

## ORIGINAL RESEARCH

# Stroke outcomes in Northern Scotland: does rurality really matter?

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## ABSTRACT

**Introduction:** Stroke is the third leading cause of death in Scotland after coronary heart disease and cancer and is a major cause of long-term disability. There is evidence in other clinical conditions such as asthma, diabetic retinopathy, and cancer that rural residents may have poorer outcomes, due to relative inaccessibility of health-service provision or because the disease is at a more advanced stage at diagnosis. However, the evidence-base for stroke care and outcomes in remote and rural areas is small and the subject matter is under-researched. This study was designed to examine, over a one-year period, the incidence and outcome of stroke occurring in the Highlands and Islands of Scotland, a large geographical area with many rural and remote settlements. The study explored whether stroke care and outcome was affected by remoteness and rurality.

**Methods:** The study was a prospective, community-based, observational survey. Patients in Highland and the Islands (Orkney, Shetland and the Western Isles) suffering first-ever stroke during a 12-month period (from 1 May 2001 to 30 April 2002) were included. All practitioners from health and social care sectors, residential homes, voluntary and charitable organisations were encouraged to notify the researchers of any individual they suspected or knew had a first-ever stroke within the designated time period. Data on 'limitation in activities' (formerly 'level of disability') and service provision were collected using questionnaires and proformas at 1, 3 and 6 months post-stroke from several sources. These included individual patients and carers, health and social care professionals, residential homes, voluntary organisations, and charitable organisations.

The analysis focused on location at time of follow up, limitation in activities and service provision. Outcomes were compared across different settlement categories. Settlements were classified as urban/accessible, remote rural and very remote, based on the Scottish Household Survey.

**Results:** In all, 303 patients with a suspected first-ever stroke were notified to the study. The resulting crude incidence of reported stroke was 1.1 per 1000. From the notifications, 239 patients were sent a consent form, of whom 118 agreed to participate in the



study. The final dataset, after exclusions for incorrect diagnosis, deaths and other reasons, was derived from 85 patients. Among these, patients from remote rural and very remote settlements were over-represented, when compared to all patients notified. The majority of patients returned home from acute hospitals during the study period and the likelihood of returning home was not related to settlement category. However, a greater proportion of patients in remote rural settlements were admitted to community hospitals and remained there at 6 months. Approximately two-thirds had some degree of disability (or limitation in activities) after their stroke. One-third of patients classed themselves as independent across all time points. Overall, the Barthel Index score increased over time (ie, patients experienced a reduction in disability) with the average score at 1 month post-stroke being 82.5 (range 0-100), at 3 months 85 (range 5-100), and at 6 months 90 (range 5-100). Uptake of services was similar across all settlement categories, with low levels of use at 6-months post-stroke. In particular, few patients used social-support and stroke-specific services, for example Chest, Heart and Stroke Scotland, and Stroke Nurse services. The proportion of patients using any service at 1, 3 and 6 months did not differ between settlement categories. Rural patients did not therefore appear disadvantaged in service provision.

**Conclusions:** The low incidence of reported stroke may have been due to a number of reasons including: death prior to notification; diagnostic uncertainty; stroke severity – failure to notify very mild or very severe stroke cases; and inadequate reporting of patients managed at home. The greater proportion of patients in remote rural settlements being admitted to community hospitals and remaining there at 6 months may reflect greater availability of community hospital places in this settlement category, but may also be influenced by stroke severity. The low uptake of rehabilitation and support services generally, combined with the relatively poor functional outcome of our patients, suggests that there may be an unmet need for rehabilitation. However, rural patients did not appear specifically disadvantaged. Our study indicates that patients developing a first-time stroke in remote and rural areas of the Highlands and Islands of Scotland are not disadvantaged compared to those in urban/accessible areas, with respect to outcome or to the utilization of health and social care services. However, functional outcomes could be improved for patients in all settlement categories.

**Key words:** outcome, rurality, Scotland, service provision, stroke.

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## Introduction

Stroke is the third leading cause of death in Scotland after coronary heart disease and cancer, and is a major cause of long-term disability<sup>1,2</sup>. Research has shown that good care which includes early multidisciplinary assessment, specialist rehabilitation and well-organised discharge and follow up improves survival and minimises disability<sup>3-5</sup>. The nature of stroke and the complexity of needs following a stroke present a huge challenge to service providers.

Epidemiological data on stroke informs service provision<sup>6</sup>. It is important to configure stroke services to reflect the local health culture<sup>7</sup>, and where appropriate, the rural

environment. Planners and clinicians require data on stroke incidence and outcome<sup>8</sup>. However, such data are limited, especially in Scotland, and are largely acquired from hospital-based practice<sup>9</sup>. Not all patients enter hospital, and those that do may represent a biased group<sup>10</sup>.

Approximately one-fifth of Scots live in rural areas. It is important to include a rural perspective in relation to health issues<sup>11</sup>, as inadequate provision and inaccessibility of health-service provision in rural areas may be detrimental, particularly for some groups of rural society<sup>12,13</sup>. Studies in the 1990s have addressed the impact of distance and rurality on the outcome of particular diseases, asthma, diabetic retinopathy and cancer, and have shown poorer outcomes for rural residents<sup>14-16</sup>.



