

Update to HoNOS-LD

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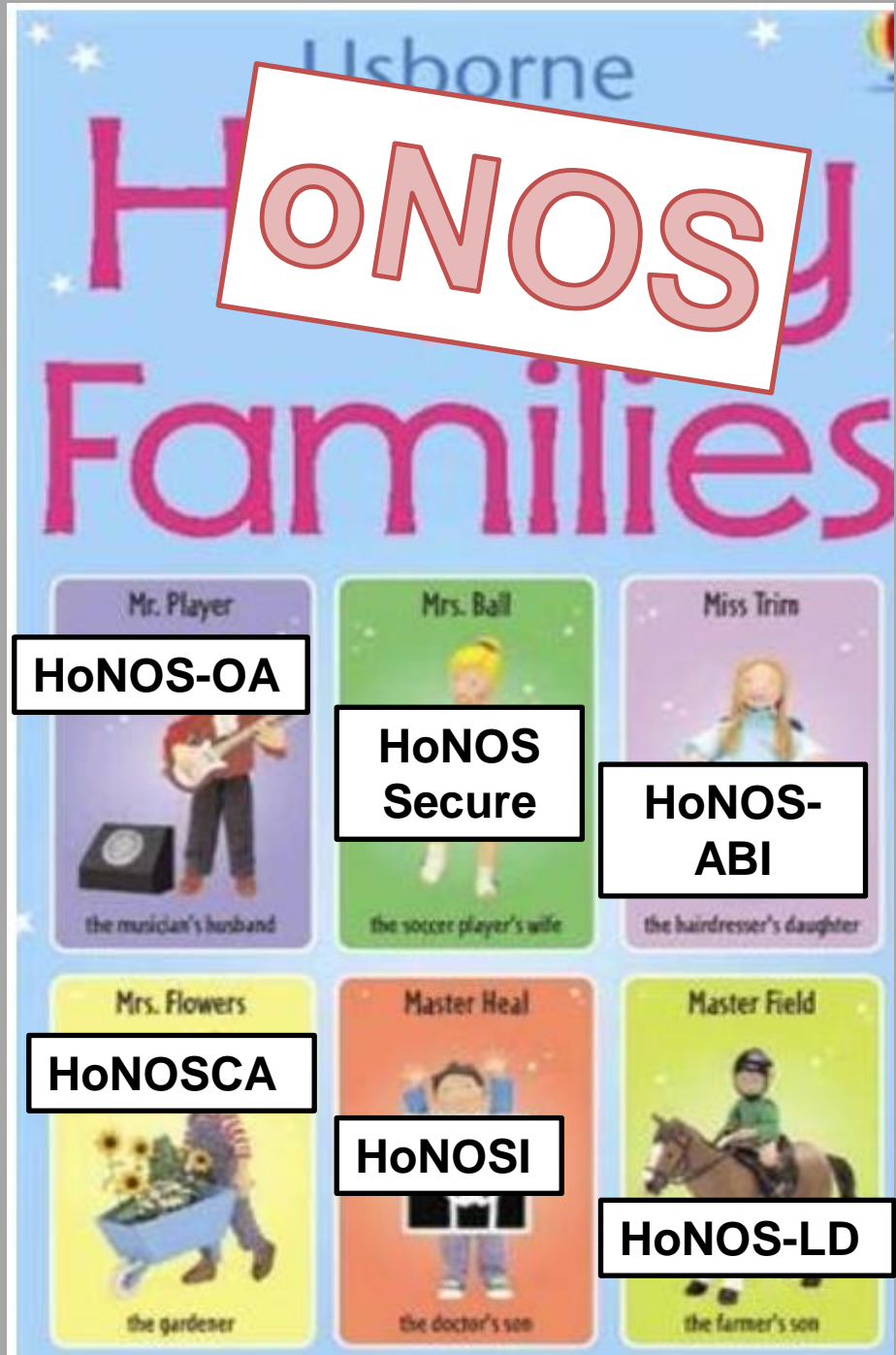
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Review and update of the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD)

Dr Jon Painter

Prof Rohit Shankar



HoNOS-OA

**HoNOS
Secure**

**HoNOS-
ABI**

HoNOSCA

HoNOSI

HoNOS-LD

Background

- Health of the Nation Outcomes Scale (HoNOS) developed in 1996 by Wing et al.
- Designed to measure the health and social care outcomes of working aged adults in receipt of secondary care mental health services
- 12 items each rated on a 0-4 severity scale

Overactive, disruptive or agitated behaviour	Depressed mood
Non-accidental self-injury	Other behavioural & mental problems
Problem Drinking or drug taking	Problems with relationships
Cognitive problems	Problems with ADLs
Physical health or disability	Problems with living conditions
Hallucinations & delusions	Problems with occupation & activities

