



RAPPOR

Research with Patient and Public Involvement: a Realist Evaluation

Marion Cowe, Elspeth Mathie and Patricia Wilson on behalf of the RAPPOR team



Public involvement in RAPPOR

- Proposal development

- the University of Hertfordshire Public Involvement in Research Group (PIRG)

- Reference groups

- Service users with learning disabilities
- Parents, children & young people with cystic fibrosis (CF)

- Co-applicants

- Marion Cowe & Diane Munday (PIRG)

- Co-researchers

- MC & DM plus a mother of child with CF

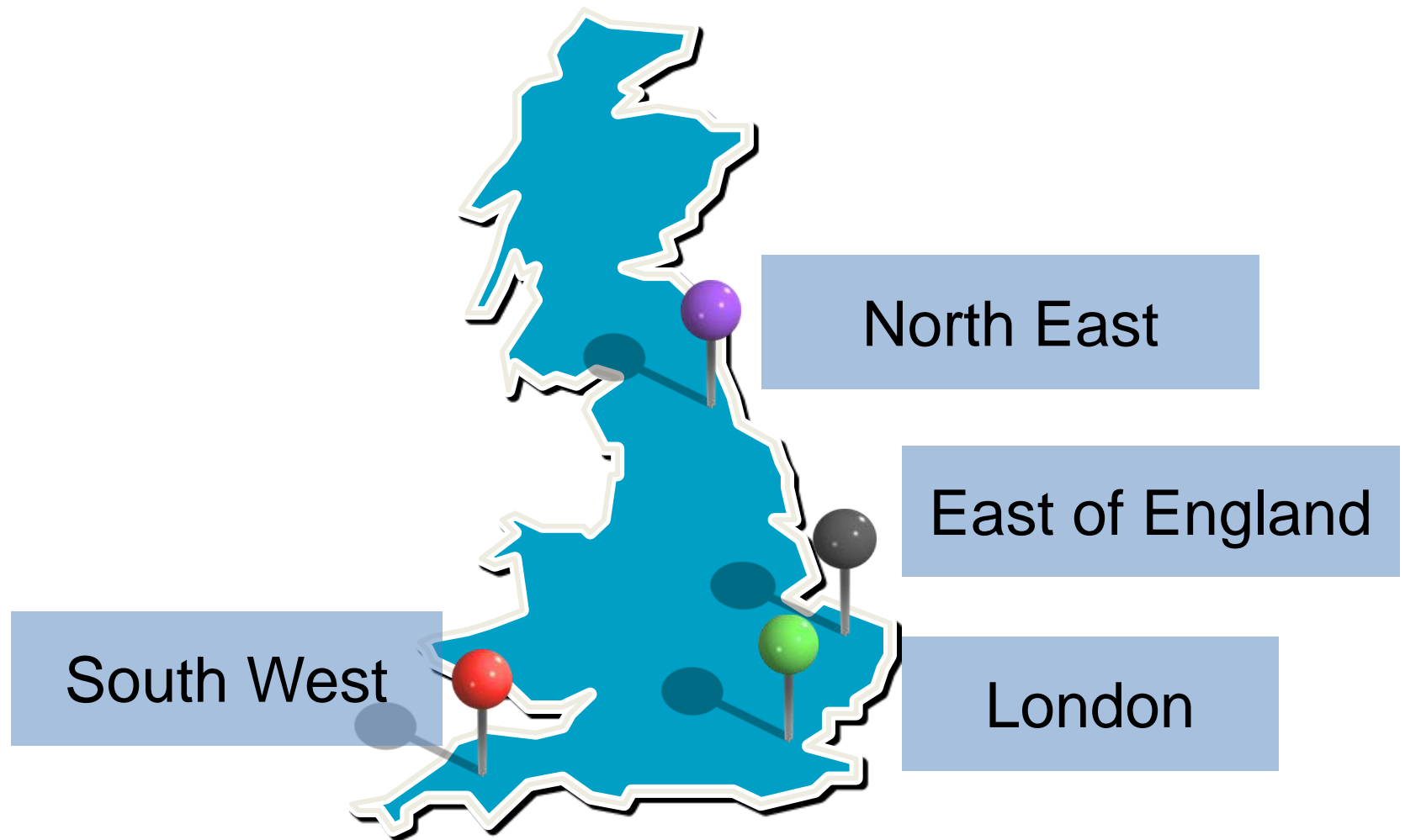
- Advisory group

- 2 members of the Norfolk PPIRes panel
- 1 lay member from Royal College of General Practitioners (RCGP)
- Independent lay chair

