What Knowledge Can Users, Carers and Practitioners Share with Researchers?

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Different Ways of Participating in Research

• Reading; lay publications and studies of peoples’ views

• Consultation e.g. questionnaire surveys, internet surveys, focus groups, exit interviews, Delphi studies, open meetings

• User groups/panels, citizens' juries, consensus conferences
New ways of data collection

- Community meetings
- Making videos, community drama
- Use of drawings, murals and photography
- Sharing oral histories
- Community surveys
- Design ethnography and use of prototypes
Involvement at Different Stages

- Defining the research question
- Designing the research
- Implementing the research design
- Analysing the research data
- Reporting the research results

(Stoeker, 1999: 850)
SMART Rehabilitation: Technological Applications for use in the hospital and at home

Engineering and Physical Sciences Research Council UK – EQUAL4 Consortium

To examine the scope, effectiveness and appropriateness of technology to support home-based rehabilitation following stroke

One example of a project where users, carers and practitioners are being actively involved
SMART: Different Types of Involvement

As Research Advisors:

• Providing an external perspective upon the project and its' progress through participation in our Expert Panel

• Reading and providing opinions on project outputs

• Giving expert clinical opinion; e.g. consultation with practitioners regarding which movements to focus on
SMART: Different Types of Involvement

As Research Participants:

• Providing views through focus group discussion

• Volunteering to participate at various stages of scientific testing and development; collection of baseline movement template data, clinical testing of the prototype device
SMART: Involving Users, Carers and Practitioners

Consortia

Stroke Association

Clinical Collaborators

Providing verbal and written information

Supporting practitioner involvement

Recruiting to focus groups

Receiving feedback about usage

Supporting practitioner involvement

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Why has Technology not Impacted upon Rehabilitation Services Yet?

• Engineering challenges

• Relevance for practitioners

• Ability to meet the needs of users and their carers

• Cost, appearance and useability

• Mainstreaming into health service provision
Perspectives of practitioners; what we already know

Remote monitoring rather than “hands on” would be a new role for rehabilitation professionals

The device would need to be tailored to meet specific clinical needs

Training and on-going support would be required
Perspectives of Users and Carers: What we already know

• The following are key issues:
  • Ease of use
  • Appearance
  • Reliability
If you had to use a walking aid, what would you want it to look like?
Designing a Device: Some Key Questions to ask Practitioners

• What will professionals be prepared to use?

• What properties will make a device clinically relevant?

• What feedback mechanisms would be most helpful
Designing a Device: Key Questions for Users

- What were your experiences of rehabilitation?

- Would you be prepared to use a device to facilitate your rehabilitation at home?

- What would encourage you to use the device?

- What could be a problem?
Designing a Device: Key Questions for Carers

- What are your views of the rehabilitation received by the person you care for?

- Would you be prepared to help the person you care for to use a device at home?

- What would be the benefits?

- What might be the problems?
Methods of Engagement: Focus Groups

Pilot focus groups completed;
• confirmed demand for this technology
• need to demonstrate what the device might be like

Further focus groups planned with users in Sheffield
Will adopt a “user centred design approach”
• Design ethnography – response to the product
• Use of prototypes – mock up versions
Infrastructure is Needed to Support Engagement

Framework for User Involvement Developed by the Sheffield Health and Social Research Consortium; to ensure that all members, researchers and the public are guided and supported in achieving best practice

The framework covers:
- induction
- training
- remuneration
- health and safety
- good practice

Also need to take into account the costs of involving staff

“Support for Science”
For More Information Visit the Following Websites;

• SMART Project

Centre for Health and Social Care Research
  www.shu.ac.uk/research/hsc

• Sheffield Health and Social Research Consortium
  www.shsrc.nhs.uk