Review and update of the health of the nation outcome scales for people with learning disabilities

PAINTER, Jon <http://orcid.org/0000-0003-1589-4054>

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Health of the Nation Outcome Scales for People with Intellectual Disabilities (HoNOS-ID): The Past, Present & Future

Dr Jon Painter

j.painter@shu.ac.uk

Sheffield Hallam University

HoNOS-LD past

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**

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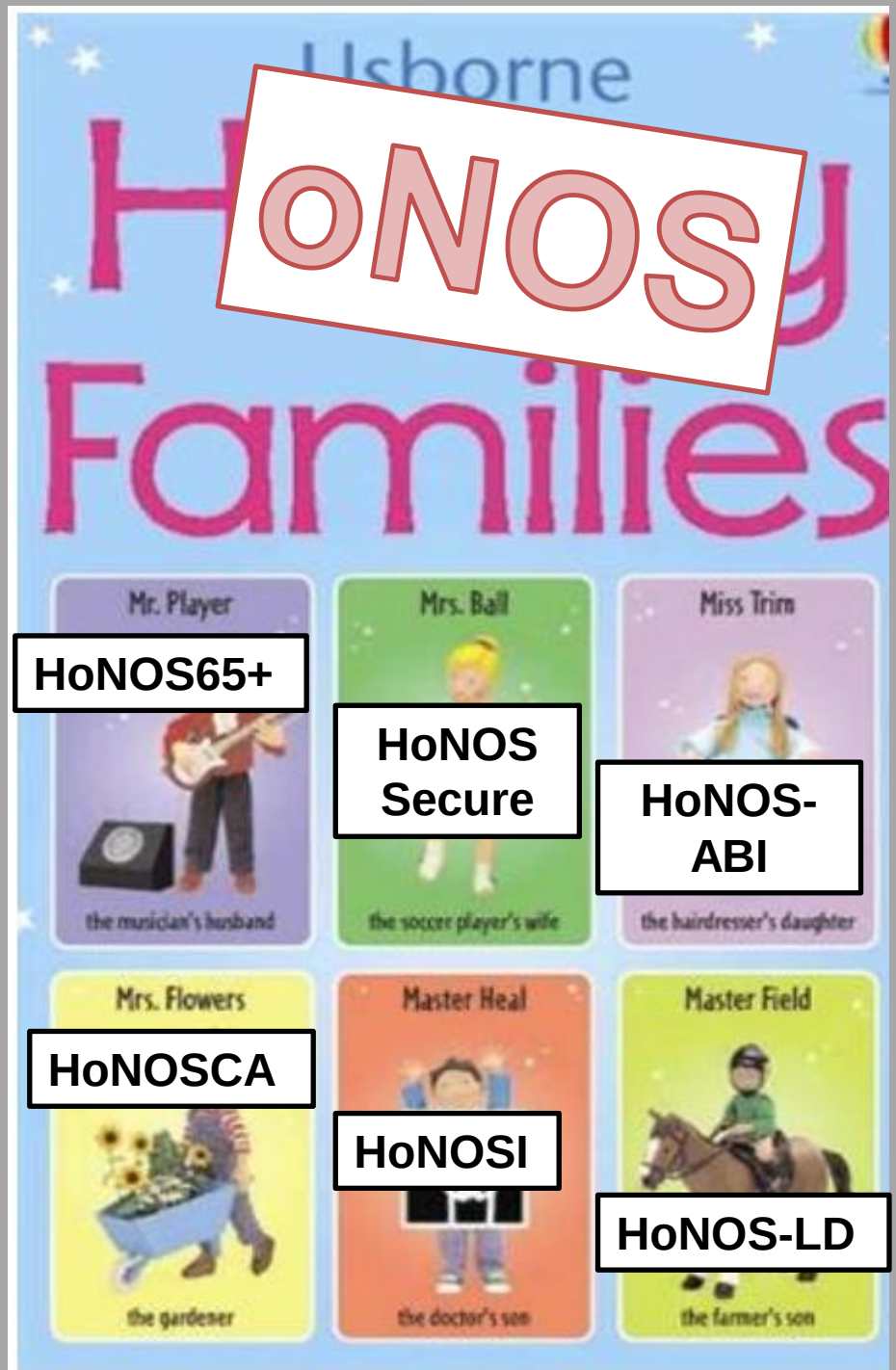