Stroke is mainly a disease of the elderly and many rural areas have a high proportion of elderly residents<sup>12</sup>. There is evidence that stroke care should be organised within specialist units and should be available for the duration of the illness<sup>4</sup>. However, the best way to provide care in areas with scattered populations in remote rural and island settings, such as Highland and the Islands of Scotland, is unclear. Highland Region alone covers an area of 26 000 km<sup>2</sup>, and this geography presents challenges to providing a stroke service. This study was designed to explore whether stroke care and outcome was affected by remoteness and rurality.

## Methods

This was a community-based survey to assess outcome of stroke and provision of services to stroke patients across Highland, Orkney, Shetland and the Western Isles. Highland and the Islands (Orkney, Shetland, the Western Isles) of Scotland include a population of approximately 280 000 over 26 000 km<sup>2</sup> (Highland alone) and 42 inhabited islands (Orkney, Shetland and Western Isles), served by approximately 114 medical practices.

Patients suffering a stroke are usually seen acutely by a general practitioner who will either refer the patient to hospital or arrange further management at home. Patients could be identified at acute presentation when they would be notified by a general practitioner, or during the early stages of treatment when notification could come from a hospital clinician or practitioner, or during the rehabilitative stage by other health, social care professionals or voluntary/charitable organisations. Notification was made by completing a project-specific form. Daily and weekly contact was made with local clinicians and practitioners. The study attempted to identify all first-ever strokes occurring in Highland and the Islands of Scotland during a 12-month period.

The study population comprised patients over the age of 18 years with a first-ever stroke registered with one of the collaborating general practitioners. The recruitment of an

individual was based on their ability to meet all of the following inclusion criteria:

- Resident within Highland, Orkney, Shetland or the Western Isles of Scotland
- A clinically apparent first-ever stroke occurring between 1 May 2001 and 30 April 2002
- Aged 18 years or over

Health and social care professionals, the voluntary sector and charitable organisations specifically involved in caring for stroke patients in Highland and the Islands were informed of the study and invited by letter to participate.

The study was prospective in nature with follow-up at 1, 3 and 6 months post-stroke to collect data on incidence, functional ability ('limitation in activities'), and the use of health and social care and voluntary sector services. Outcomes, in terms of limitation in activities, were measured by the Barthel Index (BI)<sup>17</sup>. Data collection consisted of a self-completed patient questionnaire and a professional service use data sheet. To maximise response rate to the questionnaire, one reminder letter and questionnaire was sent 2 weeks following the first mailing. Completion was by the patient or a nominated carer. A pragmatic definition of stroke was adopted, in which stroke was considered to be primarily a clinical diagnosis relying on clinical observations<sup>18</sup>. The WHO definition for the diagnosis of stroke or cerebrovascular accident was used<sup>19</sup>. Although this definition includes subarachnoid haemorrhage, patients with this diagnosis were excluded from this study. Information was requested on severity at the acute phase of the stroke. However, since subjects were enrolled into the study at varying time points after the acute event, the data were not used in analysis due to potential unreliability.

A generic definition of rurality was chosen, which classifies settlements by sparsity (population density/settlement size) and remoteness (journey time)<sup>13,20</sup>. This classification was developed for use with the Scottish Household Survey by the Environment and Rural Research Branch of the Scottish



Executive's Social Research Division<sup>21</sup>. For the analysis, the 8-fold classification was collapsed into three categories:

1. 'Urban/accessible': urban, accessible small town and accessible rural categories were grouped together (any settlement of at least 10 000 inhabitants or within 30 min driving time of a settlement of 10 000 or more).
2. 'Remote rural': remote small towns and remote rural (any settlement between 30 and 60 min driving time of a settlement of 10 000 or more).
3. 'Very remote': very remote small towns and very remote rural areas (any settlement more than 60 min driving time from a settlement of 10 000 or more).

Cases were identified using overlapping methods and hot pursuit techniques<sup>22</sup>. All practitioners from health and social care sectors, such as general practitioners, hospital clinicians, allied health professionals, community nurses, social workers, nursing and residential homes, voluntary and charitable organisations were encouraged to notify patients.

Data collected on the patient questionnaire included: place of residence and domestic circumstances (home alone or with carer) at time of follow up, health and social care services used, medication before and after stroke event, co-morbidities, BI and the Stroke-adapted Sickness Impact Profile to assess functional ability. Data on use of services were collected by self-completed proformas from health and social care professionals, and voluntary and charitable organisations. Data from questionnaires and proformas were entered into a purpose-built database designed in Microsoft Access 97 and then transferred for statistical analysis to SPSS, vers. 10.0 (SPSS Inc; Chicago, IL, USA). Descriptive statistics are presented. Continuous variables are shown as mean, median or percentiles, categorical variables as percentages.  $\chi^2$  (Chi-squared) analyses were used where appropriate. As some respondents did not complete all elements of the Stroke adapted Sickness Impact Profile, this was not used in analysis.

