Innovating in development - together

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Patient Summit, Eye-for-Pharma
Content

Clinical Development

Innovation

Potential Benefits

Patient Empowerment in Clinical Research in the UK
Clinical Development: What’s the Point?
What’s normal?

Before Humans  | Phase I  | Phase II  | Phase III  | On Market
---|---|---|---|---
Going into humans  | Dosing decision  | Benefit-risk balance signals  | Working for broader access  | Phase IV
What’s normal?

Before Humans → Phase I → Phase II → Phase III → On Market

- Going into humans
- Dosing decision
- Benefit-risk balance signals
- Working for broader access

Phase IV
What’s normal?

Before Humans  Phase I  Phase II  Phase III  On Market

- Going into humans
- Dosing decision
- Benefit-risk balance signals
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Phase IV
What’s normal?

Before Humans
- Going into humans

Phase I
- Dosing decision

Phase II
- Benefit-risk balance signals

Phase III
- Working for broader access

Phase IV
- On Market
What’s normal?

- **Before Humans**
  - Going into humans
- **Phase I**
  - Dosing decision
- **Phase II**
  - Benefit-risk balance signals
- **Phase III**
  - Working for broader access
- **On Market**
  - Phase IV
Participants

Medical team
*Clinical trial site*

Sponsor
Participants

Medical team
Clinical trial site

Sponsor
Participants

Medical team

Clinical trial site

Sponsor
Participants

Medical team

Clinical trial site

Sponsor
Potential Benefits

Participants:

- Easy-to-use way of linking to your key ‘anchor’ person at site
- Future patients likely to have more information:
  - Greater understanding about what to expect
  - Better management of side effects, which include practical tips from previous patients.
Potential Benefits

Medical team:

• See their patients quickly and easily between visits
  – Timely, but also fits with their daily routine.
• Understanding of experiences from patients across the whole study
  – Use this knowledge in patient care
Potential Benefits

Sponsor:

• Choose the recommended dose based on both clinical and patient data:
  – What the drug does and what it’s like to take it

• Chance to improve patient experience:
  – management of side effects
  – More information for most impactful events
Patient Empowerment in Cancer Research in the UK

Examples of Innovation and Influence

Richard Stephens
NCRI Consumer Lead; Chair NCRI Consumer Forum
The NCRI Consumer Forum

71 experienced cancer research Consumers on national committees, CSGs, funding, TMGs, TSCs, ethics, CCGs etc, working to help:

✓ Prioritise research for patient benefit

✓ Improve the quality of the research and enhance its impact

✓ Improve public awareness of (and support for) research

✓ Improve access to opportunities for patients to take part in research

✓ Ensure patients have conversations about taking part in research as a routine part of treatment choices ("Action On Access")
Innovations and Influence:

- Dragon’s Den – researchers bring ideas to groups of patients

- Working with pharmaceutical industry, AstraZeneca - Independent Patient Panel

- NCPES – using patient experience to drive service improvement

- “OK To Ask” – national campaign supporting better access to research

- Consumer Toolkit - supporting patient impact in research groups

- “Action On Access” – patient voice influencing policy makers on public access to research
Dragons’ Den
AZ-CLG Patient Panel
Projects 2015

Panel originally set up with support from CRN: Cancer PPI team

Projects:

• Patient Reported Outcomes Tool for 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
• Patient/Participant Charter
National Cancer Patient Experience Survey (NCPES) - Responses Show: It’s OK To Ask!

😊 1/3 of cancer patients are having discussions about research
😊 2/3 of those asked go on to take part in research
😊 95% of those asked are glad to be asked
😊 53% of those not asked would be glad to be asked
😊 Taking part in research is associated with better experience of care
😊 Significant and persistent variations:- by cancer, by age, by network and by Trust
### NCPES Findings:
**Involvement in Research = Better Patient Experience**

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

The NCRI Consumer Forum

Innovations and Influence: Useful Links

- **Dragon's Den** - researchers bring ideas to groups of patients
- **Working with pharmaceutical industry**, AstraZeneca - Independent Patient Panel
- **NCPES-Consumer Toolkit** - using patient experience to drive service improvement
- **“OK To Ask”** - national campaign supporting better access to research
- **Consumer Toolkit** - supporting patient impact in research groups
- **“Action on Access”** - patient voice influencing policy makers on public access to research
Patient and public involvement: Finding out more

NIHR Clinical Research Network:  
www.crn.nihr.ac.uk/can-help/patients-carers-public  
Email: patient.crncancer@nihr.ac.uk

NCRI:  
www.ncri.org.uk/about-us/patient-involvement  
Email: Gizem.koksal@ncri.org.uk
It can be done
It can be done

It needs to be done
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