HoNOS

HoNOS65+

HoNOS Secure

HoNOS-ABI

HoNOSCA

HoNOSI

HoNOS-LD

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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					
	Activities of daily living outside the home					
	Level of self-care					
Problem-drinking or drug-taking						
Problems with living conditions						
		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)

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HoNOS-ID Present

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"2002"

BRITISH JOURNAL OF PSYCHIATRY (2002), 180, 101–103

EDITORIAL

Psychiatrists in the UK do not use outcomes measures

National survey

SIMON M. GILBODY, ALLAN O. HOUSE and TREVOR A. SHELDON

Governmental policy statements on mental health practice over the past decade have emphasised the importance of routinely measuring individual patient outcomes (Department of Health, 1991, 1998; Secretary of State for Health, 1999). Despite the availability of various standardised tools with which to measure the symptom severity of common psychiatric disorders, patient need and wider quality of life and health status, little is known about the actual use of standardised outcomes measures by clinicians (Slade *et al*, 1999). One previous survey of 73 consultant psychiatrists from 1989 established which of a pre-specified range of symptom-based clinical measures were in use at that time (Rice & Donnelly, 1992). In view of the central role given to outcomes measurement in th... National Service F... Health (S... 1999... th... ps...

measures their trusts routinely collecte... asked them to collect.

Survey method

We conducted a postal questio... vey between July and Septembe... 500 consultant psychiatrists ... in the UK National Health Se... chosen randomly from UK N... respon-sible for the psychia... king-age adults listed in th... tory.

Questionn...

In total, 3... 500 question-naires w... hich 29 were in-comple... eligible response rate ... ified response rate ... psychia-

"pseudo-scientific gloss.."

"questioned validity, reliability & sensitivity to change"

" most commonly used was HoNOS"

"IT resources to support processes"

NATI...

Questionnaire des...

We constructed and piloted a self-completion/self-report questionnaire that sought to identify the routine standardised outcomes measures used by adult psychiatrists for the purpose of:

(a) identifying and assessing the severity of clinical disorders;

(b) identifying patients' needs and deficits in social functioning, and quality of life;

(c) monitoring patient progress;

(d) clinical audit.

Respondents were asked about the use of outcomes measures for the following problems: depression, anxiety and related disorders; schizophrenia and other psychoses; cognitive impairment; drugs and alcohol. Respondents also were asked what outcomes ... monly for identifying and assessing the severity of psychiatric disorders, with around half of clinicians using these measures either routinely or occasionally. The most commonly used measures were the Beck Depression Inventory (Beck & Ward, 1961) (61/340), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) (53/340) and the Hamilton Rating Scale for Depression (Hamilton, 1967) (46/340).

The most commonly used measure in ... detecting cognitive impairment was ... Mini-Mental State Examination (Fo... *et al*, 1975). For disorders such as s... phrenia, the majority of consult... (72.9%; 95% CI 67.9–77.6) never used standardised measures. For drug and alcohol problems, the most commonly reported measure was the CAGE questionnaire (Mayfield *et al*, 1974) (10/340).

Assessing ... quality of ...

Only a small ... questionnaire for de... and deficits in social functioning ... of life. The most commonly used was the Health of the Nation Outcome Scale (HoNOS; Curtis & Beevor, 1995). Specific 'needs assessment' tools, such as the Medical Research Council (MRC) Needs for Care and the Camberwell Assessment of Needs, rarely were reported as being used in routine practice.

Measuring clinical change over time

Standardised measures most commonly were used in order to measure change over time for depression and anxiety problems, with 19.4% (95% CI 15.3–24.0) of consultants using them either routinely or occasionally. The most commonly reported measures were the Beck Depression Inventory (49/340); the Hospital Anxiety and Depression Scale (41/340) and the Hamilton Rating Scale for Depression (23/340). For those with dementia, the most commonly used questionnaire was the Mini-Mental State Examination (60/340). For other conditions, clinicians rarely used standardised measures.

