PATIENT INVOLVEMENT IN RESEARCH

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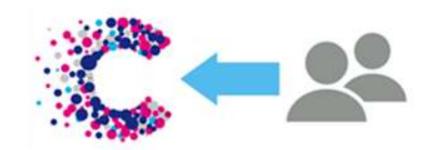


What is patient involvement?

"Doing things
with or by
people rather
just for and to
them."

"Drawing on the unique knowledge & experiences of people affected by cancer to shape and influence your research"

INVOLVEMENT, ENGAGEMENT AND PARTICIPATION





PARTICIPATION

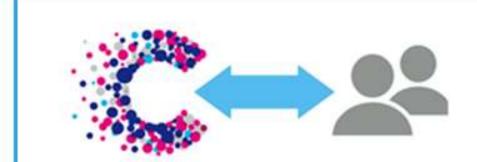
Taking part in a research study (used to be called a 'subject').

e.g. taking part in a clinical trial

ENGAGEMENT

Where information and knowledge about research is provided, with opportunities for two way communication.

e.g. lab tours, science festivals, open days



INVOLVEMENT

Where people affected by cancer are in research projects and in research organisations.

e.g. co-applicants on a research project or patients advising researchers

IMPACT ON RESEARCH AND RESEARCHERS

Can help put
research in context
and help
researchers
understand the
realities of cancer

Motivates and focuses researchers on the impact of their work

Can improve the quality and relevance of the research

Ensures accountability

Importance of patient involvement in pre-clinical research

❖ Research is funded by the public and they cannot engage and support research unless it is well communicated

Patient involvement can help researchers communicate by

Tailoring lay summary for funding applications

Providing support for the research in grant applications and beyond

Identifying ways to communicate research results

Putting their research into context

❖ Motivate researchers who may have no direct contact with patients

WHERE DO I START?



- Why are you delivering this project? What problem are you trying to solve?
- How will involvement help you solve that problem?
- What value will it add?



- What do you need people affected by cancer to do to add value to your project?
- What question(s) do you need people affected by cancer to answer to help solve your problem?
- Do you need people affected by cancer to act as advocates for your project?



At what stage(s) of the research cycle do you need to involve people affected by cancer to achieve that added value?



- Which involvement method best suits your needs?
- How/where will you recruit people affected by cancer? Who will you involve (do they need any specific experience, e.g. of participating in research)? How many people will you need?

Advocacy

- Advise on dissemination avenues
- Jointly present findings
- Write information for patients/produce a lay summary of the findings

Identify research priorities

Research

Relevance

- Identify priorities that are relevant to patients
- Refining the research question
- Identifying the ethical implications of your research

Communicate impact

Support design/ development of research

Design

- Assessing the feasibility and acceptability of a study
- Reviewing information and consent forms
- Advising on participant recruitment
- Look at benefit/risk balance

Quality

- Reviewing progress reports
- Assist in identifying themes
- Adding the patient perspective to analysis
- Identifying which outcomes are most relevant to patients



Monitor/ evaluate research

Cycle

Support delivery of research

Developing a research application

Quality

- Writing lay summaries
- Contributing to steering/project management groups to oversee delivery
- Supporting trial recruitment

Review

- Reviewing and feeding into grant applications
- Providing ethical backing and acting as advocates within the application
- Reviewing lay summaries

Developing an idea/research question A translational researcher wanted to involve people affected by cancer in their work to identify and understand what the priorities of people affected by childhood and young people acute lymphoblastic leukaemia.

How were people affected by cancer involved?

- Researcher approached CRUK
 Patient Involvement Team wanting to involve people affected by cancer in two grant applications
- Decided to consult the CRUK Cancer Insight Panel and Children and Young People's Advisory Panel via e-consultation
- Attended a face-to-face meeting with CRUK Cancer Insight Panel to develop outstanding research ideas

What training was offered to the patient representatives?

- Pre-reads given to the panel before the face-toface meeting to provide context to the research and questions to think about
- Emotional support due to the sensitive nature of the topic, those consulted were reminded of where they could seek emotional support
- Feedback provided to both panels after each consultation to know what impact their insights had

What impact did involving people affected by cancer have?

Confidence to focus research on basic science

Determined research area



What advice would you give to other researchers?

- "Just do it! Meeting the panel was inspiring and I was so impressed by how quickly they mastered the brief. I now look forward to filling in the involvement section of any funding application"
- "Think about the key questions you want to ask people affected by cancer and how to make your research lay. It really helps to improve the clarity of your aims and objectives."

"They provided a unique perspective on my research plans and I came away buzzing with new ideas and inspiration."

RESEARCHER TOOLKIT



Patient involvement can improve the quality and relevance of your work, helping you better understand and articulate the benefits your research can have for cancer patients. This toolkit provides guidance, tips and templates to help you plan, deliver and evaluate your patient involvement. Once you've planned how you want to involve patients, we can also help you find them.

Get Started

ADDITIONAL RESOURCES AND INFORMATION

- The People in Research website http://www.peopleinresearch.org/
- The Health and Care Research Wales website https://www.healthandcareresearch.gov.wales/involving-the-public-in-your-research/
- The Scottish Primary Care Research Network https://www.nhsresearchscotland.org.uk/research-areas/primary-care/get-involved
- The HSC R&D Division, Northern Ireland http://www.research.hscni.net/personal-and-public-involvement-researchers
- ❖ The INVOLVE website http://www.invo.org.uk/ is also really useful and contains resources that may support you in involving people affected by cancer in your work.