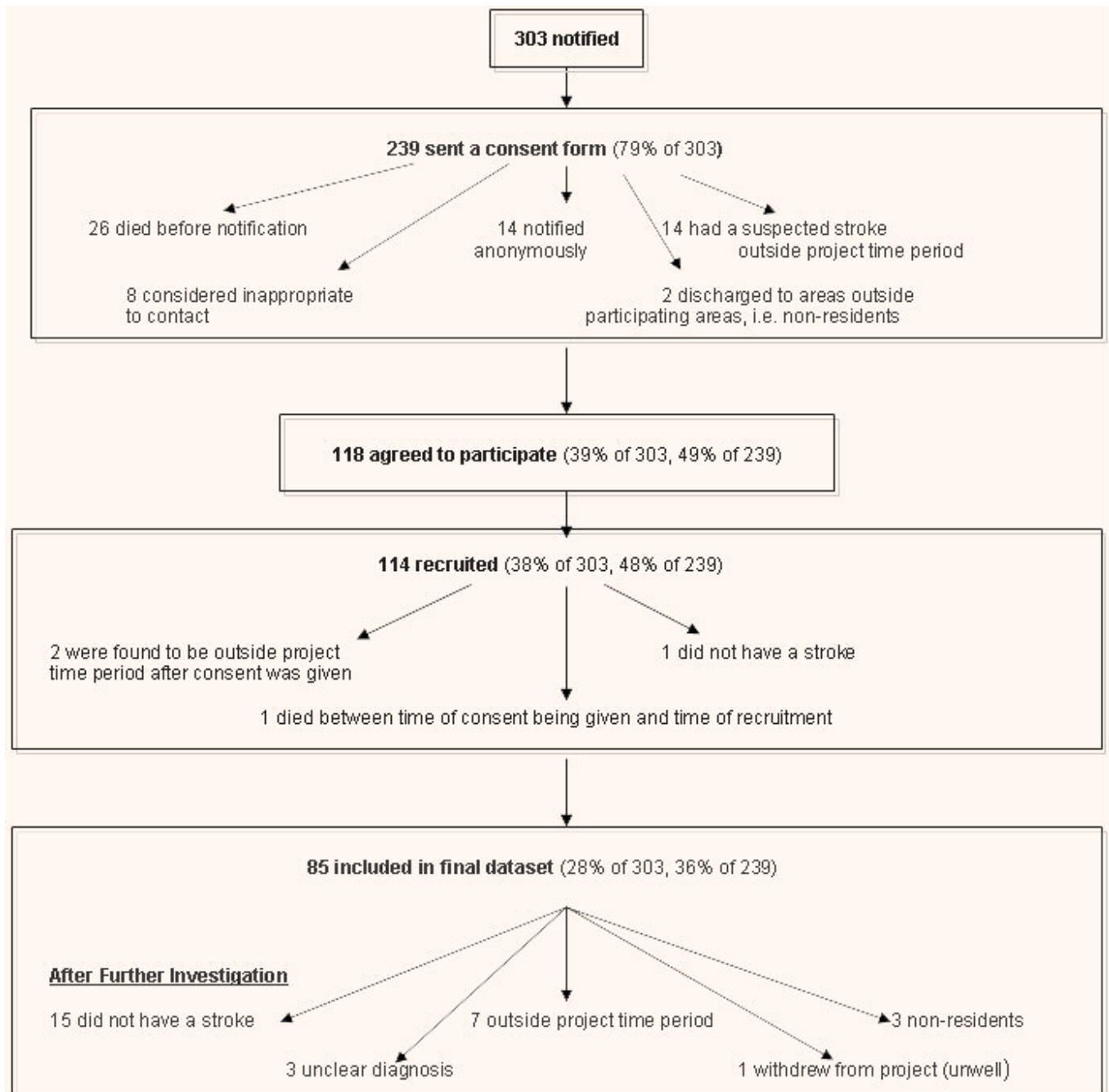
The study was approved by the research ethics committee of each participating area. Written informed consent was obtained from all patients. If the participant was cognitively impaired, dysphasic, or had altered consciousness, consent was obtained from the next of kin or carer.

## Results

### *Reported incidence and notification of patients*

Three hundred and three patients were notified with a suspected first-ever stroke. The resulting crude incidence of reported stroke was 1.1 per 1000 population. The notification and recruitment process of the project is shown (Fig 1). Of the 303 patients notified, 239 (78.9%) were sent a consent form. The remaining 64 patients were not sent a consent form due to a number of reasons such as death before notification; cases notified anonymously, the suspected stroke occurring outside the study time period; or considered by a health professional to be inappropriate to contact. Of the 239 patients who were sent a consent form, 118 (49.4%) agreed to take part in the study. Of these, 114 were recruited. Four were not recruited because two were found to be outside the time period, one died between consent being given and consent being received and one had not suffered a stroke. Of the 114 patients recruited, 85 were included in the final data set. Exclusions from the final data set were due to a variety of reasons such as: not having a first stroke; suffering the stroke outside the study time period; and where the diagnosis was unclear.