Clinical audit

...gall, standardised questionnaires were ...n less for clinical audit than for the ...poses outlined above. The most ...y reported condition for which ...were used was depression/anxiety, ...here the Beck Depression Inventory was the most common instrument; for other conditions (schizophrenia; drugs and alcohol; and dementia) the HoNOS was used.

Outcomes measures routinely collected by hospitals/trusts

Very few clinicians (46/340, 13.5%; 95% CI 10.0–17.6) reported being required routinely to collect standardised outcomes measures for ... naires, such as ... monly collected routine administrative data, such as length of stay (86.2%; 95% CI 82.7–89.9) and readmission (70.6%; 95% CI 65.4–75.4).

...ised measures by clinicians (the percentage values are given with 95% confidence intervals)

	...ification and severity ...measurement	Assessing social functioning, quality of life and needs	Measuring clinical change over time	Clinical audit
...	55.3% (49.8–60.1)	80.6% (75.9–84.7)	58.2% (52.8–63.5)	76.5% (71.6–80.9)
Occasionally	34.1% (29.0–39.4)	12.9% (9.6–17.0)	30.5% (25.7–35.8)	15.3% (11.6–19.6)
...outinely	10.5% (7.5–14.4)	6.5% (4.1–9.6)	11.2% (8.0–15.0)	4.1% (2.2–6.8)
...easures used				
	BDI, 61/340	HoNOS, 20/340	BDI, 49/340	BDI, 18/340
	HAD, 53/340	SAS, 9/340	HAD, 41/340	HoNOS, 18/340
	HRSD, 46/340			
	HoNOS, ...			
...ther psychos...				
	PANSS, 25/340			
	HoNOS, 20/340			
	BPRS, 17/340	HoNOS, 16/340		BPRS, 8/340
	Manchester Scale, 9/340			
	PSE/SCAN, 6/340			
	GAF, 5/340			
Cognitive impairm...				
Never	44.7% (39.3–50.2)	83.5% (79.2–87.3)	...5)	86.5% (82.4–89.9)
Occasionally	40.6% (35.3–46.0)	10.6% (7.5–14.4)	...9.6)	10.6% (7.5–14.4)
Routinely	14.7% (11.1–18.9)	5.9% (3.6–8.9)	...2.4)	2.9% (1.4–5.3)
Measures used				
	MMSE, 134/340	HoNOS, 13/340	.../340	MMSE, 13/340
	WAIS, 9/340	QL Checklist, 3/340	...13/340	HoNOS, 9/340
			...6/340	
Drugs/alcohol				
Never	...79.1–87.3)	88.8% (84.9–91.9)	...87.6–94.0)	91.2% (87.6–94.0)
Occasionally	...5–14.3)	5.9% (3.6–8.9)	...(2.3–6.8)	3.5% (1.8–6.1)
Routinely	5.... ...8.9)	5.3% (3.2–8.2)	...% (2.7–7.5)	5.3% (3.2–8.3)
Measures used				
	CAGE, ...40	HoNOS, 12/340	...oNOS, 10/340	HoNOS, 8/340
	SADQ, ...			

BDI, Beck Depression Inventory; BPRS, Brief Psychiatric Ra... Scale; CAN, Camberwell Assessment of Ne... ...inical Global Impression; GAF, Global Assessment of Functioning scale; HAD, Hospital Anxiety and Depression scale; H... ...OS, Health of the Nation Outcome Scale; ...ilton Rating Scale for Depression; MADRS, Montgomery–Åsberg Depression Rating Scale; MMSE, Mini-Mental State Exa... ...ation; PANSS, Positive and Negative Synd... ; PSE, Present State Examination; QL Checklist, Quality of Life Checklist; SADQ, Severity of Alcohol Dependence Questionnai... ...AS, Social Adjustment Scale; SCAN, Sc... ...r Clinical Assessment in Neuropsychiatry; SFQ, Social Functioning Questionnaire; WAIS, Wechsler Adult Intelligence Scale.

General comments relating to the use and experience of outcomes measurement

...pproximately one-third (120/340) used the ...naire to give comments. Forty ...s expressed a negative view of ...measures, question-...ceted outcome and to describe the ...ividual patient. Terms such as "simplistic" and "pseudo-scientific gloss" were us... ...one respondent expressed reservation ab... ...any scale that "divides continuous flu... ...ating process into arbitrary categories". Twenty-eight respondents explicitly questioned the basic psychometric properties of validity, reliability and sensitivity to change for available measures.

