

Stroke services need to take account of cultural/religious issues to be equitable

People of south Asian origin are more likely to have a stroke and at a younger age than the general population, but a commensurate proportion do not use stroke services, which may indicate barriers to assess. Equitable stroke services need to take account of religious and cultural issues elicited through meaningful service user involvement.

People from South Asian communities were recruited and trained to work as community researchers (CRs). With the project coordinator they moderated focus groups of community representatives. Issues from these meetings informed a framework used by the CRs to interview potential service users, past stroke service users and/or their carers. The CRs translated and verified the interviews and are currently assisting with the transcription analysis. They will also assist in publishing a report that will be used to inform stroke service redesign. The CRs will play an important part in dissemination of the findings both locally and beyond.

Collective data analysis in palliative care research: Process and outcomes

This talk focuses on the data analysis stage of a research project, which was where we made sense of all the information

we had gathered. The research was about people's experience of living with life limiting conditions like cancer and heart failure, and what they thought about health and social care services. 25 people took part in interviews or small discussion groups. An important element of the research was the involvement of a group of service users to input to and guide the research. The Service User Research Advisory Group (SURAG) met 32 times over the 3 years of the research involving 9 people in all. The analysis part of the research was thorough, complex and took place in two stages:

- As information was collected from participants initial analytic ideas were formed by the researcher and discussed with SURAG members.
- When all research information had been collected we systematically went through it all as a group to identify and agree the themes. This involved us meeting 14 times over a 9-month period, to go through transcripts amounting to 140,000 words.

The input of members of the SURAG was crucial. There were differences between the initial analysis and the group analysis.

For the people, by the people, with the people

The paper focuses on the journey of developing a participatory model for health and medical research. It is based on the experiences of the School of Population Health at The University of Western Australia and the Telethon Institute for Child Health Research in collaborating with the Health Consumers' Council (WA) Inc, an independent community-based

organisation, in the creation of Consumer and Community Advisory Councils.

Participants will learn about one model for enhancing consumer and community participation in research. The presentation will also create an exciting opportunity for two-way dialogue about sharing and learning from others' experiences and exploring ways to move forward in strengthening the voices of consumers and the community in health and medical research.

Carers involved in research

"I had to give up work to care, this makes me feel I have something to offer, it keeps my brain active"

This initiative, the first in Northumberland, has not paid lip-service to carer involvement but has changed the relationship between the statutory organisation and the people it supports for the better in the spirit of real involvement. We will happily exchange ideas and tips on how this project developed. How these carers hope to cascade their new skills to the public and how the staff hope to show other professionals real involvement of people in research

Risks and benefits of medicines: Who do you trust?

MHRA, in a previous incarnation, was somewhat secretive. That

has changed. The views of patients and the public are now a priority. MHRA wants to hear their views and engage in discussion with them.

It commissioned MORI (now Ipsos MORI) to research the views of both the public and healthcare professionals about risk, regulation and communication. The research includes six focus groups of the general public and a quantitative survey of about 2,000 people on the MORI Omnibus Survey.

MHRA and MORI expect to publish the results of the research later this year, after its completion. This paper will present the main findings. It might sketch a chain of trust: patients trust doctors, who trust pharmacists, who trust the regulator.

The National Prevention Research Initiative – a study of successful lay involvement in strategic funding of research

The National Prevention Research Initiative is a partnership of eleven major research funders brought together by the National Cancer Research Institute. The objective is to develop cost effective interventions which encourage healthy behaviour or which discourage unhealthy behaviours. The focus is on smoking, obesity, nutrition and exercise. The initial funding call in 2005 resulted in 248 initial applications. At the final stage 45 full proposals were refined down to 26 funded projects, with £7m being committed over five years. A

further call is in preparation for autumn 2006.

Roger Wilson was part of the NCRI Strategic Planning Group which founded NPRI and now serves on its Programme Board. Patient/consumer involvement has been central throughout the development of the initiative and there is representation on all decision-making groups. The Scientific Committee which reviewed both initial and full applications had six lay members, 25% of the panel. Their contribution was significant and had a number of effects on the way the programme has developed.

This presentation looks at the NPRI and its structure to see what influences helped make the involvement a success, considers the attributes the lay members involved contributed to the NPRI, and draws out some important lessons for consumer involvement in research.

Research ethics: what do you think?

There is a lot written about research ethics from a professional standpoint, that is asking doctors and professional researchers their views. While this is interesting, most people who take part in research are not doctors or professional researchers. This research looked at what service users / survivors thought about research that is of a psychological nature (i.e. not drugs trials).

Rachael Carrick facilitated a small discussion group of local service users interested in the topic. From this group a questionnaire was created to see if the themes that the group came up with were ones that a larger group of service users

would agree with. Levels of agreement and comments were gathered. The results were fed back to participants, who were then asked to reconsider their opinions given the average response of the whole group.

This paper will briefly introduce the area and how our study was conducted. We hope people will learn more about what other service users think about ethics. We hope people will contribute their own perspectives on the less straightforward ethical issues.

Service user research and why it hurts

Patsy Staddon recovered from alcoholism nearly 18 years ago and wanted to research the ways that current treatment is often unsuitable for women. Bristol's Mental Health Trust (Avon and Wiltshire) agreed to pay overheads and she has now completed four years' research which is service user inspired, designed, led and carried out.

She first interviewed other women who had or had had alcohol problems. The lengthy interviews usually happened in the woman's own home. Then many of the women met up again in small groups to talk about their problems with treatment. In the following year, Patsy interviewed local GPs and treatment providers. Recommendations from both pieces of research were given to the Mental Health Trust and to local GPs and alcohol treatment centres.

Patsy talks about how difficult it can be to be a service user researcher, but how it also gives you extra insights and opportunities--for example, other service users are more

likely to be honest with you. She describes the problems, and how she often felt an outsider as far as academics were concerned. She believes that to obtain good research results, service users must be involved at every stage of the research process.