

Patient and Public Involvement and Engagement in Experimental Medicine

BRC Seminar

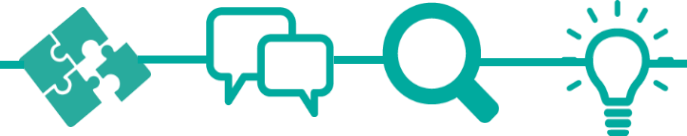
Public Programmes Team

27 November 2017



BRC Introduction – welcome and update

Professor Ian Bruce



Welcome and introduction

Dr Leah Holmes, Director of Public
Programmes

Our survey of 55 researchers said...

82% of respondents are interested in delivering both PPI and PE (with a further 16% PPI only)

45% of respondents would like training

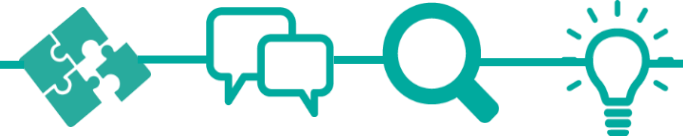
Stated as useful/very useful:

- Evaluating the impact of PPIE (94%)
- **Designing** and costing PPIE activity (92%)
- **Writing sections for grant applications** (92%)
- PPIE throughout research process (91%)



Aims of this session

- To increase researchers' knowledge and confidence in PPIE, specifically in:
- Writing PPI sections of grant applications
- Developing PE activities



| | |
|---------------|--|
| 09.00-9.15 | Registration, tea and coffee |
| 09.15-09.30 | BRC Introduction – “Welcome and update” Professor Ian Bruce- NIHR Manchester BRC Director / Connective Tissue Programme Lead |
| 09.30-09.50 | Welcome and introduction to the day <ul style="list-style-type: none"> • PPIE in the BRC • Outline and aims for the day Dr Leah Holmes – Director, Public Programmes Team |
| 9.50-10.50 | Parallel workshop one <ul style="list-style-type: none"> • PPIE in grant applications – funders requirements and writing (Suzanne Parsons - Patient and Public Involvement Manager, Public Programmes Team) • Developing public engagement activities (Annie Keane – Public Engagement Manager, Public Programmes Team) |
| 10.50— 11.00 | Coffee and tea break |
| 11.00- 11.50 | Parallel workshop two <ul style="list-style-type: none"> • PPIE in grant applications – funders requirements and writing • Developing public engagement activities |
| 11.50-12.10 | Wrap up session – PPIE support and opportunities within the BRC |
| 12.10 – 12.15 | Overview of the Research Programme Managers Network (RMPN) Charlotte Stockton-Powdrell, Senior Project Manager |
| 12.15-12.30 | Lunch and networking |





Know your audience...

1. PPI vs. PE experience

2. Overall PPIE experience

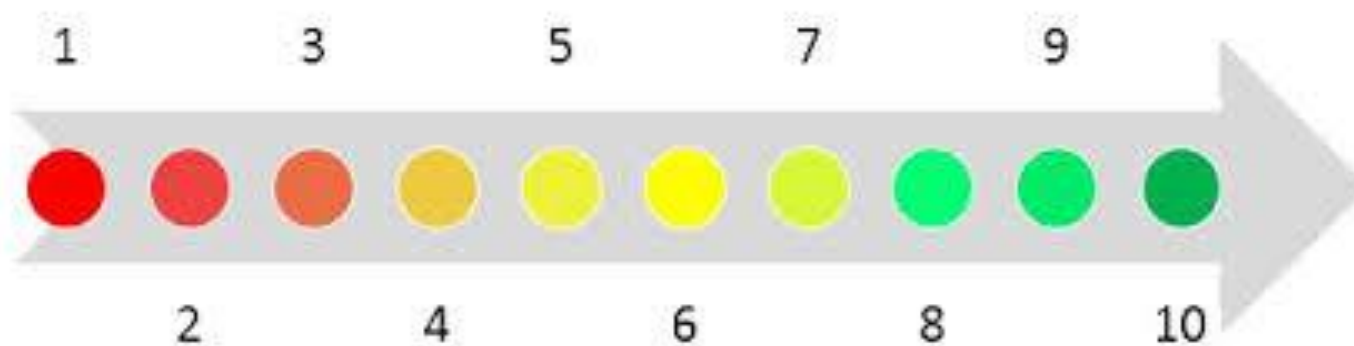
No experience

Lots of experience

Some experience

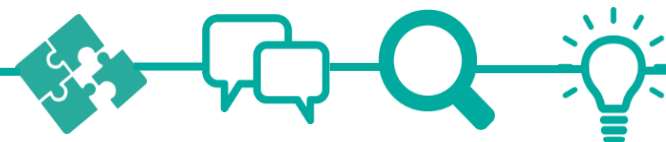


Know your audience...



