Consumers leading public consultation: the general public’s knowledge of stroke
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Background. The need to make health services and research relevant to the general public through user involvement and consultation has been recognized and formalized in guidelines and research publications.

Objectives. We had the following objectives (i) to involve and enable lay people to identify and direct a research study as co-researchers consulting members of the general public about their awareness and knowledge of stroke and stroke risk; and (ii) to consult members of the general public aged between 40 and 65 years old to identify what they know about the signs of stroke and potential risk factors in order to inform local public health programmes.

Methods. A 20-point multiple choice questionnaire was designed by two consumers trained in research skills at a year long training programme. The questionnaire was sent to 250 randomly selected patients from one general practice in North Staffordshire.

Results. A 57% response rate was achieved (142 out of 250), with 139 being appropriate for analysis. The current knowledge and awareness of stroke and stroke risk was relatively good. Almost 90% knew that stroke occurs in the brain and most correctly identified the causes as related to impaired blood supply to the brain. Further, upon recognizing signs of stroke, 96% thought it was ‘extremely important’ to get immediate treatment for someone who may be having a stroke. Seventy-eight percent of respondents stated that they would like further information about stroke. The most popular sources of information identified were: their general practice (51%); television and radio (36%); and friends and family (33%).

Conclusion. The consumers’ involvement has essentially allowed lay people to consult other members of the general public about health issues of national priority with specific local relevance. The involvement of consumers in research needs to be considered as worthwhile if it is to have any lasting impact on local or national services. Future research using consumer involvement will need to decide upon the balance between scientific integrity and the level of consumer direction.

Keywords. Consumer participation, primary health care, stroke, training.

Introduction

Explicit statements have been made for user involvement in NHS services and research.\textsuperscript{1–3} ‘User involvement’ can be defined in a variety of ways, but ultimately it is about making services and research relevant to those who use the services or are the target of research through their involvement in the processes.\textsuperscript{4}

One way in which user involvement in research has been demonstrated is the inclusion of users not as participants but as co-researchers with a key position in the research design, data collection, interpretation and dissemination processes. This approach is supported by ‘Involvement works’, the second report of the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme.\textsuperscript{2} This group was set up as part of the NHS Patient Partnership Strategy by the NHS Director of Research and Development in 1996 to advise on research priorities and funding to improve relevance, reliability and usage (paragraph 4.1–4.2).
Early examples of such consumer involvement in research processes can be found within disability literature and in part stems from disability theories dating back to the 1960s such as the theories of normalization and social role valorization (SRV). SRV seeks to ensure valued roles for people with disabilities or other socially excluded groups.5,6 The social model of disability7,8 emphasizes the imbalance of power between researchers and the researched and the frequent lack of relevance and benefit to the research ‘subject’. Walmsley9 called for ‘emancipatory research’ where the researchers and the researched are in control of the project and set the agenda, with political action or change occurring as a result of the research.

Cornwall and Jewkes10 have confirmed that consumers are interested in the gathering of knowledge to facilitate action, whilst others11 have suggested that consumer involvement is likely to “…focus efforts to disseminate and implement research findings, thus widening the influence of consumers” (p. 93).

Yet, policymakers and practitioners persist in creating barriers to consumers playing a key role in the research process or involving consumers in the first place.12 A commitment to the effort involved, by both staff and consumers, needs to be made to ensure successful involvement, and this effort needs to be sustained within a culture which listens and responds to consumers.13

A research training programme was conceived at Staffordshire University to train members of the general public to participate in research projects involving the local community. The researchers were given the opportunity to carry out a public consultation of their own choice.

This particular study is an outcome of that research training programme. It was designed and carried out by two individuals (JB and JG; termed ‘consumers’ here in line with the definition of the Consumers in NHS Research Support Unit12) participating in the programme, assisted by research staff at Staffordshire University. Others have also successfully involved lay people or ‘consumers’ in stroke research. For instance, consumers were involved in planning a trial of thrombolysis for acute ischaemic stroke, refining the design and in solving ethical issues with the research.14

The consumers in this study were interested in finding a way of reducing the incidence of stroke in the population of North Staffordshire. This interest was due to the fact that they had faced issues around stroke in their personal and working lives. The consumers viewed stroke as a significant cause of death and morbidity and were aware of the ‘sudden’ impact on family life.

