

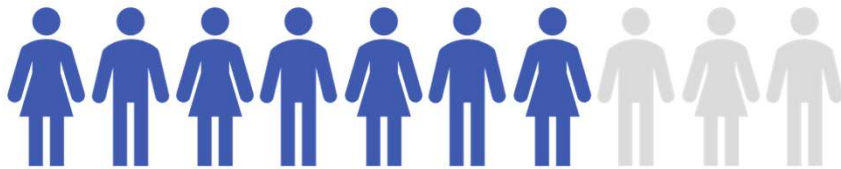
OpenPharma

Innovations in medical publishing

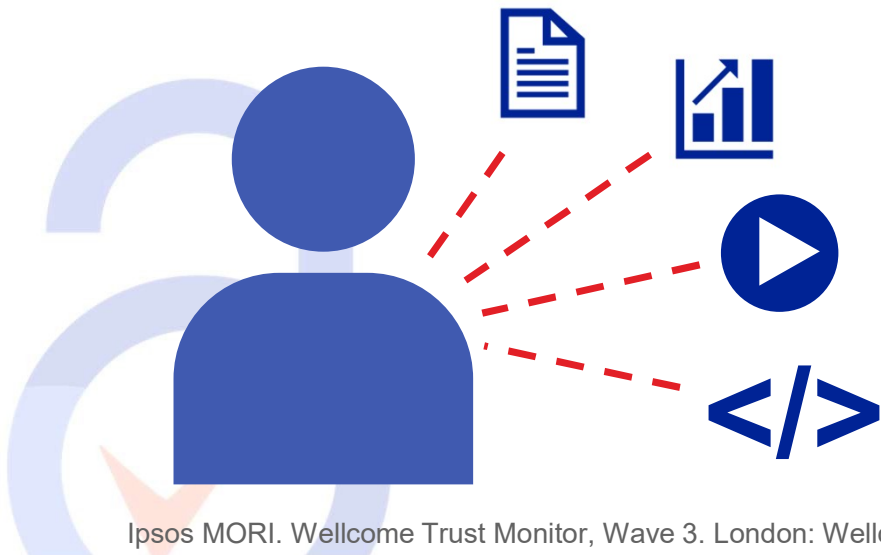


Why do we need research transparency?

