



The Patient Involvement Christmas Stocking – Some Presents Unwrapped

Richard Stephens

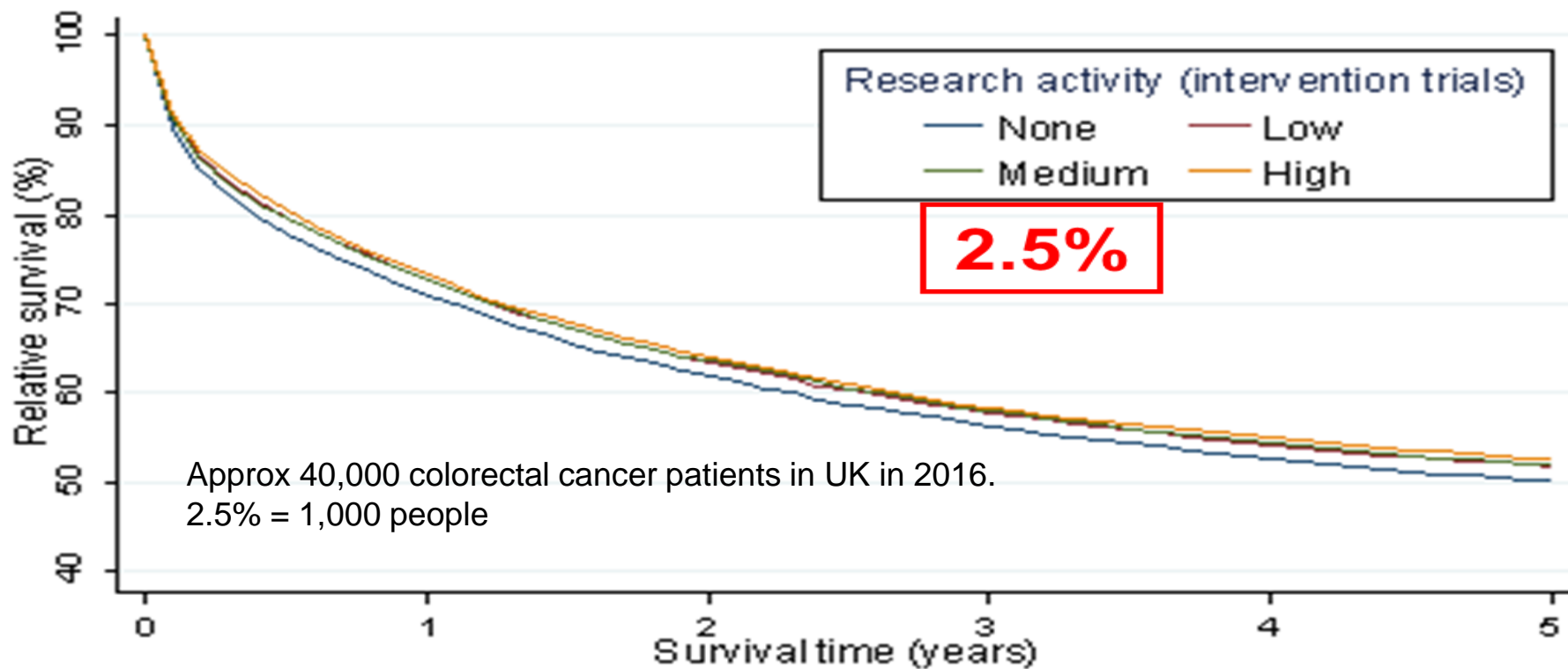


WHY IS RESEARCH IMPORTANT FOR PATIENTS?

- ✓ It designs new pathways, techniques, treatments and devices
 - ✓ It tests new pathways, techniques, treatments and devices
 - ✓ It investigates the impact of all the above on patients and on health care services and systems
- 😊 It adds skills to the workforce, which produces added benefits for patients

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




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



Cancer Patient Experience Survey (CPES)

Research Participation = Better Patient Experience

Did you have a discussion about participating in research?