Stroke is the third most common cause of death, accounting for ~10% of deaths worldwide,15 and is the largest single cause of severe disability in England and Wales. Each year 110,000 people in England and Wales have their first stroke, of whom between 10 and 16% go on to have a further stroke within the first year.16 Despite the risk increasing with age, 10,000 people under the age of 55 years have a stroke each year.17

There is evidence that improving the public’s overall health, for example controlling high blood pressure, regular physical exercise, stopping smoking and eating a healthy diet, could prevent ~40% of strokes.18,19 This preventative approach is supported by the National Service Framework (NSF) for Older People20 and was a key target within the Health of the Nation initiative.21

People in North Staffordshire and more particularly Stoke-on-Trent are more likely to die from stroke at a younger age, although for all ages stroke mortality is less per 100,000 (102.4) than in England as a whole (105.1). Stroke mortality per 100,000 for those aged between 35 and 64 years living in North Staffordshire, and in particular Stoke-on-Trent, is 20.9 and 21.4 per 100,000, respectively, both above the national average in England for this age group (19.9 per 100,000). This difference is even more marked when looking at the 65–74 years old age group, with the national average in England being 181.7 per 100,000, and figures for North Staffordshire standing at 196.5 and for Stoke-on-Trent at 221.9 per 100,000.22 These figures indicate why Stoke-on-Trent has been described as a ‘sick city’ in local news reports when reporting on official reports on the area’s health indicators.23,24 This description was an additional driver for the consumers deciding to undertake research into stroke.

Assistance from researchers at Staffordshire University enabled the consumers to search the literature on stroke, revealing major gaps in the public’s knowledge of potential risk factors and warning signs of stroke, and the potential benefits of presenting for medical help as soon as possible after stroke onset.25–29

The aim of the overarching initiative was to involve and enable lay people to direct a study identified and specified by themselves with support from university researchers.

The consumers wished to consult members of the general public about their awareness and knowledge of stroke, the causes, symptoms and possible effects, risk factors, early warning signs and how they believe they would react when stroke is suspected. They wanted to find out whether a lack of awareness about individual stroke risk and how serious a stroke can be was a reason why people do not change their lifestyle for the better. The consumers hoped that this study might be a preliminary step in reducing the incidence of stroke in the local population.

Their specific aim was to find out what local people aged between 40 and 65 years old know about the signs of stroke and potential risk factors in order to inform local public health programmes. The reason for the age-specific targeting was because the consumers felt that individuals need to be aware of the risk factors associated with stroke as early as possible to increase prevention and reduce stroke risk through changing their lifestyles.
Methods

A 20-point questionnaire with multiple options was designed by two consumers trained in research skills at a year long training programme for 19 members of the general public, run at Staffordshire University. The course participants met for half a day on an approximately monthly basis with several additional small group meetings with a collaborating academic to discuss progress of particular research studies. An application for ethics approval was successfully made by the consumers and supporting academics from the local research ethics committee. Questions were selected by the researchers from their own experience and from an initial literature search by the academic supporting their work. The questionnaire was piloted on 10 people aged 40–65 years, following which the wording and content of the questionnaires were amended accordingly.

Two hundred and fifty people aged between 40 and 65 years registered with one general practice in a deprived area of North Staffordshire were selected randomly from the practice register by the practice manager using a random number system.

A covering letter, written jointly by the consumers and one GP, was sent to each randomly selected patient with a copy of the anonymous questionnaire by the practice. This letter described the aim and objectives of the study and assured the subjects that their names and addresses were not known to the consumers and university staff. A general reminder was sent to all randomly selected patients to increase response rates.

Questionnaires were returned in freepost envelopes and, where respondents chose to append their names, those respondents were entered into a free prize draw.

The questionnaire contained four sections: causes, symptoms and possible effects of stroke; factors which increase or decrease the risk of stroke; how respondents normally find out about health-related issues such as stroke; and respondents’ demographics and lifestyles.