Respondents stated that the valid and reproducible use of outcome measures requires a robust infrastructure, particularly in terms of administration and information technology resources, to support the process (n=20). Respondents generally felt that these features were lacking and that this represented a barrier to their use. Additionally, 29 respondents felt that more time and resources would be needed if outcome measurement were to be carried out and used routinely. Twenty-two respondents stated that they did not find the results of standardised outcomes measures particularly useful in clinical practice. One respondent stated that they were more "research tools" rather than instruments that are useful in clinical practice. Another stated that the "use of scales detracts from the therapeutic relationship".

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"bear little relation to psychosocial outcomes"

"LoS & readmission rates are easier to collect"

"are easiest to manipulate"

"HoNOS seems to have found a place"

"reluctance amongst clinicians may reflect the fact they see no benefit to themselves"

"instruments must be....concise"

Comments were largely critical of the HoNOS (n=21) and related to: time to complete (n=16); inadequate psychometric properties (n=8); the lack of value added to routine clinical assessment (n=5); and the lack of enthusiasm among staff (n=7). Positive comments (n=7) included the fact that it could be completed by non-clinicians (n=4) and that it acted as a useful *aide mémoire* in clinical decision-making (n=3). One person stated that "the HoNOS, although scientifically flawed, is useful for bringing together all members of the multi-disciplinary team".

IMPLICATIONS FOR MENTAL HEALTH PRACTICE, RESEARCH AND POLICY

...urement forms a central ...ional Service Framework, with, ... stipulation of a minimum data set ... 1997), which includes the HoNOS, ... alongside care planning for all of those ... severe mental illness and a number of outcomes indicators to be implemented on a routine basis (Secretary of State for Health, 1999). The results of this survey, in particular the barriers identified to outcomes measurement, will be of particular interest to those charged with implementing the National Service Framework for Mental Health. Several areas are worthy of further discussion.

Our main finding is that the majority of psychiatrists do not use outcomes measures in their day-to-day practice. Patient needs and psychosocial problems are measured infrequently in any standardised or consistent way, despite explicit Government policy (Glover *et al*, 1997; Secretary of State for Health, 1999) to adopt measures such as the HoNOS and needs assessment tools. This may reflect a wider indifference towards and failure to address psychosocial outcomes and needs, or simply a failure to use standardised measures to assess them.

The HoNOS does seem to have f... place in measuring outcome... health services, al... Initial hopes that ... on a service-wi... measure outcome, ... needs and to judge the ... of individual trusts and teams ... however, clearly not ... concerns expressed ... the time taken to ... and the poor ... will need to be ... going to be increased.

SIMON M. GILBODY, MRCPsych, NHS Ce...
ALLAN O. HOUSE, DM, Academic Unit ...
TREVOR A. SHELDON, DSc, Departmen...
Dissemination, University of York, York; ...aviour Sciences, University of Leeds, Leeds; ...University of York, York
Correspondence: Dr S. M. Gilbody, Academ... and Behavioural Sciences, University of Leeds, ... 15 Hyde Terrace, Leeds LS2 9LT, UK. Tel: 01... 3 2433719; e-mail: s.m.gilbody@leeds.ac.uk
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On the other hand, positive aspe... comes measures were identified th... useful in deciding their place ... health services. In particular, the ... that non-medical personnel can ... instruments such as the HoNOS ... it encouraged discussion within ... clinical team are worthy of note.

Administrative measures co... by trusts – such as length of stay and r... sion rates – although easier to collect ... bear little relation to the psychosoci... come of the individual patient or cli... popu-lation. It is administrative out... es that will form the basis of the p... rmance ...lements of the NHS (Secretary ... State for Hea... 1999). Of particular con...rn is that these figures are the easiest to ...anipulate or 'improve', without conferring ...y overall health gain on the population or ...rvice under consideration (Nutley & Smith, 1998).

