

Avoiding Waste In Research – A Patient Perspective

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Two cancers, one heart emergency,
Sundry other co-morbidities,
Various aches and pains and worries

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“Hands up if you think research is a good thing!”





Why Do Patients Participate In Research?



- Altruism (and sometimes legacy)
 - benefit to future patients
 - benefit to own family (especially genetic rare conditions)
- Personal benefit
 - research studies provide better care (do they?)
 - desperation - How Do I get That Drug?
- Our doctors mention it
 - There is a culture of research surrounding the treatment
 - Existing medicine comes from research evidence

Patient Views on Waste In Research

- Waste in Research = Wasted Research
 - Research that is not reported
 - Research that is reported but not acted on
- Waste in Research = Wasting Resources
 - Samples or data that are not used
 - Failed to recruit/retain participants (though that may help in future)
 - Overtaken by other research
 - Not relevant to patients
 - Not grounded in other research or existing evidence
 - Too long to set up; misuse of GCP, bureaucracy (not regulation)
 - Token PPI and charlatan patient representatives

Patient Involvement in Research

- Our focus is on improving the quality and relevance of research for patients, not on reducing or preventing waste
- Iain Chalmers – “**add value and reduce waste**”



- Marginal benefit is still benefit (“at least we know”)
- Recognise the altruism of patients (esp research re trials)
- Broad support for real-world evidence & data sharing
- Value – usually, it’s our money as well as our participation; taxation, donation, insurance, fee



Some Involved People - The NCRI Consumer Forum



- ☺ 92 **experienced and trained** cancer research Consumers (56 patients, 22 carers, 14 who are both); all Volunteers
- 16 have international links/experience beyond UK
- 24 have been published, 1 is an academic journal editor
- 12 have scientific/research degrees/backgrounds (4 PhDs)
- 9 sit at Trustee/Board level on research-funding Charities
- 4 NHS/NIHR Managers, 1 CCG NED

- 12 patients in active treatment
- 26 of the 36 carers have been bereaved
- 34 in ftw; 19 ptw; 9 self-identified full-time patient advocates
- Ages 20-88 (but over 60% are over 50)
- Low but improving representation of ethnic/cultural minorities

