Public involvement in RAPPORT

- **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 RAPPORT

- **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**

UKCRN: UK Clinical Research Network Study Portfolio
4 geographical regions

North East

East of England

South West

London
Research approach in RAPPORT

- **Realist evaluation** drawing on Normalization Process Theory (May & Finch 2010)
  http://www.normalizationprocess.org/

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- **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?

![Bar chart showing the percentage of activities involved in the project.](image-url)
Average Score of PPI Activities by Research Topic Area: Survey

<table>
<thead>
<tr>
<th>Research Topic Area</th>
<th>Average Score</th>
<th>Range</th>
<th>Median</th>
<th>Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cystic Fibrosis</td>
<td>0.00</td>
<td>0</td>
<td>2.0</td>
<td>(n=28)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2.61</td>
<td>0-9</td>
<td>2.0</td>
<td>(n=28)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>2.57</td>
<td>0-7</td>
<td>2.5</td>
<td>(n=14)</td>
</tr>
<tr>
<td>Dementia</td>
<td>3.09</td>
<td>0-8</td>
<td>3.0</td>
<td>(n=31)</td>
</tr>
<tr>
<td>Learning Disabilities</td>
<td>4.20</td>
<td>2-6</td>
<td>4.0</td>
<td>(n=5)</td>
</tr>
<tr>
<td>Public Health</td>
<td>1.95</td>
<td>0-6</td>
<td>2.0</td>
<td>(n=25)</td>
</tr>
</tbody>
</table>
**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.

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

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.

Data Analysis: Undertaken in a participatory manner.

Dissemination: Presentations at conferences and newsletters.

Stages of Public Involvement in Research
At what stage PPI has most impact?

Design Stage
- “help set the research questions to be addressed”
- “at the setting up stage”

All Stages
- “from conception, planning, doing, dissemination”
- “throughout the project”

Challenges for Researchers

Recruitment
- Access
- Representativeness
- Diversity

Communication
- “finding users with enough understanding and time”
- “translating the research aims so that the general public find them comprehensible”

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

Bureaucratic
- Funding

Not being Tokenistic
- Time
- “research deadlines”

Confidence of PPI
- “not just the usual suspects”
- “finding new people”
- “explaining complex scientific concepts”

Funding
- “SU are busy – also illness”

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

“lay people can feel intimidated by panels of clinical experts”
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
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Emergent Findings: The figures presented are not the final figures.
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