Innovations in medical publishing
Why do we need research transparency?

Around **59%** of the public trust research by university scientists ‘**completely**’ or ‘**a great deal**’…

…**but only 32%** of the public trust research carried out by the pharmaceutical industry ‘**completely**’ or ‘**a great deal**’…

Pharma now disclose the results of nearly all their clinical trials

Baronikova S et al. Commitments by the biopharmaceutical industry to clinical trials transparency: the evolving environment. *bioRxiv* 2018;349902 doi 10.1101/349902
Is data transparency alone enough?

All stakeholders want **transparent** science

We need to be able to **access** clinical research

In a **timely** manner
What is open access?

‘Open access’ refers to peer-reviewed, full-text research articles that have been accepted for publication and are available:

- **on demand** online
- to read **without charge** to end users
What are the benefits of open access for pharma-sponsored research?

- Fast speed of dissemination
- Global communication
- Ease of reuse
- Speed of progress
- Transparency
- Trust
- Patient wellbeing
A paywall may restrict the number of readers and this might NOT help the reputation of the pharmaceutical industry (the mindset of it being a bit secretive).

Alan Thomas, patient advocate and founder of Ataxia and Me
Some publishers prevent companies from publishing unrestricted open access

- In a study of 35 medical journals with a high impact factor, 21 (60%) offered an immediate open access option with a Creative Commons licence

- Of these 21 journals:
  - CC BY was offered by 100% (21/21)
  - CC BY-NC was offered by 19% (4/21)
  - CC BY-NC-ND was offered by 86% (18/21)

- Only one of these 21 journals potentially offered immediate open access under a CC BY licence to authors irrespective of their funding source

BY, attribution; CC, Creative Commons; NC, non-commercial; ND, no derivatives
Our purpose

Open Pharma aims to connect pharma with innovations in publishing to achieve …

- a **transparent** publishing process …
- with **accessible** outputs …
- that are available **quickly** …
- using an **efficient, sustainable** process
The story so far …

- Workstream and roundtable meetings
- Industry and public engagement
- Original research
- Workshops for clients
- Educational materials
- Blog posts

In driving change in medical publishing, pharmaceutical companies are conspicuous by their absence, in spite of funding probably over half of all medical research

– Richard Smith, Chair of Open Pharma, ISMPP EU 2018
Open access research and educational material

Research

Open access policies of leading medical journals: a cross-sectional study

BMJ Open

Research

Open access guidance for pharma

Educational material and events

Why open access?

- To make all scientific research content available for anyone, anywhere in the world, to read, share, reuse and build upon

Open access guidance for pharma

Develop a company open access policy

Benefits of open access

- Increase visibility and impact
- Reach new audiences
- Support collaboration
- Foster innovation
openpharma.blog and @OpenPharma

- 518 followers on Twitter
- 422 downloads on figshare
- 278 subscribers to the blog
- 128 weekly digests
- 42 guest articles
- 2 significant new contacts directly through the blog
Open access: Shire case study


“Shire plc…has implemented a new publication policy requiring the submission of all Shire-supported research manuscripts to journals that offer public availability via open access, allowing the public to obtain free, unrestricted online access to Shire’s research promptly following publication”

ASCO case study

David Sampson, Vice President at ASCO, discovers Open Pharma via the blog website

Open access panel member at ISMPP Annual Meeting 2018

ASCO policy change to permit open access CC BY-NC-ND for commercial research
International Open Access Week, 2019

Open for Whom?
Equity in Open Knowledge

OCTOBER 21-27 #OAWeek19

The launch of the Open Pharma position statement on open access

Open access ensures that the highest quality peer-reviewed evidence is available to anyone who needs it anywhere in the world.

- Advance medical science
- Increase transparency
- Accelerate dissemination
- Globalize communication
- Improve patient care
Open Pharma position statement on open access

Open access ensures that the highest quality peer-reviewed evidence is available to anyone who needs it, anywhere in the world.

- Increase transparency
- Advance medical science
- Improve patient care
- Speed up dissemination
- Globalize communication of research

Open Pharma is a group of pharma companies, healthcare professionals, patients, and other people interested in healthcare.

**Who we are**

We work together to make pharma-funded healthcare research open and easy to access.

**What we do**

We publish our research findings online as soon as they are available.

**Patients in mind**

59% of adults (17/3/14) in the USA believe online access to medical information is important to them.

**What we believe**

Open Pharma is committed to making pharma-funded healthcare research open and easy to access.

**Contact us**

To find out more, contact us at info@opennpharma.org or visit our blog.
Our objectives

Our immediate priority

Secure authors publishing company-funded research the same right to publish open access as authors publishing research funded by other sources

All research to be made free to read from the date of publication

Any variant of Creative Commons or equivalent licence
Our objectives

**Our immediate priority**
- Secure authors publishing company-funded research the **same right to publish open access** as authors publishing research funded by other sources
- All research to be made **free to read from the date of publication**
- Any variant of Creative Commons or equivalent licence

**Our long-term goal**
- Secure authors publishing company-funded research the **same terms** as authors publishing research funded by other sources
- Free to read – **and reuse** – from the date of publication
- Sustainable use of **CC BY**
We thank all supporters and followers of Open Pharma for their valuable input.
## Endorsed by academics, patients and communicators