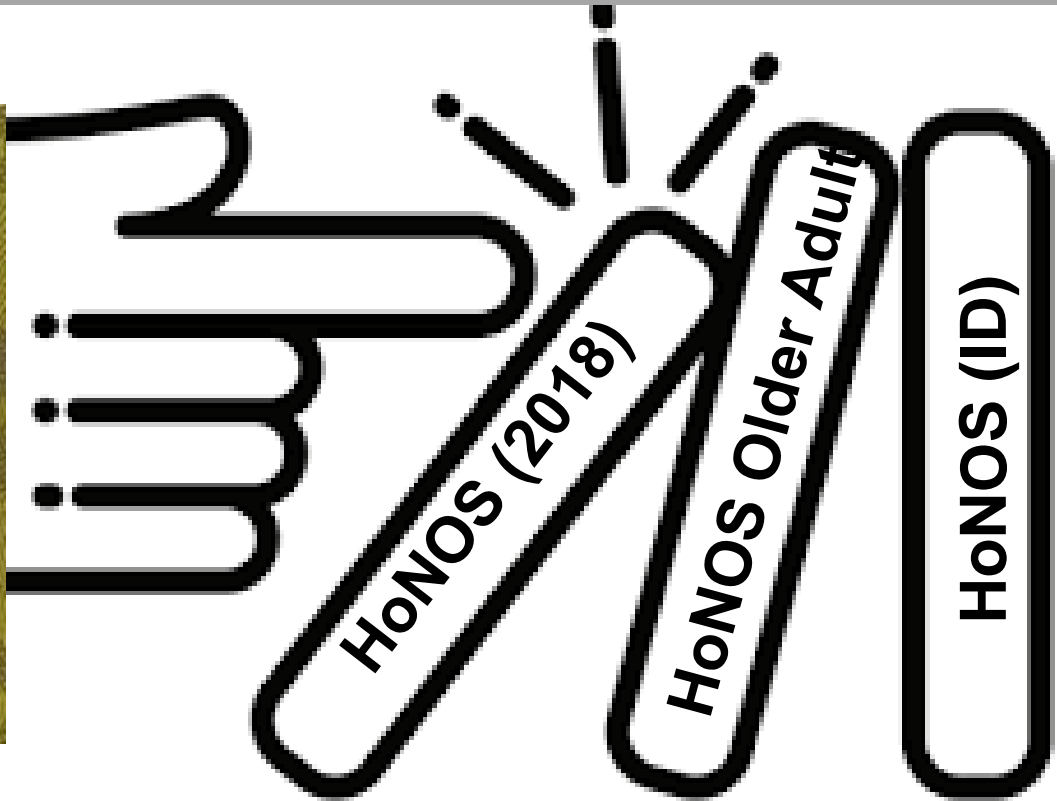
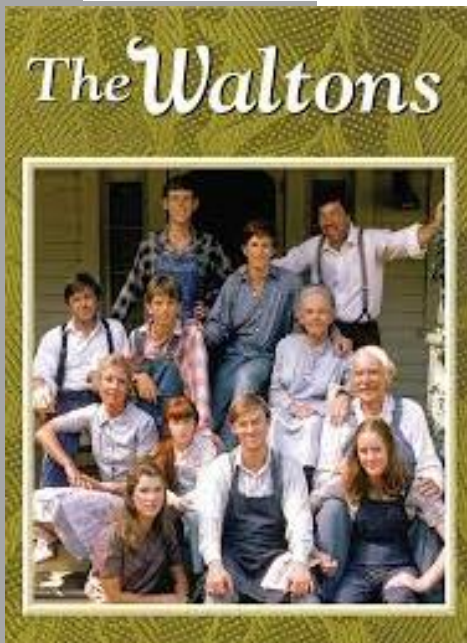
Health of the Nation Outcome Scales for People with Learning Disabilities (**HoNOS-LD)**

**Ashok Roy, Helen Matthews, Paul
Clifford, Vanessa Fowler, David M. Martin**

- Developed in 2002
- Like most versions, as a result of testing the HoNOS in a different clinical setting, and encountering issues when capturing key clinical issues (eg communication skills & movement disorders)
- Key differences include:
 - 18 items (not 12)
 - Different 0-4 severity scale
 - 4-week rating period (not 2 weeks)