Today's presentation:

- Our team
- Context and landscape
- Introduction to PPIE



Public Programmes Team

- Established in 2003
- Multidisciplinary award winning team of 10, expanding to 12 by April 2018
- Our vision – to become a UK Centre of Excellence in Engagement and Involvement
- Provide advice, consultancy and delivery across GM region, nationally and internationally
- Not-for-profit, financially self-sustaining with a 5 year business plan, investment from Wellcome



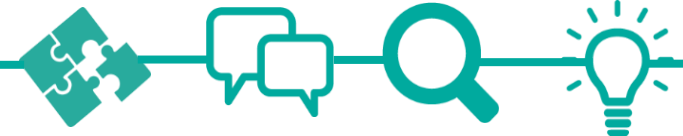
Context and Landscape

PPIE within research funding
(5-10% of funding)

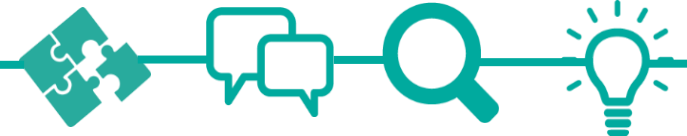
Funders getting more stringent:

- NIHR standards
- WT wanting to see more involvement practice within PE

NIHR report – Going the Extra Mile



Context and Landscape



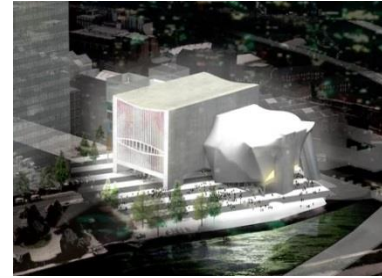
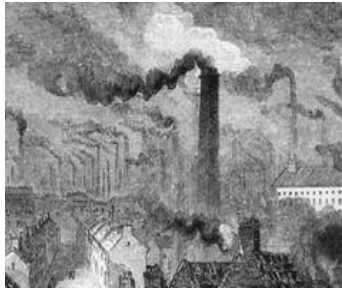
Our landscape...



Only about a third (37%) of the public trust evidence from medical research, compared to approximately two-thirds (65%) who trust the experiences of their friends and family*, according to a report launched today.



Our landscape...



This is
Manchester.
We do
things
differently
here...

Anthony H Wilson



Our landscape...

Past

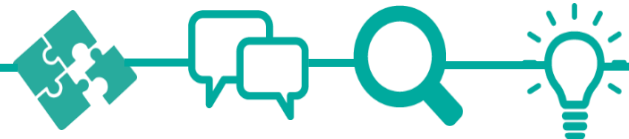
- Involvement
- The individual
- Clinical research
- Process
- Centrally controlled
- Partnership
- The committee room
- Public sector
- Patients, carers
- National focus

Present and future

- Co-production
- Communities
- Health research
- Outcomes (research)
- Citizen driven
- Collaboration
- Digital, tech, social media
- Charities and industry
- Public+
- Global movement
- Increased importance to funders
- Scrutiny and standards
- Evidence base

[Simon Denegri, NIHR]

What is Patient and Public Involvement and Engagement?



What PPI/E is not...

- Telling people about research
- Recruitment (although it can support recruitment)
- Bolted on (independent of research/researchers)



What is PPIE?

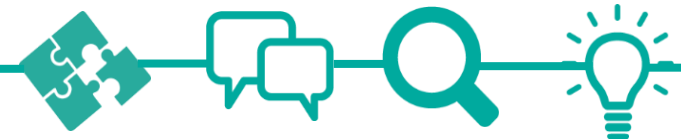
From NIHR:

‘Involvement’, ‘engagement’ and ‘participation’ in research are distinct but related activities

INVOLVEMENT: Where research is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

ENGAGEMENT: Where information and knowledge about research is provided and disseminated.

PARTICIPATION: Where people take part in a research study.

