Open Pharma Roundtable

Innovations in medical publishing

15 June 2020
Welcome, introductions, objectives and agenda

Richard Smith, Chair
<table>
<thead>
<tr>
<th>Time (BST)</th>
<th>Agenda item</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>13:45–14:00</td>
<td>Sound and equipment check</td>
<td>Richard Smith</td>
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<td>14:00–14:30</td>
<td>Welcome, introductions, objectives and agenda</td>
<td>Richard Smith</td>
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<td>14:30–15:00</td>
<td>Summary of January roundtable</td>
<td>Tim Koder and Chris Winchester</td>
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<td>15:00–15:20</td>
<td>Coffee break</td>
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<td>15:20–16:20</td>
<td><strong>Transparency</strong></td>
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<td>Open access policy 2021</td>
<td>Ashley Farley</td>
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<td>Promoting mandatory Open Access, benchmarking and overcoming barriers</td>
<td>Will Gattrell</td>
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<td>Update on the Open Pharma position statement on open access</td>
<td>Chris Winchester</td>
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<td>Discussion</td>
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<td>16:20–16:30</td>
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<td>16:30–17:00</td>
<td><strong>Accountability and Discoverability</strong></td>
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<td>Open access journals and patient impact</td>
<td>Durhane Wong-Rieger</td>
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<td>Improving the use of ORCID during the manuscript publication process</td>
<td>Sarah Sabir</td>
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<td>Discussion</td>
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<td>17:00–17:10</td>
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<td>17:10–17:40</td>
<td><strong>Accessibility</strong></td>
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<td>Publication Plain Language Summaries (PPLS)</td>
<td>Avishek Pal</td>
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<td>Preprints in the time of COVID-19</td>
<td>Steph Macdonald</td>
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<td>Discussion</td>
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<td>17:40–18:00</td>
<td><strong>Summary and close</strong></td>
<td>Richard Smith</td>
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Speakers today

Chair
• Richard Smith, Chair of Patients Know Best

Co-chair
• Tim Koder, Oxford PharmaGenesis

Speakers
• Ashley Farley, Bill & Melinda Gates Foundation
• Will Gattrell, Ipsen
• Chris Winchester, Oxford PharmaGenesis
• Durhane Wong-Rieger, Canadian Organization for Rare Disorders
• Sarah Sabir, Oxford PharmaGenesis
• Avishek Pal, Novartis
• Steph Macdonald, Oxford PharmaGenesis
Meeting participants

Members
• Slavka Baronikova, Galápagos
• Christine Vanderlinden, GSK
• Santosh Mysore, GSK
• Mette Holt, Novo Nordisk
• Paul Farrow, Oxford PharmaGenesis
• Chris Rains, Takeda
• Valérie Philippon, Takeda

Supporters
• Shweta Rane, Alexion
• Jon Druhan, AstraZeneca
• Catherine Skobe, Pfizer
• Rikke Egelund Olsen, Roche
• Janet Davies, UCB
• Linda Feighery, UCB
• Gavin Sharrock, Wiley

Participants
• Jennifer Harris, ABPI
• Andrew Balas, Augusta University
• Anna-Lisa Fisher, BI
• Richard Sands, BMJ
• David Mellor, Center for Open Science
• Mike Taylor, Digital Science
• Kirsty Reid, EFPIA
• Liz Allen, F1000
• Stephan Kuster, Frontiers
• Laura Dormer, FSG
• Jonny Patience, Informa
• Rob Matheis, ISMPP
• Jayme Trott, J&J
• Rebecca Cooney, The Lancet
• David Sampson, The NEJM Group
• Shawna Sadler, ORCID
• Deborah Dixon, OUP
• Sara Rouhi, PLOS
• Stuart Taylor, Royal Society
• Pasha Javadi, Sanofi

Apologies
• Julie Newman, Gilead

Listening
• Frederick Fenter, Frontiers
• Joanne Walker, FSG
• Simon Page, Ipsen
• Peter Llewellyn, NetworkPharma
• Brian Falcone, Oxford PharmaGenesis
• Tanya Stezhka, Oxford PharmaGenesis
• Richard White, Oxford PharmaGenesis
• Niamh O’Connor, PLOS

