in this part of the tool? iii) Is there any language in this section that is now outdated in the context of contemporary practice?		
	Likert scale responses, by HoNOS-LD item						Percentage of grouped positive and grouped negative Likert Scale responses by HoNOS-LD item				
	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Total	% Agree or strongly agree	% Disagree/ strongly disagree	No of suggestions made	No of suggestions in scope	No of suggestions actioned
Glossary	0	2	17	21	3	43	56	5			
Scale 1	0	5	10	13	5	33	55	15	10	10	4
Scale 2	0	6	8	16	3	33	58	18	11	9	5
Scale 3	1	7	9	12	2	31	45	26	12	9	4
Scale 4	0	7	3	15	5	30	67	23	7	7	2
Scale 5	0	4	9	13	3	29	55	14	10	10	7
Scale 6	2	4	5	11	4	26	58	23	12	8	7
Scale 7	3	3	7	9	6	28	54	21	8	5	4
Scale 8	0	4	8	11	5	28	57	14	10	9	5
Scale 9	0	3	8	11	6	28	61	11	7	6	6
Scale 10	0	3	5	14	6	28	71	11	5	5	3
Scale 11	1	5	5	13	4	28	61	21	10	10	10
Scale 12	2	5	6	10	5	28	54	25	8	5	4

Scale 13	0	1	8	11	8	28	68	4	8	7	7
Scale 14	0	6	7	11	4	28	54	21	12	10	5
Scale 15	0	8	8	9	3	28	43	29	10	7	4
Scale 16	Missing data	Missing data	Missing data	Missing data	Missing data	Missing data	Missing data	Missing data	6	5	4
Scale 17	1	5	5	12	4	27	59	22	4	4	2
Scale 18	0	4	9	12	1	26	50	15	11	8	7

Table 2: Survey responses to questions i-iv for each HoNOS-LD item

This information, together with the scale-by-scale qualitative feedback was used to inform the Advisory Board's deliberations which, ultimately resulted in the changes outlined in supplementary information 3 (original HoNOS-LD wording included to aid comparison with the new HoNOS-ID). The Advisory Board meetings took place monthly of which there were twelve in total over the course of the review.

Discussion

This publication follows the review of the original (working age) HoNOS (James, Painter, Buckingham et al, 2018), and HoNOS65+ (James, Buckingham, Cheung et al, 2018). These reviews were informed by each other prior to each version of the tool being finalised. However, the HoNOS-LD has some distinct and separate features and so, whilst some of the changes made to the HoNOS and the HoNOS 65+ were considered, the majority of the review was independent of previous changes.

The first survey question asked participants to identify areas of the tool requiring **simplification**. In this regard, the original tool attracted little criticism other than requests for the removal of medicalised terms such as diurnal variation. This is unsurprising given one of the tool's original aims was to be short enough for use in routine practice.

In contrast, and perhaps as a result of this same brevity, numerous areas of **ambiguity** (survey question 2) were identified by respondents. Here, the main challenge for the Advisory Board was to address these without excessively increasing the length of the scales. Examples of this include clarifying that scale 2 should capture self-harming and self-injurious behaviours regardless of motivation; and that dysphagia is to be included in scale 11. More problematic to address were the requests to quantify terms like 'occasional' and 'frequent'. The Board felt that, although this was possible, it could have unintended consequences and so such terms

were retained but efforts made to ensure they consistently equated to severity ratings across scales.

Survey respondents were also asked to identify **anachronistic language**. Some of this was straightforward to resolve, such as replacing the term 'fits' with 'seizures' (in scale 13) and the terms 'learning disability' with 'intellectual disability' throughout the tool. Other examples required a more nuanced response to ensure replacements did not inadvertently introduce ambiguity. Typically, this arose with terms that respondents deemed to be pejorative like 'behavioural problems', 'pestering', 'odd beliefs', 'failure', 'limitations' and 'incapacity.' The Board sought to ensure the tool was compatible with the ethos of current policy and value-based service delivery frameworks (for example, Positive Behaviour Support)[17] wherever possible, maintaining dignity and empathy through language, within the limits of a tool originally designed to identify service user deficits. Having addressed issues scale by scale, the Board then reviewed the changes in their entirety to ensure consistency of language and severity ratings across the scales.

To further aid this, bullet points from the HoNOS 2018's over-arching instructions were utilised.[15] Firstly, that the glossary contains examples of behaviours to be rated, rather than exhaustive lists. Secondly that ratings of 0 and 1 are generally not clinically significant, requiring no specific action other than possible monitoring for change, whereas ratings of 2 and above are regarded as clinically significant. Finally, that the person's culture must be taken into account when rating all scales.

Limitations

Although the Advisory Board were purposively recruited for their significant expertise in the use of HoNOS-LD, and the survey respondents were drawn from a representative range of professional backgrounds that was more diverse than Roy et al's original study,[6], the overall sample size (n=75) is limited in terms of the combined ID workforce of England and New Zealand. Also, because the online survey link was circulated via professional networks the response rate is unknown. However, there was a large amount of descriptive, open text responses from the survey which was sufficient to make significant changes across the scales.

As with the review of HoNOS (James, Painter, Buckingham et al, 2018), and HoNOS65+ (James, Buckingham, Cheung et al, 2018), several potentially useful improvements were identified but ultimately rejected for falling outside the project's scope. This was because they were deemed to constitute substantial changes, that would have resulted in a completely new instrument. Perhaps the most notable example of this was the implicit assumption in the tool that physical (restraint) interventions are always used appropriately.