Teams need to be resourced adequately to collect outcomes data, and the instruments that are used must be reasonably concise and easily administered (Slade *et al*, 1999). Additionally, the reluctance among clinicians to collect data on a routine basis may reflect the fact that they see little benefit to themselves or their patients' care. Outcomes measurement ...chnology' that has opportunity costs a... must be shown to be beneficial in impr... the quality of care as measured by actual outcomes of patients or communities. No direct evidence exists that there is a benefit in this ...pect for those working and being ...ed for in either primary care or specialist psychiatric services (Gilbody *et al*, 2001*a*,*b*). Successful implementation of outcomes management will need to overcome the barriers that we identified in this survey of current UK psychiatric practice.

DECLARATION OF INTEREST

None.

ACKNOWLEDGEMENTS

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REFERENCES

Beck, A. T. & Ward, C. H. (1961) An... measuring depression. *Archives of Ge...* 561–571.

Curtis, R. & Beaver, A. (1995) Healt... Outcome Scales (HoNOS). In *Measureme... Health: Contributions from the College Research Un...* (ed. J. Wing). pp. 33–46. London: Royal College ... Psychiatrists' Research Unit.

Department of Health (199...) *Nation: A Strategy for E...*

— (1998) *Mod... ...alth Services: Safe, Sound ...* ...don: HMSO.

..., H. F., Folstein, S. E. & McHugh, P. R. (1975) 'Mini-Mental State': a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, **12**, 189–198.

Gilbody, S. M., House, A. O. & Sheldon, T. A. (2001*a*) Outcome and needs assessment for schizophrenia and related disorders (Cochrane Review). In *The Cochrane Library – Issue 1*. Oxford: Update Software.

—, — & — (2001*b*) Routinely administered questionnaires for depression and anxiety: a systematic review. *BMJ*, **322**, 406–409.

Glover, G., Knight, S., Melzer, D., *et al* (1997) The development of a new minimum data set for specialist mental health care. *Health Trends*, **29**, 48–51.

Hamilton, M. (1967) Development of a rating scale for ...imary depressive illness. *British Journal of Social and ...ology*, **6**, 278–296.

...tell, P. (1974) The CAGE ... 1121–1123.

Nutley, S. ... performance impro... *of Health Services Research ...*

Rice, K. & Donnelly, P. (1992) ... consultant psychiatrists. *Psychiatric Bulle...*

Secretary of State for Health (199...) *Framework – Mental Health*. London: ...

Slade, M., Thornicroft, G. & Glover... The feasibility of routine outcome me... health. *Social Psychiatry and Psychiatric ...* 243–249.

Wing, J. (1994) Measuring mental healt... a perspective from the Royal College of ... In *Outcomes into Clinical Practice* (ed. T. Dela... pp. 147–152. London: BMJ Publishing.

Zigmond, A. S. & Snaith, R. P. (1983) The Hosp... Anxiety and Depression scale. *Acta Psychiatrica Scandinavica*, **67**, 361–370.

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"instruments must be....concise"

		Skelly & D'Antonio 2008	Hillier et al. 2010	Oyefeso 2016	Turton 2020	Hunt 20203
	Method of analysis	PCA	Clinical consensus	Factor Analysis	PCA	Mokken Analysis
	sample size	155	15 (x2 ratings)	68	2,109	571
	clinical setting	community	Inpatients	community	community	Community Team
	Number of factors / components	4	7	6	3 or perhaps 4	3
	% of variance explained	48%	???	68%	37% or 42%	??
1	Behavioural concerns (directed at others)	2	1	2	4	2
2	Behavioural problems directed towards self (self-harm and/or self-injury)	2	1	6		2
3	Other psychological and behavioural concerns		1			2
3a	behaviour destructive to property	2		2	4	
3b	problems with personal behaviours, for example, spitting, smearing, eating rubbish, self-induced vomiting, continuous eating or drinking, hoarding rubbish, inappropriate sexual behaviour			2		
3c	rocking, stereotyped and ritualistic behaviour	4		1		
3d	anxiety, phobias, obsessive or compulsive behaviour			2		
3e	Other psychological and behavioural concerns	4				
4	Attention and concentration	1	2	1	1	1
5	Memory and orientation	1	2	1	1	1
6	Communication (problems with understanding)	1	3	1	1	1
7	Communication (problems with expression)	1	3	1	1	1
8	Problems associated with hallucinations and/or delusions	4	4	3		
9	Problems associated with mood disturbance	2	4	6	2	2
10	Problems with sleeping	4	4	3	2	3
11	Problems with appetite		4	3	2	3
12	Physical problems	3	5	4		1
13	Seizures		5	4		1
14	Domestic activities	3	6	1	3	1
15	Activities of daily living in the community	3	6	1	3	1
16	Level of self-care	3	6	1		
17	Problems with relationships	2	7	5		
18	Occupation and/or meaningful activity	3	7	5	3	