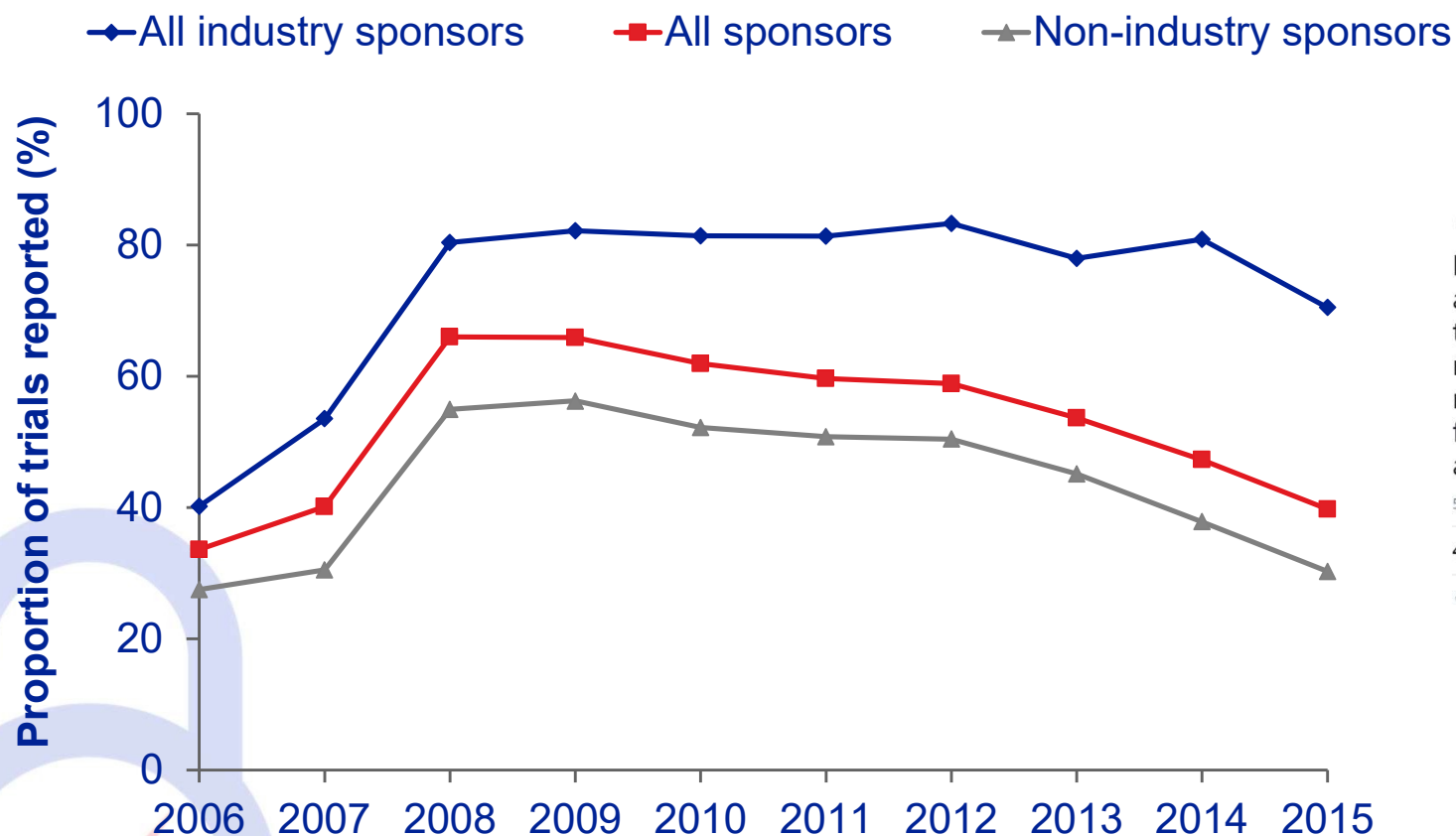
Around **59%** of the public trust research by university scientists **‘completely’ or ‘a great deal’**...



...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



ben goldacre
@bengoldacre

Following

I really don't know why so many in the audience and panel at #EvidenceLive are talking as if industry is the problem for research integrity. Our @EBMDDataLab research repeatedly shows that academic funders and institutions have poor policies and performance on trial reporting.

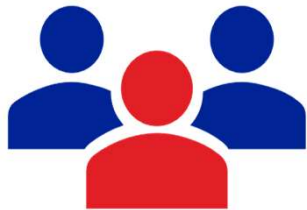
5:42 PM - 18 Jun 2018

45 Retweets 83 Likes



2 45 83

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





“

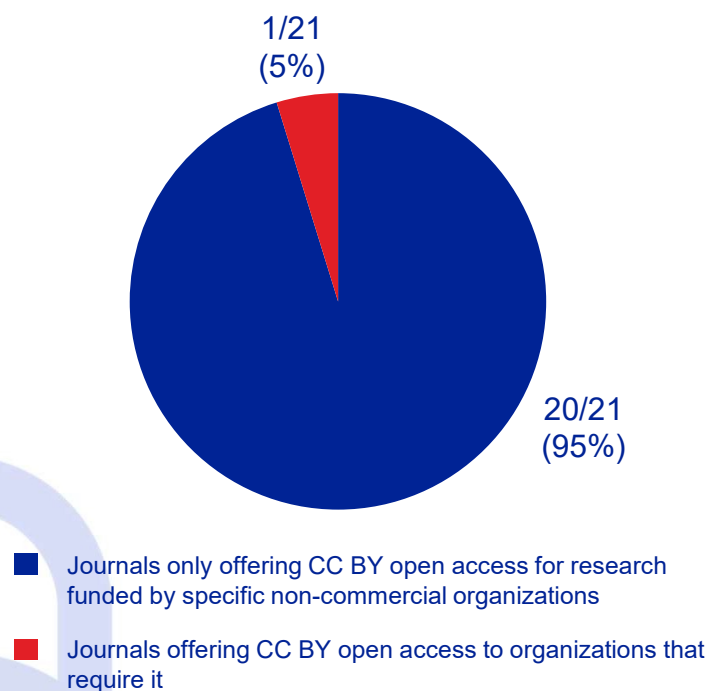
A paywall may restrict the number of readers and this might NOT help the reputation of the pharmaceutical industry (the mindset of it being a bit secretive).