Of those notified, 159 were female, 136 male. Eight patients among 14 notified anonymously had no information on sex. The mean (SD) age was 74 (10) years. Of those notified, where settlement category was known ( $n = 284$ ), 54% were from urban/accessible areas, 12% from remote rural areas and 34% from very remote areas.



**Figure 1: Stroke patient recruitment and notification.**

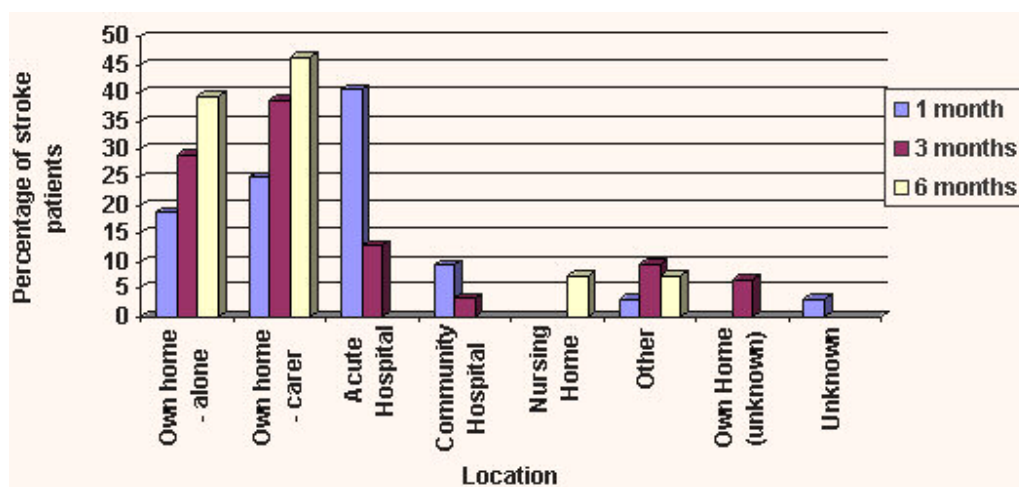


Characteristics of patients included in the final dataset are shown (Table 1). Cases included did not differ from all cases notified in terms of area of residence ( $\chi^2 = 6.9, p = 0.074$ ). However, when analysed as settlement category, a greater

proportion of those included in the final dataset came from remote rural and very remote settlements ( $\chi^2 = 7.3, p = 0.025$ ).

**Table 1: Characteristics of included patients (n = 85)**

Patient characteristic	n (%)
Sex	
Male	43 (50.6)
Female	42 (49.4)
Age (years)	
Mean [SD]	73 [11]
Minimum-maximum	45-97
Area of residence at time of stroke	
Highland	71 (83.5)
Orkney	2 (2.4)
Shetland	2 (2.4)
Western Isles	10 (11.8)
Settlement category	
Urban/accessible	32 (37.6)
Remote rural	17 (20.0)
Very remote	36 (42.4)
Admitted to hospital	
Yes	76 (89.4)
No	5 (5.9)
Stroke while in hospital	4 (4.7)



**Figure 2: Patient location by settlement category at 1, 3 and 6 months post-stroke: urban/accessible.**



## Patient location

Patient location by settlement category at 1, 3 and 6 months is shown (Figs 2-4). Seventy-six patients (89.4%) were admitted to hospital following their stroke, 5 (5.9%) remained at home and 4 patients (4.7%) suffered their stroke while in hospital. Of the 76 patients, 9 (11.8%) were admitted to GP/Community hospitals, the remaining 67 (88.2%) to acute hospitals. Of the 5 patients not admitted

to hospital, three came from remote rural and two from very remote settlements. None were from urban/accessible settlements. The majority of patients returned home from acute hospitals during the study period and the likelihood of returning home was not related to settlement category. However, a greater proportion of patients in remote rural settlements were admitted to community hospitals and remained there at 6 months ( $\chi^2=9.5, p=0.009$ ).

