

Still Evolving – Patient Engagement In Research

Supporting Patient (and Public) Engagement In Cancer Research – A Global Ecosystem And An Expanding Universe

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Patient involvement in trials – why?



It's our health!



Funders, RECs and regulators all want it.



We help improve design, delivery & dissemination.



It's our money!



Impact of patient/public involvement on aspects of trials

- ✓ **Making trials more relevant (and more likely to recruit and retain):**
so that the research results and data collected are more likely to be useful and of benefit to patients and the public (especially QoL, PROMs and PREMs)
- ✓ **Helping to define what is acceptable to participants:**
particularly in controversial or sensitive research, or where patient burden is a challenge
- ✓ **Improving the process of informed consent:**
making it easier for prospective participants to understand the research and potential risks, the rationale for the study and protocol and the importance of compliance
- ✓ **Improving the experience of participating in trials:**
checking that the practical arrangements for participants are appropriate and a respectful use of people's altruism, and are realistic for the target population (including families)
- ✓ **Improving the communication of findings to participants and the wider public:**
providing information on the progress of the research as well as the final results (including advocacy for implementation and raising awareness among the general population)
- ✓ **Helping to make research participation a routine option in the cancer pathway:**
In the UK 40% of cancer patients have discussions with doctors/nurses about research (source – CPES 2022)

Which Patients (or Public) And Why Do They Engage”?

| Public | Patient | Patient Advocate |
|--|---|--|
| Focus on societal concerns (incl inequalities, healthcare resources) | Focus on self, family (esp. genetic conditions or risks) | Focus on a group of patients, esp re stratified medicines |
| Very little knowledge of science or medicine | Different knowledge levels - from nothing, to a lot (“ <i>expert patient</i> ”) | Learns in depth knowledge about diseases & treatments |
| Short-term view: Don’t get sick | Short-term view: Live longer with good QOL | Long-term view: Improve system/research |
| Main concern: prevention or risk-reduction | Main concern: treatment, impact on family | Focus: influencing research and patient care (“ <i>patient expert</i> ”) |
| Emotions guide comments, mindsets | Emotions guide personal decisions esp. acute conditions | Emotions fuel long-term work seeking gains for patients |

Two Patient Advocates speak about their input to a trial design



Our involvement was essential because only patients can bring the perspective of patients. (1)

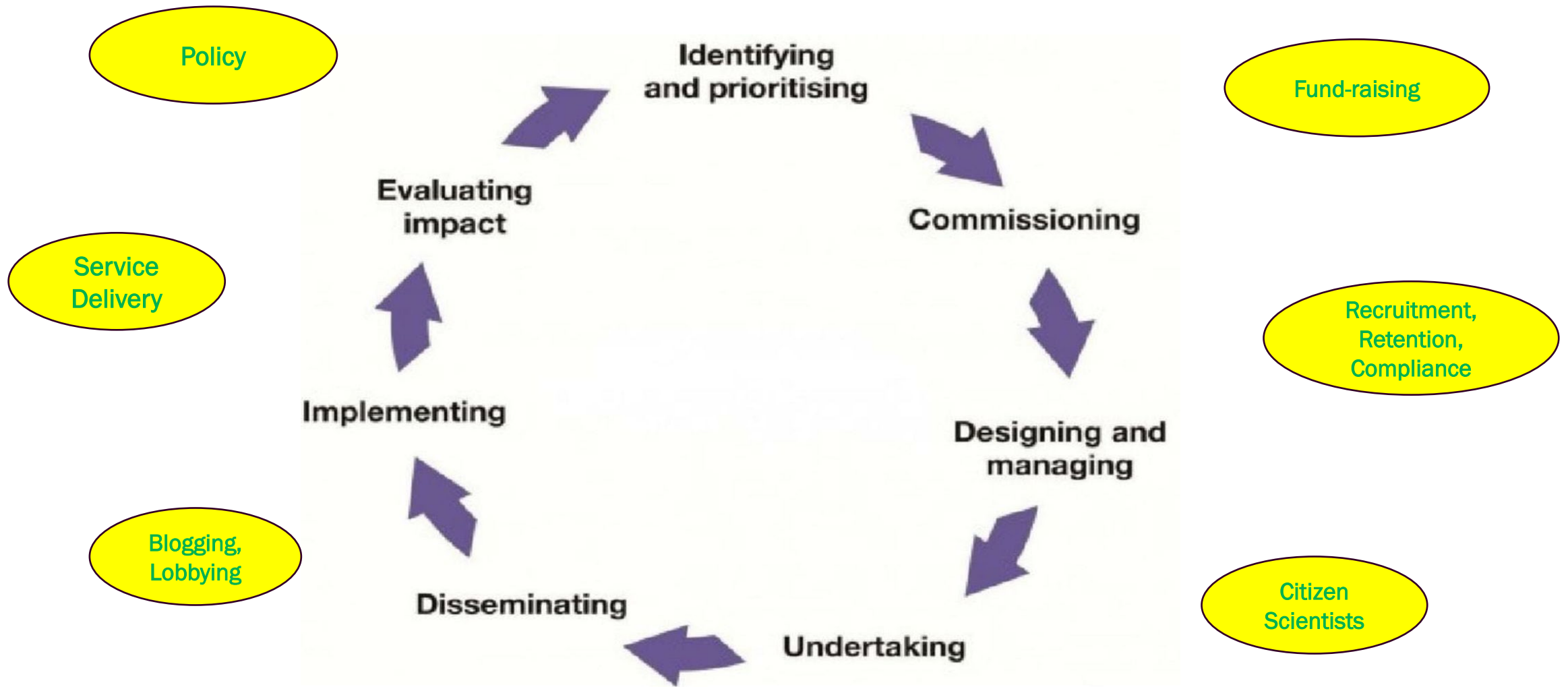
As cancer patients ourselves we have an understanding of how we approached the decisions which have to be made. (2)