”



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

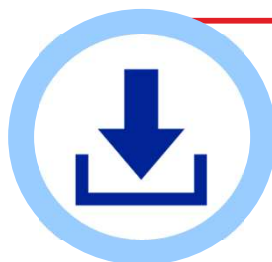
Ellison T Koder T, Schmidt L, Williams A, Winchester CC. Open access policies of leading medical journals: a cross-sectional study. *BMJ Open* 2019;9:e028655.

Our purpose

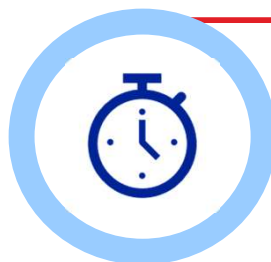
Open Pharma aims to connect pharma with innovations in publishing to achieve ...



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

”

Educational material and events

Open access guidance for pharma

Educate internal teams on the issues and opportunities with open access

Within the publication and commercialisation process, **Understand** the different license restrictions

Develop a company open access strategy

Why open access?

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

Benefits for all

Benefits to pharma

Transparency

Speed of dissemination

Free to access

Collaboration

Patient wellbeing

Global dissemination

Avoids transfer of value for reprints

Innovation

Benefits of open access

- Open access articles:
 - encourage viewing of more articles than paywall access^{1,2}
 - appear to be downloaded more and receive more citations than subscription articles, indicating a greater academic impact^{3,4}
 - appear to have a broader societal impact based on altmetric data^{5,6}
 - can facilitate public and commercial reuse of research results (depending on the restrictions of the licenses, which is beneficial for collaboration, education and innovation⁷)
 - increase transparency of research results^{8,9,10}
 - are no different in terms of quality when compared with subscription articles¹¹