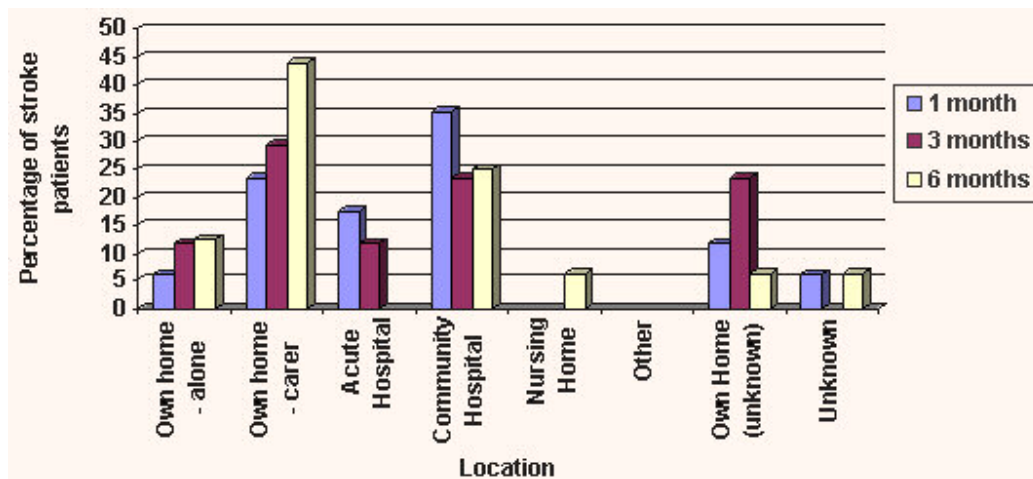


Figure 3: Patient location by settlement category at 1, 3 and 6 months post-stroke: remote rural.

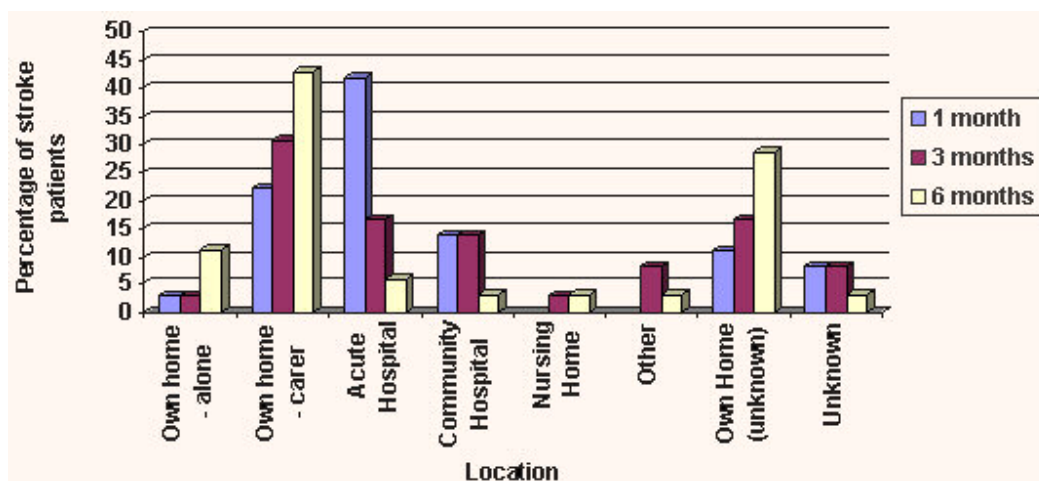


Figure 4: Patient location by settlement category at 1, 3 and 6 months post-stroke: very remote.



### Functional ability ('limitation in activities')

Limitation in activities by settlement category at 1, 3 and 6 months and the proportion of patients in each functional ability level are shown (Figs 5-7, respectively). Approximately two-thirds had some degree of disability (or limitation in activities) after their stroke. Only one-third of patients classed themselves as independent across all time points. Overall, the BI score increased over time (ie, patients

experienced a reduction in disability), with the average score at 1 month post-stroke being 82.5 (range 0-100), at 3 months 85 (range 5-100), and at 6 months 90 (range 5-100). However, when examined by settlement category, only patients from urban/accessible settlements showed a consistent increase in the BI score over the 6-month period post-stroke. Across all time points, a greater proportion of patients from remote rural settlements reported severe disability but this was not statistically significant.

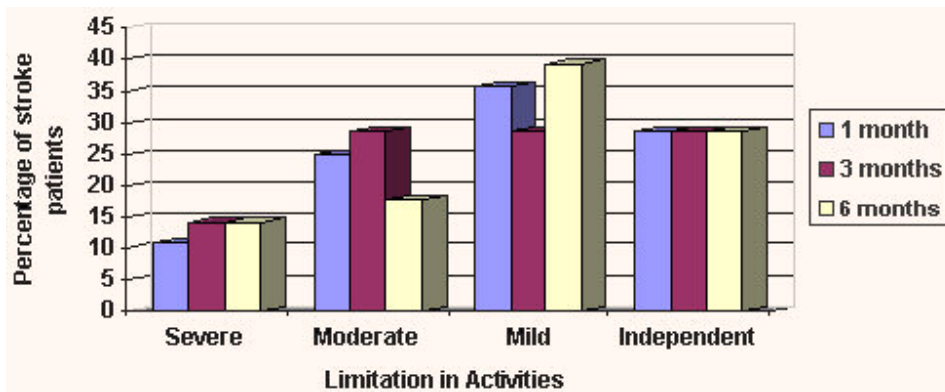


Figure 5: Limitation in activities at 1, 3 and 6 months post-stroke as measured by the BI: urban/accessible.