Data were collated and analysed by the supporting academics using the SPSS statistics package. The statistical questions to be asked of the data were predominantly determined by the consumers. The consumers were interested to see whether responses would differ depending upon the age group of respondents (ages 40–52 years compared with ages 53–65 years). They were also particularly interested to see if there were significant differences in responses between respondents who smoked and respondents who did not smoke, those who were taking medication compared with those not taking medication and those who perceived they had an active lifestyle in comparison with those with a self-perceived moderately active or inactive lifestyle. Basic frequencies for each point in the questionnaire were calculated along with cross-tabulations (chi-square) for each of these in relation to the consumers’ areas of interest outlined above and basic demographic data.

The consumers were co-authors in a local report of the questionnaire findings and additionally presented their findings to local health and social care professionals, academics and lay people as part of the project dissemination.

Results

A total of one hundred and forty-two people (out of 250) responded, giving a response rate of 57%. Of these, three people were excluded because they were outside the study age range. The remaining 139 (56%) formed the basis of the results reported herein.

Respondents’ demographics and lifestyles

Forty percent (56 out of 139) were men and 59% (82 out of 139) were women (one person did not give their gender). Thirty-five percent (48 out of 139) of respondents were aged 40–49 years; 44% (61 out of 139) were aged 50–59 years; and 21% (29 out of 139) were aged 60–65 years (one person did not give their age). There was no significant difference in knowledge of stroke between the age groups 40–52 and 53–65 years (chi-square: $P = 0.5$). Thus we considered the data of all age groups as a whole in relation to their knowledge of stroke and stroke risk.

None of the respondents had had a stroke, but 66% (92 out of 139) said they had close friends or relatives who had. Eighty percent (111 out of 139) of respondents said they had tried to eat a healthy diet, 27% (37 out of 139) were smokers (one person did not provide this information), 19% (27 out of 139) described their lifestyle as ‘very active’ and 66% (92 out of 139) thought their lifestyle was ‘moderately active’.

Causes, symptoms and possible effects of stroke

Almost 90% knew that stroke occurs in the brain and, in addition, most correctly identified the causes related to impaired blood supply to the brain, as seen in Table 1.

<table>
<thead>
<tr>
<th>Causes of stroke</th>
<th>% who ticked condition (n = 139)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accident</td>
<td>7</td>
</tr>
<tr>
<td>Reduced blood supply</td>
<td>42</td>
</tr>
<tr>
<td>Narrow or blocked blood vessels</td>
<td>57</td>
</tr>
<tr>
<td>Starvation</td>
<td>0</td>
</tr>
<tr>
<td>Sudden shock</td>
<td>12</td>
</tr>
<tr>
<td>Blood clot</td>
<td>65</td>
</tr>
<tr>
<td>Over-exertion</td>
<td>10</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>69</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3</td>
</tr>
</tbody>
</table>

The questionnaires were returned in freepost envelopes and, where respondents chose to append their names, those respondents were entered into a free prize draw.
Many respondents recognized the signs of a stroke, as seen in Table 2. In addition, 96% of respondents thought it was ‘extremely important’, 3% thought it ‘might be important’ and 1% thought it was ‘not important’ to get immediate treatment for someone who may be having a stroke.

Factors which increase or decrease the risk of stroke
When asked to identify whether stroke risk was increased, decreased or had no effect in relation to a list of particular actions or health statuses (see Table 3), >70% of respondents correctly identified the increased impact of high blood pressure, high fat diet, taking a daily aspirin, taking moderate exercise and stopping smoking.

Over 50% of respondents correctly identified that overeating, excess alcohol and long-distance flying increased stroke risk. Those which were identified by a <50% majority of respondents were actions which individuals were less certain about, as both eating spicy food and taking birth control pills received the highest ‘don’t know’ responses and the highest no response, along with the no response of 22% respondents in relation to the impact of long-distance flying.

The responses from those who smoked were not significantly different from those who did not smoke (chi-square: \( P = 0.07 \)), with the majority of respondents realizing that to stop smoking would decrease the chance of having a stroke (see Table 3).