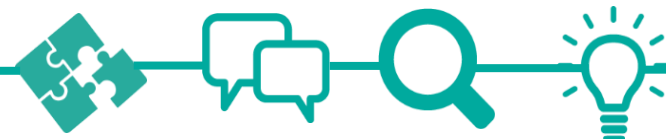


(Deliberately) Blurred lines

Communications – imparting key messages/ advocacy, researcher absent

Engagement – sharing information, stimulating thinking, non-advocating, **listening and acting on**, researcher present

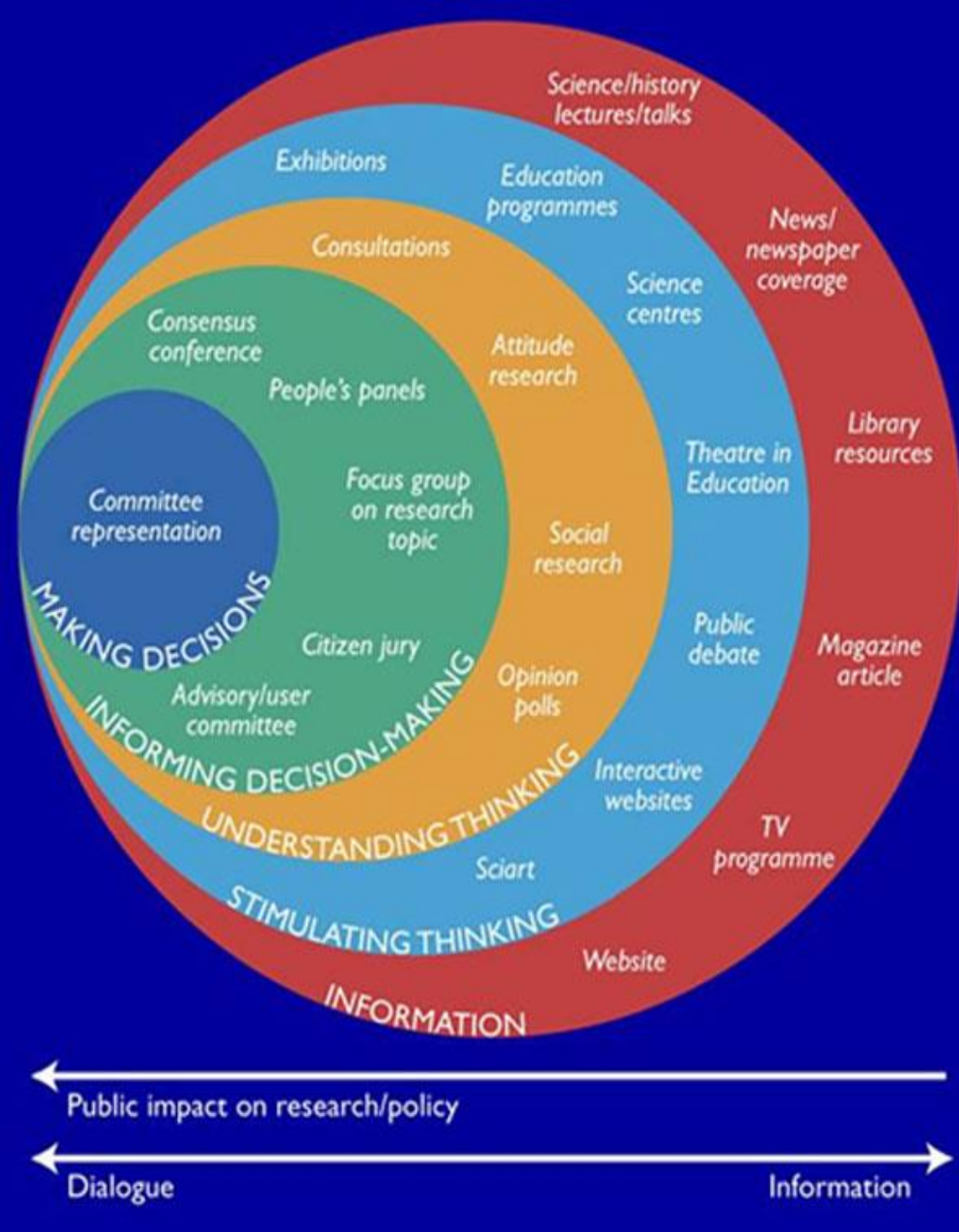
Involvement – empowering change and **listening and acting on**, researcher present



Engagement and involvement – a non-linear spectrum

Interfacing with people, research, communications, policy

Wellcome Trust 'onion' model



Why do it?