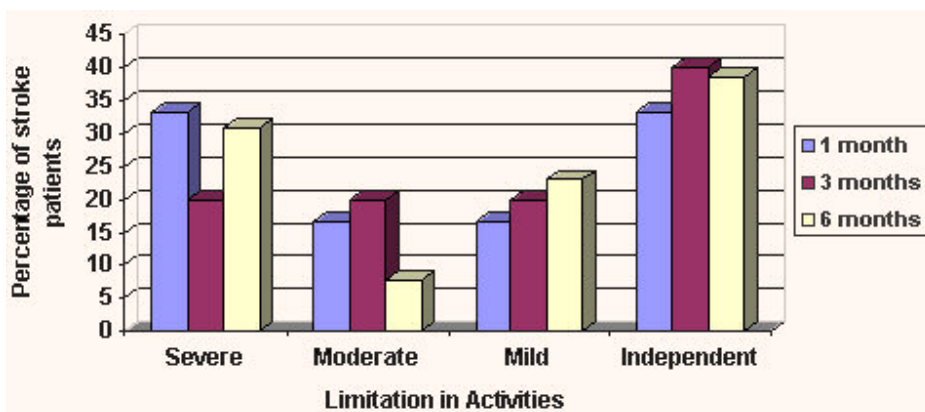


Figure 6: Limitation in activities at 1, 3 and 6 months post-stroke as measured by the BI: remote rural.



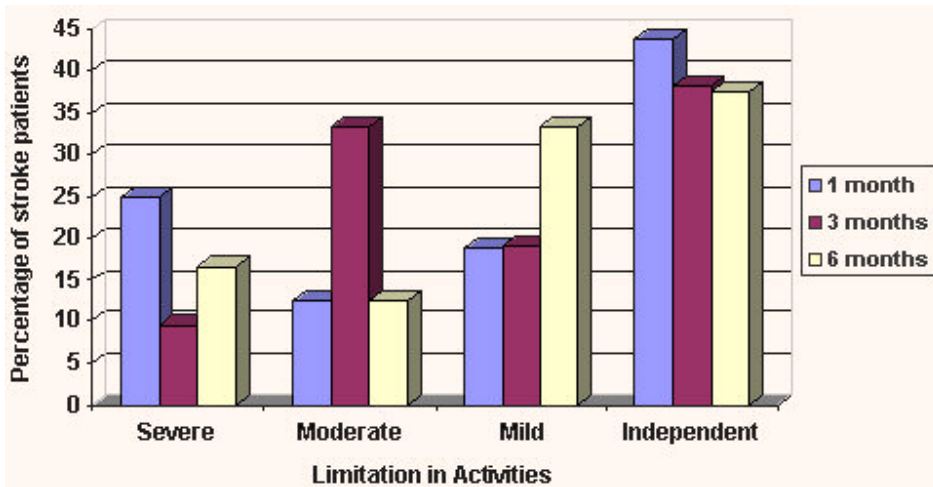


Figure 7: Limitation in activities at 1, 3 and 6 months post-stroke as measured by the BI: very remote.

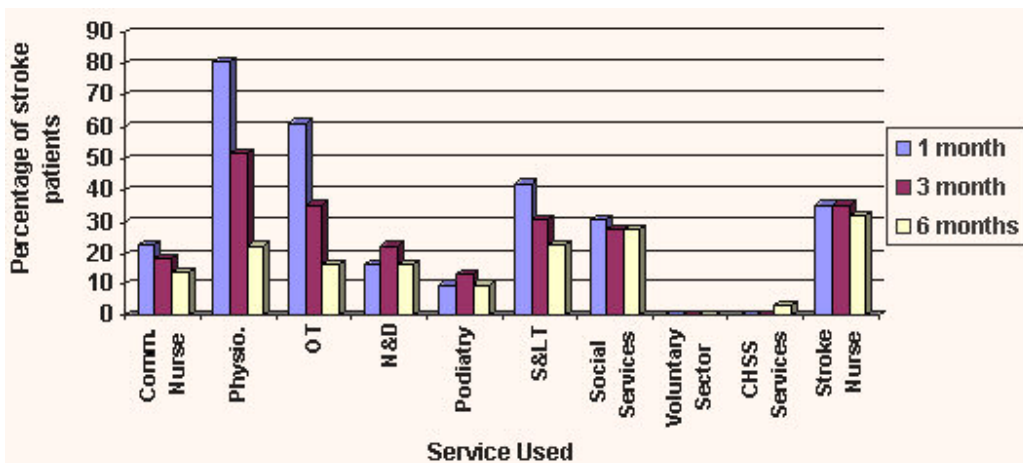


Figure 8: Patients receiving health and social services at 1, 3 and 6 months Post-Stroke: Urban/accessible. Comm. Nurse, community nurse; Physio, physiotherapy; OT, occupational therapy; N&D, nutrition & dietetics; S<, speech & language therapy; CHSS Services, Chest, Heart and Stroke Scotland Services.

