Ambulance ambassador for BME elders

Many ethnic minority elders are unsure when to contact emergency health services and anxious about what will happen if they dial 999. This means that sometimes the ambulance is called too late.

Community groups have said that they want to know more about the early signs of life-threatening conditions such as heart attacks, stroke and hypothermia. They want to understand what happens when they dial 999, and they want to be reassured that the Ambulance staff will treat them with dignity and respect.

In this presentation people will learn about a special "Ambassador" post that has been established within the Ambulance Trust to work specifically with African, Caribbean and Asian elders. They will learn how the Trust has built its relationship and understanding of the health needs of these elders, and enhanced their effective use of 999 and patient transport services.

Social care service users' experiences of individual budgets: An evaluation from one Local Authority pilot

Coventry City Council was one of the thirteen local authorities which piloted

Individual Budgets for social care service users. Unlike the national evaluation of
Individual Budgets, Coventry City Council commissioned Coventry University to
evaluate their pilot by capturing service users' perspectives and experiences of the
extent to which Individual Budgets had empowered them.
The evaluation therefore aimed to capture service users' experiences and
perspectives. It did this by involving service users from the start. The methods were
eclectic in that service users were supported by the research team to present their
experiences via video diaries, 'bloggs', scrap books, drama.
Having an Individual Budgets in social care (and, possibly in health care too) is a
vehicle for empowering service users as service users:

- are able to set the agenda
- have increased choice and autonomy over how their needs were met
- are able to grow and develop holistically
- have increased flexibility of service provision
- are more fully part of their communities

Reflections on users and user involvement in community research

In this paper we will consider user involvement in our participatory research to understand the everyday, real life

experiences of social networks, neighbourhoods, and communities in relation to individuals' sense of health and wellbeing. The research we report on has been conducted in a socially, economically and culturally diverse inner-city neighbourhood in a large British city. We will consider the nature of engagement with different users and potential users of the research. The users of our research include residents who live in the area, including those who have participated in the research; members of voluntary, community and faith sector organisations; and public sector organisations such as the Primary Care Trust and local universities. We will comment on the ways in which engagement and control in the research has been possible with these different user groups. In particular we will focus on: 1) the parallels and dissonances between users' and researchers' interests in and expectations of the design and substantive outcomes of research; 2) the spaces and scales at which users are working (or in the case of participant-users, living) and at which the research is conducted; and 3) the position of public and professional users relative to the position of the researchers. Points for discussion will focus on the nature of user-engagement in the research process and the possible uses of community research by public, third sector and community organisations.

Involving patients in researching the management of back pain in primary care

An example of patient involvement at various levels in a large research project and support provided to encourage useful patient involvement.

Summary

Back pain is a common but difficult condition to treat, both for individual patients and healthcare professionals in primary care. The current project was set up to collaboratively learn about how back pain can be managed better using quality improvement principles. Nine GP practices have been recruited that will attend a series of workshops and meet in their practice teams to identify barriers to managing back pain and come up with small changes that address these barriers.

Patients and representatives of patient groups have been involved at various levels of this project:

- A representative of a national patient organisation was involved in writing the project proposal and grant application.
- A patient and a representative of a national patient organisation are members of the steering group.
- Each GP practice has included a patient representative in their practice team.

This presentation will focus on what support the steering group has put in place for individual practice team to enable them to involve patients in their project. Furthermore it will report on an introductory meeting for all patient representatives before the first workshop and feedback from patient on the first workshops. Such feedback has been useful in exploring the difficulties that some practice teams had in recruiting patient representatives.

Point for discussion

In this project support was provided for patient representatives and the wider practice teams to stimulate useful patient involvement. The question is why some practices had no difficulties in recruiting and involving patients,

while other teams had much more difficulties in this. Was the support inadequate? Or does this reflect the fact that characteristics of useful patient involvement range widely and a more individualised approach is necessary?

Learning outcome

- Learn from an example of patient involvement at various levels of a large research project in primary care.
- Identify what support is needed to enable others to include patients in their project teams.
- Explore some of the difficulties and concerns in recruiting patient representatives.

DOCTER (Diagnosis of Cancer, the Economic Reality): Issues in user-led research

The poster reports on the progress of the DOCTER project. DOCTER stands for Diagnosis of Cancer: The Economic Reality. This project aims to study the 'true' cost of a cancer illness to the patient, their family, society and the NHS. The project has now been funded by the Trent RDSU in support of consumer led research.

The project is led by David Ardron, with input from the Consumer Research Panel.

The poster presentation will discuss the motivation for the DOCTER project, how the project was instigated, the problems that we have encountered and how we have tried to overcome them.

The poster presentation will also provide an introduction to the North Trent Consumer Research Panel and the diverse projects that they have been involved in.

It is hoped that the presentation will lead to a discussion about how to get consumer led research off the ground and the process and practicalities of consumer led research.

It is also hoped that by showcasing some of the other work that goes on in the North Trent Consumer Research Panel the audience will learn more about the valuable contribution that local research panels have to make.

Faith communities and ambulance services

We are organising a major summit which will bring members of Leicester's diverse faith communities and Ambulance service managers and paramedics together for the first time. This will be the first time such an event has been held in the UK. It will take place in August 2008. The objectives are to generate community engagement in the work of the Ambulance Trust, identify key issues, raise awareness of the links between faith and health, and foster improved understanding and relationships between the Ambulance services and faith communities. The Leicester Council of Faiths and Charnwood Community Arts are working with the Ambulance service to hold this event.

The presentation will let people know how the summit was organised, and how people from faith communities were involved. People can also find out how ambulance services have improved as a result listening to people of faith.

People will learn why faith is important to many people when they are ill, and how ambulance services can respect the religious wishes of the public whilst still carrying out their duties.

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User controlled research: building together on what we know and exploring next steps

Late in 2005, INVOLVE published the first national review of User Controlled Research (undertaken by the presenters). Produced from a service user perspective, it offered information about the definition, strengths and weaknesses of user controlled research. As well as making clearer what it is and what it can offer, however, it also highlighted concerns about the future of user controlled research and difficulties that it faces.

The project involved service users. The aim of this workshop is to open up and take forward discussion, involving people from a wider range of perspectives, in a safe environment. Through group discussion it will seek to enable people to contribute the lessons from their own experience as well as learning from the new knowledge that we now have.

Reporting briefly on key findings from the review, the session will open up discussion of issues and questions for the future to be explored through the perspectives of mainstream researchers, managers, practitioners, policy makers, research commissioners, academics, etc, to add to what we have already

learned from service users.

It will consider how user controlled research's weaknesses may be addressed; how it can make its most helpful contribution and what might be helpful next steps