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PCA components derived purely from the largest statistical loadings for each HoNOS-LD item

HoNOS-LD Item		Component			
		1	2	3	4
14	Domestic activities	0.834			
15	Activities of daily living in the community	0.759			
4	Attention and concentration	0.726			
7	Communication (problems with expression)	0.720	-0.424		
6	Communication (problems with understanding)	0.719		-0.385	
5	Memory and orientation	0.707	-0.445		
18	Occupation and/or meaningful activity	0.616			
10	Problems with sleeping	0.535			
1	Behavioural concerns (directed at others)		0.570	-0.462	
3	Other psychological and behavioural concerns		0.564		
9	Problems associated with mood disturbance	0.386	0.395		
16	Level of self-care	0.452		0.609	
11	Problems with appetite	0.411		0.573	0.458
17	Problems with relationships		0.532		-0.579
2	Behavioural problems directed towards self (self-harm and/or self-injury)				0.415
Eigenvalues		4.90	1.82	1.43	1.18
Percentage of variance		32.67	12.14	9.56	7.83

Balancing clinical with statistical validity

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Component 1

- Domestic activities
- ADL in the community
- Attention and concentration
- Occupation and/or meaningful activity
- Problems with sleeping

Component 2

- Other psychological and behavioural concerns

Component 3

- Behavioural concerns (directed at others) 2 or 3
- Level of self-care 1 or 3

Component 4

- Behavioural problems directed towards self (self-harm and/or self-injury)
- Problems with relationships 2 or 4
- Problems with appetite 1,3 or 4

- Communication (problems with expression) 1 or 2
- Communication (problems with understanding) 1 or 3
- Problems associated with mood disturbance 1 or 2
- Memory and orientation 1 or 2

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"HoNOS seems to have found a place"

- Is the HoNOS-LD psychometrically sound?
- Is the HoNOS-LD total meaningful?
- Can we lose any of the 18 HoNOS-LD items?
- Does a factor structure & sub-totals help

- Probably yes
- Sort of
- Probably no
- Probably yes

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HoNOS-ID yet to come...