Tim Ellison presents a recorded 2-hour event in Open Pharma

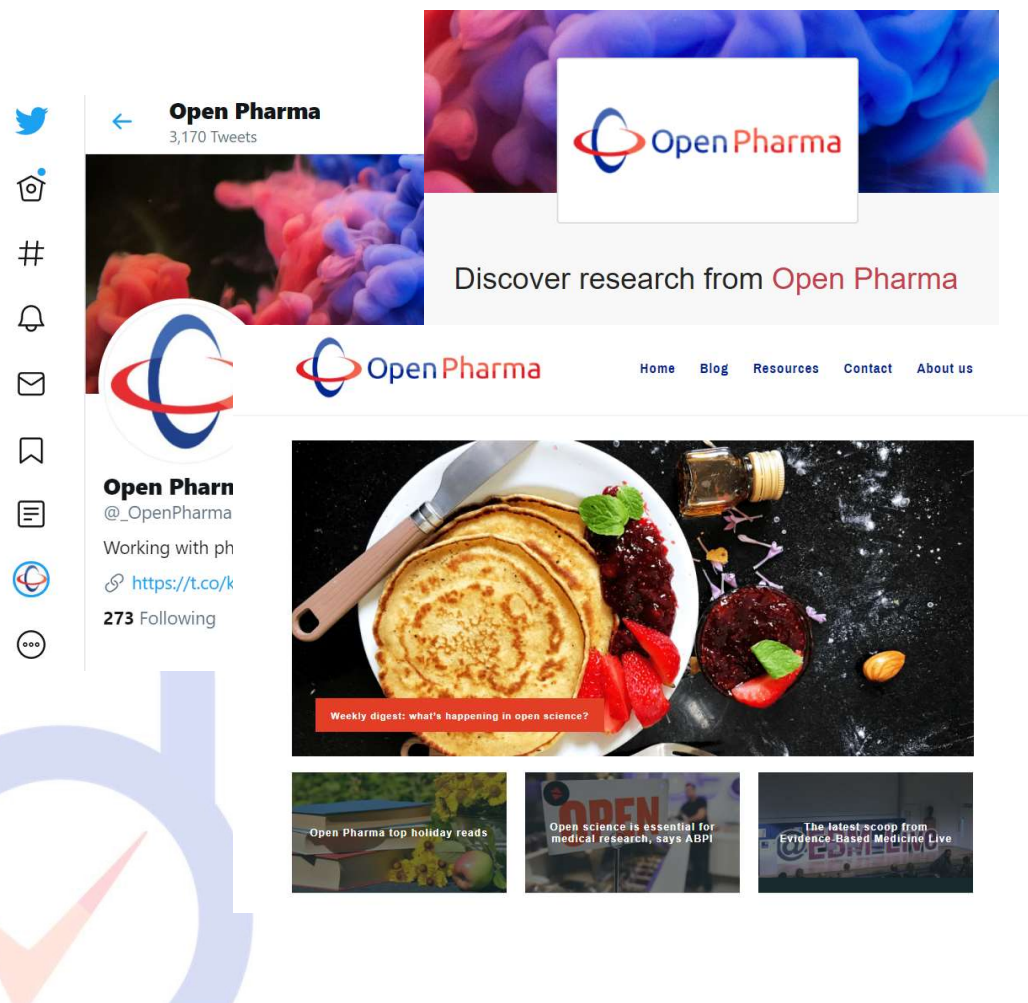
Clinical trial transparency - let's talk

Open Pharma - the story so far

Open Pharma is a not-for-profit organisation, established in 2014, with the mission to make all scientific research content available for anyone, anywhere in the world, to read, share, reuse and build upon.

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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



1. Shire. Available at: <https://www.shire.com/en/newsroom/2018/january/xajhds> (accessed 29 Jan 19)

2. Ipsen. Available at: <https://www.ipsen.com/ipsen-commits-to-making-all-its-published-scientific-research-freely-accessible-to-everyone/> (accessed 29 Jan 19)

