On becoming organised and involved in doing health research: Norfolk Conversation Partners

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Patient & Public Involvement: the National Institute for Health Research

- Patients and public are encouraged to be involved
- Professional researchers are encouraged to involve the public & health service users
  - Identifying topics for research; developing proposals and key research questions
  - Conducting studies
  - Communicating / publicising findings
- INVOLVE (http://www.invo.org.uk/) supports active public involvement
  - Research done with or by members of the public, not to, about or for them
It can be daunting to become involved

Get actively involved in research activities

Many patients and public members work with researcher professionals and clinicians (e.g., doctors, nurses) and get actively involved in the different stages of research and associated activities.

Increasingly patients, carers and members of the public are contributing their perspectives to the way clinical research is designed, commissioned, managed and supported. Active involvement in clinical research is very different from being a participant in a study. It means:

- research done with members of the public, not to, about or for them
- getting involved in the research process or activity itself
- making sure that clinical research is relevant, useful and to the benefit of the NHS and the people who use it.

The NIHR Clinical Research Network has a commitment to this work because we know that the more ‘patient friendly’ clinical research is, the more successful it is likely to be, and the more likely it is that it will benefit NHS patients.

Get in contact

There are a number of specialist research Networks within the NIHR Clinical Research Network and each has a Patient and Public Involvement Lead. To find out more about getting actively involved return to our PPI homepage and click the contact us button.

If you are interested in going wider than the NIHR Clinical Research Network for active involvement opportunities see Find us in research. This website is to help...
Some barriers to involvement

- Professional researchers
  - Sceptical about involving patients and carers
  - Not necessarily skilled at user involvement
  - Defining & dictating the terms of involvement
- Inequalities in power and control
- Institutional regulation e.g.
  - Bureaucracies, terminology and timeframes
- Lack of support
- Inadequate resources e.g. time; money to support involvement
Stroke survivors becoming involved

- Despite a desire & commitment to improve stroke services UK stroke survivors
  - Do not appear to be politicised
  - Do not have a history of activism, oppression or organisation as an embodied health movement

- Stroke & aphasia organisations e.g.
  - The Stroke Association: funds research; campaigns and lobbies etc
  - Connect – the communication disability network: develops services with & for people with aphasia; provides training etc
  - Speakability: information services; self-help groups etc
  - The Tavistock Trust for Aphasia: funds research; “acts as a catalyst in pulling together charities working in the same area” etc
  - Different strokes – focus on younger stroke survivors

- Volunteers taking over local groups as a result of funding cuts in public & voluntary sectors
Some barriers to organisation & involvement for stroke survivors

- In the first six months (or more)
  - Focus on recovery
    - Addressing impairments
    - Addressing impact of impairments e.g. emotional turmoil
    - ‘Getting back to life’
- Physical and communicative barriers
- Social occasions or group meetings may provoke anxiety
  - Social isolation
  - Depression
  - Lack of engagement
- Feeling “useless”
• Kagan (1995): *competence* of aphasic adults can be revealed through conversation

• Jordan & Kaiser (1996): call for professionals “to work in partnership with disabled people to help them achieve their goals”

• Social model approaches and aphasia therapies
  ◦ Academics debate the application of the social model to therapy
  ◦ Therapists begin to accept the limitations of an exclusive focus on impairments

• Supported communication / conversation
  ◦ Addressing disabling barriers
  ◦ Developed currency as an intervention approach
The Conversation Partner scheme

- Connect pilot study: Conversation Partner scheme in S.E. London
  - Volunteers visiting people with aphasia
  - Supports isolated individuals and helps them re-connect with life
  - Volunteers trained by people with aphasia

- CP scheme rolled out at UEA, 2004-5
  - ‘Training the trainers’ programme starts in 2005
    - On-going links to a national Conversation Partner scheme network
Norfolk Conversation Partners

- People living with aphasia
- Trained to be trainers
- Using experiential and embodied expertise to train
  - Healthcare students
  - Stroke professionals
  - Rehab teams
- Getting together for change
  - Addressing
    - Communication skills
    - Attitudes & values

Face-to-face student training
Stroke Intense, Summer
Norfolk Broads

Peter Eccleshare

Living with stroke and aphasia
Personal stories
Supporting conversations

Stroke & aphasia DVD

Supported communication ‘pocket guide’

Supporting communication for access and participation

NHS  UEA University of East Anglia

The NHS working in partnership with education:
Cambridge University Hospitals NHS Foundation Trust • NHS Norfolk
Norfolk Community Health & Care NHS Trust
Conversation Partners: doing ‘being involved’

- Involvement is produced (or not) through
  - Network connections
  - Individuals, groups, spaces and diverse sets of linked objects

- ‘Involvement’ is
  - Specific: produced in particular ways at any one time
  - Fragile: networks need careful attention to become sustained and stable
  - ‘Involving’ and ‘being involved’

- Developing a common purpose through meaningful action
  - Meeting, sharing, doing
Supported Communication to Improve Participation in Rehabilitation (SCIP-R)

- Norfolk Conversation Partners
  - Identified ‘supported communication’ training as research focus
- Involved in governance
- Staff participant assessment & training

- Dissemination
- Finding a focus
  - Members meet and discuss future directions
  - Facilitated by Connect
  - Supported by researchers
- Members on Trial Steering Committee
- Members develop training content and resources
- One:one assessment / training
- Individuals, spaces, objects produce experiential learning
Research “in the wild”
- Service users building collective expertise
- “...knowledge produced by non-expert groups through their participation, practices, exploitation of existing experiences, negotiations with other groups, and new organisational configurations” (Galis, 2011) e.g.
  - Contributions of conversation partners (aphasia experts) and rehabilitation staff towards training content, materials and processes
  - Developing and testing new ways of doing
- Working on co-production of reporting on involvement
What we have learned from involving and being involved?

- As a service user learning about
  - Being empowered by being part of the research process
  - Making people think before they speak – speed; using supportive techniques and resources etc leading to quality of conversation
  - We may have ‘lost’ our voices but with the right techniques we can still be heard

- As a researcher learning about
  - Involvement practices
  - Lack of easy fit between involvement ‘categories’ and practices
  - Risks posed by codifying involvement or involvement measurement practices: “measurable neat pieces of activity” (Purtell et al., 2012)
Bibliography

- Connect – the communication disability network [http://www.ukconnect.org/](http://www.ukconnect.org/)