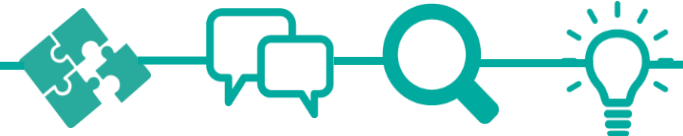


Why do it?

| | Socially isolated | #DesignforMSK | Your Rheum | Leading Disability Policy Group in workplace |
|--------------------------|--------------------------|--|---|---|
| Patient | | Improved confidence A way in... | Being listened to A sense of helping others | Taking direct action to support patients/ employees |
| Patient community | | Peer support network Increased public awareness of young people with musculoskeletal conditions | Peer support network Research outputs are more patient-centred? | Improved disability policy in that workplace Shared learning and shared confidence |
| Researchers | | Greater awareness of patient needs Increased skills and confidence to involve and engage | Greater awareness of patient needs Increased skills and confidence to involve | |
| Research | | | Increased patient expertise and experience informing research Improved research? | |

A reflection...

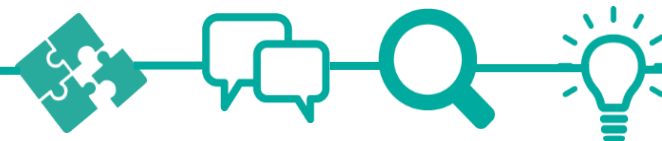
- You can't assume you know what people think or how they will act
- Democracy
- Influence/ bias/ objectivity
- Remain campaign – relied on the influence of experts
Leave campaign – used affective/emotional engagement



Workshops

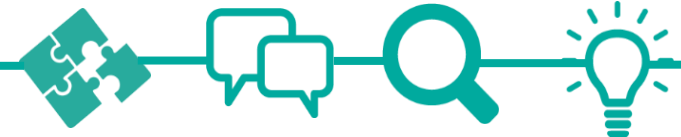


PPIE within the BRC and CRF



Our strategic focus areas:

- Prioritising **diversity and inclusion** within our contributors, audiences and approaches
- Experimenting with arts-led approaches; innovating across and between **engagement and involvement**
- Delivering gold standard **evaluation and research** which informs a continuous cycle of improvement in our practice
- **Building PPI/E capacity** within researchers, contributors and practitioners



The next 5 years...

- 
- A group of diverse people are standing in a dark room, each holding up a bright, glowing light source. The lights create a starburst effect, illuminating the scene and casting long shadows on the floor. The people are dressed in casual attire, and their expressions are focused on the lights they are holding. The overall atmosphere is one of collective vision and optimism.
1. Research-led PPIE
 2. Demand-led PPIE
 3. Talent development and capacity building
 4. Celebrating our community

BRC/CRF 5 year delivery

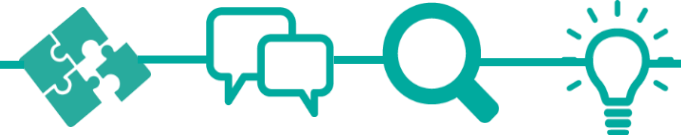
| | Y1 | Y2 | Y3 | Y4 | Y5 |
|----------------------------------|--|--|---------------------------|---------------------------|---------------------------|
| PPI | Ongoing and bespoke Increased diversity of contributors through demand-led programme and online PPI | | | | |
| PE | Ongoing and bespoke | | | | |
| Centralised PPIE projects | Respiratory | Dermatology +1 | Hearing Health +1 | MSK +1 | |
| Training | Needs assessment and ongoing delivery, opportunities through talent development strand | | | | |
| Monitoring, evaluation, research | Baseline and ongoing | Ongoing – plans to publish at least 4 peer-reviewed papers | | | Summative evaluation work |
| Celebrating our community | Ongoing | Summer picnic and ongoing | Summer picnic and ongoing | Summer picnic and ongoing | Summer picnic and ongoing |

