

Public Involvement in Research

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INVOLVE Group Member

Lay member of

- NIHR Advisory Board
- SDO Priority Setting Panel
- various NHS Programme
Grants for Applied Research
Sub-Panels and
SDO Commissioning Groups



INVOLVE – who we are

National advisory group established
in 1996.

Funded by the National Institute for
Health Research supported by the
INVOLVE Coordinating Centre

Promoting active involvement
of the public in

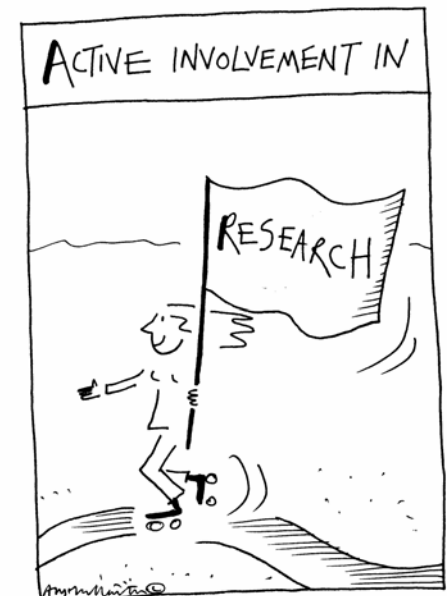
- NHS
- public health
- social care research

'Public' includes

- patients
- service users
- carers
- and representatives of people who use services

Research carried out with or by the public and not to, about or for the public

Involvement can take many forms from consultation and collaboration through to user controlled research



Why is public involvement in research important?



Because ...

It increases the relevance of the research -

People should have a say in research that is
intended to benefit them (or those they care for)

It improves the quality of the research:

Adds insight to the design, methods and findings
Assists in dissemination and implementation

Policy of Public Involvement in the NIHR

- **Best Research for Best Health (2006)**
- **Research Governance Framework (2001 & 2005)**
- **Requirement for evidence of involvement in funding applications**
- **Public involvement in assessment process e.g. peer review, commissioning boards**

Best Research for Best Health (2006)

Mission:

We aim to create a health research system in which the NHS supports outstanding individuals, working in world-class facilities, conducting leading edge research, *focused on the needs of patients and the public*

Research Governance Framework (2005)

‘Participants or their representatives should be involved wherever possible in the design, conduct, analysis and reporting of research’

‘..major advisory bodies in NHS R&D programmes should normally have at least two consumer representatives’

Requirement for evidence of involvement in funding applications

Details of involvement (*including the provision of adequate funding*) in grant applications is one of the assessment criteria

Public involvement in commissioning process

- **Priority setting**
- **Lay review**
- **Commissioning boards / selection panels**

Putting it into practice – some of the common *barriers*

- Not knowing how to find people who would like to become involved
- Not being sure how to involve them
- Not knowing about the ethics implications

In twos or threes.....



- If you have experience of public involvement, what would your advice be to someone doing so for the first time

or...

- If you have not had direct experience of public involvement, what are your top two or three questions about how to ensure successful involvement?

Some enablers – NATIONAL:

remit to advise on public involvement

INVOLVE

- website (www.invo.org.uk)
- publications
- research project database
- enquiries
- building an evidence / knowledge base

NIHR CLINICAL RESEARCH NETWORKS
public involvement leads

Some more enablers – REGIONAL:

South West Research Design Services (RDS)

www.rds-sw.nihr.ac.uk

help with preparing research proposals

RDS Public involvement lead:

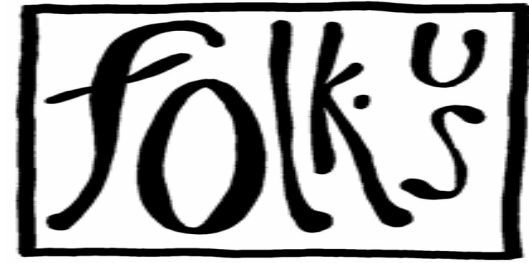
Julie Hapeshi julie.hapeshi@glos.nhs.uk

Devon area: Folk.us www.folkus.org.uk

Provides support and advice to researchers on
public involvement

Rachel Purtell, Director r.a.purtell@exeter.ac.uk

What is Folk.us?