The changes outlined in this paper are based on expert consensus alone. Given the original tool was designed as a Clinician Rated Outcome Measure (CROM) this is an acceptable first

step however, as with the updated versions of HoNOS and HoNOS 65+, they now require empirical testing and to form part of a meaningful consultation with service users. However, undertaking such studies would require funding and preferably involvement from all countries that have heavily invested in the existing HoNOS-LD to date. This issue is being actively pursued by members of the Advisory Board. Furthermore, although these changes are intended to improve reliability and validity, they do not obviate the continued need for training in the use of the scales.

Conclusion

The HoNOS LD was found to have continued clinical utility but was in need of updating. The resulting HoNOS-ID addresses many of the participants' suggestions, creating a measure more in keeping with contemporary ID practice. Service user consultation, and further research (with a focus on practical application within different clinical settings) is now required to test these changes in preparation for introduction into the national datasets of England and New Zealand.

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Supplementary Information #1

Advisory Board Membership			
Name	Profession	Affiliation	Country
Mick James	Registered Mental Health Nurse	Royal College of Psychiatrists	England
Jon Painter	Registered Nurse LD & Registered Mental Health Nurse	Sheffield Hallam University	England
Ashok Roy	Psychiatrist	Coventry and Warwickshire Partnership Trust	England
Rohit Shankar	Neuropsychiatrist	University of Plymouth	England
Barry Ingham	Clinical Psychologist	Cumbria, Northumberland, Tyne and Wear NHS FT	England
Mark Smith	Clinical Lead	Te Pou	NZ
Nicola Adams	Nurse Educator	Te Pou	NZ
Sandra Baxendale	Information analyst	Te Pou	NZ

International Review of HoNOS-LD - Survey of raters

Participant INFORMATION:

International Review of HoNOS-LD - Survey of raters

The HoNOS-LD has been in use since its publication in 2002 without any revision of the glossary. Other versions of the HoNOS family have recently undergone review and a joint review of the HoNOS-LD has been therefore agreed between teams in England and New Zealand. This project will not necessarily lead to a new version of the tool and the intention of the review is not to make any major changes to the tool. The agreed scope is to consider minor changes to words or phrases that will make the HoNOS-LD easier to use in the field and ensure its language is appropriate to the contemporary care provision of people with Intellectual Disabilities, whilst maintaining its integrity and maintaining current core rules.

NB. No local changes should be made to the current tool and data collection processes. Any future changes will be coordinated centrally.

The study is being collaboratively undertaken by:

Sheffield Hallam University, The Royal College of Psychiatrists, Te Pou (New Zealand)

About this survey:

1. **Why have you asked me to take part? –** We are asking people who work in the field of Learning Disabilities who use the HoNOS-LD to reflect on their experience of using the scales in routine practice, and then to make suggestions about areas that they feel might benefit from improvement through revision. This survey guides you through the various sections of the scales and asks for feedback under specific categories.
2. **Do I have to take part?** NO- It is up to you to decide if you want to take part. If you do decide to take part, you can still decide not to answer one or more questions. You can also ask for your responses to be omitted for up to one week after completion by contacting the researchers
3. **Are there any possible risks or disadvantaged in taking part**. We do not foresee any risks or disadvantages of completing the survey.
4. **What are the possible benefits of taking part?** The information you provide will form part of the evidence that the Review Board will consider when proposing amendments to the HoNOS-LD. This should result in a better clinical tool for both service users and staff.
5. **Will anyone be able to connect me with what is recorded and reported?** Your responses will be saved digitally and stored on the University's dedicated research server and only be seen by the researchers. This is subject to strict data security measures that comply with the Data Protection act and GDPR.
6. **Who will be responsible for all of the information when this study is over**? Throughout the study the lead (Dr Jon Painter) will be responsible for safeguarding all data in accordance with the University's GDPR compliant policies and procedures.
7. **Who will have access to it?** Only Dr Jon Painter and a research assistant will have access to the raw data. They will translate these data into anonymised reports for use by members of the review board and potential publications.
8. **What will happen to the information when this study is over?** At the end of the study, all data will be securely stored on the university's dedicated research servers for a period of ten years to allow for any follow up post publication. The project folder will only be accessible to the project's principal investigator.
9. **How will you use what you find out?** The primary use of your responses will be to help the review board decide on the changes to HoNOS-LD they will propose. We may also include responses in the peer reviewed publication however this will be done in a way that ensures no individual or organisation can be identified.
10. **How long is the whole study likely to last?** The review process is anticipated to take approximately 18 months to complete.
11. **How can I find out about the results of the study?** The results, in the form of a proposed set of changes to the wording of the scale glossaries, will be published on the RCPsych website as well in a peer reviewed journal (subject to acceptance).

