

# What is Patient and Public Involvement/Engagement in Research?



Patient and public involvement in research means research done "with" or "by" the public not "to" or "for" them. For Example: Get involved in identifying the priorities of the research. Adding comments or developing the information leaflet for the patient. Interviewing the research participant

Engagement where information and knowledge about Research is provided and disseminated.

## why involve/engage patient and public?



To help ensure that the information provided to the participants are in appropriate and accessible language and content

Extra expertise based in the patient understanding to their condition they might be able to make judgments or have different thoughts which the professional did not consider

To help ensure the methods proposed for the research are appropriate and acceptable to the real context

To help with including voices that are heard less in research

Increase likelihood of results being implemented due to patient support

Analysis of benefits/risks

# Levels of patient and public involvement/Engagement

01

## consultation

Obtain feedback or opinions from patients regarding how to recruit other patients for the study or advice for the questions in the questionnaires



02

## collaboration

In this stage the researchers, and patients or the member of the public in every approach of the study process become partners and make decisions together.



03

## Patient controlled

In this stage the patient or the member of the public control, direct and manage the research process.



## IDENTIFYING & PRORITISING

Identify the topic of the research and the research question.



## DESIGN

Ensure the method /protocol is appropriate for the patient. Help with recruitments Named as co-applicant. Define outcome measures. Devolve research tools.



## FUNDING & COMMISSIONING

Review and draft research funding proposal. Ensure the research and method are ethical,

## RESEARCH CYCLE



## MONITORING & EVALUATION

Collaborate with researchers to evaluate the research process. Evaluate the impact of the involvement on the research. Patient, member of the public reflect on their role and what they learn



## IMPLEMENTATION

## DISSEMINATION



Advise on a venues for dissemination Jointly present research finding. Contribution to publications. collaborate in publishing results.



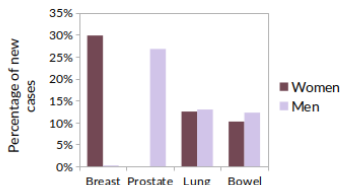
## UNDERSTANDING & ANALYSING

Collaborate in data collection e.g. Survey. Analyse/interpret data and result.

## Case Study: Cancer

Cancer is the leading cause of death in the UK

Most common cancers, 2016-18



200+ types of cancer

3 in 20 women  
diagnosed with  
breast cancer



Approximately 2  
in 14 men  
diagnosed with  
prostate cancer



\*The top four most common types of cancer, shown in the bar chart on the left, accounted for 53% of all new cases during 2016-18

Breast cancer accounted for 30% of new cases in women, whilst prostate cancer was the most common type in men at 27%

\*Data from Cancer Research UK. Cancer incidence for common cancers. Updated March 2020.

## Clinical trials

A type of involvement that allows researchers and patients to work together to find out if a new treatment or procedure:

- Is safe
- Has side effects
- Is better than existing treatments
- Affects quality of life



### Benefits

For you	For researchers
Opportunity to make improvements to a range of treatments and interventions	Gain relevant insights into patient care
Inform future decision-making in designing treatments and ongoing care	Maximise use of research funding Making a difference to people's lives

### Challenges

For you	For researchers
Time commitment Concerns around data collection and use or re-use	Gaps in knowledge about certain types of cancer, such as skin melanoma
For patients: uncertainty of trying new treatments and interventions	Recruitment of under-represented groups: - people aged under 25 years - parents of children aged under 16



An analysis of 166 research papers published on Web of Science referencing Public and Patient Involvement and Engagement in cancer research indicated 31% overall positive sentiment, contrasted with 11% negative

STRATEGIES FOR INVOLVING  
PATIENT/PUBLIC IN RESEARCH.  
Benefits and Challenges



Benefits



**CONSULTATION**

Seeking advice and feedback from patients,  
their families and the public



**COLLABORATION**

Ethical research  
Complementary skills  
Focused and relevant research  
Power sharing – Inclusion – Respect – Reciprocity



**PATIENT CONTROLLED**

Little or no chance of exclusion  
Focus on the needs of service users



**CONSULTATION**

Public reluctance due to consultation fatigue  
A facilitator may be needed



Added cost and time consuming  
Training may be needed  
Unwilling to share control of the research



Challenges



**PATIENT CONTROLLED**

## Strategies for engaging with patients/ intermediaries (e.g. charities, healthcare workers/ NHS) in research

### Community Based Participatory Research (CBPR)

These are partnerships involving academic researchers, services and communities. The aim is to identify the community needs and then working together to develop programmes. In CBPR community researchers are recruited and trained to gather data in their community, identify health issues and potential solutions. Various research designs can be used ranging from questionnaire based surveys to Photovoice.



### Area Based Initiatives

These are policy initiatives aimed at tightly defined geographical areas and used by the UK government to tackle problems associated with urban deprivation. Examples include the NDC (New Deal for Communities) programme and Health Action Zones.



### Community engagement in planning

Participatory budgeting, deliberative polling, citizens juries, user panel



### Co-production projects

There is community input into the design process and shared delivery between professionals and communities through community-based services, volunteering and peer support networks.

- Co-creating high quality engagement outputs. An arts led approach, amplification via social media

#### References

[https://www.rds-ynihr/wp-content/uploads/2015/01/RDS\\_PPI-Handbook\\_2014-v8-FINAL-11.pdf](https://www.rds-ynihr/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf)  
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