**Correct as of 5 November 2019**

### Individuals

| Alan Thomas, Ataxia & Me | Danielle Grover, patient advocate |
| Scott Armit, Ataxia & Me | Elizabeth Kinder, patient advocate |
| E. Andrew Balas, Biomedical Research Innovation Laboratory, Augusta University | Richard Stephens, patient advocate |
| John Wallace, Autoinflammatory UK | Tracy Zervakis, patient advocate |
| Gavin Giovannoni, Barts and the London School of Medicine and Dentistry | Trishna Bharadia, patient advocate |
| Val Tate, communications consultant | Rosario Strano, Pedalling4Cure |
| Katie Foxall, ecancer | Angela Sykes, Pfizer |
| Martin Delahunty, Inspiring STEM | Courtney Leo, Pfizer |
| Alben Sigamani, Narayana Health | J.R. Meloro, Pfizer |
| Michael De Rosa, National Ataxia Foundation | Ellie Challis, PTEN UK & Ireland |
| Peter Llewellyn, NetworkPharma Ltd. | Dermot Ryan, Respiratory Effectiveness Group |
| Pali Hungin, Newcastle University | Victoria Woods, Patient and Public Engagement, Thames Valley Cancer Alliance at NHS England |
| Kajsa Wilhelmsson, Oxford Health System Reform Group | Sophie Berry, Smith & Nephew |
| Adele Buss, Oxford PharmaGenesis | John Gonzalez, Solanum Medical Communications Ltd. |
| Cassy Fiford, Oxford PharmaGenesis | Zbys Fedorowicz, The Care Combine and North West Anglia NHS Foundation Trust |
| Emma Bolton, Oxford PharmaGenesis | Stuart Taylor, The Royal Society |
| Francesca Ounsworth, Oxford PharmaGenesis | Erik Michels, UCB |
| Jessica Hardy, Oxford PharmaGenesis | Rachel Giles, Regenerative Medicine Center, UMC Utrecht |
| Mark Rolfe, Oxford PharmaGenesis | Meredith Hays, Department of Medicine, Uniformed Services University |
| Nicolas Bertheleme, Oxford PharmaGenesis | Martin Rosser, University College London |
| Paul Farrow, Oxford PharmaGenesis | Stephen Bradley, University of Leeds |
| Richard White, Oxford PharmaGenesis | Robert Sim, Department of Respiratory Science, University of Leicester |
| Sally Bardell, Oxford PharmaGenesis | Iain Chalmers, Centre for Evidence-Based Medicine, University of Oxford |
| Tim Ellison, Oxford PharmaGenesis | Edith Sim, Department of Pharmacology, University of Oxford |
| Tim Koder, Oxford PharmaGenesis | Chas Bountra, Nuffield Department of Clinical Medicine, University of Oxford |
| Zoe Watts, Oxford PharmaGenesis | Stevan Harnad, University of Southampton |
| Charles Boyce, patient | Álvaro Díaz, Departamento de Biodciencias, Universidad de la República, Uruguay |
| Emily Medina, patient | Ronald Munatsi, Zimbabwe Evidence Informed Policy Network |
| Jeannie Smithball, patient | |

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## Endorsed by patient groups, charities, pharmaceutical companies and publishers

Correct as of 5 November 2019

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<th>Organizations</th>
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<td>Zimbabwe Evidence Informed Policy Network</td>
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I recently met a physician from Southern Africa engaged in perinatal HIV prevention, whose primary access to information was abstracts posted on the Internet. Based on a single abstract, they had altered their perinatal HIV prevention programme from an effective therapy to one with lesser efficacy.

Had they read the full-text article they would have undoubtedly realized that the study results were based on short-term follow-up, a small pivotal group [and] incomplete data, and [were] unlikely to be applicable to their country's situation. Their decision to alter treatment based solely on the abstract’s conclusions may have resulted in increased perinatal HIV transmission.

Professor Arthur Ammann
Co-founder of Global Strategies for HIV Prevention
Who’s behind this?

**Open Pharma is**... a collaborative, multi-sponsor, non-profit project at Oxford PharmaGenesis

**Oxford PharmaGenesis is**... an award-winning HealthScience communications consultancy providing services to the healthcare industry, professional societies and patient groups

**Supporters:**
- AstraZeneca
- Roche
- Pfizer
- UCB
- Wiley

**Members:**
- Takeda
- Novo Nordisk
- GSK
- Gilead Sciences
- Galápagos

**Financial contributors and previous hosts**
- Wellcome
- The BMJ

**Our specialties**
- Medical affairs
- Commercial and marketing
- Value demonstration
- Real-world evidence
- Rare diseases
- Patient engagement
- Policy

**Our services**
- Strategic consultancy
- Publications
- Medical communications
- Events and meetings
- Digital
- Internal capability building
- Innovative solutions
Engagement and collaboration

novo nordisk
Genetic Alliance
EUROPEAN MEDICINE AGENCY
ucb
Imperial College London
NATIONAL LIBRARY OF MEDICINE
University of Exeter
The YODA project
F1000 Research
OXFORD UNIVERSITY PRESS
ASAPbio
MHRA
Creative Commons

Crossref
NCBI
Altmetric
University of Liverpool
COPE

AstraZeneca
Taylor & Francis Group
ORCID
Takeda
WILEY

abpi
Roche
GSK VACCINES
Pfizer
ENVISION PHARMA GROUP

National Institute for Health Research
Cambridge Medical Communication
SANOFI
Cold Spring Harbor
CEBM University of Oxford
H1
BMJ
DIGITAL SCIENCE

Biomedical Research and Training Network
BISON
Institute of Translational Medicine
The YODA project
EUROPEAN MEDICINE AGENCY

NATIONAL LIBRARY OF MEDICINE
THE ROYAL SOCIETY
INNOVATE UK

AllTrials
Aries systems

American Society of Clinical Oncology
PATIENTS KNOW BEST

Bill & Melinda Gates Foundation
CHAN ZUCKERBERG
abpi

EFPIA
The Lancet
What do you think?

Do you agree?

Yes
Sign our position statement today!

No
Tell us why! We must know.

Get involved, learn, debate

https://openpharma.blog/
 @_OpenPharma
Innovations in medical publishing