Legal basis for research for studies: Sheffield Hallam University undertakes research as part of its function for the community under its legal status. Data protection allows us to use personal data for research with appropriate safeguards in place under the legal basis of **public tasks that are in the public interest.** A full statement of your rights can be found at https://www.shu.ac.uk/about-this-website/privacy-policy/privacy-notices/privacy-notice-for-research. However, all University research is reviewed to ensure that participants are treated appropriately and their rights respected. This study was approved by UREC. Further information at https://www.shu.ac.uk/research/ethics-integrity-and-practice

Contacts: Details of who to contact if you have any concerns or if questions occur after you have completed the survey are: Dr Jon Painter Telephone 0114-2252376 E-mail j.painter@shu.ac.uk

You should contact the Data Protection Officer if:

- you have a query about how your data is used by the University
- you would like to report a data security breach (e.g. if you think your personal data has been lost or disclosed inappropriately)
- you would like to complain about how the University has used your personal data DPO@shu.ac.uk

You should contact the Head of Research Ethics (Professor Ann Macaskill) if: you have concerns with how the research was undertaken or how you were treated a.macaskill@shu.ac.uk Sheffield Hallam University, Howard Street, Sheffield S1 1WBT Telephone: 0114 225 5555

Participant Consent:

International review of HoNOS-LD - survey of raters *Please select the response that applies to each of the 5 statements below*

	Response	
	Yes (1)	No (2)
1. I have read the information about this study.	○	○
2. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any point by contacting the principal investigator	○	○
3. I agree to provide information to the researchers under the conditions of confidentiality set out in the Information Sheet.	○	○
4. I wish to participate in the study under the conditions set out in the information.	○	○
5. I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes.	○	○

INSTRUCTIONS:

There are 4 sections to the survey:

- Section 1 asks about your background and HoNOS-LD expertise; .
- Section 2 asks for your opinions about the overarching rating instructions of the HoNOS-LD
- Section 3 asks for your opinions about each of the 12 scales of the HoNOS-LD; and
- Section 4 asks for any final comments you have about the HoNOS-LD or the survey.

To assist you with answering the questions, the relevant parts of the HoNOS-LD will be presented.
Most questions will ask you to rate your opinion using a 4-point scale. There will also be some open-ended questions, which we encourage you to use to elaborate on your responses. Importantly, there are no right or wrong answers – we are solely interested in your expert opinion. The survey should take approximately 30 minutes to complete.

SECTION 1- ABOUT YOU

What is your main professional background? (select one)

- ○ Nurse (1)
- ○ Registered Psychologist (2)
- ○ Psychiatrist (4)
- ○ Social worker (6)
- ○ Occupational therapist (7)
- ○ Other - please write in (8) _____

Which country do you work in?

- ○ United Kingdom (1)
- ○ New Zealand (2)

What are your area(s) of expertise in working with the HoNOS? (select all that apply)

- ☐ Rating the HoNOS-LD or reviewing HoNOS-LD ratings made by others (1)
- ☐ Research in the measurement properties of the HoNOS-LD and/or measuring clinical effectiveness with the HoNOS-LD (2)
- ☐ HoNOS-LD staff training and/or using HoNOS-LD results at a macro level (e.g., to monitor service quality) (3)
- ☐ Other – write in (4) _____

How many years have you worked in intellectual disability services?

0 5 10 15 20 25 30 35 40 45 50

Move slider to indicate your response ()

How many years have you worked with the HoNOS-LD?

0 5 10 15 20 25 30 35 40 45 50

Move slider to indicate your response ()	

In which healthcare setting(s) have you worked with the HoNOS-LD? (select all that apply)

- ☐ Inpatient (1)
- ☐ Community (2)
- ☐ Outpatient (3)
- ☐ Other - write in (4) _____

How often do you use HoNOS-LD ratings to inform care/treatment?

0 10 20 30 40 50 60 70 80 90 100

Move slider to an approximate percentage ()	

How useful do you find HoNOS-LD in your practice?

- ○ Not at all useful (1)
- ○ Slightly useful (2)
- ○ Moderately useful (3)
- ○ Very useful (4)
- ○ Extremely useful (5)

Considering your background and expertise, how confident are you in providing your opinion about the content of the HoNOS-LD? (select one)

- ○ Not at all confident (1)
- ○ Somewhat confident (2)
- ○ Confident (3)
- ○ Very confident (4)

SECTION 2 OVER-ARCHING RATING INSTRUCTIONS

Please read the HoNOS-LD overarching rating instructions, then answer the questions below.

Summary of rating instructions

(a) Complete the front sheet including, ICD-10 diagnoses and subjective rating
(b) Rate each in order from item 1 to 18.
(c) Do not include information rated in an earlier item.
(d) Rate the person over the previous 4 weeks.
(e) Rate the most severe problem that has occurred during the period rated.
(f) All items follow the five-point rating format similar to the other HoNOS instruments:

0 = no problem during the period rated;
1 = mild problem;
2 = moderate problem;
3 = severe problem;
4 = very severe problem. Rate 9 if unknown

Thinking about these HoNOS-LD overarching rating instructions, in your opinion…

What could be changed to simplify this part of the tool?

_____

_____

What could be changed to reduce ambiguity in this part of the tool?

_____

_____

Is there any language in this section that is now outdated in the context of contemporary practice?

_____

_____

Overall, this section is 'fit for purpose'

- ○ Strongly disagree (1)
- ○ Disagree (2)
- ○ Neither agree / disagree (3)
- ○ Agree (4)
- ○ Strongly agree (5)

What could be changed to simplify this part of the tool?

_____

_____

SECTION 3 - THE HoNOS-LD SCALES

Please read the glossary for the scale, then answer the questions below.

1) Behavioural Problems (directed at others) Include behaviour that is directed to other persons. Do not include behaviour that is directed towards self (Scale 2) or primarily at property or other behaviours (Scale 3). Rate risk as it is currently perceived. 0= No behavioural problems directed to others during the period rated.1= Irritable, quarrelsome, occasional verbal abuse.2= Frequent verbal abuse, verbal threats, occasional aggressive gestures, pushing or pestering (harassment).3= Risk, or occurrence of, physical aggression resulting in injury to others requiring simple first aid, or requiring close monitoring for prevention. 4= Risk, or occurrence of, physical aggression producing injury to others serious enough to need casualty treatment and requiring constant supervision or physical intervention for prevention (e.g. restraint, medication or removal)
Thinking about this scale:

What could be changed to simplify this part of the tool?