Facilitation and reporting
• Victoria Lee, Oxford PharmaGenesis
• Debbie McNicol, Oxford PharmaGenesis
• Francesca Ounsworth, Oxford PharmaGenesis
• Zoe Watts, Oxford PharmaGenesis

ABPI, Association of the British Pharmaceutical Industry; BMJ; British Medical Journal; BI, Boehringer Ingelheim; EFPIA; The European Federation of Pharmaceutical Industries and Associations; FSG, Future Science Group; GSK; GlaxoSmithKline; ISMPP; International Society for Medical Publication Professionals; J&J, Johnson & Johnson; NEJM, New England Journal of Medicine; OUP, Oxford University Press; PLOS, Public Library of Science
Objectives

• Build on discussions from the January roundtable
• Gain a further understanding of US perspectives on open access and how we can secure mandatory open access policies
  • Provide attendees with an update on the White House consultation and Plan S
• Explore the ways patients' access and discover medical information and how we can build trust using ORCID
• Listen to and gauge attendees' experiences and perspectives on plain language summaries and preprints
Summary of January roundtable

Tim Koder and Chris Winchester, Oxford PharmaGenesis
## Open Pharma 2019 achievements

### Open Access Week 2019
- Launch of the Open Pharma position statement on open access
- Article on the position statement published in *The Telegraph*
- Open Pharma and Pint of Science event ‘Clinical trial transparency – lets talk’

### Publications
- ‘Open access policies of leading medical journals’ published in *BMJ Open*
- ‘Access all areas’ published in *Research Fortnight*
- ‘Registration and use of ORCID by pharma’
- ‘How open are pharma publications?’

### Engagement
- We welcomed two new Members and two new Supporters

### Blog, Twitter and other communications

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<th>January 2019</th>
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<td><strong>326</strong> followers on Twitter</td>
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<td><strong>152</strong> subscribers to the blog</td>
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<td><strong>84</strong> weekly digests</td>
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<td><strong>30</strong> original articles</td>
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<td><strong>526</strong> followers on Twitter</td>
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<tr>
<td><strong>286</strong> subscribers to the blog</td>
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<tr>
<td><strong>130</strong> weekly digests</td>
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<tr>
<td><strong>42</strong> original articles</td>
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- Launch of the Open Pharma figshare page **1840 views and 573 downloads**
- Delivered presentations at the 48th EMWA Conference, LERU Information & Open Access Policy Group meeting, ABPI workshop: Open Access and Transparency and OpenCon
- Facilitated panel and roundtable discussions at European ISMPP, ISMPP Annual Meeting and the CBMRT BioMedical Transparency Summit
- ORCID discussions at Agency Executive Forum and MPIP
- Introductory and update calls with DataCite, EFPIA, medRxiv, NISO, PLOS, WHO and several new biopharma companies

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Figures correct as of 17 January 2020

ABPI, Association of the British Pharmaceutical Industry; *BMJ, British Medical Journal*; CBMRT, Center for Biomedical Research Transparency; EFPIA, European Federation of Pharmaceutical Industries and Associations; EMWA, European Medical Writers Association; LERU, League of European Research Universities; ISMPP, International Society for Medical Publication Professionals; MPIP, Medical Publishing Insights & Practices; NISO, National Information Standards Organization; PLOS, Public Library of Science; WHO, World Health Organization
Recent Open Pharma achievements
On 20 January 2020 …

Members, Supporters and Advisors of Open Pharma met for a roundtable discussion at GSK House to discuss open access, patient and public involvement in medical communications, and the visibility of publications.
Session 1: shaping policy with the Open Pharma position statement

Attendees discussed
- The wide support and coverage of the Open Pharma position statement on open access
- Considerations for pharma mandating open access
  - accessibility and discoverability
  - author freedom
  - cost
  - avoid perception of cherry-picking

Next steps
- Continue to work with publishers to develop their open access models
- Work with institutions/libraries who are in close contact with the authors
- Communicate with authors and provide education on open access
- Understand the impact of libraries not renewing subscriptions with big publishers
- Explore potential for read-and-publish agreements
Attendees discussed

