How can pharmaceutical companies work with patients for patients?

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Disclosures

Simon Page is an employee of Ipsen

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Working with patients, for patients

1. Open access to publications
2. Acknowledgement of patients’ contributions
3. Plain language summaries for publications
4. Involvement of patients in publications
Open access to publications
What is “open access”?  

What is “open access”? 

More groups are committing to open access

References:
3. [https://openpharma.blog/position-statement-on-open-access/](https://openpharma.blog/position-statement-on-open-access/) [accessed: 9 December 2019]
More groups are committing to open access

References:

Position statement on open access

Pharmaceutical companies, which fund approximately half of all biomedical research, are now leaders in the publication and disclosure of research. However, access to much company-funded research is restricted by journal paywalls. We, as Open Pharma, a group of pharmaceutical companies and other research funders, alongside healthcare professionals, regulators, patients, publishers and other stakeholders in healthcare, recognize the importance of publishing research with open access, where papers can be read without payment of a one-off access charge or subscription. Open access ensures that the highest quality, peer-reviewed evidence is available to anyone who needs it, anywhere in the world. Publishing with open access improves transparency, advances medical science and, we believe, ultimately improves patient care.

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100% of Ipsen-affiliated research has been published open access during the first half of 2019

“Patients cannot wait.”
David Meek
CEO, Ipsen
Acknowledgement of patients’ contributions
Acknowledging patients in publications:

We encourage authors to fully acknowledge the contribution of patients and the public to their research where appropriate.

Saying thank you

Acknowledging patients in publications:

- Thank you letters to patients/families coinciding with patient’s last study visit
- Follow-up letter at study end, letting them know that the study is complete & the next development stage planned

1. BMJ website: [https://www.bmj.com/about-bmj/resources-authors/article-submission/authorship-contributorship](https://www.bmj.com/about-bmj/resources-authors/article-submission/authorship-contributorship) [accessed: 9 December 2019]
Plain language summaries
for publications
Plain language summaries for publications – why?

- Beneficial for understanding – for everyone!
- Supports discussions between HCPs and patients
- Quicker to read than full manuscript
- Overcome knowledge or language barriers
- Democratises information

Language in plain language summaries is important. Words have different meanings in different contexts...

<table>
<thead>
<tr>
<th>Word</th>
<th>Everyday interpretation</th>
<th>Scientific interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Error/uncertainty</td>
<td>Mistake/lack of certainty</td>
<td>Deviation from true value</td>
</tr>
<tr>
<td>Significant</td>
<td>Important</td>
<td>Unlikely to occur by chance</td>
</tr>
<tr>
<td>Positive</td>
<td>Good</td>
<td>Greater than 0/Confirmatory</td>
</tr>
<tr>
<td>Theory</td>
<td>Hunch/speculation</td>
<td>Scientific understanding</td>
</tr>
<tr>
<td>Trial</td>
<td>Test/examination by judge</td>
<td>Medical study</td>
</tr>
<tr>
<td>Bias</td>
<td>Unfair prejudice</td>
<td>Systematic offset</td>
</tr>
<tr>
<td>Scheme</td>
<td>Unethical plot</td>
<td>Plan of action</td>
</tr>
<tr>
<td>Failure</td>
<td>0/10</td>
<td>Was not successful</td>
</tr>
</tbody>
</table>

Enlist the help of 9-year-olds...

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Enlist the help of 9-year-olds...

**Total hip arthroplasty**

**Indications for the surgery**

Mohammed: Because your hips are old and rotten. When you played football, it was weak and it broke. You told me you cannot walk. That is because it is old and you need to have hip surgery.

Jaime: Because yours is rotten. Because it's painful. Because you can't run and you want to be a sprinter. Because yours is wasting away like an old pair. It's past its sell by date.

**Complications and risks**

Mohammed: You can die!!!!!!

Emily: The bone could be put in badly. The replacement bone could be dirty, and you could get blood poisoning.

Amber: Cut open the leg chop off bone, put metal in the bone, put cement in the leg, so the metal doesn’t move.

Plain language summaries – a novel approach...

- Enlist the help of 9-year-olds...

Involvement of patients in publications
Where could we include patients in the process?

Planning
- Participate as authors
- Review the manuscript in development

Writing
- Participate in advisory boards
- Guest member of publication steering committee

Publishing
- Act as a peer reviewer on the manuscript
- Help to develop lay summary

Post-publication
- Assess the value and usefulness of publications
- Help design future studies
- Advise how to communicate publication (Social Media, press releases, etc.)
- Assist with enhancements for the publication
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Thank you
Questions?