_____

_____

What could be changed to reduce ambiguity in this part of the tool?

_____

_____

Is there any language in this section that is now outdated in the context of contemporary practice?

_____

_____

Overall, this section is 'fit for purpose'

- ○ Strongly disagree (1)
- ○ Disagree (2)
- ○ Neither agree / disagree (3)
- ○ Agree (4)
- ○ Strongly agree (5)

NB. This four question format was repeated for all 18 scales

Section 4 – FINAL COMMENTS

You have now answered all the questions. If you have any final comments about the content of HoNOS-LD or about this survey, please write them below.

_____

_____

Comparison of original (HoNOS-LD) and new (HoNOS-ID)

ORIGINAL HoNOS-LD wording	REVISED HoNOS-ID wording
Summary rating instructions: (a) Complete the front sheet including ICD-10 diagnosis and subjective rating (b) Rate each item in order from 1 to 18. (c) Do not include information rated in an earlier item. (d) Rate the person over the previous 4 weeks. (e) Rate the most severe problem that has occurred during the period rated (f) All items follow a five-point rating format similar to other HoNOS instruments: 0=no problem during the period rated; 1=mild problem; 2=moderate problem; 3=severe problem; 4=very severe problem. Rate 9 if unknown	Summary rating instructions: (a) Always refer to the glossary when rating each item. (b) Rate each item in order from 1 to 18. (c) Do not include information rated in an earlier item. (d) Rate the most severe problem that has occurred over the previous 4 weeks. (e) All items follow a five-point rating format: 0=no problem during the period rated; 1=mild problem; 2=moderate problem; 3=severe problem; 4=very severe problem. • The glossary contains examples of behaviours to be rated but these are examples NOT exhaustive lists of things to be considered. Therefore, at times, referring to the underlying rating format above may be helpful. • As a guide, ratings of 0 and 1 are not clinically significant, requiring no specific action other than possible monitoring for change. Ratings of 2 and above are regarded as clinically significant and would warrant recording in the clinical record for ongoing monitoring. A rating of 2 may be incorporated in the care plan. Ratings 3 and 4 should always be incorporated in the patient's care plan. • Take into account factors such as the person's culture and the context when assessing whether specific behaviours, experiences or beliefs are problematic. • When a lack of information from assessment means rating is not possible, a 9 is used to denote this. Where possible, this should be avoided, because missing data make scores less comparable over time or between settings.
1. Behavioural problems (directed at others).	**1. Behavioural concerns (directed at others).**

Include behaviour that is directed to other persons. Do not include behaviour that is directed towards self (Scale 2) or primarily at property or other behaviours (Scale 3). Rate risk as it is currently perceived. 0= No behavioural problems directed to others during the period rated. 1= Irritable, quarrelsome, occasional verbal abuse. 2= Frequent verbal abuse, verbal threats, occasional aggressive gestures, pushing or pestering (harassment). 3= Risk, or occurrence of, physical aggression resulting in injury to others requiring simple first aid, or requiring close monitoring for prevention. 4= Risk, or occurrence of, physical aggression producing injury to others serious enough to need casualty treatment and requiring constant supervision or physical intervention for prevention (e.g. restraint, medication or removal).	Include concerning behaviour that is directed to any other person. Do not include concerning behaviour that is directed towards self (Scale 2) or primarily at property or any other concerning behaviours (Scale 3). Rate risk as it is currently perceived. 0= No concerning behaviours directed to others during the period rated. 1= Irritable, argumentative, occasional verbal abuse. 2= Frequent verbal abuse, verbal threats, occasional aggressive gestures, pushing or intimidation). 3= Risk, or occurrence of, physical aggression resulting in injury to others requiring simple first aid, or requiring close monitoring for prevention. 4= Risk, or occurrence of, physical aggression producing injury to others serious enough to need emergency medical attention and requiring constant supervision or physical intervention for prevention (e.g. restraint, medication or removal).
2. Behavioural problems directed towards self (self-injury) Include all forms of self-injurious behaviour. Do not include behaviour directed towards others (Scale 1), or behaviour primarily directed at property, or other behaviours (Scale 3). • 0= No self-injurious behaviour during the period rated. • 1= Occasional self-injurious behaviour (e.g. face-tapping); occasional fleeting thoughts of suicide. • 2= Frequent self-injurious behaviour not resulting in tissue damage (e.g. redness, soreness, wrist-scratching). • 3= Risk or occurrence of self-injurious behaviour resulting in reversible tissue damage and no loss of function (e.g. cuts, bruises, hair loss). • 4= Risk or occurrence of self-injurious behaviour resulting in irreversible tissue damage and permanent loss of functions (e.g. limb contractures, impairment of vision, permanent facial scarring) or attempted suicide.	2. **Behavioural problems directed towards self (self-harm and/or self-injury)** Include all forms of self-injurious behaviour. Do not include concerning behaviour directed towards others (Scale 1), or concerning behaviour primarily directed at property, or other behaviours (Scale 3). 0= No self-injurious behaviour during the period rated. 1= Occasional mild self-injurious behaviour; occasional fleeting thoughts of suicide. 2= Frequent self-injurious behaviour not resulting in tissue damage (e.g. redness, soreness, wrist-scratching); more frequent thoughts or talking about suicide. 3= Risk or occurrence of self-injurious behaviour resulting in reversible tissue damage and no loss of function (e.g. cuts, bruises, hair loss). 4= Risk or occurrence of self-injurious behaviour resulting in permanent tissue damage and/or permanent loss of functions (e.g. limb contractures, impairment of vision, permanent scarring) or attempted suicide.
3. Other mental and behavioural problems This is a global rating to include behavioural problems not described in Scales 1 or 2. Do not include behaviour directed towards others (Scale 1), or self-injurious behaviour (Scale 2). Rate the most prominent behaviours	3. **Other psychological and behavioural concerns** This is a global rating to include behavioural disturbance not described in Scales 1 or 2. Do not include concerning behaviour directed towards others (Scale 1), self-injurious behaviour (Scale 2) or behaviours that are clearly