NCRI is a partnership of UK cancer research funders

Charities



CANCER
RESEARCH
UK



Bloodwise
Beating blood cancer since 1960

**WE ARE
MACMILLAN.
CANCER SUPPORT**

welcometrust

breast cancer
now



tenovus
cancer care
gofal cancer

Health departments



Department
of Health



**CHIEF
SCIENTIST
OFFICE**



Public Health
Agency



Ymchwil Iechyd
a Gofal **Cymru**
Health and Care
Research **Wales**

Research councils

MRC

Medical
Research
Council



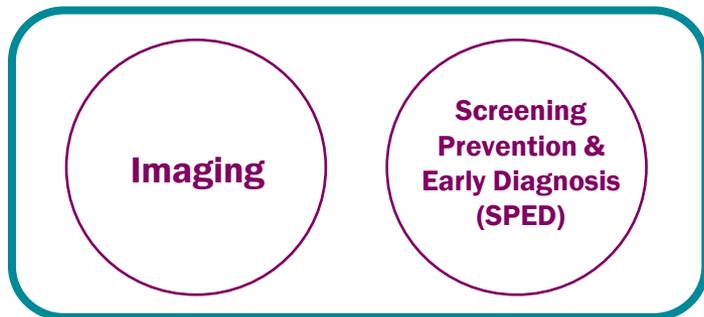
BBSRC
bioscience for the future

E · S · R · C
ECONOMIC
& SOCIAL
RESEARCH
COUNCIL



The NCRI Clinical Studies Groups – structure

18 NCRI
CSGs



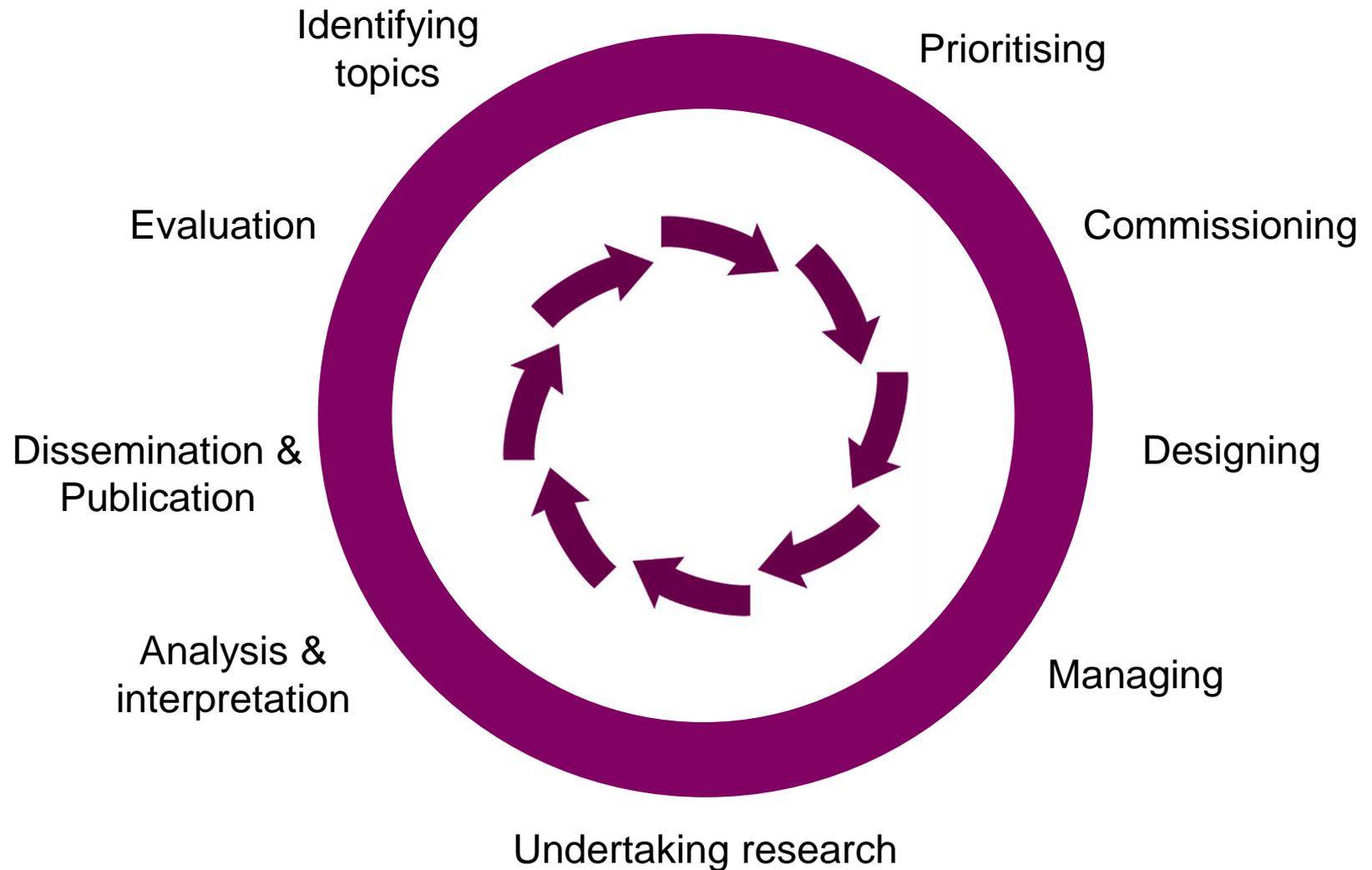
2 Advisory
Groups

Involvement – Adding Value (and preventing/reducing waste)





NCRI Consumers and the Research Cycle



Dragons' Den 2012 - AstraZeneca

We rarely get the opportunity to understand matters directly from the patient.

It was interesting to really understand what makes a patient want to enrol on a clinical trial.

I was impressed by the real interest of the advocates working in partnership with the Pharmaceutical industry to provide insights that could potentially result in faster, more efficient and better targeted studies.





AZ-Forum Projects 2015-16

- Patient Reported Experiences/Outcomes Tool (Phase IV clinical trial)
- Phase I-II Ovarian Cancer Trial
- Co-production of an app for real-time patient reported experiences (*)
- Lung Cancer Phase IV study
- Immuno-Oncology Informed Consent Forms
- Joint presentations – eyeforpharma, ISMPP, early phase conference
- Hackathon – “*My Clinical Trial*” app (with The Christie Hospital)

(*) *PROACT*, published in *Trials*, June 2016

Dragons' Den 2016 – 11 tables; 117 people





National Cancer Patient Experience Survey (NCPES)

It's OK To Ask/Tell Patients About Research!