We also explained that not every patient understands the concept of absolute and relative risk, and we worked with the team to make patient decision aids clearer. (3)

Lesley Turner & Hilary Stobart, CRAF

1. Also true for carers, the general public, or particular communities or populations
2. The patient perspective (and/or our carers)
3. The Patient Advocate role

The INVOLVE Research Cycle (1996)



<https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437>



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|----------|----------|---------|---------------|-----------------------|---------------------|-----------------|-------------|
| About us | The PSPs | Top 10s | JLA Guidebook | News and Publications | Making a difference | Current surveys | The JLA Lab |
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The James Lind Alliance

The James Lind Alliance (JLA) is a non-profit making initiative bringing patients, carers and clinicians together in JLA Priority Setting Partnerships (PSPs). The JLA PSPs identify and prioritise unanswered questions or evidence uncertainties that they agree are the most important, so that health research funders are aware of the issues that matter most to the people who need to use the research in their everyday lives.



<https://www.ncri.org.uk/areas-of-interest/living-with-beyond-cancer/>



ESC Clinical Practice Guidelines on **Cardio-Oncology: What Patients Need to Know**

CARDIO-ONCOLOGY
NURSES SYMPOSIUM

HOSPITAL LA PAZ SEPTEMBER, 30th

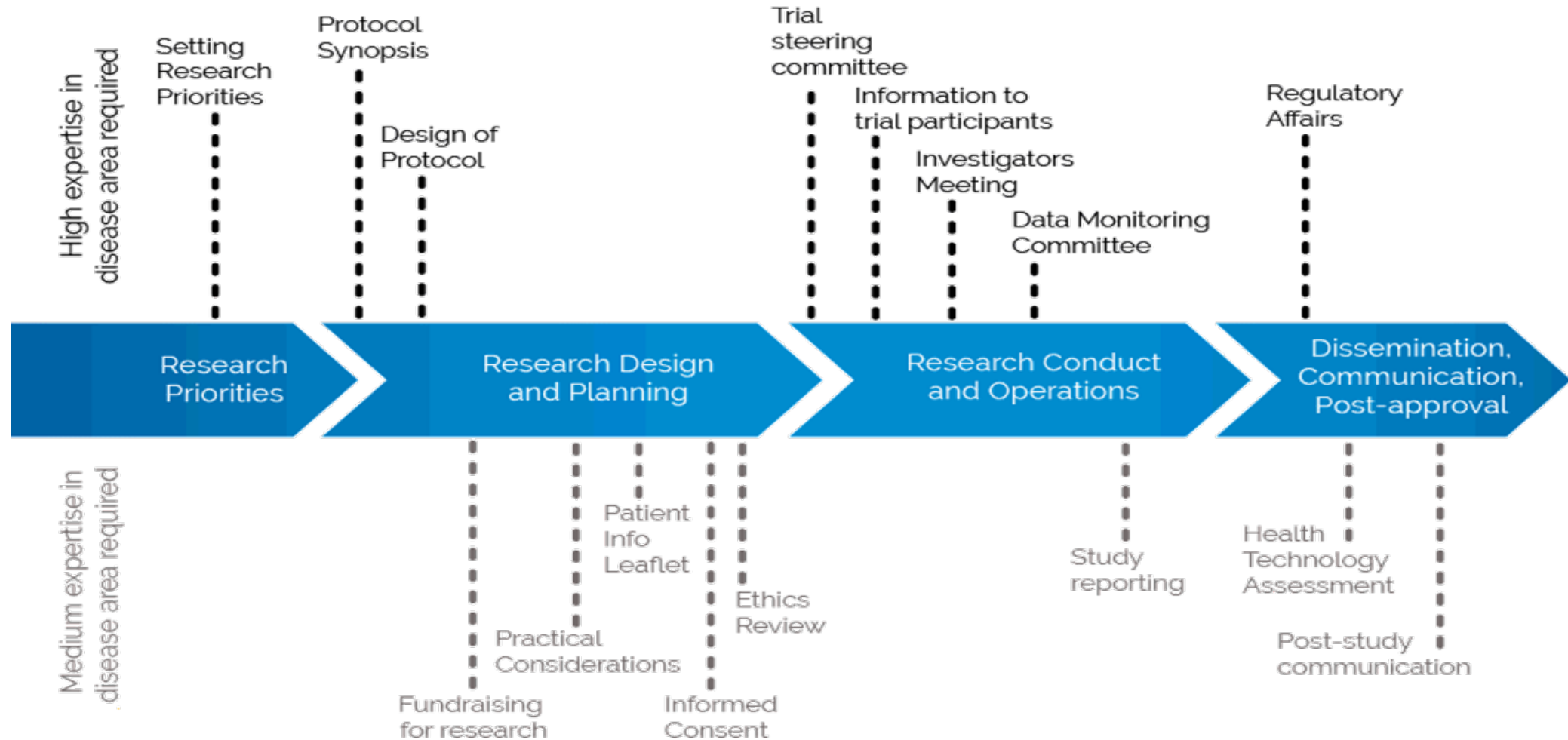
Risks, decision aids, managing illness and treatments

The ESC clinical practice guidelines on cardio-oncology for patients were written by a multidisciplinary team of healthcare professionals, including doctors, nurses, scientists **and patients**, & intended mainly for use in clinics & hospitals with the aim of ensuring the language was **inclusive & non-technical**.



<https://www.escardio.org/Guidelines/Clinical-Practice-Guidelines/Cardio-oncology-guidelines>

Patient involvement opportunities along the drug development pathway



Source: Geissler, Ryll et al (2016): www.eupati.eu

use MY data

✓ Our vision is of -

☺ Every patient in the UK willingly giving their data to support medical research and their own care

✓ Our mission is -

☺ To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data for research and improving healthcare

The Patient Data Citation:

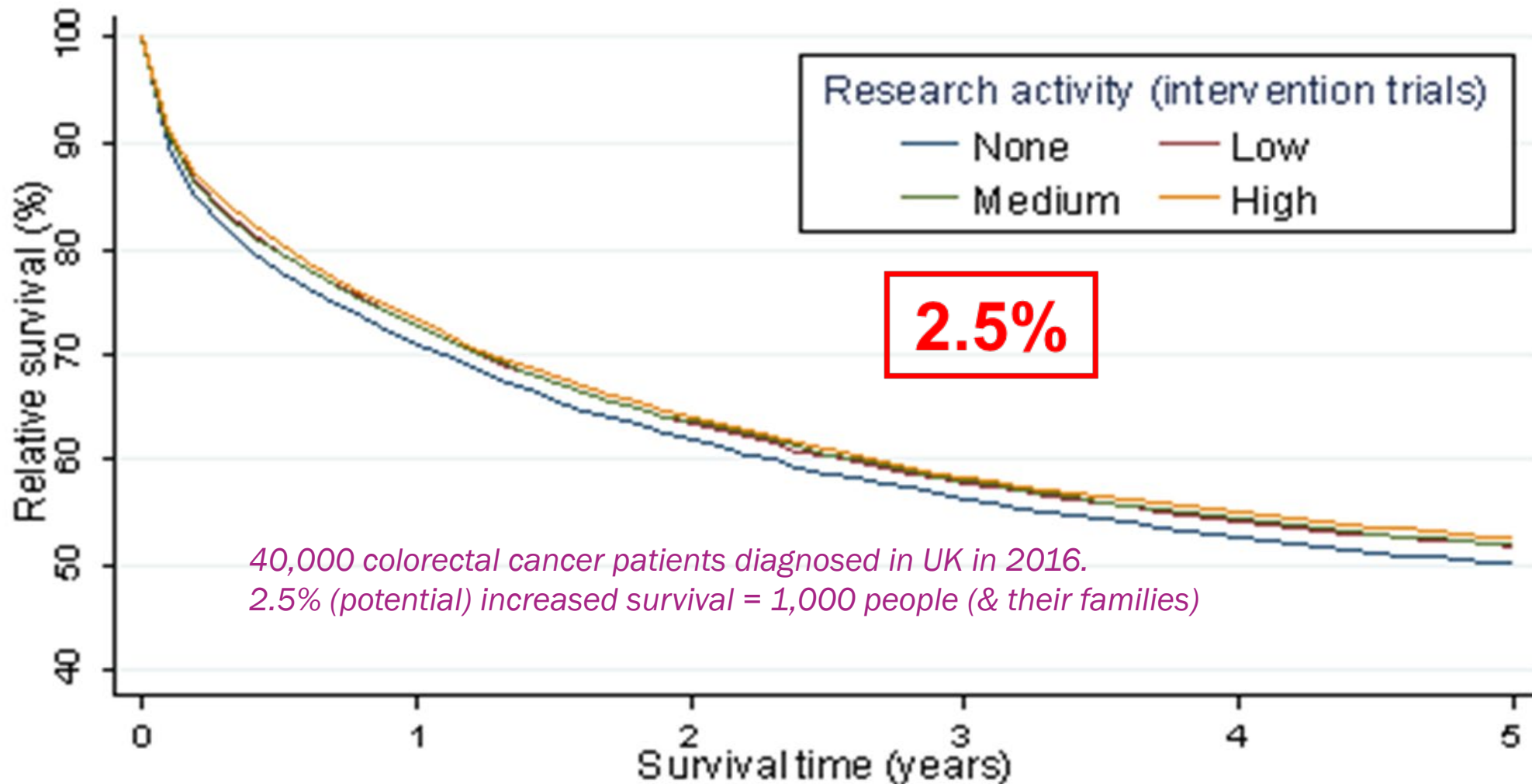
“This work uses data provided by patients and collected by the NHS as part of their care and support.”

<https://usemydata.org/>



High hospital trial activity and improved colorectal cancer survival outcomes: A population-based study

<http://gut.bmj.com/content/66/1/89>



Cancer Patient Experience Survey (CPES) - England



Questions and Responses on Research, 2012-17

Since your diagnosis, has anyone had a discussion with you about research?

- ☺ 390k patients responded 2012-17; consistently 60k+ annually;
 - ☺ 32% of cancer patients have discussions about research **40% (CPES 2022)**
 - ☺ 67% of those who have a discussion go on to take part in research
 - ☺ 95% of those who have a discussion were comfortable having the discussion
 - ☹ 53% of those who did not have a discussion would have preferred to have had it
- Variations by tumour type are as expected from the trial portfolio.
- Variations by ethnicity mirror known inequalities in incidence & outcomes
- Variations by age are narrowing but patients over 70 or 14-24 are still significantly less likely to be asked.
- Whether or not patients have the discussion about research is the biggest geographical inequality in the all the survey answers; from 12-15% of patients in poorest-performing Trusts to over 50% of patients in best performers. Best performers are consistently good, poorest 10% Trusts are often different each year (usually attributed to resourcing issues e.g. staffing).

