Co-Producing research with patient partners

Dr Rona Smith
Senior Research Associate, University of Cambridge
Honorary Consultant in Nephrology and Vasculitis
- Public and patient involvement in research
- Patient led research hub (PLRH)
- Case studies of co-production of research by PLRH
What do we mean by Patient and Public Involvement (PPI)?

The ‘researchers’
What do we mean by Patient and Public Involvement (PPI)?

The ‘researchers’

The ‘researched’
What do we mean by Patient and Public Involvement (PPI)?

The ‘researchers’

The ‘researched’

Involvement puts members of the public on the research team

The ‘research team’
Why perform PPI in research?

• Improves the quality and relevance of research.
• Uses methodologies that participants are more likely to engage with, can
• Reduce research waste
Mismatch of expectations

Adapted from Crowe et al, Res Inv Engage 2015
What does good PPI look like in a trial?

✓ Involves a variety of relevant voices
✓ Starts early and encompasses the full research process
✓ Actively pursues inclusivity & diversity
✓ Uses methods appropriate to audience and research
✓ Focuses on communication and clarification
✓ Acknowledges contributions and provides feedback
✓ Reflects on outcomes
PPI throughout the trial process

**Design**

- Refine research question
- Identify important outcomes
- Protocol feasibility and acceptability
- Recruitment strategies
- Review patient-facing documents
PPI throughout the trial process

**Design**
- Refine research question
- Identify important outcomes
- Protocol feasibility and acceptability
- Recruitment strategies
- Review patient-facing documents

**Delivery**
- Committee representation
- Recruitment ambassadors
- Data/results interpretation
PPI throughout the trial process

**Design**
- Refine research question
- Identify important outcomes
- Protocol feasibility and acceptability
- Recruitment strategies
- Review patient-facing documents

**Delivery**
- Committee representation
- Recruitment ambassadors
- Data/results interpretation

**Dissemination**
- Audience mapping
- Information placement
- Accessible language
- Message identification
- Co-authorship
- Dissemination plans
Types of PPI

• Consultation

• Collaboration

• Co-production
Types of PPI

• Consultation
  • Asking people for their views
  • One off meetings - patient panel

• Collaboration

• Co-production
Types of PPI

• Consultation
  • Asking people for their views
  • One off meetings - patient panel

• Collaboration
  • active, on-going partnership with members of the public in the research process
  • members of a steering committee for a research project
  • design, undertake and/or disseminate the results of a research project

• Co-production

https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/
Types of PPI

• **Consultation**
  • Asking people for their views
  • One off meetings - patient panel

• **Collaboration**
  • active, on-going partnership with members of the public in the research process
  • members of a steering committee for a research project
  • design, undertake and/or disseminate the results of a research project

• **Co-production**
  • Researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge

[INVOLVE 2018](https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/)
Types of PPI

Traditional PPI

Industry \(\rightarrow\) Academia \(\rightarrow\)

Clinical Need Academic Interest Commercial Opportunity

Research Proposal \(\rightarrow\)

PPI Input \(\rightarrow\)

Funding
Patient Led Research Hub

Supporting patient-led research
Co-producing clinical trials with patient organisations
Patients can submit new proposal. Infeasible or additional background work may lead to feasibility uncertain. PLRH facilitates collaboration between patients & researchers. Aligning with existing research priorities can make the proposal feasible. Funding application can be submitted if it is feasible. Patients can submit new proposals if it is infeasible.
Types of PPI

**Traditional PPI**

- Industry
- Academia

  - Clinical Need
  - Academic Interest
  - Commercial Opportunity

  - Research Proposal
  - PPI Input
  - Funding

**PLRH Approach**

- Patients

  - Patient organisation, support group, charity

  - Technical feasibility assessment

  - Feasible
    - Funding application
  - Feasibility uncertain
    - Additional background work
  - Infeasible
    - PLRH facilitates collaboration between patients & researchers
    - Patients can submit new proposal
Establishing the PLRH

- Support and co-produce research ideas proposed by patient organisations
- Free from research agenda: any original research idea on any healthcare topic
- Patient organisation maintains active role throughout project: multidisciplinary team with patients, researchers, clinicians
- Focus on patient priorities benefits funding applications
- Partnership builds trust with patient population: increased recruitment & adherence, wider dissemination network
Establishing the PLRH