present. Include: A, behaviour destructive to property; B, problems with personal behaviours, for example, spitting, smearing, eating rubbish, self-induced vomiting, continuous eating or drinking, hoarding rubbish, inappropriate sexual behaviour; C, rocking, stereotyped and ritualistic behaviour; D, anxiety, phobias, obsessive or compulsive behaviour; E, others. • 0= No behavioural problem(s) during the period rated. • 1= Occasional behavioural problem(s) that are out of the ordinary or socially unacceptable. • 2= Behaviour(s) sufficiently frequent and severe to produce some disruption of and impact on own or other people's functioning. • 3= Behaviour(s) sufficiently frequent and severe to produce significant disruption and impact on own or other people's functioning, requiring close monitoring for prevention. • 4= Constant, severe problem behaviour(s) producing major disruption of and impact on functioning requiring constant supervision or physical intervention for prevention	driven by social or cultural beliefs.' Rate the most prominent behaviour present in each category (if applicable). Include: A, behaviour destructive to property; B, problems with personal behaviours, for example, spitting, smearing, eating rubbish, self-induced vomiting, continuous eating or drinking, hoarding rubbish, inappropriate sexual behaviour; C, rocking, stereotyped and ritualistic behaviour; D, anxiety, phobias, obsessive or compulsive behaviour; E, others. 0= No behavioural concerns during the period rated. 1= Occasional behavioural concerns that are out of the ordinary or socially unacceptable. 2= Behaviour(s) sufficiently frequent and/or severe to produce some disruption of and impact on own or other people's functioning. 3= Behaviour(s) sufficiently frequent and severe to produce significant disruption and impact on own or other people's functioning, requiring close monitoring for prevention. 4= Constant, severe concerning behaviour(s) producing major disruption of and impact on functioning requiring constant support or physical intervention for prevention.
4. Attention and concentration Include problems that may arise from underactivity, overactive behaviour, restlessness, fidgeting or inattention, hyperkinesis or arising from drugs. • 0= Can sustain attention and concentration in activities/programmes independently during the period rated. • 1= Can sustain attention and concentration in activities/programmes with occasional prompting and supervision. • 2= Can sustain attention and concentration in activities/programmes with regular prompting and supervision. • 3= Can sustain attention and concentration in activities/programmes briefly with constant prompting and supervision.	4**. Attention and concentration** include problems that may arise from underactivity, overactive behaviour, restlessness, fidgeting or inattention, hyperkinesis or arising from prescribed and/or over the counter medication. 0= Can sustain attention and concentration in tasks/activities independently during the period rated. 1= Can sustain attention and concentration in tasks/activities with occasional prompting and support. 2= Can sustain attention and concentration in tasks/activities with regular prompting and support. 3= Can sustain attention and concentration in tasks/activities briefly with constant prompting and support. 4= Cannot participate in tasks/activities even with constant prompting and support.

• 4= Cannot participate in activities and programmes even with constant prompting and supervision	
5. Memory and orientation Include recent memory loss and worsening of orientation for time, place and person in addition to previous difficulties. • 0= Can reliably find their way around familiar surroundings and relate to familiar people. • 1= Mostly familiar with environment/person, but with some difficulty in finding their way. • 2= Can relate to environment/person with occasional support and supervision. • 3= Can relate to environment/person with regular support and supervision. • 4= Not apparently able to recognise or relate to people and environments.	5. **Memory and orientation** Include recent memory loss and worsening of orientation for time, place, and person in addition to previous difficulties. Do not include issues relating to level of understanding. 0= No forgetfulness, consistently orientated to time, can reliably find their way around familiar surroundings and recognise familiar people. 1= Occasional forgetfulness, mostly orientated to time, environment & person, but with some difficulty e.g. in finding their way or recognising familiar people. 2= Some difficulty remembering events; remains orientated to time, environment & familiar people with occasional support / guidance. 3= Severe memory loss; remains orientated to time, environment & familiar people with regular support / guidance. 4= Very severe memory loss; little/ no awareness of time of day. Not apparently able to recognise or relate to familiar people and environments.
6. Communication (problems with understanding) Include all types of responses to verbal, gestural and signed communication, supported if necessary with environmental cues. • 0= Able to understand first language (mother tongue) about personal needs and experience during the period rated. • 1= Able to understand groups of words/short phrases/signed communication about most needs. • 2= Able to understand some signs, gestures and single words about basic needs and simple commands (food, drink, come, go, sit, etc.). • 3= Able to acknowledge and recognise attempts at communication with little specific understanding (pattern of response is not determined by nature of communication). • 4= No apparent understanding or response to communication.	**6. Communication (problems with understanding)** Include all types of responses to verbal, gestural and signed communication. Rate the current level with **all** existing support (e.g. alternative/augmentative communication systems, picture exchange; talking mats). 0= Able to understand first language about personal needs and experience during the period rated. 1=Able to understand groups of words/ short phrases/signed communication about most needs. 2= Able to understand some signs, gestures and single words about basic needs and simple commands (food, drink, come, go, sit, etc.). 3=Able to acknowledge and recognise attempts at communication, but little specific understanding regardless of nature of communication. 4=No apparent understanding or response to communication.
7. Communication (problems with expression)	**7. Communication (problems with expression)**