Cancer Patient Experience Survey (CPES)

Research Participation = Better Patient Experience

| 2013 | Did not have a discussion | Had discussion but did not go on to participate | Had discussion and did go on to participate |
|---|--|---|---|
| Rating of care as excellent or very good | 87.2% | 90.2% | 91.9% |
| Rating of care as less than excellent or very good | 12.8% | 9.8% | 8.1% |
| |  |  |  |

Useful Sources/Resources (1 of 2):

PFMD (Patient-Focussed Medicines Development) - <https://patientfocusedmedicine.org/>

Part of The Synergist, a European organisation promoting and supporting partnerships

EUPATI (European Patient Academy for Therapeutic Innovation) - <https://eupati.eu/>

– mostly industry-focussed, superb training course for patient advocates, plus free toolkit and training materials online

PCORI (Patient-Centred Outcomes Research Institute): - <https://www.pcori.org/>

USA; producing research in Involvement and as well as encouraging Involvement in research

Patient and Public Involvement Toolkit – Julia Cartwright & Sally Crowe (2011)

The best basic guide for researchers on when/why/how to Involve people (but mostly f2f)

Patient Engagement for the Life Sciences – Guy Yeoman and Mitchell Silva (2018)

A Handbook for Industry, from the former AZ global VP for Patient Centricity and the former Chair of Eupati

Useful Sources/Resources (2 of 2):

NIHR-INVOLVE - <https://www.nihr.ac.uk/>

UK Standards For Involvement plus guidance on payments to patients/PPI representatives

GRIPP2 – <https://www.bmj.com/content/358/bmj.j3453>

A checklist to improve reporting of patient and public involvement in research

CRUK (Cancer Research UK) Patient Involvement Toolkit for Researchers -

<https://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers>

Toolkit aimed at academic and mostly clinical researchers, with several exemplar case studies. Cancer-specific but does cover several phases and types of trial/study.

MRC CTU PPI Resources – Co-designed templates and guidance - <https://www.mrcctu.ucl.ac.uk/patients-public/patient-and-public-involvement/ppi-resources/> (Including the model PIS and advice for patients on TMGs and TSCs)

International Patient and Public Involvement Network - <https://intppinetwork.wixsite.com/ippin> Good idea; currently a work in progress

Academic Journal: *Research Involvement and Engagement*

<https://researchinvolvement.biomedcentral.com/>

- ✓ Online, open-access BMC journal; fees may be waived for patient/carer/public co-authors
- ✓ Vision – “nothing about us without us”
- ✓ Two joint Editors-in-Chief; one academic and one patient
- ✓ Patient involvement in production; co-authors, peer reviewers, editorial board
- ✓ Every paper reviewed by patients/public
- ✓ Every submission required to have a Plain English Summary

The screenshot shows the homepage of the journal. At the top, the title 'RESEARCH INVOLVEMENT AND ENGAGEMENT' is displayed in green and blue. A navigation bar includes 'Home', 'Authors', 'Reviewers', 'About this journal', and 'My Research Involvement and Engagement'. A green button in the top right corner says 'Accepting submissions'. Below the navigation bar, there are several content blocks: 'Now accepting submissions' with a call to action to submit manuscripts; 'Editorial Board' listing the Editors-in-Chief (Sophie Staniszewska and Richard Stephens) and the Editorial Board members (Adewale Adebajo, John Amany, Peter Beresford, Louca-Mai Brady, Sarah Buckland, Iain Chalmers, Neil Churchill, and Sally Crowe); 'Aims & scope' describing the journal as interdisciplinary and co-produced by patients and researchers; and 'Editors' profiles'. On the right side, there is an 'Email updates' section with a sign-up form and a 'Sign up' button, and a 'Submit a manuscript' section with buttons for 'Register', 'Sign up for article alerts', 'Contact us', 'Follow BioMed Central', and 'Support'.

The world's first journal dedicated to publication of research focused on public involvement and engagement in health and social care and patient issues. Published 120+ papers in 2023, 40% with patient/community co-authors.

Cancer Research Advocates Forum (CRAF-UK)

Top Tips and Handy Hints

Involve patients (groups, advocates etc) as early as possible

(formally on TMGs, TSCs, Committees etc, or informally, eg focus groups or coffee mornings or public workshops – and go to where the people are; community centres, faith buildings, online and social media.)

- ? Will patients join this study (is it relevant to us – real outcomes or surrogate ones)?
- ? OFS or PFS (with or without QoL and PROMs – and which instruments to use)?
- ? Will we stay on the study (how do we cope with our situation yet also comply with your protocol, not to mention extra samples and visits)?
- ? Will we understand the patient information and consent form? (Can we write/review it?)
- ? Could patients help support participants, or help with recruitment, or dissemination of results, or link to charities, faith or patient groups?
- ? Can we disseminate the results and help your study change practice more quickly?

