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The Stroke Association UK Stroke Survivor Needs Survey

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Overview

- Aim and methods
- Headline findings:
 - health needs
 - social participation
- Higher risk of need?
- Implications

Background

- Stroke: an acute event with long-term physical, psychological and social consequences
- Focus so far on acute: limited research into long term needs
- Long term care underdeveloped

Background: stroke has long term consequences



“Stroke patients may spend several days or weeks in hospital, but it is in the months and years after discharge that they, their families and carers experience the full impact of stroke.”

National Audit Office 2010

Aims

1. To estimate levels of self reported long term need in stroke survivors (1-5 years)
2. To compare levels of need between stroke survivors in England, Scotland, Wales & Northern Ireland

“Need”

- Self reported
- Identification of specific unmet needs
- Changes in everyday circumstances

Methods: sampling frames

Cross sectional survey with stroke survivors recruited through:

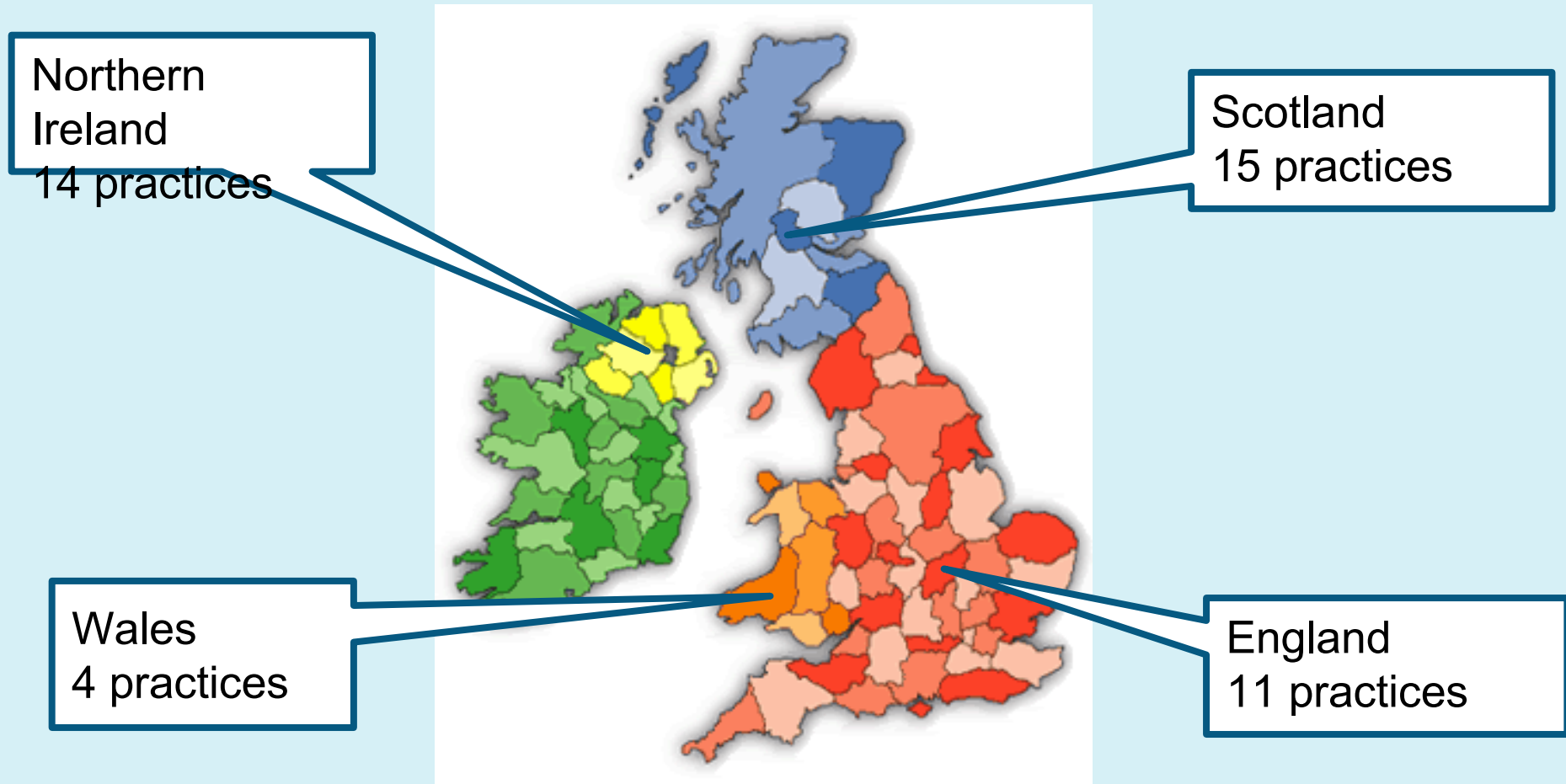
1.MRC GPRF practices across the UK

2.SLSR & OXVASC: population registers

“validation”

National sample

(MRC General Practice Research Framework)



Population registers sample

OXVASC

- 2002 - ongoing
- Needs survey with annual follow up



SLSR

- 1995 - ongoing
- Needs survey with annual follow up



Questionnaire development

- To meet TSA brief
- Existing questions from validated questionnaires.
- 44 closed questions:
 - information about stroke;
 - health after stroke;
 - everyday living;
 - work and leisure;
 - friends, family and use of support groups;
 - finances;
 - demographic information
- Reviewed by KCL Stroke Research Patients & Family Group

Fatigue question

Since your stroke, have you had enough help with fatigue problems (feeling tired all the time)?