- 😊 32% of cancer patients have discussions about research
- 😊 67% of those asked go on to take part in research
- 😊 95% of those asked are ok to be asked
- 😐 53% of those not asked are ok to be asked

- 😊 380k patients responded 2012-17; consistently 60k+ annually (*); world's largest cancer patient experience survey

- 😊 7 posters produced by NCRI Consumer Forum 2013-17 on these results; <http://www.ncri.org.uk/resources/ncri-consumer-forum/>

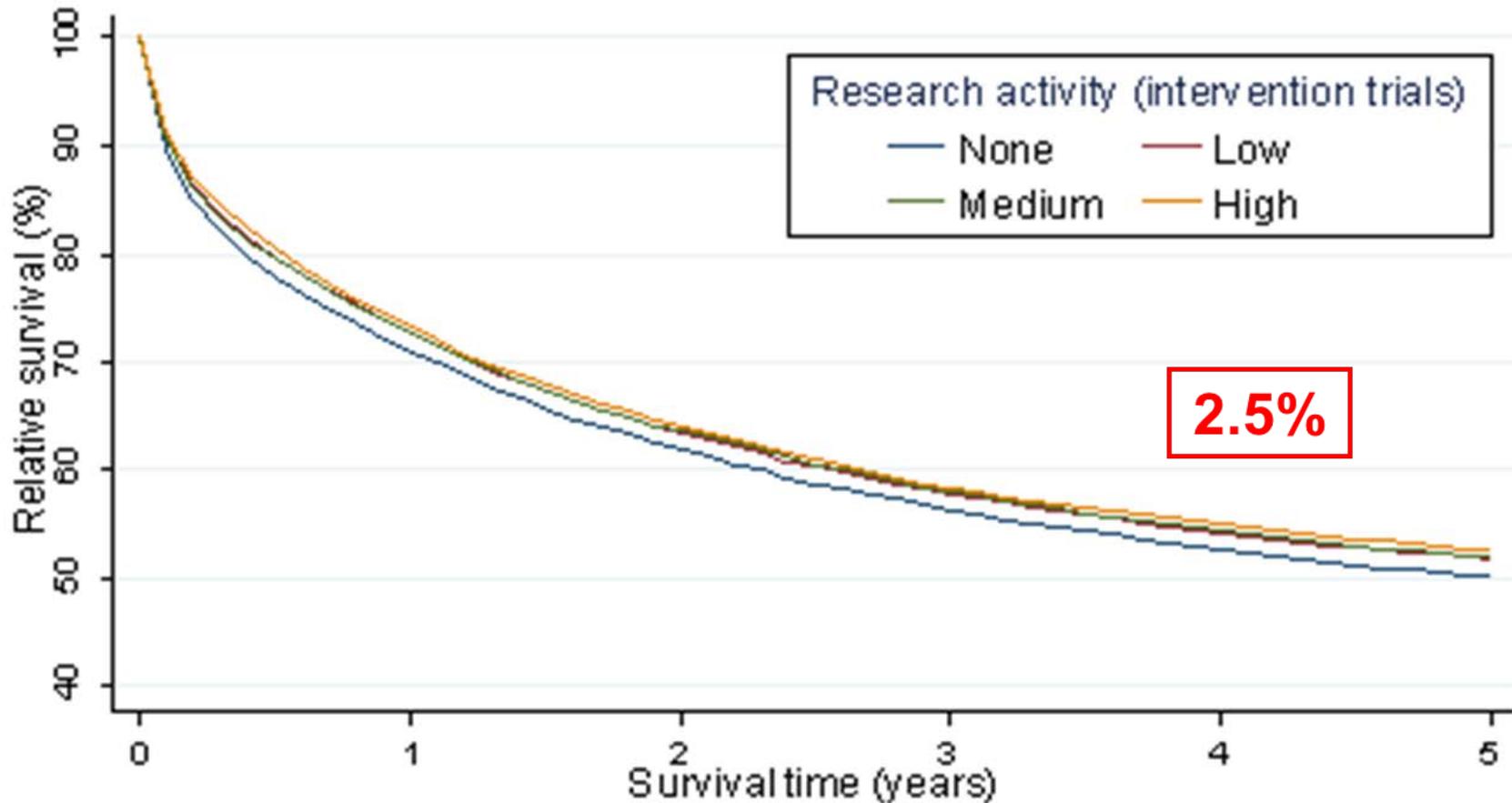
National Cancer Patient Experience Survey (NCPES)