Include all attempts to make needs known and communicate with others (words, gestures, signs). Rate behaviour under Scales 1, 2 and 3. • 0= Able to express needs and experience during the period rated. • 1= Able to express needs to familiar people. • 2= Able to express basic needs only (food, drink, toilet, etc.). • 3= Able to express presence of needs, but cannot specify (e.g. cries or screams when hungry, thirsty or uncomfortable). • 4= Unable to express need or presence of need	Include all attempts to make needs known and communicate with others (through words, gestures, signs, and/or using communication aids). Do not rate behaviour already captured under Scales 1, 2 and 3. 0= Able to effectively express needs and experiences during the period rated. 1= Able to express basic, and some complex needs but with some difficulties/limitations. 2= Able to express basic needs only (food, drink, toilet, etc.). 3= Able to express presence of needs (e.g., pain), but cannot specify (e.g. cries or screams when hungry, thirsty or uncomfortable). 4= Unable to express need or presence of need.
8. Problems associated with hallucinations and delusions Include hallucinations and delusions irrespective of diagnosis. Include all manifestations suggestive of hallucinations and delusions (responding to abnormal experiences, e.g. invisible voices when alone). • 0= No evidence of hallucinations or delusions during period rated. • 1= Occasional odd or eccentric beliefs or behaviours suggestive of hallucinations or delusions. • 2= Manifestations of hallucinations or delusions with some distress or disturbance. • 3= Manifestations of hallucinations or delusions with significant distress or disturbance. • 4= Mental state and behaviour are seriously and adversely affected by hallucinations or delusions with severe distress or disturbance.	**8) Problems associated with hallucinations and/or delusions.** Include hallucinations, pseudo-hallucinations, and delusions irrespective of diagnosis and patient's ability to self-report. Include all behaviours suggestive of hallucinations and delusions (e.g., responding to abnormal experiences such as voices not heard by others, and paranoid delusions). Do not include behaviours rated in scales 1-3 0= No evidence of hallucinations and/or delusions during period rated. 1= Occasional odd or eccentric beliefs or behaviours suggestive of hallucinations and/or delusions but little or no apparent distress. 2= Hallucinations and/or delusions with some distress or disturbance. 3=Hallucinations and/or delusions with severe distress or disturbance. 4= Hallucinations and/or delusions resulting in very severe distress or disturbance.
9. Problems associated with mood changes Include problems associated with low mood states, elated mood states, mixed moods and mood swings (alternating between unhappiness, weeping and withdrawal on one hand and excitability and irritability on the other). • 0= No evidence of mood change during period rated. • 1= Mood present but with little impact (e.g. gloom).	**9) Problems associated with mood disturbance.** Include problems associated with low mood states, elated mood states, mixed moods and mood swings (alternating between unhappiness, weeping and withdrawal on one hand and excitability and irritability on the other) that impact on the person's ADL and/or social interactions. 0= No evidence of mood disturbance during period rated.

• 2= Mood change producing significant impact on self or others (e.g. weeping spells, decrease in skills, withdrawal and loss of interest). • 3= Mood change producing major impact on self or others (e.g. severe apathy and unresponsiveness, severe agitation and restlessness). • 4= Depression, hypomania or mood swings producing severe impact on self and others (e.g. severe weight loss from anorexia or overactivity, agitation too severe to allow time to be engaged in meaningful activity).	1= Mood disturbance present but with little distress or impact (e.g. gloomy spells). 2= Mood disturbance producing moderate impact on self and/or others (e.g., decrease in skills, withdrawal, loss of interest, over-enthusiasm, restlessness). 3= Mood disturbance producing severe impact on self and/or others (e.g., severe lack of motivation, agitation, restlessness, and/or over-ambitious decision-making, overactivity). 4= Mood disturbance producing very severe impact on self and/or others (e.g. near complete withdrawal, significant weight loss from loss of appetite or overactivity; inability to engage in meaningful activity; dangerously over-ambitious decision-making, disregard for risk).
10. Problems with sleeping Do not rate intensity of behaviour disturbance — this should be included in Scale 3. Include daytime drowsiness, duration of sleep, frequency of waking and diurnal variation of sleep pattern. • 0= No problem during the period rated. • 1= Occasional mild sleep disturbance with occasional waking. • 2= Moderate sleep disturbance with frequent waking, or some daytime drowsiness. • 3= Severe sleep disturbance or marked daytime drowsiness (e.g. restlessness/overactivity/waking early) on some nights. • 4= Very severe sleep disturbance with disturbed behaviour (e.g. restlessness/overactivity/waking early most nights).	**10) Problems with sleeping** Include duration, quality, and pattern of sleep, (e.g., daytime drowsiness, frequency of waking and disturbance of sleep pattern). Do not rate intensity of behaviour disturbance already rated in Scale 3. 0= No sleep problems during the period rated. 1= Occasional mild sleep disturbance (e.g., occasional night-time waking and/or daytime drowsiness). 2= Moderate sleep disturbance (e.g., frequent night-time waking, and/or daytime drowsiness). 3= Severe sleep disturbance (e.g., marked daytime drowsiness, and/or night-time restlessness/ overactivity/ waking early) several times per week. 4= Very severe sleep disturbance (e.g., restlessness/ overactivity/waking early most nights and/or regular, prolonged daytime sleeping).
11. Problems with eating and drinking Include both increase and decrease in weight. Do not rate pica — which should be rated in Scale 3. This scale does not include problems experienced by people who cannot feed themselves (e.g. people with severe physical disability). • 0= No problem with appetite during the period rated. • 1= Slight alteration to appetite.	**11) Problems with appetite.** Include both increases and decreases in appetite, fluid intake and/or weight. Do not rate pica - which should be rated in Scale 3 or dysphagia (swallowing problems) which should be rated at scale 12. 0= No change in appetite during the period rated. 1= Slight alteration to appetite but no adverse effects. 2= Significant alteration in appetite (e.g., declining meals/seeking more food than usual) but no weight change (e.g., managed with supplements).