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%
			

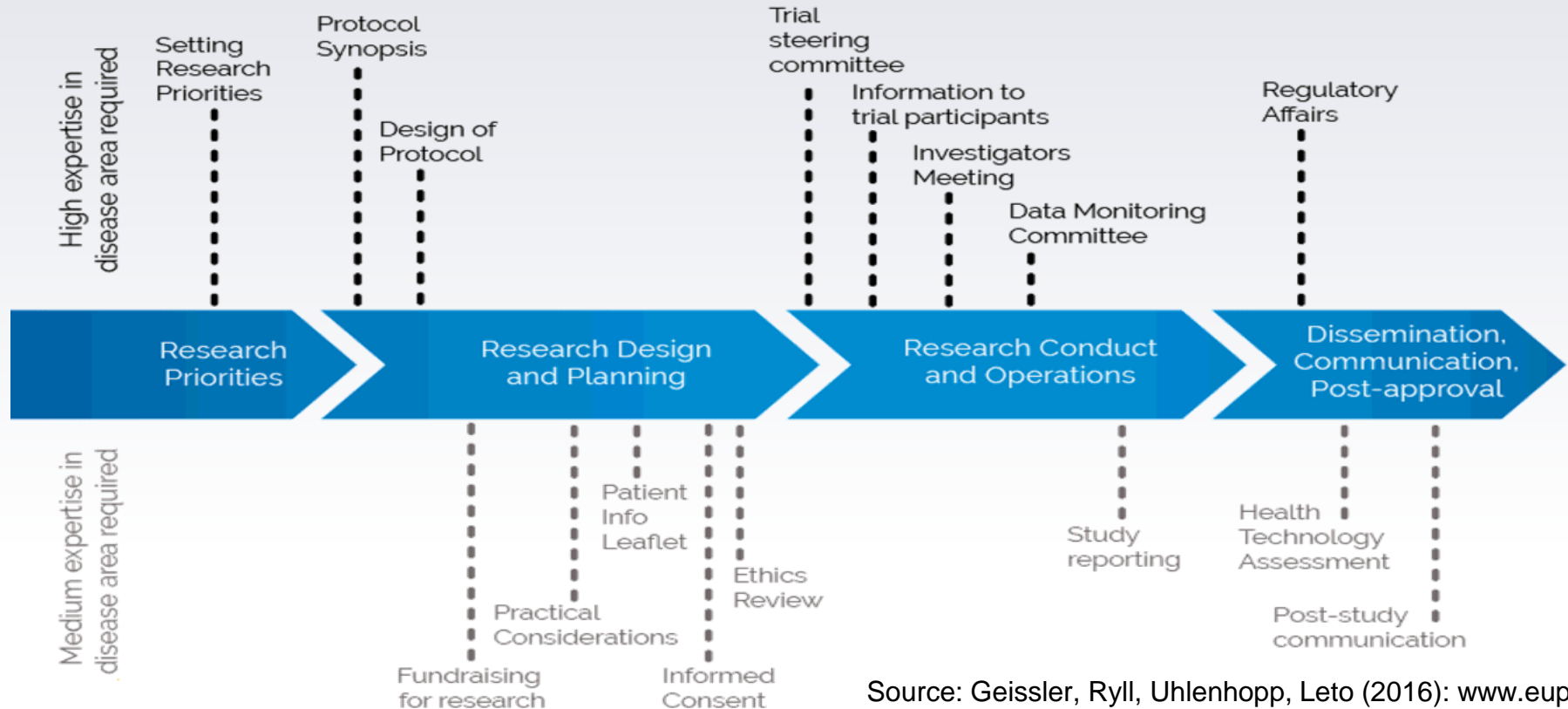
WHY IS PUBLICATION IMPORTANT FOR PATIENTS?

- ★ So our doctors make decisions based on evidence
- ★ So WE make decisions based on evidence
- ★ So that ALL the evidence is available to EVERYONE

AND

- ★ IT'S OUR HEALTH
- ★ It's our evidence
- ★ It's our money too - who funds research anyway?

Patient involvement within the R&D life cycle



Source: Geissler, Ryll, Uhlenhopp, Leto (2016): www.eupati.eu

Do patients want to be involved
in academic publications?

Do patients want to read
academic journals?

Do most patients even
know or care about
academic publishing?



NO NO NO





YES!!!

But what about
patient groups and
patient advocates?



HO HO HO

WHY DO PATIENTS PARTICIPATE IN RESEARCH? WHY DO PATIENTS GET INVOLVED IN RESEARCH? WHERE/HOW ARE PATIENTS INVOLVED IN RESEARCH?

Participation:

- 😊 Self-help:
 - Better care
 - Novel treatments
- 😊 Help Others
 - Fellow patients
 - Our family
- 😊 Doctors offer the opportunity
 - Trial as treatment
 - Culture of research

Involvement:

- 😊 Self-help
 - Give something back
 - Skills/experience
- 😊 Help others
 - Patients, family
 - Researchers, doctors
- 😊 Researchers offer the opportunity
 - Involvement adds value
 - Funders or regulators require it

Where/How?

- 😊 Design
 - Acceptability
 - Patient info
- 😊 Delivery
 - Recruitment, retention
 - TMG/TSG et al
- 😊 Dissemination
 - Social media
 - Patient groups



Patient Involvement in Publication
is still not a significant role for us,
but clearly it should be!



PATIENT INVOLVEMENT

THE GIFT...