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%
			

High hospital research participation and improved colorectal cancer survival outcomes: a population-based study

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



Dissemination(and Patient/Consumer Involvement)

- Our World
 - Online Communities and local groups
 - Charities; focus groups and newsletters
 - Patient Champions and their Stories

- NIHR Dissemination Centre
 - Advisory group; patient reps and patient co-chair
 - Lay readers for publications
 - Special editions for patients, nurses and other hcp groups

NCRI-JLA Priority Setting Partnership: Living With and Beyond Cancer

- 1500 patients and health care staff asked 3,000 questions; over half already had answers from research
- Remaining questions grouped into 54 researchable ones
- 3000 people voted online to identify 27 from 54 questions as priorities
- Final top ten chosen in all-day workshop (to be announced 6th Nov)
- NCRI will work with funders and researchers to implement the priorities
- Patient representatives have been 50% of steering group and final workshop and will support funders (lobby, persuade, kick, scream etc)

More information: www.ncri.org.uk/jla, www.ncri.org.uk/lwbc



Partners in cancer research



James
Lind
Alliance

Priority Setting Partnerships



NCRI Consumer Forum: Advocacy on Policy



Every (UK cancer) patient should be:

- aware of the importance of research - NIHR's Patient Research Ambassadors; "I Am Research" campaign;
- Informed of relevant research opportunities (*Action on Access*) AND that to participate or not is their choice and their decision
- aware of the importance of data sharing (individual opt-out available in UK, but cancer registration is exempt) and of donating tissue or other samples for bio-banking

"We aren't tipping the scales; we're removing some of the barriers."



NCRI Consumer Forums: Advocacy on Practice

- Patient Experience (2 out of 6 themes of Cancer Strategy)
 - living with cancer and its treatments - QoL, PROMs, follow-up
 - living beyond cancer and its treatments - “Survivorship”
 - NCRI JSL PSP (in set-up spring 2017)
- *AllTrials* campaign – trials registered, reported and results available
- *useMYdata* and *data saves lives* – broad & enduring consent (esp for trial data); mandatory registration (Caldicott review)
- Change practice faster – NICE early warnings and rapid review; case studies project with MRC CTU
- Eligibility – clinical criteria, not arbitrary age (except U16)

Yes, This Is All Good Stuff – So Get Involved!!



Research Involvement and Engagement

- World's first (and still the only) journal in this field
 - Founded 2015; now publishing 4-5 papers per month
 - BMC (publishers) reduce/waive fees for patient authors
 - Plain language summary required on submission
- Academic Research Journal
 - Online Open Access
 - Open Peer Review
 - Iterative review process (sometimes 3-way)
- Patient Co-Editor-In-Chief
 - Patient Representatives = 50% of Editorial Board
 - Every paper reviewed by patients
 - Patient reviews have equal weight



Dragons' Den (with very friendly Dragons)

**NCRI Conference, Glasgow
4-6 November 2018**



Your chance to meet consumers, try out your ideas, tell us your problems and let us help you put your world to rights.

Especially suitable for junior researchers, for Industry, and/or involvement at early stage of study design



NCRI Consumer Forum – Top Tips and Handy Hints That We Offer to The Research Community

Involve consumers (patients and carers) as early as possible

(formally on TMGs, TSCs, Committees etc., or informally, eg focus groups or coffee mornings, or public workshops)

- Will patients join this study (why)?
- Will they stay on the study (why)?
- Will they understand the patient information and consent form?
- Does the ethics committee need convincing? Or the funder?
- Could patient advocates help support participants, or help with recruitment, or dissemination of results, or link to charities and patient groups? Can consumers help your study change practice more quickly?

NB: Include in your funding bid realistic consumer support costs (including training, dissemination, event attendance)

Patients and carers and families and friends



consumers@ncri.org.uk