• 2= Severe alteration in appetite with no significant weight change. • 3= Severe disturbance with some weight change during the period rated. • 4= Very severe disturbance with significant weight change during the period rated	3= Severe change in appetite with some weight change during the period rated. 4= Very severe change in appetite causing significant weight change during the period rated.
12. Physical problems Include illnesses from any cause that adversely affects mobility, self-care, vision and hearing (e.g. dementia, thyroid dysfunction, tremor affecting dexterity). Do not include relatively stable physical disability (e.g. cerebral palsy, hemiplegia). Behavioural disorders caused by physical problems should be rated under Scales 1, 2 and 3 (e.g. constipation producing aggression). • 0= No increased incapacity due to physical problems during the period rated. • 1= Mildly increased incapacity, for example, viral illness, sprained wrist. • 2= Significant incapacity requiring prompting and supervision. • 3= Severe incapacity requiring some assistance with basic needs. • 4= Total incapacity requiring assistance for most basic needs such as eating and drinking, toileting (fully dependent).	**12) Physical problems.** Include adverse effects of all illnesses on mobility, self-care, vision, and/or hearing (e.g., dementia, thyroid dysfunction, tremor affecting dexterity). Do not include relatively stable physical disability (e.g. cerebral palsy, hemiplegia). 0= No increased impairment due to physical problems during the period rated. 1= Mild physical impairment e.g. due to common cold or sprained wrist, but remains independent. 2= Significant physical impairment requiring prompting and/or some practical support and/or aids and adaptations (e.g. hand rails). 3= Severe physical impairment requiring practical assistance with some basic needs (e.g. eating and dressing). 4= Almost completely physically dependent on others, requiring practical assistance with most basic needs such as eating and drinking, toileting at all times.
13. Seizures Include all types of fits (partial, focal, generalised, mixed, etc.) to rate the short-term effect on the individual's daily life. Rate the effects of the fits. Do not include behavioural problems caused by, or associated with, fits (use Scales 1, 2 and 3). • 0= No increased incapacity due to physical problems during the period rated. • 1= Occasional seizures with minimal immediate impact on daily activities (e.g. resumes after seizures). • 2= Seizures of sufficient frequency or severity to produce a significant immediate impact on daily activities (e.g. resumes activity after a few hours).	**13) Seizures.** Include the effects of all types of seizure events on the individual's daily life. Do not include behaviours already rated under Scales 1, 2 and 3. 0= No adverse impact from seizures during the period rated. 1= Seizures with minimal immediate impact on daily activities (e.g., resumes activity soon after seizures). 2= Seizures of sufficient frequency or severity to have a significant, immediate, but relatively brief impact on daily activities. 3= Seizures of sufficient frequency or severity to have a severe, immediate, and lengthy impact on daily activities. May also require simple first aid for injuries etc. 4= Frequent, poorly controlled seizures requiring urgent clinical attention and/or prolonged recovery time.

• 3= Seizures of sufficient frequency or severity producing a severe immediate impact on daily activities requiring simple first aid for injuries etc. (e.g. resumes activities next day). • 4= Frequent poorly controlled seizures (may be accompanied by episodes of status epilepticus) requiring urgent clinical attention.	
14. Activities of daily living at home Include such skills as cooking, cleaning and other household tasks. Do not rate problems with daily living outside the home (Scale 15). Do not rate problems with selfcare (Scale 16). Rate what is seen regardless of cause, for example, disability, motivation etc. Rate performance not potential. Rate the current level achieved with the existing support. • 0= Performs or contributes towards activities of daily living at home. • 1= Some limitations in performing or contributing towards household tasks. • 2= Significant limitations in performing or contributing towards household tasks (e.g. failure to wash or tidy up, difficulty in preparing meals). • 3= Major limitations in performing or contributing towards household tasks (e.g. home neglected, dirty, untidy; no domestic routine). • 4= Gross neglect or danger resulting from no apparent contribution to daily living activities	**14) Domestic activities** Include such skills as cooking, cleaning and other household tasks. Do not rate problems with daily living in the wider community (Scale 15). Do not rate problems with self-care (Scale 16). Rate severity regardless of cause, for example, disability, motivation etc. Rate actual performance not potential. Rate the current level **with all existing support**. 0= No problems performing or contributing towards domestic activities (e.g. able to undertake tasks independently or as part of a team in shared accommodation). 1= Some difficulties in performing or contributing towards domestic tasks (e.g. completes tasks, but needs prompts and/or guidance). 2= Significant difficulties in performing or contributing towards domestic tasks (e.g. unable and/or unwilling to wash or tidy up, difficulty in preparing meals). 3= Major difficulties in performing or contributing towards domestic tasks (e.g. living conditions dirty, untidy; no domestic routine). 4= Gross self-neglect or risk resulting from dangerous practices and/or complete absence of domestic activity (e.g. dangerous food hygiene practices, unsafe use of appliances etc.)
15. Activities of daily living outside the home Include skills such as budgeting, shopping, mobility and the use of transport, etc. Do not include problems with activities of daily living at home (Scale 14). Do not rate problems with self-care (Scale 16). Rate the current level with the existing support. • 0= Regular use of facilities and public amenities (e.g. shopping). • 1= Some limitation in activity (e.g. difficulty with the use of public amenities or transport).	**15) Activities of daily living in the community** Include skills such as budgeting, shopping, mobility and use of transport, etc. Do not include problems with domestic activities (Scale 14). Do not rate problems with self-care (Scale 16) or employment (scale 18). Rate the current level **with all existing support**. 0= Regularly uses community facilities and public amenities as necessary (e.g. shops, public transport etc.). 1= Encounters some difficulties when undertaking community-based tasks (e.g. struggles at times to use public amenities or transport).