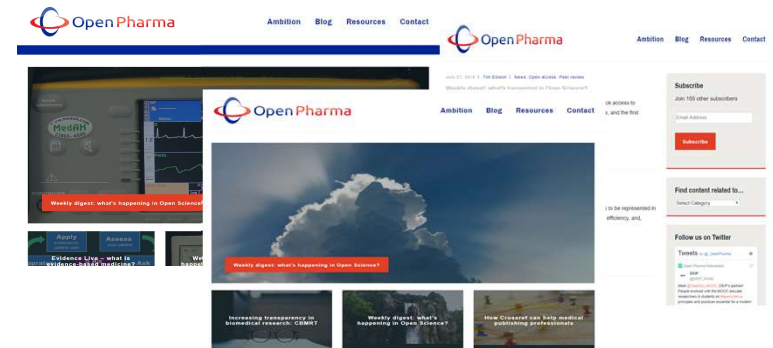
ASCO case study



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

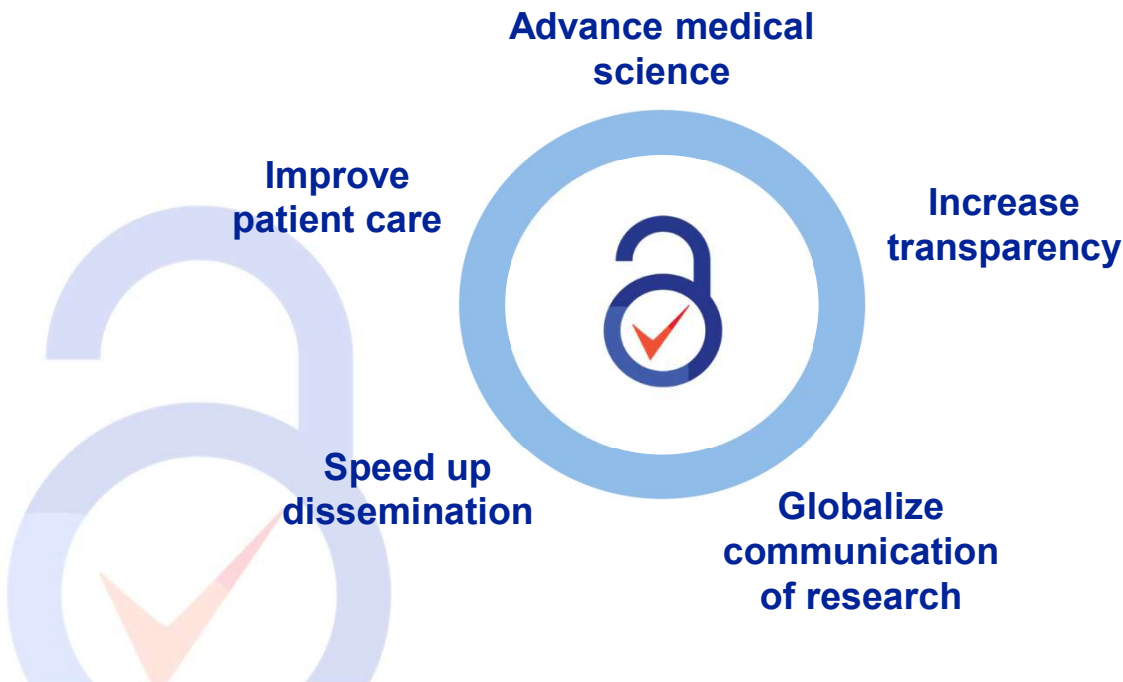


International Open Access Week, 2019



Open 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




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

Our current project
On the 21 October 2019, we are releasing a statement to say that: All pharma-funded research involving patients should be made available to anyone who wants to read it, anywhere in the world, as soon as it is published.

What we do
We work together to find ways to make pharma-funded healthcare research quick and easy to access.

We push for change with patients in mind
59% of adults (1778/3014) in the USA searched online for medical information in the past year and 1 in 4 came across a request to pay for access.¹

Our immediate priority
Our immediate priority is to secure authors publishing company-funded research to publish open access as authors publishing research funded by other sources, so it can be made free to read from the date of publication. This would enable pharmaceutical companies to follow the lead of other research funders in requiring all the research they fund to be open access, without impacting on journal choice.^{2,3} In order to provide publishers with their policies and protect their copyright interests, any variant of Creative Commons licence could be used.

Our long-term goal
Our long-term goal is to secure authors publishing company-funded research the same as authors publishing research funded by other sources, so that all research can be made free to read from the date of publication. This would enable pharmaceutical companies to follow the lead of other research funders in maximizing the impact of the research they fund. Open Pharma is committed to working closely with publishers and pharmaceutical companies to ensure that the gold standard Creative Commons Attribution (CC BY) licence can be used.⁴

Acknowledgements
This Open Pharma position statement on open access represents the opinions of the individuals: Catherine Skobe (Pfizer), Chris Rains (Takeda), Chris Winchesser (Oxford PharmaGenesis), (Oxford), Lisa Baltzer (Novo Nordisk), Sarah Sabir (Oxford PharmaGenesis) and Valerie Phillips (Oxford PharmaGenesis). We thank the members, supporters and others who have provided Pharma for their input and valuable discussion.

