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

Approx 40,000 colorectal cancer patients in UK in 2016.
2.5% = 1,000 people
Cancer Patient Experience Survey (CPES)
Research Participation = Better Patient Experience

Did you have a discussion about participating in research?

<table>
<thead>
<tr>
<th></th>
<th>2013 Did not have a discussion</th>
<th>2013 Had discussion but did not go on to participate</th>
<th>2013 Had discussion and did go on to participate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rating of care as excellent or very good</td>
<td>87.2%</td>
<td>90.2%</td>
<td>91.9%</td>
</tr>
<tr>
<td>Rating of care as less than excellent or very good</td>
<td>12.8%</td>
<td>9.8%</td>
<td>8.1%</td>
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</tbody>
</table>

©www.ncri.org.uk/resources/ncri-consumer-forum/
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

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 NO
YES!!!

But what about patient groups and patient advocates?
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
Acceptibility
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

<table>
<thead>
<tr>
<th>Artificial Intelligence</th>
<th>Robotics &amp; Hardware</th>
<th>Real World Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention &amp; screening</td>
<td>Surgery</td>
<td>Digital technology</td>
</tr>
<tr>
<td>Diagnostics &amp; imaging</td>
<td>Radiotherapy</td>
<td>Mass data sets</td>
</tr>
<tr>
<td>Prognostic &amp; treatments</td>
<td>Testing</td>
<td>Standardisation of collection</td>
</tr>
<tr>
<td>Palliative &amp; terminal care</td>
<td>Home hospitals</td>
<td>Blockchain, cloud etc</td>
</tr>
</tbody>
</table>

### Genetics
- Stratified medicine
- Gene editing
- Tissue banking
- Bio resources

### Nanotechnology
- Car-T Cells
- Immunotherapy
- Targeted Therapies
- Dose control

### 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

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?

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

AND the NIHR Dissemination Centre: www.dc.nihr.ac.uk
PATIENT ADVOCATES AND GROUPS GOING GLOBAL

STORMing Cancer – CRUK Grand Challenge Project
Patient Advocates/Groups:
San Francisco, Montreal, Israel, UK, Australia

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

EU Funding for Umbrella Groups

Eyeforpharma funded ImPatient mini conference
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*

MERRY CHRISTMAS
A HAPPY AND HEALTHY NEW YEAR

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