• 2= Significant limitations of activity relating to any one of: shopping, use of transport, public amenities. • 3= Major restrictions in activity relating to more than any one of: shopping, use of transport, public amenities. • 4= Severe restrictions in the use of shops, transport, facilities, etc.	2= Has significant difficulties with at least one aspect of community-based tasks (e.g. with shopping / use of transport / public amenities etc.) 3= Experiences major difficulties with multiple community activities (e.g. travelling to AND using shops or public amenities). 4= Unable to perform most community-based tasks (e.g. very severe difficulties with shopping, travel etc.)
16. Level of self-care Rate the overall level of functioning in activities of self-care such as eating, washing, dressing and toileting. Rate the current level achieved with the existing support. Rate appearance not motivation. • 0= Appearance and personal hygiene maintained. • 1= Some deficits in personal appearance, personal hygiene or attention to health (e.g. poor grooming). • 2= Significant deficits in personal appearance, personal hygiene or attention to health causing a problem with social acceptability, but not sufficient to pose a health risk (e.g. body odour, unkempt hair or nails). • 3= Major deficits in personal appearance, personal hygiene or attention to health posing a health risk (e.g. skin rashes, gum infection, not fully dressed). • 4= Gross self-neglect with severe difficulties relating to appearance, hygiene and diet posing a major health risk (e.g. pressure sores).	**16) Level of self-care** Rate the overall level of functioning in activities of self-care such as, washing, dressing and toileting. Do not include problems arising from poor motivation. Rate the current level **with all existing support**. 0= Self-care and personal hygiene adequately maintained. 1= Minor issues with self-care, personal hygiene or attention to health (e.g. poor grooming). 2= Self-care, personal hygiene or attention to health leads to problems with social acceptability and/or moderate health risk (e.g. body odour, unkempt hair or nails). 3= Self-care, personal hygiene or attention to health poses a significant health risk (e.g. skin rashes, gum infection, inadequately dressed). 4= Very severe self-neglect with difficulties relating to self-care, hygiene that pose a major health risk (e.g. pressure sores).
17. Problems with relationships Include effects of problems with relationships with family, friends and carers (in residential and day/leisure settings). Measure what is occurring regardless of cause, for example, somebody who is known to have good relationships may still display problems. • 0= Positive and frequent contact with family or friend or carers. • 1= Generally positive relationships, but some strain or limitations in contact.	**17. Problems with relationships** Rate what is occurring regardless of cause. Include effects of problems with relationships with family, friends and carers (including where the person is living and/or where they spend their day/leisure time). Include intimate/romantic relationships here. Include all aspects of their relationships including the person's level of satisfaction. 0= Positive contact with family or friend or carers. 1= Generally positive relationships, but some strain or limitations in contact. 2= Some positive relationships, but current disruptions of contact or worsening of relationships.

• 2= Some positive relationships, but current disruptions of contact or worsening of relationships. • 3= Difficulties in relationships with risk of breakdown or infrequent contact. • 4= Significant relationships broken down with no current contact.	3= Difficulties in relationships with risk of breakdown or infrequent contact. 4= All significant relationships broken down and/or no current contact
18. Occupation and activities Rate the overall level of problems with quality of daytime environment. Take account of frequency and appropriateness of, and engagement with, daytime activities. Consider factors such as lack of qualified staff, equipment and appropriateness with regard to age and clinical condition. Do not rate problems with self-care (Scale 16). • 0= Fully engaged with acceptable range of activities. • 1= Uses reasonable range of activities, but some limitation of access or appropriateness. • 2= Uses limited range of activities, limited availability or appropriateness. • 3= Attends daytime activity irregularly. • 4= No engagement with daytime activity.	**18. Occupation and/or meaningful activity** Rate the overall appropriateness of the person's daytime environment i.e. how well they meet the person's needs. Take account of frequency and appropriateness of, and engagement with, occupational, educational and/or leisure activity. Consider factors such as lack of suitably skilled staff, equipment and activities with regard to age and clinical condition. Do not rate problems with self-care (Scale 16). 0= Fully engaged with wide range of opportunities. 1= Uses reasonable range of opportunities, but some limitation of access or appropriateness. 2= Uses limited range of opportunities, limited availability or appropriateness. 3= Attends occupational, educational and/or leisure activity irregularly. 4= No engagement with occupational, educational and/or leisure activity.