To find out more, contact us at oxfordproject@pharmagenesis.com or visit our blog:
<http://www.pewintnet.org/2013/01/15/health-online-2013> (Accessed 10 October 2019)

Do you agree with our statement? If you do, we would welcome your support and endorsement of the statement – as an individual or on behalf of patient groups.

This includes patients, members of the public, researchers, patient advocates, caregivers, nurses, GPs, consultants, health economists, payers, journalists and politicians.

This will help to advance medical science and improve patient care.

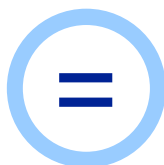
It will also allow patients involved in the studies to access the end results and for those taking a new drug to find out more about the research behind it.

This helps to advance medical science and improve patient care.

1

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

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 **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**

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Endorsed by academics, patients and communicators

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Endorsed by patient groups, charities, pharmaceutical companies and publishers



Organizations

Ataxia & Me
Autoinflammatory UK
Cambridge Rare Disease Network
Galapagos NV
International Kidney Cancer Coalition
Kidney Research UK
Observational and Pragmatic Research Institute Pte
Oxford Health Policy Forum
Oxford PharmaGenesis
Pedalling4ACure
Solanum Medical Communications Ltd.
SUDEP Action
The Aarskog Foundation
ThinkSCIENCE, Inc.
Zimbabwe Evidence Informed Policy Network

Publishers

Betasciencepress Publishing
ecancer
F1000 Research Ltd.
Frontiers
Future Science Group
Wiley

A reminder about why open access matters

“ 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*



HIV, human immunodeficiency virus

The PLoS Medicine Editors. The impact of open access upon public health. *PLoS Medicine* 2006;3:e252

Who's behind this?

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

Supporters:

- AstraZeneca
- Roche
- Pfizer
- UCB
- Wiley

Members:

- Takeda
- Novo Nordisk
- GSK
- Gilead Sciences
- Galápagos

Financial contributors and previous hosts

- Wellcome
- The BMJ

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

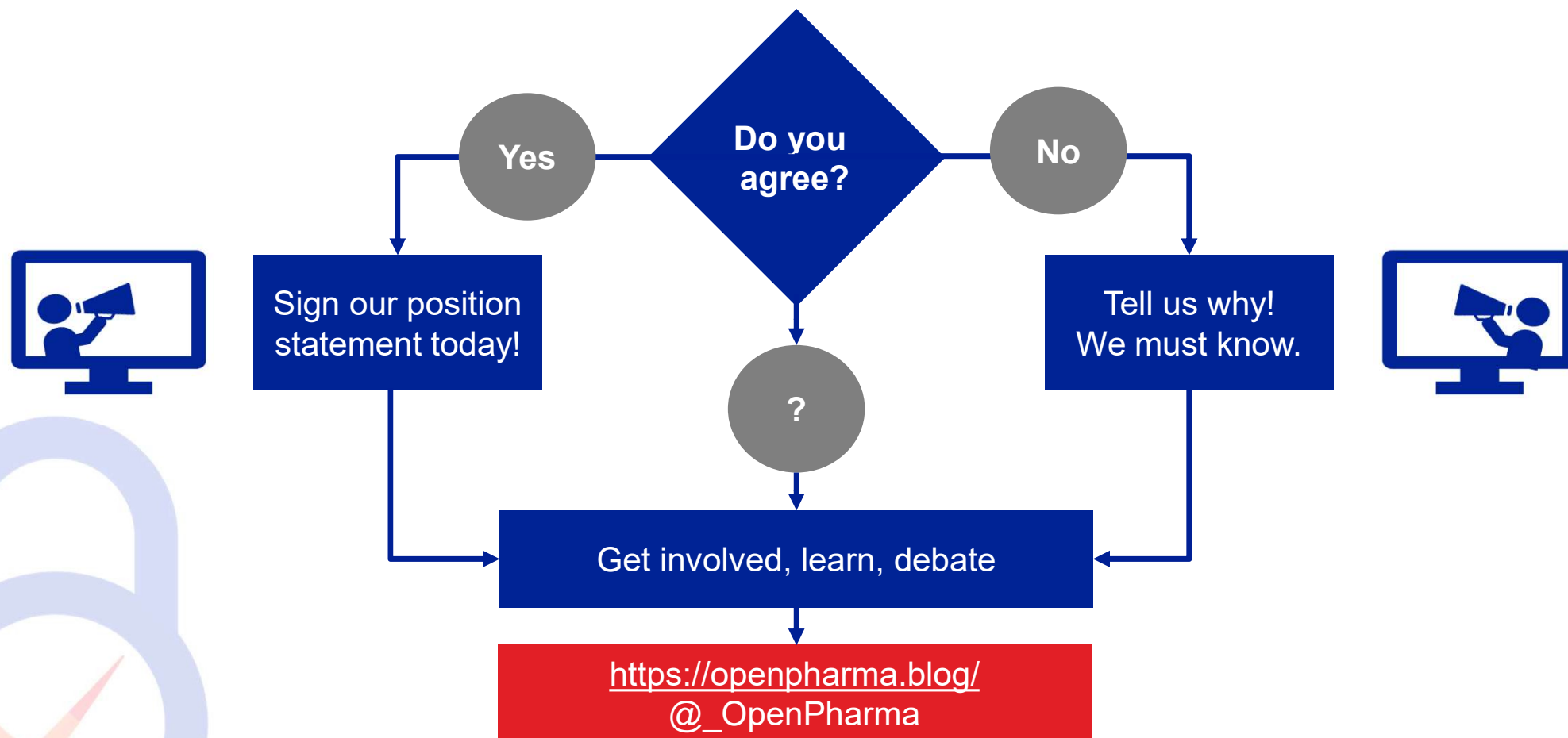


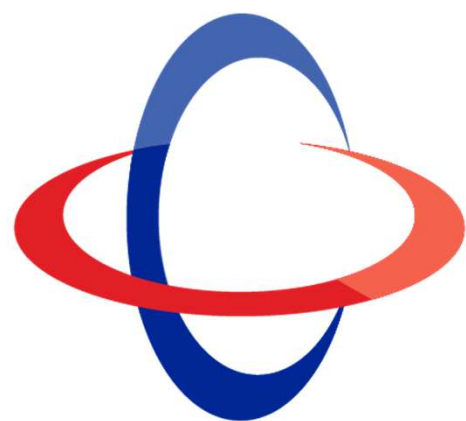
Engagement and collaboration



novo nordisk Genetic Alliance National Institute for Health Research
EUROPEAN MEDICINE AGENCY Crossref Cambridge Medical Communication
ucb Imperial College London CHAN ZUCKERBERG INITIATIVE ELSEVIER Bill & Melinda Gates Foundation
NATIONAL LIBRARY OF MEDICINE abpi AstraZeneca SANOFI Cold Spring Harbor
University of Exeter GSK VACCINES Taylor & Francis Group CEBM University of Oxford
The YODA project Pfizer Roche ORCID Takeda WILEY Wellcome Trust
F1000 Research ENVISION PHARMA GROUP NCBI H1 BMJ DIGITAL SCIENCE
OXFORD UNIVERSITY PRESS THE ROYAL SOCIETY Innovate UK efpia The Lancet
ASAPbio Altmetric Gilead Sciences MHRA COPE University of Liverpool AllTrials Aries systems
Creative Commons ISMPP American Society of Clinical Oncology PATIENTS KNOW BEST

What do you think?





OpenPharma

Innovations in medical publishing