...THAT KEEPS ON GIVING

EXCITING THINGS IN MEDICAL RESEARCH

Artificial Intelligence

Prevention & screening
Diagnostics & imaging
Prognostic & treatments
Palliative & terminal care

Genetics

Stratified medicine
Gene editing
Tissue banking
Bio resources

Robotics & Hardware

Surgery
Radiotherapy
Testing
Home hospitals

Nanotechnology

Car-T Cells
Immunotherapy
Targeted Therapies
Dose control

Real World Evidence

Digital technology
Mass data sets
Standardisation of collection
Blockchain, cloud etc

Publication

Open Access
Lay Summaries
Patient Reviewers
Patient Authors

EXCITING THINGS IN PATIENT INVOLVEMENT

Robotics & Technology

PBT: lobbying for protected time for research

Lone dialysis research: led by patients

Data Embassies: allow access in, not send data out

Publications

Open Access: not just to the papers but to the reviews

Lay Summaries: MRC CTU joint patient-researcher Plain English training

Patient Reviewers: asking for training; ready supply of volunteers

Patient Authors: more co-authors, rare but increasing as lead or even sole authors

AI & Real World Evidence

Digital technology: smart phones; PROMs & clinical alerts

useMYdata – patient-led group

PROMs: V.A.L.U.E. *Variation to (my) Actual Life and Usual Experience*

Genetics

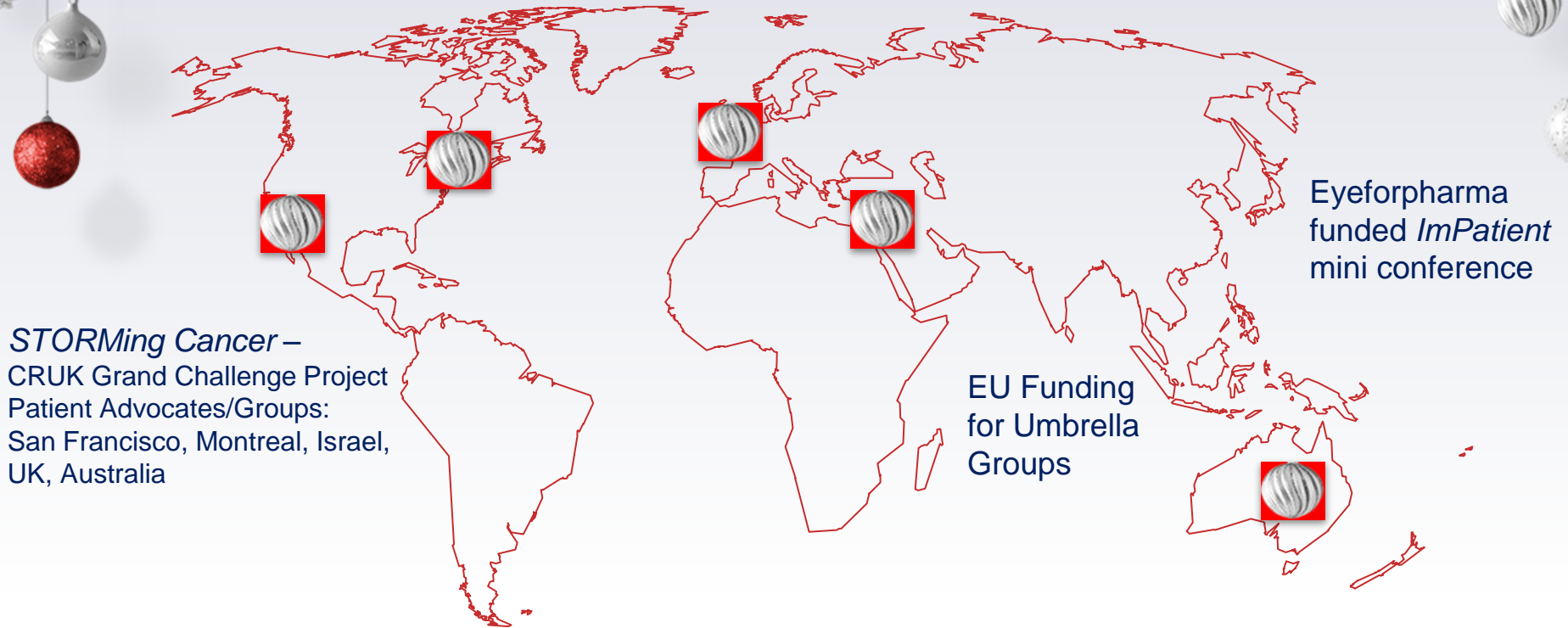
Gene editing – participants in 100,000 Genome project starting the discussion

Tissue banking/bioresources – patient-to-patient consenting

Should consent become instruction?

AND the NIHR Dissemination Centre: www.dc.nihr.ac.uk

PATIENT ADVOCATES AND GROUPS GOING GLOBAL



Cochrane et al interested in supporting global linking of
researchers including patient researchers

EXCITING THINGS IN PATIENT PUBLICATIONS: THE JOURNAL OF RESEARCH INVOLVEMENT AND ENGAGEMENT



- 😊 Online open-access
- 😊 Two Co-Editors-in-Chief; one academic, one patient
- 😊 Patient involvement in co-production; as peer reviewers and on editorial board
- 😊 2018's most cited paper was patient authored; Roger Wilson's *Patient led PROMs must take centre stage in cancer research*

<https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0092-4>

**MERRY CHRISTMAS
A HAPPY AND HEALTHY NEW YEAR**



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