Clinical trials: the patient perspective and importance to healthcare communications

Just 3 thoughts

NetworkPharma: Presentation, Dr Alex Wyke, PatientView
June 19th 2014
Thought

Patients need to be persuaded of the **value** of the clinical trial process

... through **inclusion** in that process — from beginning to end
In 2011, PatientView asked patient groups to specify where they thought future NHS budget should be spent — the answer was **not on technology**

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invest more in preventive medicine, and less on treating illnesses</td>
<td>31%</td>
</tr>
<tr>
<td>Focus more on the healthcare needs of the most-vulnerable members of society—even if other people might experience a more poorly-funded healthcare service as a result</td>
<td>28%</td>
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<tr>
<td>Link the healthcare systems of neighbouring countries, so that these healthcare systems can all work more closely together—with the aim of cutting overheads, while improving standards across the board</td>
<td>23%</td>
</tr>
<tr>
<td>Invest more in healthcare technology (particularly drugs, medical devices, and e-technologies)—even if other parts of the healthcare system might be deprived of funds as a result</td>
<td>18%</td>
</tr>
</tbody>
</table>

Respondents doubt the promise of healthcare technology

Source: 2011 PatientView study of 400 UK patient groups, *Value in Healthcare* (conducted for Hill & Knowlton Strategies)
Patients are not always persuaded by the evidence that is provided on the efficacy and safety of drugs

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients need more information on the risks and benefits of treatment</td>
<td>Clinical outcomes are NOT always the best measure of a valuable treatment</td>
</tr>
<tr>
<td>Patients and public have a role to play in medical research</td>
<td>Patients need to know if they demand certain medicines other patients may suffer</td>
</tr>
<tr>
<td>Patients need the best treatment or care even if other patients suffer</td>
<td>Drug regulators place too heavy an emphasis on safety denying patients valuable treatments</td>
</tr>
</tbody>
</table>

- **Less than 50%** of UK patient groups agreed with the statement ...
  “Only medicines subject to proper clinical testing can be judged on value”

- **Just over 80%** of UK patient groups agreed that ...
  “clinical outcomes are NOT always the best measure of a valuable treatment”

Source: 2011 PatientView study of 400 UK patient groups, Value in Healthcare (conducted for Hill & Knowlton Strategies)
Patients want a say in health technology assessment— to make outcomes relevant to patients

Percentage of patients who want to have a say in HTA to make outcomes relevant to patients

- Yes: 52%
- Sometimes: 30%
- No, this activity should be left to doctors: 11%
- I do not know: 7%

Source: 2011 PatientView study of 400 UK patient groups, *Value in Healthcare* (conducted for Hill & Knowlton Strategies)
So, what do patients want from their treatments?

Source: 2011 PatientView study of 400 UK patient groups, *Value in Healthcare* (conducted for Hill & Knowlton Strategies)

“Each person is different. People need education and help to study their health disability, so that they can manage it better. The ‘one size fits all’ is destructive for people with long-term health disabilities”

–UK mental health group

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Thought 2

As active participants in the clinical-trial process, patients believe it their right to **access all** clinical-trial information ...

... in other words, they want **complete transparency**
Potent advocacy on the subject

AllTrials.net calls for the publication of clinical study reports from all clinical trials since the 1990s (both positive and negative)

- Signed by 476 organisations, including GSK
- 78,689 signatures
Potent advocacy on the subject

BMJ

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NEWS

Transparency campaigners welcome new rules for clinical trials in Europe

BMJ 2014; 348 doi: http://dx.doi.org/10.1136/bmj.g2579 (Published 3 April 2014)

cite this as: BMJ 2014;348:g2579

• A step in the right direction, say campaigners
• But ... more needs to be done
Thought

→ The sharing of healthcare data, and
→ patient involvement in clinical trials (not just as subjects)
will both become vital

... for big data to become viable, and to fuel further research
People want their data to remain private … unless they see the benefits of shared data

In the UK, a 2010 nationwide survey of 6,000 people by the New Economics Foundation (on behalf of the Wellcome Trust) found a majority belief that patients should be able to choose whether they are included in any digital database containing personal health data:

• 80% of adults wanted some form of consent mechanism
• 86% of young people wanted some form of consent mechanism
A growing global consumer movement dedicated to protecting individual digital privacy is now reacting to new e-technologies.
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So, a lot has to be done ...
**Initiatives supporting patient involvement in the clinical trials process**

*Funded by IMI, the European Commission, the NHS*

*Spearheaded by academics*

*Informational health apps*

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Industry initiatives which can be used by patients

*Involving industry ... but, thus far, only available to researchers*

Bayer, Boehringer Ingelheim, GSK, Lilly, Novartis, Roche, Sanofi and ViiV Healthcare ...

Yale University School of Medicine

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For more information ...

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