- The use of publication enhancements to increase the reach of data using the appropriate channels
- The acceptability of using enhancements to increase research discoverability
- Potential strategies for aligning the development of publication enhancements across pharma, journals and publishers

Next step

- The next step is to engage with additional publishers to discuss common standards for publication enhancements
Session 3: visibility of publications

Attendees discussed
• The scientific integrity of preprints and the level of expertise of those providing feedback
• The use of self-archiving repositories to increase research accessibility
• Available options for publishing research via the green open access route

Next step
• Continue to work with pharma to facilitate the understanding of different open access publishing routes
Building on January’s discussions

Today, we will:

• Gain a further understanding of US perspectives (publishers, institutes and libraries) on open access
• Explore the ways in which we can help patients’ access and discover medical information and how we can build trust using ORCID
• Discuss options for pharmaceutical companies wanting to explore publishing plain language summaries, preprints and other enhanced content
Transparency
Transparency

- **Gates Foundation open access policy** – Ashley Farley, Bill & Melinda Gates Foundation
- **Promoting mandatory open access, benchmarking and overcoming barriers** – Will Gattrell, Ipsen
- **Update on the Open Pharma position statement on open access** – Chris Winchester, Oxford PharmaGenesis
- **Discussion** – All
OPEN ACCESS POLICY 2021
Modernized for Impact and Compliance

Ashley Farley, Program Officer
Knowledge & Research Services Team / OA Team
June 2020
WHY OPEN ACCESS MATTERS TO THE FOUNDATION

Barrier-free access to foundation-funded research advances innovation and helps create a world where everyone has the opportunity to lead a healthy and productive life.

Broad and unfettered dissemination of primary research for greater impact and reuse aligns with our Global Access Commitment.

During the pandemic it has never been more apparent the importance of access to research and research transparency to find solutions to tough problems.
Wellcome and Gates join bold European open-access plan

The Wellcome Trust has also announced how it will implement the plan, which could provide a blueprint for others.
NEW DRIVER FOR CHANGE: PLAN S

- Launched by cOAlition S in September 2018
- Gates and Wellcome joined the cOAlition in 2019
- Strives to couple bold OA policy changes with realistic implementation strategy
- Journal Checker Tool in active development

Plan S requires that, from 2021, scientific publications that result from research funded by public grants must be published in compliant Open Access journals or platforms.
COALITION S: BUILDING AN ALLIANCE OF FUNDERS AND STAKEHOLDERS
Rapid & Transparent Publishing

Gates Open Research is a platform for rapid author-led publication and open peer review of research funded by the Bill & Melinda Gates Foundation.
Promoting mandatory Open Access, benchmarking and overcoming barriers

Open Pharma Roundtable Meeting, June 15 2020

Will Gattrell
Ipsen commits to making all published scientific research freely accessible to everyone through the following actions:

- **Open Pharma Position Statement**
- **ISMPP poster on Open Access**
- **Ipsen Corporate Website**
- **Ipsen Social Media**
- **ISMPP U seminar on Open Access**
- **Mention on Richard Smith’s BMJ Blog**
- **BMJ Open article on journal Open Access policies**
- **Updated policy on Ipsen Website**
- **Ipsen Social Media**
- **ISMPP poster**

Ipsen met commitment to make all publications Open Access in 2019 and endorsed the Open Pharma Position Statement.

Additionally, Ipsen communications and news are updated on the following platforms:

- **Ipsen Employee Website**
- **Ipsen Global Newsletter**
- **Ipsen publications educational series**

For more information, please refer to the **ISMPP abstract submission on Open Access TBC**.
Benchmarking
The historical Open Access record for Ipsen

Would a mandatory OA policy affect journal choice?

- Immediate OA would have been possible for 93.6% of articles
- 35% of articles were made OA by paying an APC to a hybrid journal
- 31.4% of articles appeared in OA journals
- 23% of articles became OA following a journal embargo period
- 40% of articles were not OA because of journal policies

- Hybrid journal (APC paid by Ipsen)
- OA not possible
- Paid access

How can articles be reused?