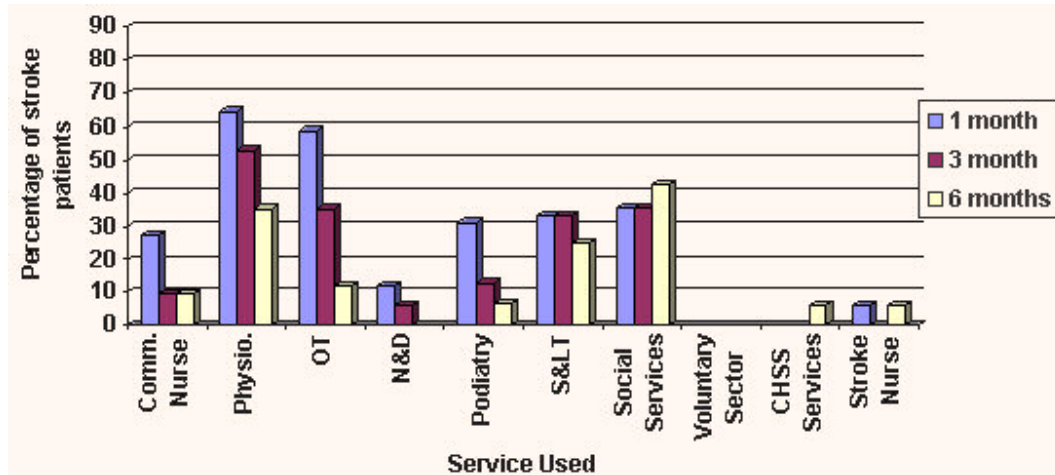
### Utilisation of health and social services

Use of health and social services reported by health care professionals, classified by settlement category, is shown (Figs 8-10). The service most commonly provided from the time of the stroke event at 1 and 3-months post-stroke was physiotherapy. However, the involvement of this service, along with the other core elements of a multidisciplinary stroke team, such as occupational therapy, and speech and language therapy, decreased with time, irrespective of settlement category. With respect to charitable organisations,

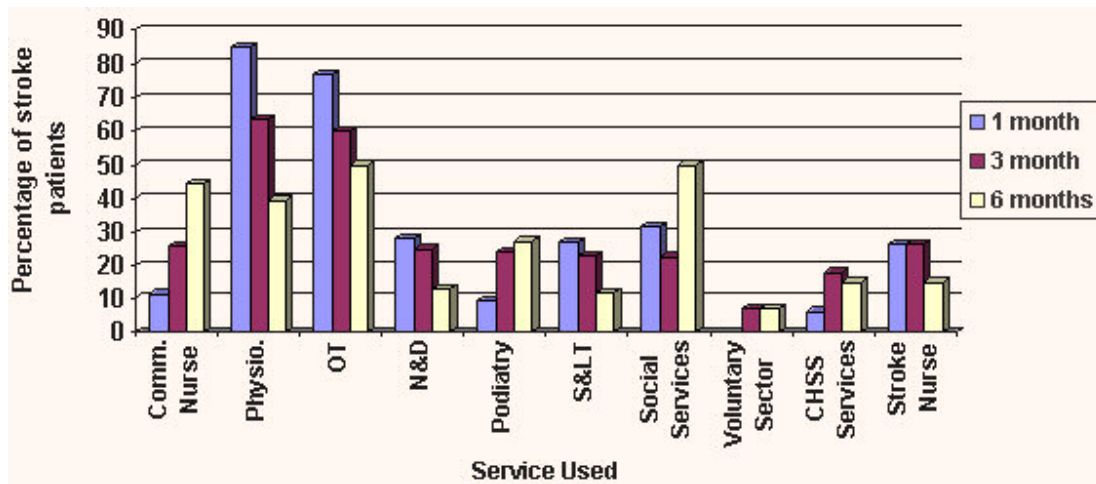
services provided by Chest, Heart and Stroke Scotland (CHSS), for example Stroke Clubs and the Voluntary Stroke Services, increased over time. However, the percentage of patients being provided with stroke-specific and social support services over a 6-month period was low. Social services were the most commonly received service for all patients 6 months after their stroke. The uptake of services was similar across all settlement categories, with patchy use of services and low levels of use at 6-months post-stroke. The proportion of patients using any service at 1, 3 and 6 months did not differ between settlement categories



( $\chi^2 = 17.9, p = 0.464$ ;  $23.2, p = 0.281$ ;  $29.8, p = 0.074$  respectively). Rural patients did not therefore appear disadvantaged in service use.



**Figure 9: Patients receiving health and social services at 1, 3 and 6 months Post-Stroke: Remote rural.** Comm. Nurse, community nurse; Physio, physiotherapy; OT, occupational therapy; N&D, nutrition & dietetics; S<, speech & language therapy; CHSS Services, Chest, Heart and Stroke Scotland Services.



**Figure 10: Patients receiving health and social services at 1, 3 and 6 months Post-Stroke: very remote.** Comm. Nurse, community nurse; Physio, physiotherapy; OT, occupational therapy; N&D, nutrition & dietetics; S<, speech & language therapy; CHSS Services, Chest, Heart and Stroke Scotland Services.