Research approach in RAPPOR

- **Realist evaluation**
drawing on Normalization
Process Theory (May &
Finch 2010)
<http://www.normalizationprocess.org/>
- **UKCRN portfolio studies**
within **6 topic areas**:
Learning disabilities,
public health, dementia,
arthritis, diabetes, cystic
fibrosis
- **Stage 1 : Scoping of the
UKCRN portfolio**
 - Non-commercial, current or
completed within last 2 years
 - National snapshot
- **Stage 2: Survey of chief
investigators in 4
regions**

4 geographical regions



Research approach in RAPPOR

- **Realist evaluation**
drawing on Normalization Process Theory (May & Finch 2010)
<http://www.normalizationprocess.org/>
- **UKCRN portfolio studies within 6 topic areas:**
Learning disabilities, public health, dementia, arthritis, diabetes, cystic fibrosis
- **Stage 1 : Scoping of the UKCRN portfolio**
 - Non-commercial, current or completed within last 2 years
 - National snapshot
- **Stage 2: Survey of chief investigators in 4 regions**
- **Stage 3: Case studies**
 - 23 across 4 regions and 6 topic areas
 - PI processes, outcomes and impact tracked for 18 months

UKCRN Portfolio: 1464 studies identified nationally in 6 topic areas

Total studies included 838

Scoping: 478
(outside 4 areas)

E-mails to Chief investigators, websites

Documents: Protocols, articles, reports to funders

219 documents from 182 studies

Information from 38% of studies

Survey: 360
(4 Areas)

E-mail January 2012
(16.8% response rate)

2nd Reminder:
February 2012

101 Responses
28% Response Rate

Patient and Public Involvement:

Scoping:

- 51% of studies reviewed had some mention of PPI (information very patchy and variable)
- Little standardised recording of PPI

Survey:

- 79% of studies said they had some form of PPI

Topic:

- Learning Disability Studies had higher PPI
- Second most PPI: dementia (Survey) Arthritis (scoping)
- Dementia had the highest numbers of PPI

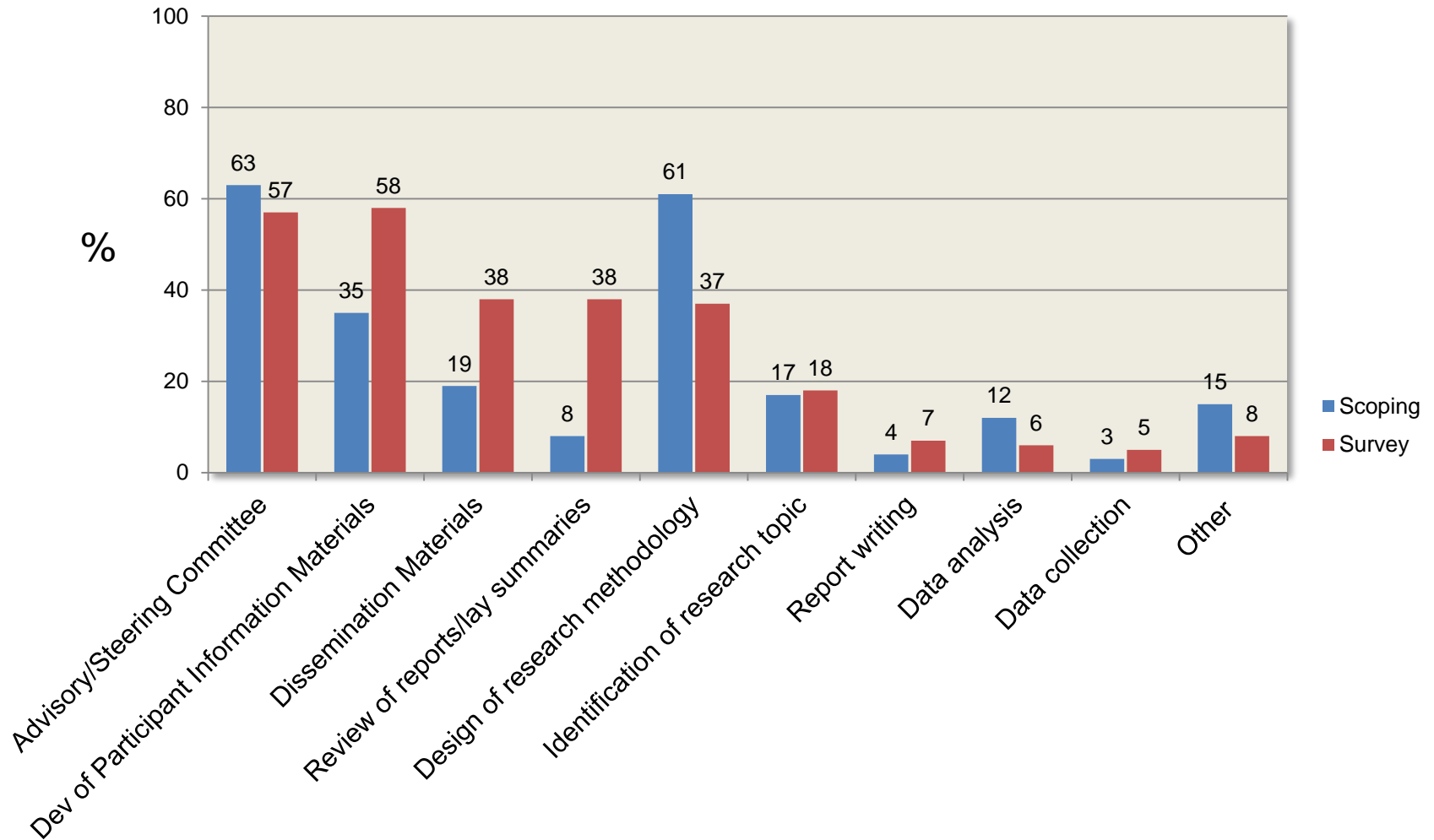
Funder:

- NIHR studies highest percentage of studies with PPI
- Charity funded studies

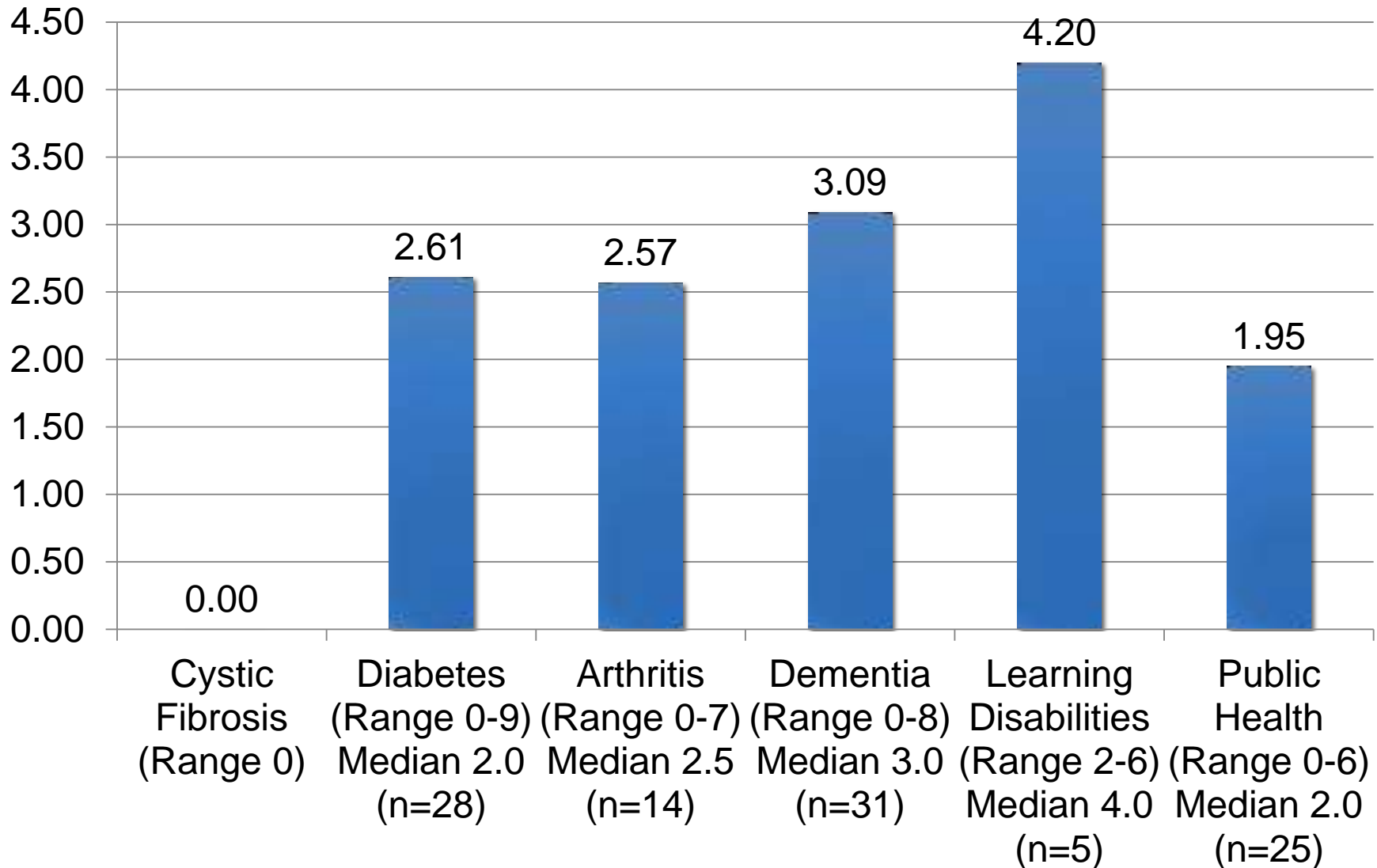
Study Design:

Qualitative and quantitative studies had the highest levels of PPI followed by clinical trials

What activities have (will) lay people/service users been involved in the project?



Average Score of PPI Activities by Research Topic Area: Survey



Scoping: Arthritis Study

2 PPI on
**steering
committee**

Dissemination:
1 PPI (member of local
Arthritis Support Group) and
researchers hope to
work together on
short report of study
findings to circulate
to support group
members

Stages of Public Involvement in Research

Members of local
Consumer Advisory
Group consulted and
influenced format of
protocol, in particular
lay summary and
methodology

Scoping: Learning Disability Study

Choosing Topic To Study:

People with LD decided we should look at

x

Research Methodology:

People with LD decided what questions & how to ask them

Steering Committee:

>50% of the research advisory group are people with LD

Data Analysis:

Undertaken in a participatory manner

Stages of Public Involvement in Research

Funding:

People with LD were involved in writing the forms

Ethics:

Attended meeting. Easy read application form

Data Collection:

Co-researchers undertook interviews and ran focus groups

Dissemination:

Presentations at conferences and newsletters

At what stage PPI has most impact?

“help set the research questions to be addressed”

Design Stage

“at the setting up stage”

All Stages

“from conception, planning, doing, dissemination”

“throughout the project”

Challenges for Researchers

“finding users with enough understanding and time”

Recruitment

Access
Representativeness
Diversity

“not just the usual suspects”

“finding new people”

“translating the research aims so that the general public find them comprehensible”

Communication

“explaining complex scientific concepts”

“lay people can feel intimidated by panels of clinical experts”

Confidence of PPI
Managing PPI **expectations**
Maintaining PPI **over time**

“SU are busy – also illness”

“PPI not possible at grant application...not all studies are funded”

Bureaucratic Funding

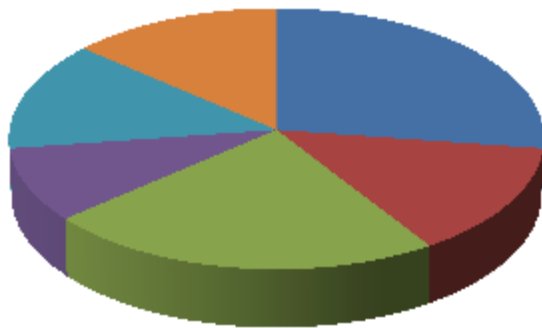
Not being Tokenistic

Time

“research deadlines”

23 case studies

Funder



- RfPB
- Programme Grant
- Charity
- HTA
- Research Councils
- Other

Design



- Basic science
- CTIMP
- RCT
- Cohort
- Qualitative
- Mixed methods
- Database
- Systematic review
- Survey

RfPB: Research for Patient Benefit
 HTA: Health Technology Assessment

CTIMP: clinical trial of an investigational medicinal product
 RCT: Randomised control trial

A common emerging theme: Study Participants or Public Involvement?

“I think that public involvement has the most impact at the testing stage of research. Without willing volunteers to take part in the research, new treatments or interventions could not be tested” (Survey: Diabetes - clinical trial)

“So you got involved in the study because you’re on the board....

“I’m actually one of the patients that gave a skin sample”
(Case Study 16 Interview PPI)

“So you were giving feedback as a participant on the trial ? *And I did some recruitment as well because they were running short of elderly* (Case Study 08 interview PPI)

Conclusion

- Information about PPI difficult to track down
- Huge variation of PPI activities between studies
- Strong regional history and embedding of PPI evident
- Merged involvement, engagement and participation
- Case study data required to get a deeper understanding

**Watch
this
space**

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Department of Health Disclaimer

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Emergent Findings: The figures presented are not the final figures.

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