- 17.3% of articles can be reused commercially without additional permissions or fees (CC BY licence)
- 43.2% of articles can be reused non-commercially without additional permissions or fees (any CC licence)

- Immediate OA
- Deferred OA (after embargo)
- Paid access

Benchmarking

The 2019 Open Access record for Ipsen

Pre-OA-commitment cohort (2013–2017), N = 121

- Immediate OA: 72.7%
- Deferred OA: 2.5%
- Paid access: 24.8%

Post-OA-commitment cohort (Jan–Sep 2019), N = 26

- Immediate OA: 26.9%
- Deferred OA: 19.7%
- Paid access: 80.8%

Proportion of manuscripts (%)

Post-OA-commitment cohort (Jan–Sep 2019), N = 26

- 26.9% of manuscripts with immediate OA can be reused commercially without additional permissions or fees (= CC-BY licence)
- 19.7% of manuscripts can be reused only after a permission request and fee payment

CC licence types

- CC-BY
- CC-BY-NC-SA
- CC-BY-NC
- CC-BY-NC-ND
- Journal-specific licence

Page et al. Open sesame! Evaluation of an open access commitment on Ipsen-sponsored publications. Presented at ISMPP EU, January 2020
Overcoming barriers

Planning, education and communication are key

• Ipsen: in a unique position?
  • Small enough to be agile, big enough to make a difference
  • Publications team is structured by function, rather than product, which facilitates alignment and roll out

• Clear, measurable definition of the Open Access commitment at the outset
  • Commitment encompasses company-sponsored research only; contracts for investigator-sponsored studies now encourage publishing Open Access

• Communicated commitment internally and externally regularly, and at implementation
  • Everyone has been supportive, in particular authors and patient centricity

• Updated relevant documents, training materials, SOPs, author materials etc, as soon as possible

• Global budget available to pay Open Access charge where affiliates did not budget
  • Educating everyone to set budget aside for future publications
Update on the Open Pharma position statement on open access

Chris Winchester, Oxford PharmaGenesis
How well do you think pharma is doing in promoting and implementing open access?

• Pharma is doing very little or nothing to promote or implement open access
• Pharma is doing okay, but there is a long journey ahead
• Pharma is doing very well, but there’s a little more work to do
• Pharma is doing exceptionally well in promoting and implementing open access
Pharma was lagging but is starting to take the lead

Large pharmaceutical companies have been publishing an increasing proportion of their scientific papers in open access journals

Pharmaceutical companies can achieve up to ~80% by encouraging open access

And up to 100% by mandating open access

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.

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

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<th>Our immediate priority</th>
<th>Our long-term goal</th>
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<tr>
<td>Secure authors publishing company-funded research the <strong>same right to publish open access</strong> as authors publishing research funded by other sources</td>
<td>Secure authors publishing company-funded research the <strong>same terms</strong> as authors publishing research funded by other sources</td>
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<td>All research to be made <strong>free to read</strong> from the date of publication</td>
<td>Free to read – <strong>and reuse</strong> – from the date of publication</td>
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<td>Any variant of Creative Commons or <strong>equivalent licence</strong></td>
<td>Sustainable use of <strong>CC BY</strong></td>
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BY, Attribution; CC, Creative Commons
Endorsements from individuals, organizations, pharmaceutical companies and publishers

152 endorsements

27 endorsements from other organizations

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<tr>
<th>Organizations</th>
<th>1–2 endorsements</th>
<th>3–5 endorsements</th>
<th>6–30 endorsements</th>
<th>31+ endorsements</th>
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<td>Observational and Pragmatic Research Institute Pte Ltd</td>
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Correct as of 22 May 2020; n = 142 individual endorsements

M-CM, macrocephaly-capillary malformation; MDPI, Multidisciplinary Digital Publishing Institute; PLOS, Public Library of Science; SUDEP, sudden unexpected death in epilepsy
We thank all Members, Supporters and Followers of Open Pharma for their valuable input

