

# EVALUATION OF A NEW PATIENT-CENTRED MONITORING TOOL FOR MEASURING LONGER-TERM UNMET NEEDS AFTER STROKE (LUNS)

Kirste Mellish  
*on behalf of*  
LoTS care LUNS study team

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LoTS care

Unmet needs after stroke study



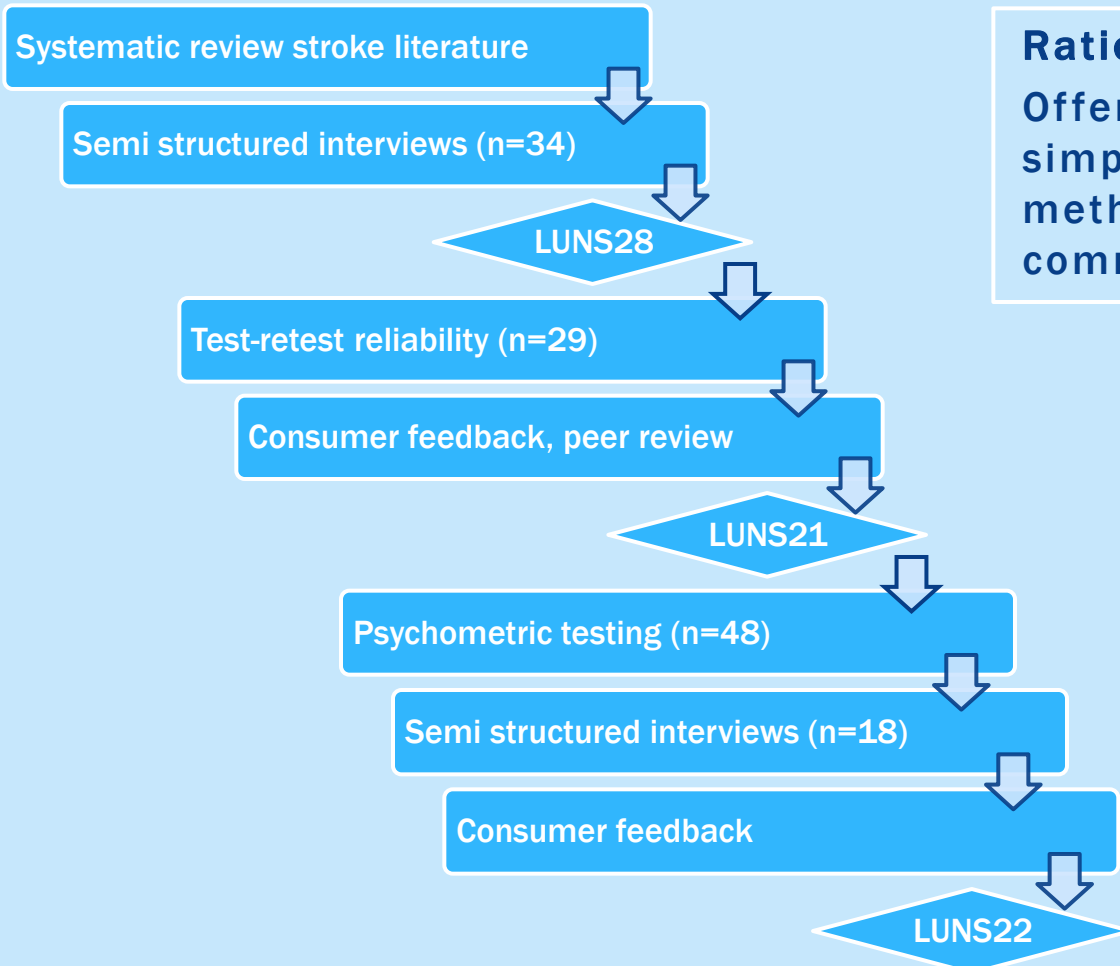
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# DEVELOPMENT OF LUNS

LoTS care

Unmet needs after stroke study



## Rationale

Offer service providers a simple, reliable & systematic method for monitoring community stroke care

## Face & content validity

## Acceptability

- Unobtrusive
- Reflected stroke experience
- Time taken to complete (n=16)
  - Median: 6 min (3 - 12 min)

# THE LUNS QUESTIONNAIRE



- LUNS is a 22 item questionnaire that:
  - Addresses multiple domains of the longer-term stroke experience
    - Information needs eg information on stroke, financial advice
    - Services eg personal care, home adaptations, medication review
    - Emotional and social consequences eg depression, driving, employment
    - Health problems and related issues eg pain, incontinence, falls
  - Aims to identify longer-term unmet needs of stroke patients
    - “Expressed needs that are not satisfied by current service provision”