HoNOS (1996)	HoNOS-LD (2002)	0 No probs	1 Mild probs	2 Moderate probs	3 Severe probs	4 Very severe probs
Overactive, aggressive, disruptive or agitated behaviour	Behavioural problems (directed at others)					
Non-accidental self-injury	Behavioural problems directed towards self (self-injury)					
Problems associated with hallucinations and delusions	Problems associated with hallucinations and delusions					
Problems with depressed mood	Problems associated with mood changes					
Problems with relationships	Problems with relationships					
Problems with occupation and activities	Occupation and activities					
Other mental and behavioural problems	Other mental and behavioural problems					
	Problems with sleeping					
	Problems with eating and drinking					
	Communication (problems with understanding)					
	Communication (problems with expression)					
Cognitive problems	Attention and concentration					
	Memory and orientation					
Physical illness or disability problems	Seizures					
	Physical problems					
Problems with activities of daily living	Activities of daily living at home	0 (No probs)	1 (minor problem requiring no action)	2 (mild problem but definitely present)	3 (moderately severe prob)	4 (severe to very severe prob)
	Activities of daily living outside the home					
	Level of self-care					
Problem-drinking or drug-taking						
Problems with living conditions						

Updates to HoNOS Family

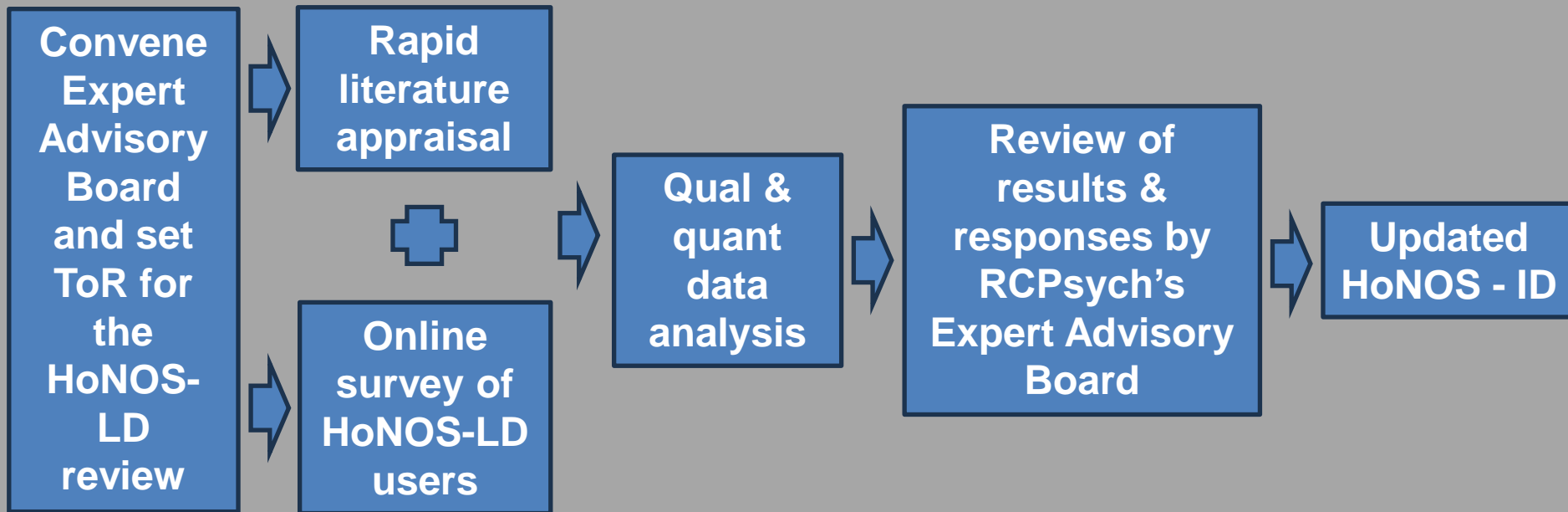


James, M., Painter, J., Stewart, M., & Buckingham, B. (2018). A Review and update of the Health of the Nation Outcome Scales (HoNOS). *BJPsych Bulletin*, 42 (2), 63-68. <http://doi.org/10.1192/bjb.2017.17>

James, M., Buckingham, B., Cheung, G., McKay, R., Painter, J., & Stewart, M. (2018). Review and update of the Health of the Nation Outcome Scales for Elderly People (HoNOS65+). *British Medical Journal (BMJ)*. <http://doi.org/10.1192/bjb.2018.68>

Painter, J., Adams, N., Ingham, B., James, M., Majid, M., Roy, A., ... Smith, M. (2023). Review and update of the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD). *International Journal of Social Psychiatry*. <http://doi.org/10.1177/00207640231175773>

Update process



Aim:

To review and improve the HoNOS-LD's utility in contemporary intellectual disability services whilst retaining its original objectives and five-point severity ratings

**Convene
Expert
Advisory
Board
and set
ToR for
the
HoNOS-
LD
review**

Advisory Board Membership			
Name	Profession	Affiliation	Country
Mick James	Registered Mental Health Nurse	Royal College of Psychiatrists (National HoNOS Advisor)	England
Jon Painter	Registered Nurse LD & Registered Mental Health Nurse	Sheffield Hallam University (HoNOS & HoNOS 65+ EAG member)	England
Ashok Roy	Psychiatrist	Coventry and Warwickshire Partnership Trust (HoNOS-LD author)	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

Changes needed to result in a tangible improvement (e.g. simplification/ clarification/ removal of anachronisms) and:

- maintain the original instrument's integrity as far as possible.
- maximize 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 five-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 4weeks 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.