Catherine Skobe
Senior Director, Publications Innovative Solutions Lead, Pfizer

Chris Rains
Head of GMA Medical Functions, Takeda

Chris Winchester
CEO, Oxford PharmaGenesis

Julie Newman
Associate Director, HIV, Gilead

Lise Baltzer
Director Global Publications, Novo Nordisk

Sarah Sabir
Medical Writer, Oxford PharmaGenesis

Valérie Philippon
Head, Global Publications, Takeda
Coverage from Open Pharma

Reflecting on the release of the Open Pharma position statement on open access

Today, just over two weeks from the launch of the Open Pharma position statement on open access, we reflect on how the statement came about, the benefits it offers to different types of stakeholders and the success it has had so far.
Reach of the position statement

Future Science Group @futuresciencegp · 18 Nov 2019
Reinforcing our commitment to #openaccess publishing, @futuresciencegp are very proud to support the @OpenPharma position statement on openaccess #openforall #medicalresearch

The Telegraph
Drug companies urged to make research available to health workers in poorer countries

OpenPharma @OpenPharma · May 21
We are pleased to welcome @rarediseases and Outcomes Positive Inc. to a group of over 30 other organizations who have endorsed the #OpenPharma position statement on OpenAccess. You can read and endorse the OpenPharma position statement below.
Cumulative monthly endorsements

Cumulative monthly figures do not include the endorsements of the six authors of the position statement.
Comments from individual endorsers

“A vital element of open access is ‘knowledge mobilization’ – bringing as many relevant stakeholders to engage with published research as possible to maximize its reuse and impact. Open access offers a way to maximize contact with multiple audiences, spark new ideas and understanding, and ensure new interventions and treatments can reach those that need them as soon as possible.” –Rebecca Lawrence, F1000Research

“One of the persistent challenges facing various stakeholders in the health sector in Zimbabwe and other low- to middle-income countries is physical and cognitive access to relevant credible evidence to use in identifying research priorities, doing the research, develop policy and in making programme interventions to ensure universal health coverage, posing a serious threat for the health sector.” –Ronald Munatsi, Zimbabwe Evidence Informed Policy Network

“If we are committed to “doing the right thing for patients”, then we must all support open access and transparency.”

–John Gonzalez, Solanum Medical Communications Ltd

“Science should be open. Research cannot be kept locked for access to a limited few. It’s contrary to the principles of doing clinical research. We make volunteer participants give us valuable results and then block the end users from using the same to help these volunteers.”

–Alban Sigamani, Narayana Health

“Important step in enabling patient groups and charities to share relevant information with the community and build an informed society.”

–Alan Thomas, Ataxia and Me
Next steps for the position statement

- Secure additional pharma company endorsements
  - What discussions have been initiated?
  - What resources will be helpful to secure endorsement?
  - What are the barriers?

Update to the ICMJE recommendations (December 2019)
“Policies that dictate where authors may publish their work violate the principle of academic freedom”
If you haven’t done so already, what are the reasons for not signing the Open Pharma position statement on open access?

• I haven’t had a chance to sign it yet, but it’s on my list to do
• I agree with the position statement but cannot sign it without my company’s backing
• I don’t think the position statement calls for enough action
• I don’t agree with the position statement
• I haven’t read it yet
• Other, reason not listed
Discussion

All
Accountability and Discoverability
Accountability and Discoverability

- **Open access journals and patient impact** – Durhane Wong-Rieger, Canadian Organization for Rare Disorders
- **Improving the use of ORCID during the manuscript process** – Sarah Sabir, Oxford PharmaGenesis
- **Discussion** – All
Should pharma provide scientific information to patients?