- Yes, definitely
- Yes, to some extent
- No, I did not get enough help
- I did not want help
- I did not have any fatigue problems

Survey method

- Participants aged >18 years, living at home
- 1-5 years after first stroke
- National sample:
 - identified and contacted by practice nurses
- Population registers
 - questionnaire during routine annual follow up

Data analysis

- Basic frequencies using chi squared tests for associations
- Comparisons between:
 - nations (national sample)
 - socio-demographic groups, disability levels, and cognitive status (population registers sample)
 - national (weighted) and population registers samples

Data analysis

- Multivariate analysis to identify predictors of total number of unmet needs (population registers sample)
- Deprivation scores using Index of Multiple Deprivation (IMD) 2007 derived from postcodes (England only)

Response rates

- National sample: 60%
- Population register samples: 78%
- No significant differences between non responders and responders (population registers sample)

Respondents

	National, n (%)	Registers, n (%)
Total	571	228
Age, mean (sd)	69.9(12.3)	66.3(13.0)
Age		
<65 years	171(30)	95(41.7)
Gender		
Male	310(55)	132(59.5)
Ethnicity		
White	558(99.6)	160(73.1)
Time since stroke		
1-2 years	143(26)	93(41.9)
3-4 years	246(44.7)	62(27.9)
5+ years	161(29.3)	67(30.2)

Results

- 51% reported having no unmet needs
- Of those reporting unmet needs, total number per respondent ranged from 1-13, median 3
- Few significant differences between 2 samples

Information

- 54%: more information about stroke
- No differences by age, gender, ethnicity, disability level or time since stroke
- Significantly different by nation ($p=0.009$):
 - Northern Ireland=66%
 - Wales=65%
 - England=54%
 - Scotland=49%

Unmet health needs

	N reporting problem (weighted %)	Need unmet (%)	Need met to some extent (%)
Mobility	321 (58.4)	25	43
Falls	265 (43.9)	21	47
Incontinence	217 (37.2)	21	40
Pain	249 (39.5)	15	51
Emotional	244 (38.4)	39	34
Speech	194 (34.3)	28	33
Sight	212 (37.2)	26	39

Other unmet needs

	N reporting problem (weighted %)	Need unmet (%)	Need met to some extent (%)
Fatigue	301 (51.7)	43	36
Concentration	260 (44.7)	43	41
Memory	260 (42.8)	59	25
Reading	148 (23.2)	34	43

Changes in social participation

- 52% unable to return to work or reduced hours
 - Significantly higher in Black and other ethnic groups compared to Whites ($p=0.006$, *population registers*)

- 67% reported loss in leisure activities
 - Significantly higher in Black and other ethnic groups compared to Whites ($p=0.012$, *population registers*)

Impact on finances

- 18% of those working at time of stroke reported a loss of income since stroke
- 31% reported increased expenses
- 16% (25% population registers) reported need for benefits advice

Family

- 42% reported a negative change in relationship with partner
- 26% reported negative changes in family relationships

Deprivation and need

- Respondents in most deprived areas in England reported significantly higher loss of income since stroke ($p=0.007$)
- Living in deprived area associated with reported need for benefits advice ($p<0.001$)

Predictors of unmet need (*population registers*)

- The number of unmet needs increased with worsening disability (BI), $p=0.014$
- Black stroke survivors reported more unmet needs than Whites, $p=0.032$

Discussion

- ***The good news:*** half reported no unmet needs
- ***The bad news:*** half reported unmet needs.
- In domains where provision in place: *information, incontinence, falls, psychological problems*
- Higher levels of unmet need in domains not typically addressed by current services: *fatigue, memory, concentration*

Groups at higher risk?

- No differences by
 - age
 - gender
 - time since stroke
- Higher unmet need:
 - disability, including communication disability
 - ethnic minority stroke survivors
 - people living in poorest areas

Cautions

- Bias in cross-sectional surveys
 - Population registers as validation
- Self report – a weakness or a strength?
 - 1/3 reported emotional problems
 - cf pooled estimate of depression: 33%, Hackett et al. 2005
- Possible that not all needs directly related to stroke
 - stroke needs or health/wellbeing needs?

Implications

- Wide range of consequences, some we haven't begun to address
- Targeted approach to long term support warranted
- Intervene early

Can we learn from those who don't report long term needs?



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- **General practice research nurses**
- **Registers teams**
- **The Stroke Association**

Further details

- McKeivitt C, Fudge N, Redfern J, Sheldenkar A, Crichton S, Rudd AG, Forster A, Nazareth I, Silver L, Rothwell PM, Wolfe CDA. Self reported long term needs after stroke. Stroke. 2011;42:1398-1403.



http://www.stroke.org.uk/information/our_publications/other_material/needs_survey.html



NIMAST Conference 2011 The Stroke Journey

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Lagan Valley Island Centre