Seventy-two percent (98 out of 136) of those responding about their perceived risk of stroke thought that their chances of having a stroke were \(<5\) (using a scale from 1 to 10 with 1 being ’not at risk’ and 10 being ‘high risk’). Smokers (\( n = 37 \)) did not perceive their risk of stroke (mean 4.9) to be significantly greater than those (\( n = 98 \)) who did not smoke (mean 4.5) (\( t = 1.13, P = 0.3 \)) (one person did not indicate whether they smoked or not). However, those taking medication for high blood pressure (\( n = 528 \)) had a significantly higher mean perceived risk of stroke (5.9) than those (\( n = 107 \)) not taking medication (4.3) (\( t = 3.8, P < 0.001 \)) (one person did not indicate whether or not they were taking medication for high blood pressure).

Ninety-nine percent (136 out of 137) of those responding to the question about preparedness to change their lifestyle indicated that they would change their lifestyle if they thought their chances of having a stroke were high. Those who said they would make a permanent lifestyle change (\( n = 119 \)) had a lower mean perceived risk of stroke (4.4) compared with those (\( n = 18 \)) who would make a temporary change or no change (5.7) (\( t = 2.6, P = 0.01 \) by \( t \)-test). Smokers were less likely than

### Table 2: General public’s understanding of signs indicative of a stroke

<table>
<thead>
<tr>
<th>Which of the following are early signs of stroke?</th>
<th>% who ticked sign of stroke ((n = 139))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe headache</td>
<td>27</td>
</tr>
<tr>
<td>Loss of balance</td>
<td>35</td>
</tr>
<tr>
<td>Loss of consciousness</td>
<td>24</td>
</tr>
<tr>
<td>Slurred/loss of speech</td>
<td>73</td>
</tr>
<tr>
<td>Vomiting</td>
<td>4</td>
</tr>
<tr>
<td>Weakness and/or numbness on one side</td>
<td>81</td>
</tr>
<tr>
<td>Dizziness</td>
<td>22</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7</td>
</tr>
</tbody>
</table>

### Table 3: General public’s reported beliefs of effects of particular actions or health status on stroke risk

<table>
<thead>
<tr>
<th>Which of the following will increase, decrease or have no effect on the risk of stroke?</th>
<th>% identifying effect action has on stroke risk ((n = 139))^a</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Increased</td>
</tr>
<tr>
<td>Eating spicy food</td>
<td>8</td>
</tr>
<tr>
<td>Over-eating</td>
<td>67</td>
</tr>
<tr>
<td>Birth control pills</td>
<td>35</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>94</td>
</tr>
<tr>
<td>Stopping smoking</td>
<td>12</td>
</tr>
<tr>
<td>Moderate exercise</td>
<td>1</td>
</tr>
<tr>
<td>Long-distance flying</td>
<td>54</td>
</tr>
<tr>
<td>Excess alcohol</td>
<td>67</td>
</tr>
<tr>
<td>High fat diet</td>
<td>86</td>
</tr>
<tr>
<td>Daily aspirin</td>
<td>1</td>
</tr>
</tbody>
</table>

^a Where figures do not total 100% this is due to rounding.
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A high proportion of respondents showed a reasonable level of awareness of stroke and its causes. The majority correctly recognized the need for immediate treatment in the event of stroke, crucial for increasing the effectiveness of stroke care.

The introduction of educational programmes for the community about stroke risk, the importance of presenting for treatment along with encouraging the engagement of people at high risk of stroke to reduce those risk factors could all contribute to the reduction in the incidence of stroke. Such education should be targeted at the wider population as well as individuals, as they may be a source of health information to others. The media which would reportedly reach more people according to participants in this study are GP practices, television and radio, friends and relatives.

Extrapolating from the results of this study to the general population of Stoke-on-Trent or beyond is limited by the respondents being from one general practice only. However, the practice had not run any special initiatives to educate the patient population and is based in a deprived area where the population typically have low educational attainment. The response rate was acceptable for a local patient survey; however, it is accepted that this level of response also limits the generalizability of the results, particularly as those responding may have more interest in or knowledge of stroke than those who have not responded. This interest may be reflected in the number of participants (66%) who reported knowing someone who had had a stroke.