- Yes, it is our obligation
- Yes, but we have to be careful
- No, but I can see the value in doing so
- Absolutely not, it contradicts the safeguarding we have in place
- Don’t know
OPEN ACCESS JOURNALS AND PATIENT IMPACT

DURHANE WONG-RIEGER, PHD
CANADIAN ORGANIZATION FOR RARE DISORDERS, PRESIDENT & CEO
RARE DISEASES INTERNATIONAL, CHAIR
FEES TO ACCESS

TERRIFYING COMPUTER NOTIFICATIONS
WHY PATIENTS NEED ACCESS TO PUBLISHED PRIMARY RESEARCH

Many types of patient users

• Individual end users: participate in informed decision making, input to research, trial design, ethics reviews, health institutions
• Patient organizations: advice to patients; input to research, trial design, PROMs, access, HTA, health systems, and policy
• Patient researchers: participate, interpret, disseminate, apply finding
• Patient authors and reviewers: conduct or collaborate on original research, comment on research findings, peer review

Patients have been mostly absent from the debate

• Not considered as relevant user (unique barriers and needs)
• Not represented in dialogues (patient advocacy as driver)
• Considerations of public access and impact in designing OA (not just citations)
WHAT IS THE CURRENT ACCESS STATUS FOR PATIENTS?

Personal (N of 1)

- Husband with PD developed psychosis and dementia: psychiatrist prescribed medication
- Good news: several up-to-date summary articles were available for free to download
- Bad news: about half of the articles referenced in these summary overviews were NOT available to gain better understanding as to the patients in trials, etc.
- In the end, decided to try recommended medications, one of which seriously aggravated the symptoms with side effects; the other, given in very low dosage, is tolerated and seems to have reduced hallucinations and depression

Primary research difficult to find

- Clinical trial findings
- Cost-effectiveness reports
- Rare disease research

25%
CASE: PATIENT AND PATIENT GROUP ACCESS (OR NOT)

MARTIN EVE
Humanities researcher, open access innovator and cerebral vasculitis patient

• I was dealing with four teams: neurology, vascular, rheumatology, and stroke. I was bounced from one team to another, with different narratives, access to relevant research felt necessary for me to understand what the likely prognosis would be... to be able to read the literature and feel some sort of patient-led conversation was taking place was heartening and got me through.

ERNESTO PRIEGO
Multi-scholar and carer

• My father... was a super healthy person all his life. A motor-neuronal disease hit him suddenly. Doctors said it was Parkinson's, but when he started hallucinating, I started doing some research and found out that a lot of the literature I wanted to access to show my father’s doctors and my family were paywalled. Around the time... Ebola was all over the media. I did some research and realised most of the... research was paywalled. I created a dataset and crowdsourced on Twitter the access and license types of these articles.

CHRISTY COLLINS
Mother and M-CM patient advocate

• Signe got a formal diagnosis of M-CM when she was about eight months old from a local geneticist. He sent us on our way with only a few paragraphs of information....
• ... we can’t depend on all of our doctors to consult the published research literature about M-CM.... It’s not practical for doctors to spend a lot of time learning about a syndrome that they may see only once in their careers... parents will make the time to learn everything they can — and this is why the inaccessibility of medical papers to patient families is so very frustrating. Some of the people most motivated to do this research are unable to.
PATIENT “LIFELINES” TO ACCESS RESEARCH

Phone a friend

- In university with library account (willing to find or willing to loan out ID)—but not all universities have all journals
- If drug-related, in a “pharma” friend (willing to bend the rules)
- In patient organization

Search alternatives

- Open Access Journals: ScienceOpen, F1000Research, Unpaywall
- Pirated Articles: Sci-Hub

Become a Researcher (Join Research Sharing Network)

- Join ResearchGate
- Join Mendeley
- Join Research project through UK Participatory Research Network, PCORI, National Center for Advancing Translational Sciences (NCATS) Toolkit for Patient-Focused Therapy Development, CIHR Support for Patient-Oriented Research (SPOR)
WHAT ELSE NEEDS TO BE DONE

- Drop Open Access fees for patient authors to publish
- Provide plain language research reports (for all lay readers)
- Increase “research literacy” of public and patient users to interpret and apply research findings
- Develop appropriate “metrics” beyond citations to demonstrate impact (uptake in healthcare/clinical practice, discussions in social and other media, impact on policy or access, etc.)
- Include patients on editorial and other expert boards
- Include patients in advocacy on Open Access

Increase "research literacy" of public and patient users to interpret and apply research findings.
Improving the use of ORCID during the manuscript publication process

Sarah Sabir, Oxford PharmaGenesis
What is an ORCID iD?