Updates to HoNOS Family

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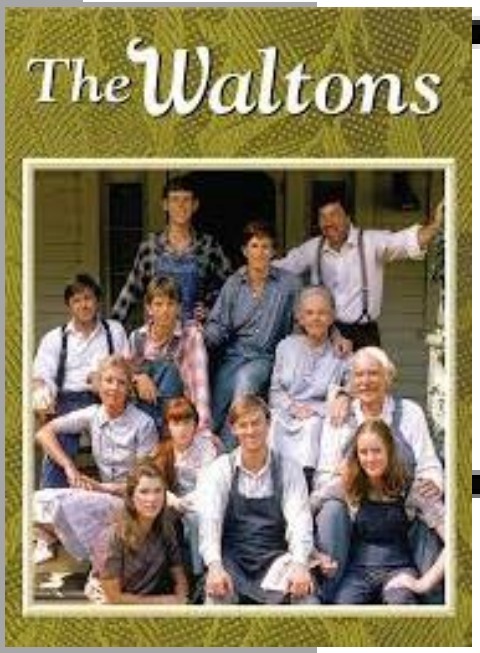
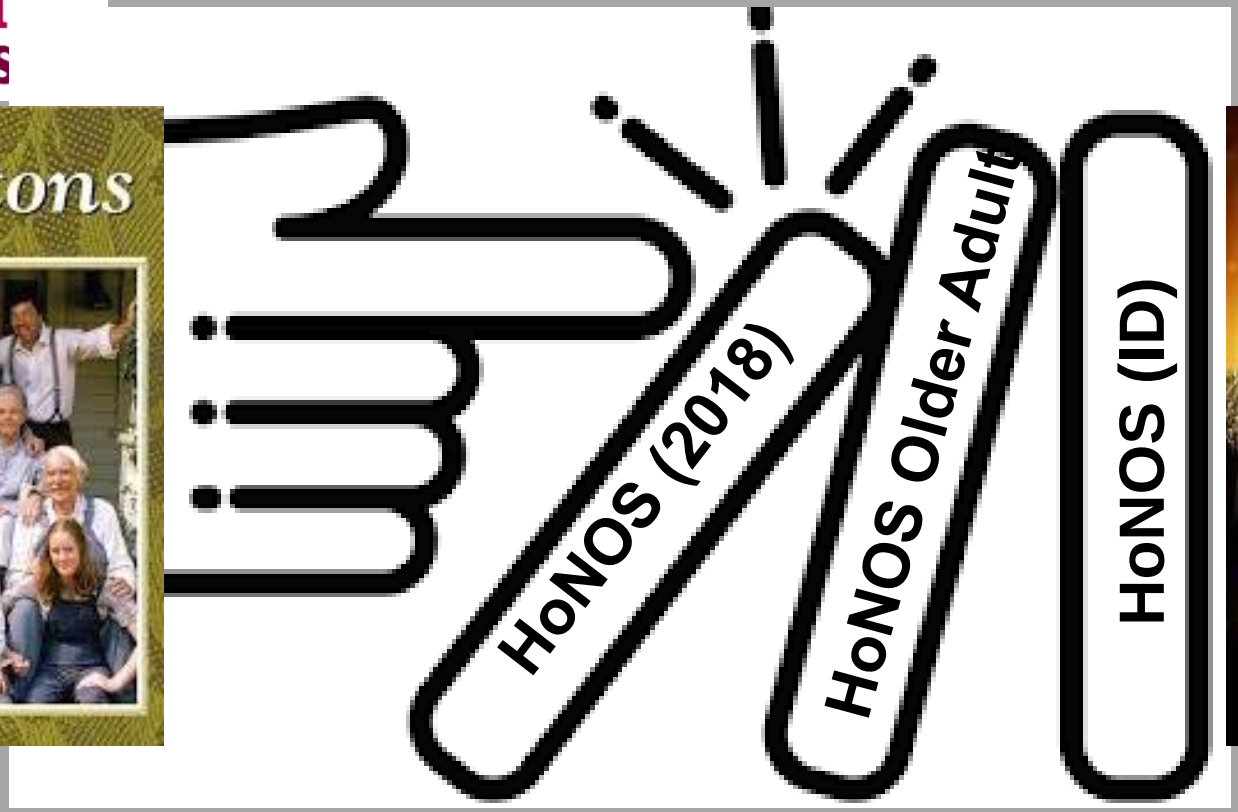