## ■ Example questions

YES NO

■ I regularly get pain and nothing seems to ease it

■ I would like help to find out about, or to apply for, benefits

■ Count: 1 for yes (unmet need), 0 for no (no need / met need)

# STUDY METHODOLOGY



## Evaluation of the acceptability, reliability and validity of LUNS

- Phase 1 (n=350, 29 sites)
  - Patients returning home after  $\geq 3$  days in hospital post stroke
  - English speaking patients without cognitive impairment or aphasia (6CIT / FAST) – “normal communication” group
  
- Phase 2 (n=500, 40 sites)
  - Patients returning home after  $\geq 14$  days in hospital post stroke
  - Included patients with cognitive impairment / aphasia / non English speaking (with a proxy) (40% in “impaired communication” group)
  
- Questionnaire pack 1 posted at 3 or 6 months post stroke
  - LUNS, GHQ12, SF12, FAI, impairment manikin, help with completion
  
- Questionnaire pack 2 posted 1 week after return of pack 1
  - LUNS, SF12, help with completion, change in health status

# STUDY POPULATION



## ■ Demographic data

	Number recruited	Age (years) (median)	Gender % male	Living % alone	Ethnicity % white
All patients	850	73	54	40	97
“Normal”	651	71	56	41	98
“Impaired”	199*	79	48	39	96

\*138 cognitive impairment (6CIT), 56 aphasia (FAST), 3 non English speaking

## ■ Stroke data

	Pathology % infarct	LOS (days) (median)	Post stroke Barthel score (discharge)		
			<15 (%)	15 -19 (%)	20 (%)
All patients	90	27	37	39	24
“Normal”	91	22	31	41	28
“Impaired”	86	46	55	34	11

# ACCEPTABILITY OF LUNS



## ■ Response rates

	Recruited	Pack 1 sent	Pack returned	Response rate
All patients	850	770	529	69%
“Normal”	651	614	438	71%
“Impaired”	199	156	91	58%