- A **persistent digital identifier** that distinguishes an account holder from every other researcher.
- An ORCID iD can be **connected** with the researcher’s professional information.

---

Enter once, reuse often¹

Over **1140 organizations** are ORCID members²

Over **8.8 million researchers** have an ORCID iD²

77 publishers are ORCID members²

---

Uptake of ORCID by pharma employees

- ORCID registration by internal employees increased by **120%** across the **six companies** studied from **June 2017** to **June 2019**

- **GSK**, one of the companies studied, showed a **higher than average** uptake of ORCID with an increase in registrations of **242%**
Use of ORCID in publications

- PubMed data were extracted for 843 papers from 346 journals, listing 10,091 internal employees and external collaborators.

- 28% of papers listed at least one ORCID iD (234 out of 843).

- Papers that listed an ORCID iD mostly did so for only one author only (67.5%).

- Papers that listed at least one ORCID iD also listed for more than one author per paper (32.5%).
Use of ORCID in publications

4% of authors were listed with an ORCID ID (388 out of 10,091)

For authors listed with an ORCID ID and who authored multiple publications, ORCID IDs were mainly inconsistently listed.

a total number of authors = 388. One author was found to have two ORCID iDs (1/388); b number of authors = 121
Stages at which an ORCID iD may have been captured during the manuscript publication process

- The data extracted from PubMed assume that ORCID iDs have been captured during the publication process in order to be entered into the metadata.
Engaging with publishers to identify opportunities to improve the use of ORCID

- Incorporation of ORCID information into author guidelines
- Improved visibility of ORCID to authors during manuscript submission
- Addition of ORCID iDs to title page of article template documents
- Increased visibility and communication of ORCID in emails to authors and additional communication to co-authors
- Incorporation of ORCID iD prompts at reviewer and proof stages
Discussion

All
Accessibility
Accessibility

- Publication plain language summaries – Avishek Pal, Novartis
- Preprints in the time of COVID-19 – Steph Macdonald, Oxford PharmaGenesis
- Discussion – All
Publication Plain Language Summaries (PPLS)

Open Pharma Meeting – June 15, 2020

Avishek Pal
What propelled our PPLS journey?

Envision PFMD PLS workshop 2018

ISMPP Annual Meeting 2019

Open Pharma 2020 / ISMPP EU 2020

Virtual conferences 2020
How did we approach it?

- Nomenclature finalization
- Cross-divisional working group
- Endorsement from Legal and Compliance
- PPLS toolkit rollout
- Discussion with Comms, Patient Relations/Advocacy
- Phase-wise implementation
- Internal advocacy and championing
A more enabling external landscape!

Made WITH Patients @PF... · 18.05.20
Plain Language Summaries #PLS included in @TADrugSafety - working towards better #patientengagement 🎉 Check out the article now.
journals.sagepub.com/doi/full/10.11... @SAGEClinMed @AarhusUni

Therapeutic Advances in... · 20.02.20
We are delighted to announce that Plain Language Summaries (#PLS) are now a submission requirement in @TADrugSafety to support #patientengagement in scientific publishing.

This was done in collaboration with @PFMDwithPatient 🎉

Plain language summaries now a publishing require... patientfocusedmedicine....

You Retweeted
Therapeutic Advances in... · 06.05.20
Introducing our first article with a Plain Language Summary (#PLS)! We are delighted to be working towards better #patientengagement 🎉

The full #OpenAccess article by @charp_s et al. can be accessed here: bit.ly/2X0Szt

Laura mckeaveney @Laura... · 19.05.20
If we truly want to include the patient community in our decision making processes, we need to make the process of engagement transparent, simple and less burdensome. Novartis is proud to roll out the legal agreements. Thanks WECAN/MPE/PFMD for a great collaboration.

Made WITH Patients · 14.05.20
"The reference agreements will have a connection with @imi_paradigm & @EFPIA Patient Think Tank, an example of how this project can link to other initiatives & expand," says F...
What have we dabbled in?