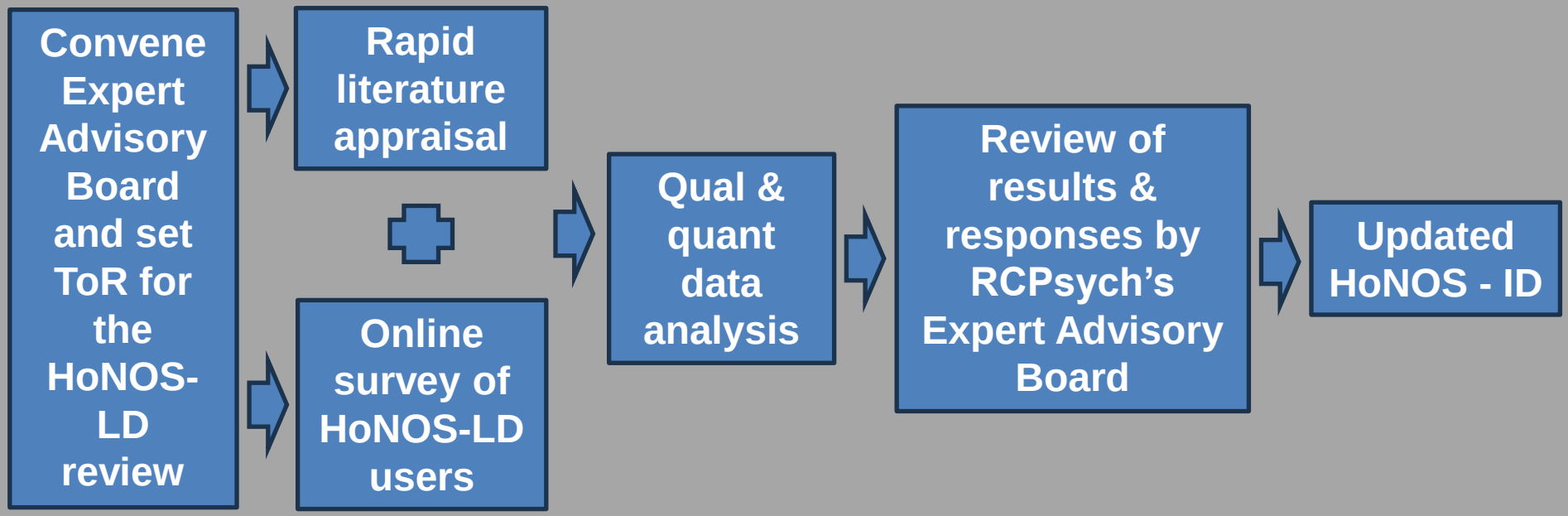


James, M., Painter, J., Stewart, M., & Buckingham, B. (2018). A Review and update of the Health of the Nation Outcome Scales (HoNOS). *BJPsych Bulletin, 42* (2), 63-68. http://doi.org/10.1192/bjb.2017.17

James, M., Buckingham, B., Cheung, G., McKay, R., Painter, J., & Stewart, M. (2018). Review and update of the Health of the NationOutcome 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



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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**
Jon Painter	Registered Nurse LD & Registered Mental Health Nurse	Sheffield Hallam University (HoNOS & HoNOS 65+ EAG member)	England
Mick James	Registered Mental Health Nurse	Royal College of Psychiatrists (National HoNOS Advisor)	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.**

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Online survey of HoNOS-LD users

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').

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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	- Subjectivity of terms used
		  ○ frequency not well-defined 'occasional' and 'frequent' can be open to interpretation (53) (49) (77) (55) (35) (76)
		  ○ 'pestering,' 'harassment,' 'quarrelsome' - outdated, subjective, lacking empathy, negative, not commonly used (46) (53) (76) (77) (35) (44)
		  ○ 'Casualty' an ambiguous term (44) (45) (77)
		  ○ The use of the word behavioural 'problems' (11) (38) (79) (51) - should be renamed as 'behaviours of concern'
		  ○ Phrasing indicates that the patient is the problem (49) (76) (51) (62)
		  ○ '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)

HoNOS- 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	3	33	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

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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 ‘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’

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https://www.rcpsych.ac.uk/events/in-house-training/health-of-nation-outcome-scales

Health of the Nation Outcome Scales (HoNOS)

What's new?

webpage updated 30 June 2023

HoNOS for People with Intellectual Disability (HoNOS-ID)

The Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) has been used widely for 20 years, but like other original versions of the HoNOS family, has not been updated to reflect contemporary clinical practice. As well as its use in UK services, New Zealand have mandated the HoNOS-LD for routine monitoring and outcome measurement across their intellectual disability services at a national level.

Following on from the review of the HoNOS and HoNOS65+, the Royal College of Psychiatrists convened an advisory board with membership from the UK and New Zealand. The board consisted of multi-disciplinary professionals with expertise in working with people with intellectual disabilities and its aim was to propose amendments to the HoNOS-LD. Views and experience from the countries involved were used to produce a series of amendments intended to improve intra- and interrater reliability and improve validity, rather than a more radical revision. This update is called HoNOS-ID to reflect the changing nature of the population and services provided to meet their needs.

View the results of the review

Further work is now being undertaken looking at exploratory factor analysis; confirmatory factor analysis; internal consistency; test-retest reliability; sensitivity to change and inter-rater agreement.

View the final version of the revised tool (PDF)

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The story so far.....

- 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

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