PPI Infrastructure

| BRC Theme | Status |
|-------------------------------|---|
| Cancer | Monthly meetings established |
| Dermatology | In development |
| Hearing health | In development – First introductory meeting November 2017 |
| Musculoskeletal | Face to face group established |
| Respiratory | First meeting held October 2017 |
| Young people's advisory group | First meeting – 2 December 2017 |

Support from our team

- Ideas
- Knowledge of funders/funding
- Grant writing
- Costing for PPIE
- Planning
- Delivery
 - Knowledge of opportunities
 - Access to PPI infrastructure
 - Partnerships
- Evaluation
- Training



Who's who?

| | Public Programmes Team | Academic PPIE lead(s) |
|--------------------------------|--------------------------------------|-------------------------------------|
| Advanced Radiotherapy | Olivia Joseph | Ananya Choudhury |
| Hearing Health | | Catherine Wright |
| Respiratory | | Janelle Yorke |
| Cancer Precision Medicine | Katharine Cresswell | Jenny Royle |
| Prediction and Early Detection | | Emma Crosbie |
| Musculoskeletal | Emily Robinson | Wendy Thomson |
| Dermatology | | Abigail Langton Mark Farrar |
| CRF | Steven Edwards | |
| | Cassie Wilson (Comms and Engagement) | |
| | Safina Islam (Communities Lead) | |
| | Suzanne Parsons (Manager) | |
| | Annie Keane (Manager) | |
| | Leah Holmes (Director) | Kevin Munro (Deputy PPIE lead, BRC) |

Our asks of you...

Get involved

e.g. bring your research to a panel

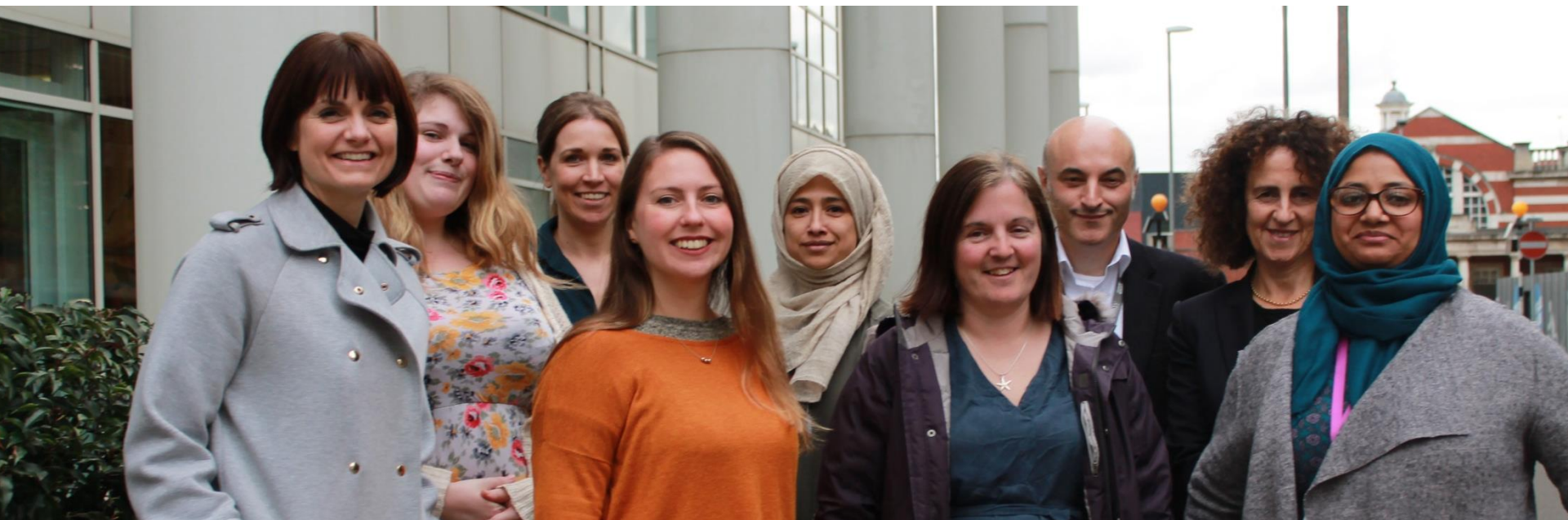
Help us to recruit (inclusively)

Give us enough notice

Trust us







publicprogrammes@mft.nhs.uk



[Public Programmes Team](#)



[@researchdialog](#)

[T: 0161 276 6614](tel:01612766614)