Conference abstract summaries

Plain language conference posters

Classic PPLS

Abstract summaries for EULAR

External comms about Conference abstract summaries

Plain language FAQs
Where are we headed?

- Expanding dissemination channels
- Exploring secondary use of PPLS

- Who develops?
  - ??
- Who approves?
  - ??
- Independent review?
  - ??
- Which channels?
  - ??
- Secondary audiences?
  - ??

Expanding dissemination channels
Exploring secondary use of PPLS
Thank you
Preprints in the time of COVID-19

Steph Macdonald, Oxford PharmaGenesis
Rapid communication is key in medicine

A preprint is a version of a scientific manuscript posted on a public server prior to formal peer review.

- Free of charge
- Fast speed of dissemination
- Citable, findable and discoverable
  - Associated with a unique DOI allowing for version control
  - Can be cited in research/grants/proposals
- Feedback enablement before publication

PLOS¹

DOI, digital object identifier
The rise of biomedical preprints\textsuperscript{a}

\textsuperscript{a}does not include 6000 preprints on relevant OSF platforms
What constitutes a preprint server?

- SSRN (1994)
- bioRxiv (2013)
- medRxiv (2019)

Assign DOIs and take all types of data

- figshare
- zenodo

Expose some or all of the peer-review process

- CellPress
- Sneak Peek
- F1000 Research
Praise for preprints

The Covid-19 outbreak highlights the potential of preprints

A recent posting on bioRxiv may have been erroneous, but the mistakes picked up within hours, notes Kristen Sadler.

March 2, 2020

By Kristen Sadler

Twitter: @KristenSadler18

The emergence of Covid-19 is testing the limits of many global systems, and not the least among them is the quality control for scientific content.

Growing share for preprints

Since it was first reported by WHO in Jan 5, 2020, over 60 000 cases of a novel coronavirus disease (COVID-19) have been diagnosed in China, with exportation events to nearly 50 countries, as of March 6,
Full-genome evolutionary analysis of the novel corona virus (2019-nCoV) rejects the hypothesis of emergence as a result of a recent recombination event

D. Paraskevis, E.G. Kostaki, G. Magiorkinis, G. Panayiotakopoulos, S. Tsiodras

doi: https://doi.org/10.1101/2020.01.26.920249

Launched in June 2019, medRxiv is a HealthScience-specific preprint server.
What research should be shared as a preprint?

Real world evidence
- PRO validation
- Burden of illness study
- Epidemiology

Preclinical research
- In vitro/animal studies
- Assay/diagnostic validation

Clinical research
- Unapproved drug trial
- Label extension trial
- Off-label clinical trial

Research that can be preprinted

Research that cannot be preprinted

Over 90% of research can be made available as a preprint
## Summary of journal policies

<table>
<thead>
<tr>
<th>Journal</th>
<th>Accepts articles published as preprints</th>
</tr>
</thead>
<tbody>
<tr>
<td>The NEW ENGLAND JOURNAL of MEDICINE</td>
<td>✔</td>
</tr>
<tr>
<td>JAMA Network</td>
<td>Posting as a preprint will necessitate the decision as to whether publication will bring new/meaningful insight</td>
</tr>
<tr>
<td>Journal of Clinical Oncology®</td>
<td>✔</td>
</tr>
<tr>
<td>Annals of Internal Medicine®</td>
<td>No mention of preprints</td>
</tr>
<tr>
<td>THE LANCET</td>
<td>✔</td>
</tr>
</tbody>
</table>
Why preprints, why now?

• Many conferences have been cancelled or postponed owing to COVID-19
• However, we need to make sure that data and clinical expertise are shared with the public as soon as possible
• COVID-19 has changed perceptions on open science and preprints
• We now have medRxiv, a preprint server specifically dedicated to health sciences and our needs
Do you think that the submission of preprints by pharma will increase after COVID-19?

• Yes, preprints are important for the rapid dissemination of research
• Yes, but it will be a while yet
• Yes, in some research areas, but not all
• No, clinical trial research should be peer-reviewed before publication
• I don’t know
Discussion

All
Summary and close
Thank you!