A further limitation of the study associated with the response rate is that the illiteracy rate is high for adults in Stoke-on-Trent, so it may be that many of the non-smokers to reply that they would change their lifestyle permanently if they thought that their stroke risk was high (Mann–Whitney test: $z = 2.38$, $P = 0.02$).

How respondents normally find out about health-related issues

Even though most respondents thought that their chances of having a stroke were low to average, 78% (108 out of 139) stated that they would like further information about stroke. Figure 1 displays the frequency of responses provided when asked from where they usually get health information.

Discussion

Members of the public trained in basic research methods by university academics identified pertinent topics, questions and methods and led the research process exploring the knowledge of stroke and stroke risk within a general practice in Stoke-on-Trent.

Although the public’s awareness of stroke and stroke risk was relatively good, the local area does not have a good record of general health in official reports of health indicators. There seems to be a discrepancy between the incidence of stroke and the public’s knowledge and their willingness to make changes.

The direct and indirect economic costs of stroke to individuals, their families, health and social services, the workforce and employers are high. Any reduction in the incidence of stroke would have immense benefits and should justify the investment in preventative measures, such as individuals making lifestyle changes.
non-respondents were illiterate, thus creating bias in the nature of respondents. With this issue in mind, it may have been more appropriate to use an alternative research methodology such as interviews or focus groups.

Future research should seek more in-depth information about what patients understand by a healthy diet and lifestyle, moderate exercise and other preventative measurement, checking whether individuals’ classifications of their own lifestyles are accurate. The inclusion of measures of health belief and behavioural change would also be beneficial in exploring whether individuals, whilst understanding their risk of stroke, are able to make or maintain the necessary lifestyle changes.

The consumers’ involvement has essentially allowed lay people to consult other members of the general public about health issues of national priority with specific local relevance. Consumers deciding upon and directing the research study has effectively brought together two national priorities together, namely, the vision for user involvement in the processes of health service research, and the National Service Framework for Older People, which identifies service developments to improve stroke services in the UK including primary and secondary prevention in the community. The consumers, as representatives of their community, were able to select a topic which would be of local public concern and angle the enquiry so that the specific questions posed were likely to be relevant to the community.

This local initiative supports the theory of inclusive research as being essential to ensure both the relevance and benefit of the research to the research participants. It also serves to reduce the imbalance of power between researchers and the researched.

In order for this user involvement research to have an impact on local health services, the final study reports should be considered by and acted upon by key professionals working for the health service. Ultimately, if user involvement research is to be worthwhile, it needs to be valued by policymakers and practitioners. Consumers will only be interested in continuing to support and participate in health consultations if they feel that their efforts are taken seriously.

Consumer involvement takes time and skilled resources to enable the lay participation to be effective. Achieving a balance between the priorities and enthusiasm of the consumers, the NHS and the constraints of ethics and scientific principles of research is key. For example, the consumer’s lack of experience required academic support and yet the academics could not help so much that they provided undue direction. For some, this may be seen as a limitation of the study, for others it will be viewed as an important strength. For example, as academics, we may have targeted a wider age group or aimed to make the questionnaire more scientific, but for consumers this may have decreased the relevance or allowed them as consumers to become too ‘professionalized’. The weighing up of the input and balance of power within the research process obviously depends upon the perspective you take.

The dissemination of the findings is involving the consumers reporting back to the practice involved and to various NHS bodies, through a local report and presentation. As discussed previously, the results will be disseminated by the consumers, which is particularly beneficial because they will do this in a ‘user friendly’ way. The results will inform the local public health programme, the development of local stroke prevention services, and assist GP practices in the area not only to meet the milestones to be achieved in primary care by 2004, but also to reduce the incidence of stroke in Stoke-on-Trent. The benefit to the general practice of both the consumer involvement and their research study is arguably great. Not only have they been able to engage their patients in identifying what they believe are relevant local research issues, they have also, through this engagement, been able to promote the importance of stroke awareness and prevention and identify the knowledge and health promotion opportunities of a sample of their population. Involving consumers in research, wherever you may be gives rise to the opportunity of both learning to involve and learning to understand local issues.

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Conflicts of interest: None

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