The Folk.us Aim

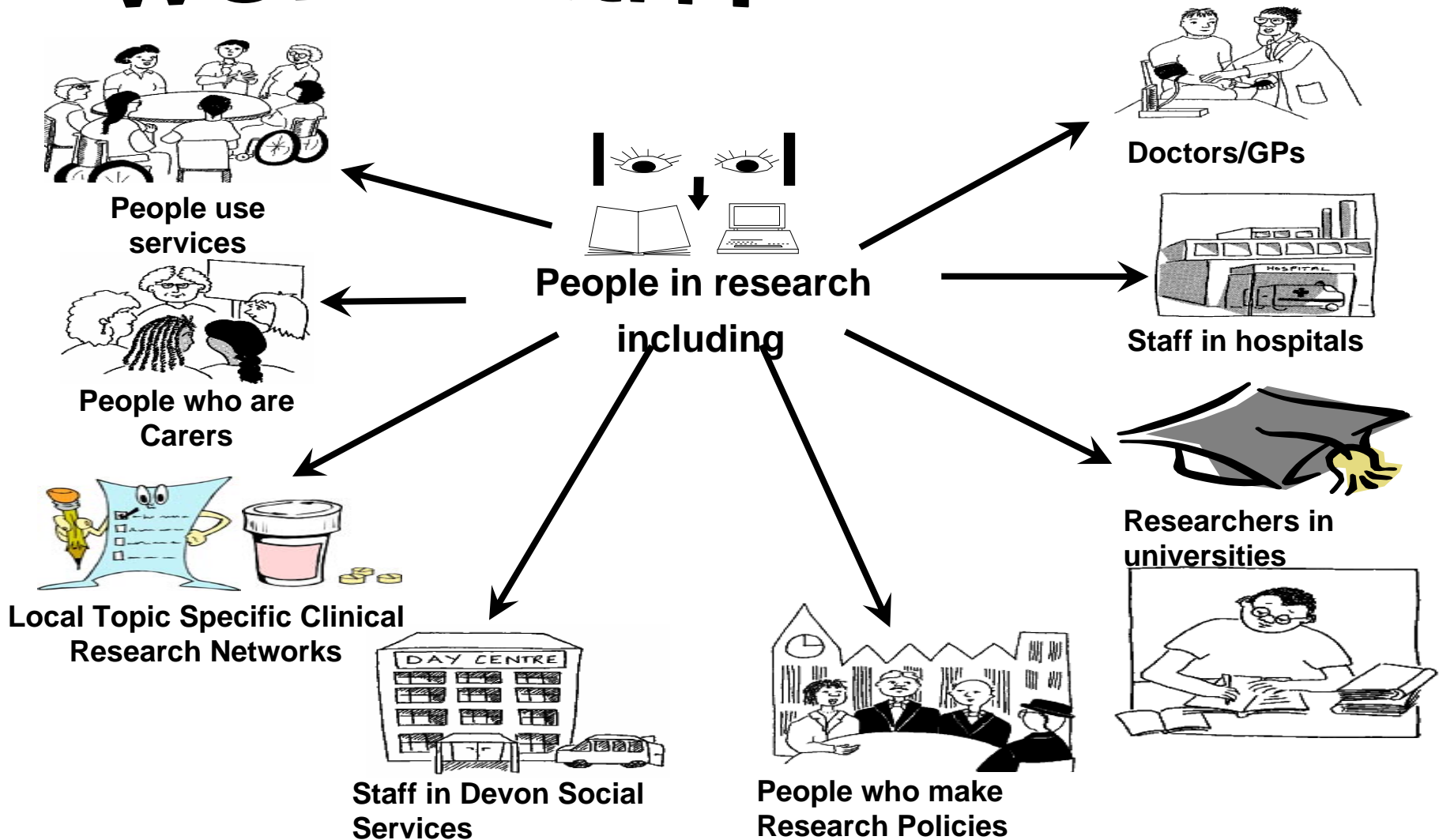
Folk.us supports and develops patient, service user and carer involvement in health and social care research activities to ensure that those who use services and those who care for those who use services inform and guide research at all stages.

Folk.us is funded by the Department of Health and we are part of the Peninsula Medical School and are based within the Royal Devon and Exeter NHS Foundation Trust.

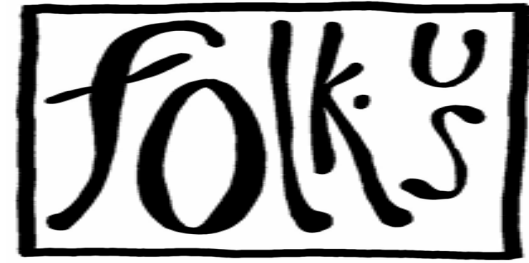


Who do we work with?

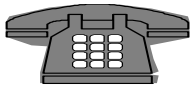
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What Folk.us offers



We give advice about involving people in research to staff and patients and carers



By telephone, email or in person.

We work along side research projects

Supporting staff and patients and carers

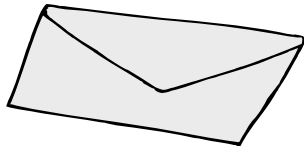
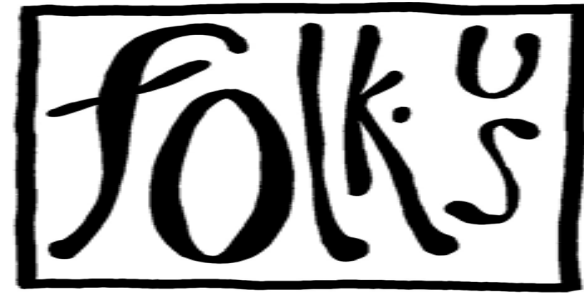
We work with the Local
Clinical Research Networks

Assisting with the design and
agenda for patient days.

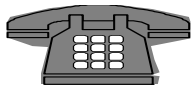


Advising on the structure of
involvement in the networks.

If you would like
to find out more
then please contact
Folk.us!



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