Clinical Trials and
The NCRI Consumer Forum

Nineteen Years of Patient and Carer Involvement

Richard Stephens
Chair, NCRI Consumer Forum

richard.stephens@ncri.org.uk
NCRI is...
A partnership of UK cancer research funders
The NCRI Consumer Forum – Who Are We?

😊 92 experienced and trained cancer research Consumers
  😊 56 patients,
  😊 22 carers
  😊 14 who are (or have been) both
  😊 all Volunteers

• 12 patients in active treatment
• 26 of the 36 carers have been bereaved
• 27 in full-time employment; 14 part-time; 6 self-employed
• 9 self-identified full-time patient advocates
• Ages 19-88; 60% aged 50+ (down from 70% in 2012)
• 8% representation of ethnic/cultural minorities (2% in 2012)
• 3 university students; 5 PhDs (4 in science)
• 14 have scientific degrees and/or research backgrounds
• 28 Consumers left school at 15/16
The NCRI Clinical Studies Groups – structure

18 NCRI CSGs

Primary Care
Psychosocial Oncology & Survivorship
Supportive & Palliative Care
Teenage, Young Adults & Testis

Bladder & Renal
Brain
Breast
Colorectal
Children's Cancer & Leukaemia
Gynaecological
Haematological Oncology

Head & Neck
Lung
Lymphoma
Prostate
Sarcoma
Skin
Upper Gastrointestinal

Imaging
Screening Prevention & Early Diagnosis (SPED)

2 Advisory Groups
The NCRI Clinical Studies Groups – structure

18 NCRI CSGs

- 15-20 scientific members
- 2 consumer members
- 2 trainees
- 1 funder representative

18 NCRI CSG Sub Groups
(35 with consumers to date)

65 NCRI CSG Sub Groups
- 10 core members
  - to include 1 consumer over time
NCRI’s Other Clinical Research Groups And Themes

- CTRad – Radiotherapy
- CM-Path – Cellular & Molecular Pathology
- Consumer Involvement Initiatives & Projects
- Surgery
- Living With and Beyond Cancer PSP
The NCRI Consumer Forum – Who Are We?

😊 92 experienced and trained cancer research Consumers

- 16 have international links/experience beyond UK
- 24 have been published, 1 is an academic journal editor
- 9 sit at Trustee/Board level on research-funding Charities
- 4 NHS/NIHR Managers, 1 CCG NED, 1 research unit manager
- 27 NIHR CRN Patient Research Ambassadors
- 17 on Trial Management Groups
- 21 on Trial Steering Committees
- 8 on ECMC groups (Experimental Cancer Medicine Centres)
- 9 on Cancer CTU groups (Clinical Trials Units)
- 5 hold contracts with industry
The NCRI Consumer Forum – Group and Individuals

Support for/endorsement of programmes/campaigns –

- Concord 2 (mortality and survival across 56 countries);
- NIHR Cancer & Nutrition Infrastructure Collaboration;
- Public Health England Prevention and Screening;
- Early Diagnosis initiative;
- Tissue Banking and patient-to-patient consenting;
- 100,000 Genomes Project;
- NHS England Genomic Medicine Centres
- National Cancer Strategy (creation and review)
- NICE Guidelines (and fast-track for practice-changing studies)
- Research Ethics Committees training (and research)
- NHS England Cancer Patient Experience Advisory Group
- NHS England National Cancer Advisory Group
- Thank-you letters and newsletters for participants
- And the NCRI work for which we are recruited originally
Patients As Research Partners – Dissemination

STAMPEDE Trial  
NCT00268476

Results define new standard-of-care for prostate cancer

Video for patients and public
https://vimeo.com/149626704

+ 8 regional roadshows from
National Cancer Patient Experience Survey (NCPES)
Questions and Responses on Research

😊 330k patients responded 2012-16; consistently 60k+ annually

😊 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

Taking part in research associates with better experience of care;

😊 88% of all cancer patients are satisfied/v satisfied with care;
  86% for those who do not participate, 93% for those who do

😊 7 posters produced by NCRI Consumer Forum 2013-17 on these results; shown at NCRI and NCRAS Conferences; available at [http://www.ncri.org.uk/resources/ncri-consumer-forum/](http://www.ncri.org.uk/resources/ncri-consumer-forum/)
High hospital research participation and improved colorectal cancer survival outcomes: a population-based study
http://gut.bmj.com/content/66/1/89

Approx 40,000 colorectal cancer patients in UK in 2016. 2.5% = 1,000 people.
Most viewed poster, NCRI Conference, November 2017

1st Prize at PHE-NCRAS Cancer Outcomes Conference, June 2017
AZ-Forum Projects 2014-16

- Phase I-II Ovarian Cancer Trial
- Co-production of an app for real-time patient reported experiences (*)
- PRO tool (Phase IV; lung cancer)
- Immuno-Oncology Informed Consent Forms
- Joint presentations – eyeforpharma, ISMPP, early phase conference
- Hackathon – “My Clinical Trial” app (with The Christie Hospital)

For patients, a model of face-to-face working can be labour-intensive and often cannot meet industry timetables; however face-to-face is excellent for wider discussions and a range of views and experiences

(*) PROACT, published in Trials, June 2016