## Conclusions

### *Reported incidence, notification, recruitment and inclusion*

The crude incidence of stroke reported in this study was lower than would be expected from published data<sup>23,24</sup>. This probably reflects under-reporting of cases, although there may be other contributory factors. The estimated age- and sex-standardised incidence of first-ever stroke in Scotland in 2000 was 2.29 per 1000 [Source: Information and Statistics Division (ISD), Common Services Agency], and that quoted in the 1994 SNAP Report<sup>10</sup> was 2.98 per 1000. The present study included only patients who were resident and suffered their stroke in the study catchment area. In contrast, ISD figures include patients resident in the catchment area irrespective of where their stroke event occurred. It has been suggested previously that 'health-status data pertaining to catchment areas consisting of small and rural communities is perhaps best used for trend analysis rather than for factual comment on health status'<sup>25</sup>. It is unlikely, however, that differences in catchment population would explain the difference between our reported incidence and ISD figures. The definition of first-ever stroke used in our study was identical to that used in the record linkage from which the ISD figures were obtained. However, the 1994 SNAP report data<sup>10</sup> included transient ischaemic attacks, and may have included stroke as a secondary diagnosis, whereas our study included only primary diagnosis of stroke.

Under-reporting in our study may have occurred for several reasons. A substantial proportion of stroke patients die within 3-4 weeks after a stroke event<sup>26,27</sup>, and potential patients may have died prior to notification. Practitioners may have failed to notify cases because of uncertainty about the diagnosis, for example, where they were unsure if the patient had suffered a transient ischaemic attack. Professionals may have felt it inappropriate to notify patients at either end of the stroke-severity spectrum who also may not have been referred to health and/or social services, reducing other potential routes of notification. Doctors opting to manage patients at home may have been reluctant

to report cases. We are aware from local research, in which scenarios were presented to GPs, that a significant proportion of stroke patients may be managed at home (JG Macfarlane, pers. comm., 2001). To determine stroke incidence accurately and allow time trends to be considered, a community-based stroke register would be required. This would also allow risk factors, co-morbidities and outcomes to be recorded<sup>28</sup>.

### *Location*

The proportion of patients at home in urban/accessible and very remote settlements was similar at 6 months post-stroke. This is in keeping with previous observations that the majority of stroke patients admitted to hospital eventually return home. However, we found a higher proportion of patients living at home at 6 months compared with past studies in which, at 6 months, between 60% and 70% of survivors of first-ever stroke were living at home<sup>10,29</sup>. A greater proportion of patients in the remote rural category were admitted to community hospitals and remained there at 6 months. This may reflect greater availability of community hospital places in this category, but may also be influenced by stroke severity.

### *Limitation in activities*

Only a third of our patients classed themselves as independent at 1, 3 and 6 months post-stroke. This is lower than would be expected from previous literature, which suggests that half of all stroke patients will regain independence, mostly within 6 months<sup>27,30</sup>. More patients reported severe disability/limitation in activities in our study than in published reports of outcome<sup>31</sup>. The reasons for this poor functional outcome remain unclear and are concerning. Although data collected on severity at onset of the stroke were considered unreliable due to collection at different time points, it is likely that our study population was biased towards those with milder strokes. This raises the possibility that rehabilitation of stroke patients throughout the participating areas is inadequate.



## Utilisation of health and social services

Uptake of services was equivalent across all settlement categories. The use of rehabilitation services decreased over time, and social service use increased. Patchy uptake of services was apparent, the level of use at 6 months post-stroke being low. Patients may have been unaware of the existence of such services or felt they did not require them at their stage of recovery. However, the relatively poor functional outcome of our patients suggests that there is an unmet need for rehabilitation. Our findings are similar to past research which has shown that organised care and the level of specialist services provided may reduce or cease within a few months of discharge<sup>32</sup>, and that the involvement of health and social services in the long-term management of stroke patients is minimal<sup>33,34</sup>. In our study, physiotherapy was the most common, and occupational therapy the next most common, service received, as previously shown by others<sup>35,36</sup>. Although use of services was generally low, rural patients did not appear specifically disadvantaged. However, our data suggest that use of rehabilitation services needs to be enhanced irrespective of settlement category.

Our study explored service use, rather than service provision. Historically, health, social and voluntary services have tended to be less accessible in rural areas than in more densely populated areas<sup>13</sup>, elderly people in rural areas receiving fewer health care services than those in urban areas<sup>37</sup>. However, research carried out in the 1990s showed that access to health care in rural Nebraska was as good, if not better, than access to health care in urban parts of the same State<sup>38</sup>. Other researchers have reported better service provision in rural areas in specific circumstances and localities, for example community and social provision for older people (health visitors, district nurses, meals-on-wheels)<sup>12,39</sup>.

Our findings must be interpreted in the light of the relatively low proportion of patients who could be included in the final dataset. Patients from the remote rural and very remote categories were slightly over-represented in our final dataset, compared to all those notified. Our study suggests that

patients developing a first-time stroke in remote and rural areas are not disadvantaged compared to those in urban/accessible areas with respect to outcome or to the utilization of health and social care services. However, functional outcomes could be improved for all patients and there may be a general unmet need for rehabilitation and support services.

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