• Support and **co-produce research ideas** proposed by patient organisations
• Free from research agenda: **any original research idea on any healthcare topic**
• Patient organisation maintains active role throughout project: **multidisciplinary team with patients, researchers, clinicians**
• Focus on patient priorities **benefits funding applications**
• Partnership builds trust with patient population: **increased recruitment & adherence, wider dissemination network**

• Core funding from Cambridge Biomedical Research Centre
• Nested within the Cambridge Clinical Trials Unit
• Supported by the University of Cambridge School for Clinical Medicine
• Governed by the Cambridge University Hospitals PPI Research Oversight Group
55 research ideas from 24 patient organisations & 24 individuals

44 health conditions

23 feasible projects
0 pending review

Patient Led Research Hub

ALL PLRH projects updated 03 October 2022
55 research ideas from 24 patient organisations & 24 individuals

44 health conditions

23 feasible projects
0 pending review

3 referred to specialist research centres
2 linked to ongoing studies
5 deferred at proposer request

13 co-produced proposals

3 projects in development

6 active, funded projects
3 completed projects

ALL PLRH projects updated 03 October 2022
<table>
<thead>
<tr>
<th>55 research ideas</th>
<th>ALL PLRH projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>from 24 patient organisations &amp; 24 individuals</td>
<td>updated 03 October 2022</td>
</tr>
<tr>
<td>44 health conditions</td>
<td>32 projects not feasible</td>
</tr>
<tr>
<td>23 feasible projects</td>
<td>9 without support from a UK patient organisation</td>
</tr>
<tr>
<td>0 pending review</td>
<td>7 did not respond to follow-up</td>
</tr>
<tr>
<td>3 referred to specialist research centres</td>
<td>6 proposals without new research component (e.g. treatment already available or awareness campaign)</td>
</tr>
<tr>
<td>2 linked to ongoing studies</td>
<td>5 from organisations already supported by experienced research teams</td>
</tr>
<tr>
<td>5 deferred at proposer request</td>
<td>3 unable to commit to project</td>
</tr>
<tr>
<td>13 co-produced proposals</td>
<td>2 direct requests for funding</td>
</tr>
<tr>
<td>3 projects in development</td>
<td>6 active, funded projects</td>
</tr>
<tr>
<td>3 projects in development</td>
<td>3 completed projects</td>
</tr>
</tbody>
</table>

Patient Led Research Hub
Feasible proposals

Research Priority

- Improving symptom management / quality of life, 43%
- Increasing patient support / disease awareness, 4%
- Investigating new or repurposed treatment, 30%
- Understanding the disease pathway, 22%

Increase patient support / disease awareness, 4%
Feasible proposals

### Research Priority
- Improving symptom management / quality of life, 43%
- Increasing patient support / disease awareness, 4%
- Understanding the disease pathway, 22%
- Investigating new or repurposed treatment, 30%

### Research Topic
- Neurology, 31%
- Renal, 31%
- Gastrointestinal, 3%
- Endocrine, 13%
- Musculoskeletal, 9%
- Haematology, 4%
- Mental health, 2%
- Autoimmune, 2%
Key Challenges

- Managing patient expectation
- Efficiently engaging researchers & clinicians
- Sourcing seed funding to support feasibility work
- Appropriately involving patients throughout project
- Building a PLRH network
- Increasing core capacity
Supporting inclusive involvement

• Inclusivity takes planning and conscious effort
• ‘One-size-fits-all’ thinking results in contributors of that ‘size’
• Offer a variety of ways to get involved
• Think broadly about the groups that are underheard in your research
• Direct invitations can help – use your networks and invite people personally
• Make use of existing community groups – and go to them first
• Enter others’ ‘comfort & convenience’ zones
• Ask about needs before and after first meetings
• Plan for end of study
Enabling success

Resources
- Staff
- Financial
  - Reimbursement
  - Honoraria
  - Accessibility
- Skills & training

Attributes
- Commitment
- Leadership
- Consistency
A new way of working……..
A new way of working…….
Rare disease focus

Most rare diseases are serious & life-altering, many are life-threatening or fatal. Recent study identifies almost 11,000 different rare diseases.

A rare disease is defined as affecting <1 in 2000, as per EU & UK definition. Only 5% of rare diseases have an approved treatment.

3 in 10 children with a rare disease will die before their 5th birthday. Approximately 3.5 million people are living with a rare disease in the UK.
Rare disease focus
Case studies
Case studies
Case studies
"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well"

Professor Dame Sally Davies (Chief Medical Officer England, Foreword in Staley report, 2009)