Consent

Demographics

Experience with HoNOS-LD

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').

**Online
survey of
HoNOS-LD
users**

	Respondents Attributes	
Country of practice	United Kingdom	65
	New Zealand	10
Clinical Setting	Exclusively inpatient	7
	Exclusively community/outpatient	43
	Inpatient & Outpatient	25
Nature of usage	Clinical practice	70
	HoNOS-LD training	9
	Macro-level (eg service evaluation)	9
	Research	5
	Other	2
Profession	Nurse	37
	Psychiatrist	11
	Psychologist	9
	Speech & Language Therapist	8
	Occupational Therapist	6
	Physiotherapist	2
	Behavioural Specialist	2
Confidence in ability to provide helpful insights	Very confident	10
	Confident	38
	Somewhat confident	24
	Not confident	3
Mean duration of practice in LD		16.8yrs (SD 10.1yrs)
Mean duration of HoNOS LD use		8.0yrs (SD 5.28yrs)

RAG rating responses

HoNOS-LD scale	Issues identified in published literature	Issues raised by survey respondents Red = out of scope, not to be discussed Amber = to be discussed Green = def in scope
1 – Behaviour toward others	Nil	<ul style="list-style-type: none"> - Subjectivity of terms used <ul style="list-style-type: none"> o frequency not well-defined ‘occasional’ and ‘frequent’ can be open to interpretation (53) (49) (77) (55) (35) (76) o ‘pestering,’ ‘harassment,’ ‘quarrelsome’ - outdated, subjective, lacking empathy, negative, not commonly used (46) (53) (76) (77) (35) (44) o ‘Casualty’ an ambiguous term (44) (45) (77) o The use of the word behavioural ‘problems’ (11) (38) (79) (51) - should be renamed as ‘behaviours of concern’ o Phrasing indicates that the patient is the problem (49) (76) (51) (62) o ‘requiring physical interventions’ – assumes physical intervention always appropriately used (76) - Ratings do not reflect whether risk is managed i.e. use of medication is required to prevent aggression (34) (35) - The threat of aggression is not included (62) (95) - Subjectivity of the assessment of risk (62) (51) - Does not separate risk from actual occurrence/events (76)

HoNO S- LD section	Overall, this section is fit for purpose								Simplifications? Ambiguities? Outdated language?		
	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Total	% Disagree / strongly disagree	% Agree or strongly agree	No of suggestions made	No of suggestions in scope	No of suggestions actioned
Glossary	0	2	17	21	3	43	5	56			
Scale 1	0	5	10	13	5	33	15	55	10	10	4
Scale 2	0	6	8	16	2	32	18	58	11	9	5
Scale 3	1	7	9	12	2	31	26	45	12	9	4
Scale 4	0	7	3	15	5	30	23	67	7	7	2
Scale 5	0	4	9	13	3	29	14	55	10	10	7
Scale 6	2	4	5	11	4	26	23	58	12	8	7
Scale 7	3	3	7	9	6	28	21	54	8	5	4
Scale 8	0	4	8	11	5	28	14	57	10	9	5
Scale 9	0	3	8	11	6	28	11	61	7	6	6
Scale 10	0	3	5	14	6	28	11	71	5	5	3
Scale 11	1	5	5	13	4	28	21	61	10	10	10
Scale 12	2	5	6	10	5	28	25	54	8	5	4
Scale 13	0	1	8	11	8	28	4	68	8	7	7
Scale 14	0	6	7	11	4	28	21	54	12	10	5
Scale 15	0	8	8	9	3	28	29	43	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	22	59	4	4	2
Scale 18	0	4	9	12	1	26	15	50	11	8	7

Example updates

- Clarifying that scale 2 should capture self-harming and self-injurious behaviours, regardless of motivation
- Clarifying that dysphagia is to be included in scale 11
- Replacing the term ‘fits’ with ‘seizures’
- Replacing “Learning Disability” with “Intellectual Disability”
- Highlighting that it is the person’s (not the rater’s) culture that must be considered when rating items
- Lots of linguistic changes to improve consistency of severity ratings across items AND with other members of the ‘HoNOS family’

Conclusion

- HoNOS –ID addresses many, but not all, issues raised about the HoNOS-LD
- Some suggestions were simply out of scope
- HoNOS-ID is already being introduced in some services
- HoNOS-ID is a better and more contemporary tool with which to capture clinical outcomes
- HoNOS-ID use provides new opportunities to research, analyse, and publish from the resulting data sets
- HoNOS-ID needs you!