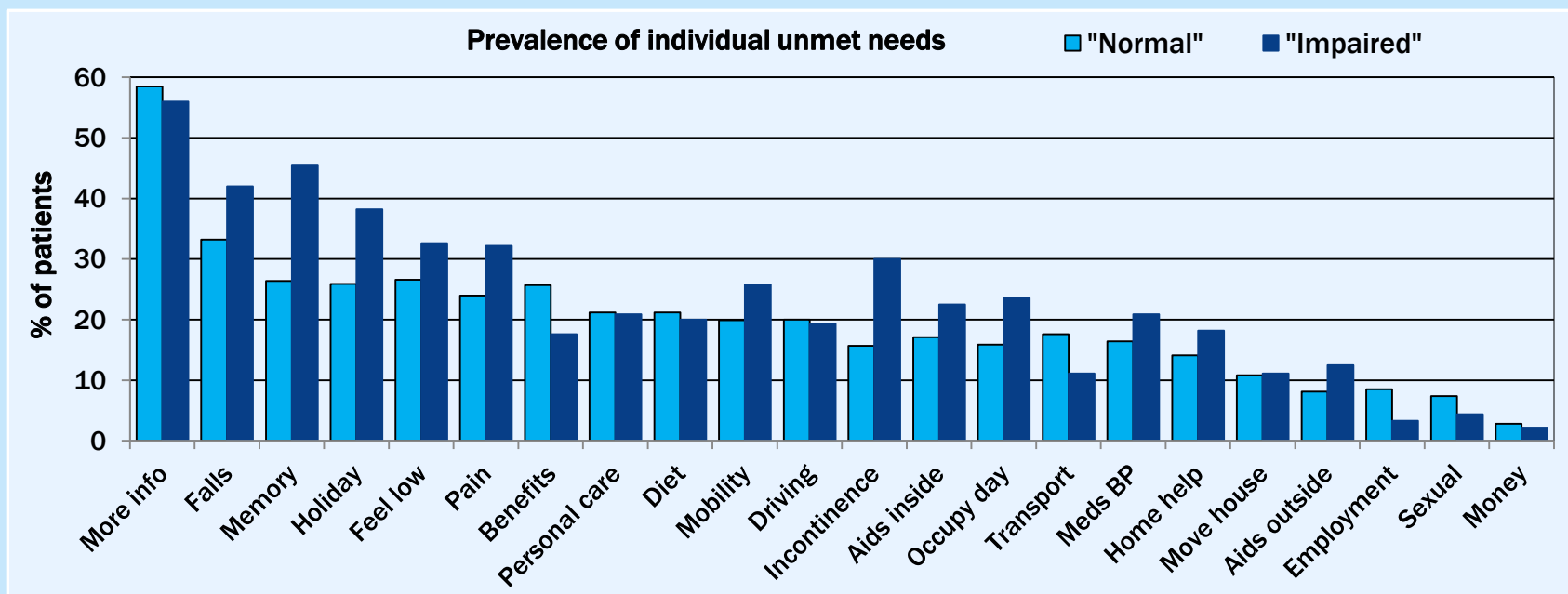
## ■ Missing data

Questionnaire	% fully completed	% missing items
LUNS	85	3.5
General Health Questionnaire 12	90	2.7
Frenchay Activities Index	88	2.2
Short Form 12	84	4.0

(all patients; data comparable for “normal” / “impaired” groups)

# LUNS RESPONSES

	Number of unmet needs			Months post stroke	Proxy completion
	Median	Min - Max	Mode		
All patients	4	0 - 19	0	3 - 10	6%
“Normal”	4	0 - 19	0	3 - 9	4%
“Impaired”	5	0 - 17	5	5 - 10	13%



# CONCURRENT VALIDITY

## Comparison of number of unmet needs with outcome measures

	Spearman's correlation coefficient with LUNS			
	GHQ12	FAI	SF12 PCS	SF12 MCS
All patients	0.519	-0.302	-0.355	-0.469
“Normal”	0.525	-0.382	-0.400	-0.484
“Impaired”	0.442	0.088	-0.082	-0.331

- **GHQ12 (General Health Questionnaire 12)**
  - Mood & emotional wellbeing; higher score represents lower mood
- **FAI (Frenchay Activities Index)**
  - Extended activities of daily living (domestic tasks & leisure activities)
- **SF12 (Short Form 12)**
  - Quality of life (physical and mental health components)



# TEST-RETEST RELIABILITY (1)

	Number of patients			Days between packs 1 & 2 (median)	Number of unmet needs	
	Return pack 1	Return pack 2	“No change in health”		Pack 1 (median)	Pack 2 (median)
All patients	529	460	336	14	3	3
“Normal”	438	382	275	14	3	3
“Impaired”	91	78	61	15	4	4

## Agreement of individual items between pack 1 and pack 2

- All patients

	Number of items	% agreement	kappa
Moderate agreement	14	78 – 94	0.45 – 0.59
Good agreement	8	81 – 99	0.61 – 0.67

# TEST-RETEST RELIABILITY (2)

Agreement of individual items between pack 1 and pack 2

- “Normal communication” group

	Number of items	% agreement	kappa
Moderate agreement	10	78 - 95	0.42 - 0.60
Good agreement	11	82 - 96	0.61 - 0.69
Very good agreement	1	100	0.86

- “Impaired communication” group

	Number of items	% agreement	kappa
Fair agreement	7	78 - 95	0.25 - 0.38
Moderate agreement	12	75 - 92	0.41 - 0.56
Good agreement	3	87 - 97	0.65 - 0.67

# CONCLUSIONS



- **Face and content validity**
  - Literature review, consumer involvement, peer review
  
- **Acceptability**
  - Quick to complete, good response rates, minimal missing data
  
- **Test-retest reliability**
  - Moderate – good agreement of individual items at two timepoints
  - Lower agreement for some items in aphasia / cognitive impairment
  
- **Concurrent validity**
  - Number of unmet needs shows modest inverse correlation with mood, quality of life and extended activities of daily living
  - Number of unmet needs correlated only with mood and mental component of quality of life in aphasia / cognitive impairment

# ONGOING / FUTURE WORK



- Use of LUNS as a monitoring tool
  - Simple and reliable method for identifying the number and types of longer-term unmet needs for an individual patient or in a service
- Explore further the suitability of LUNS in patients with cognitive impairment / aphasia
- Investigate the potential of LUNS as an outcome measure to measure the level of longer-term unmet need
  - Internal consistency
  - Dimensionality – factor analysis, Rasch analysis
  - Responsiveness (sensitivity to change)

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SRN Adopted Studies Stand (stands 6 & 7)

[kirste.mellish@bthft.nhs.uk](mailto:kirste.mellish@bthft.nhs.uk)

[www.lotscare.co.uk](http://www.lotscare.co.uk)

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