Open Pharma Roundtable

Innovations in medical publishing

15 June 2020

OpenPharma

Welcome, introductions, objectives and agenda

Richard Smith, Chair

Agenda

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

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

Apologies
- Julie Newman, Gilead

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

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

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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[a]

Blog, Twitter and other communications

January 2019	January 2020
326 followers on Twitter	**526** followers on Twitter
152 subscribers to the blog	**286** subscribers to the blog
84 weekly digests	**130** weekly digests
30 original articles	**42** original articles

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

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

Session 2: patient and public involvement

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

OpenPharma

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

BILL & MELINDA GATES foundation

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.

NEWS · 05 NOVEMBER 2018

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.

Richard Van Noorden

NEW DRIVER FOR CHANGE: PLAN S

- Launched by cOAlition S 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

COALITION S: BUILDING AN ALLIANCE OF FUNDERS AND STAKEHOLDERS

Supported by

National funders

Charitable and international funders

European funders

Gates Open Research

BROWSE GATEWAYS & COLLECTIONS HOW TO PUBLISH ABOUT BLOG MY ACCOUNT SIGN IN

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

SUBMIT YOUR RESEARCH OR BROWSE ARTICLES

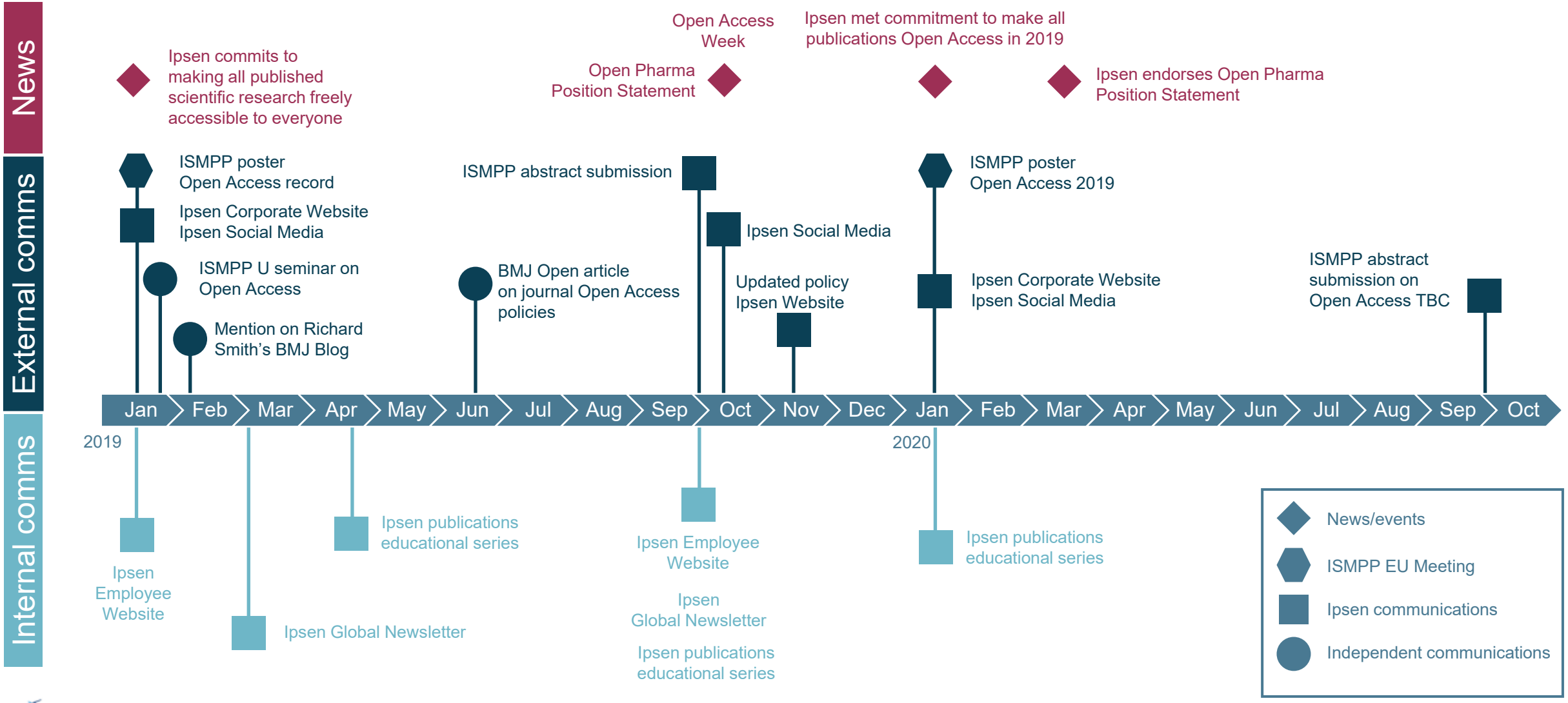
BILL & MELINDA GATES foundation

Promoting mandatory Open Access, benchmarking and overcoming barriers

Open Pharma Roundtable Meeting, June 15 2020

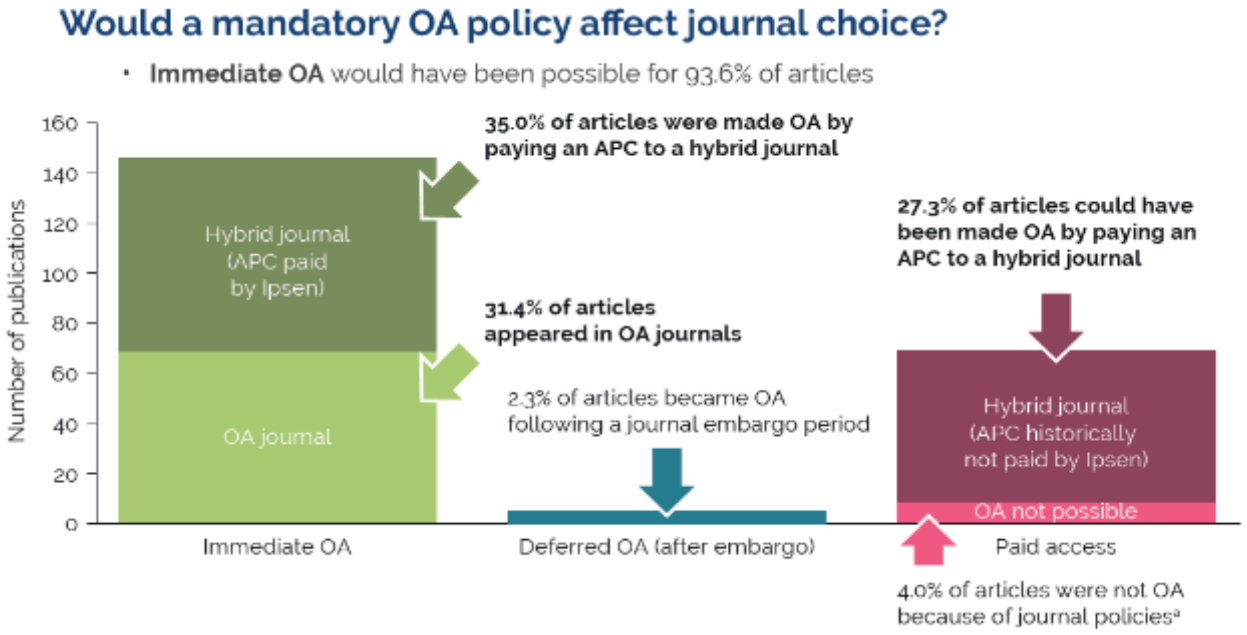
Will Gattrell

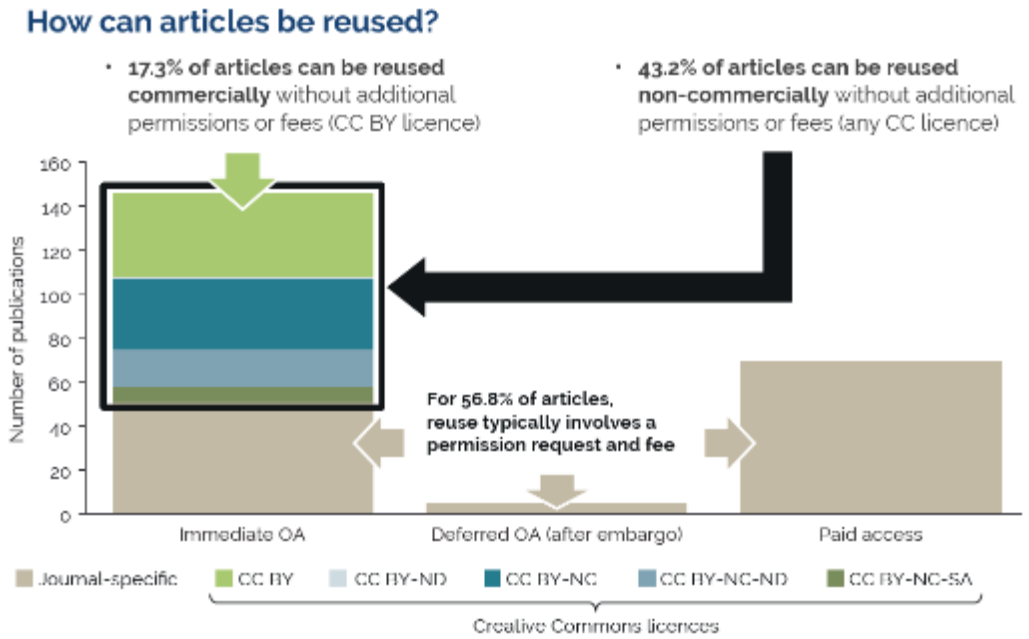
Promoting mandatory Open Access



Benchmarking

The historical Open Access record for Ipsen



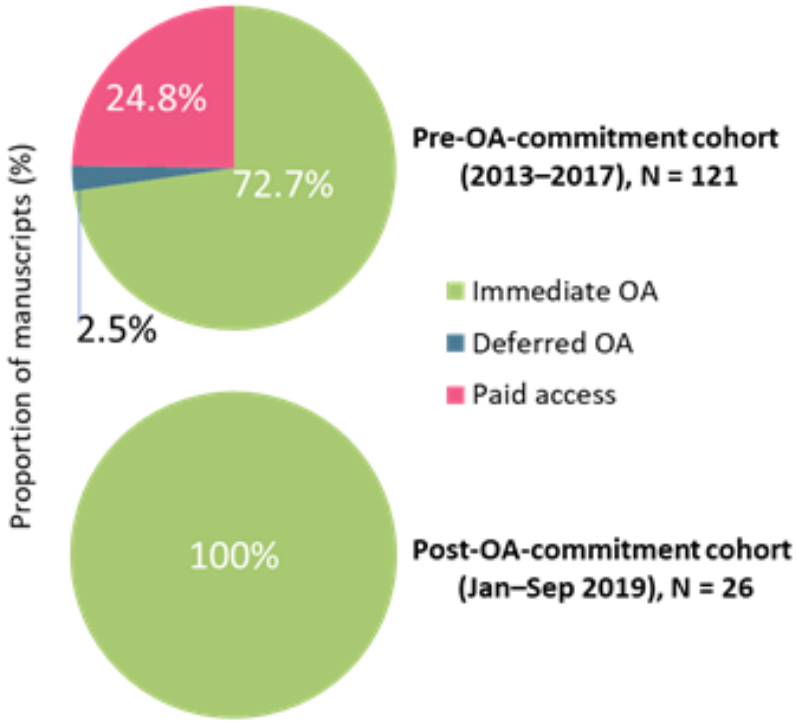


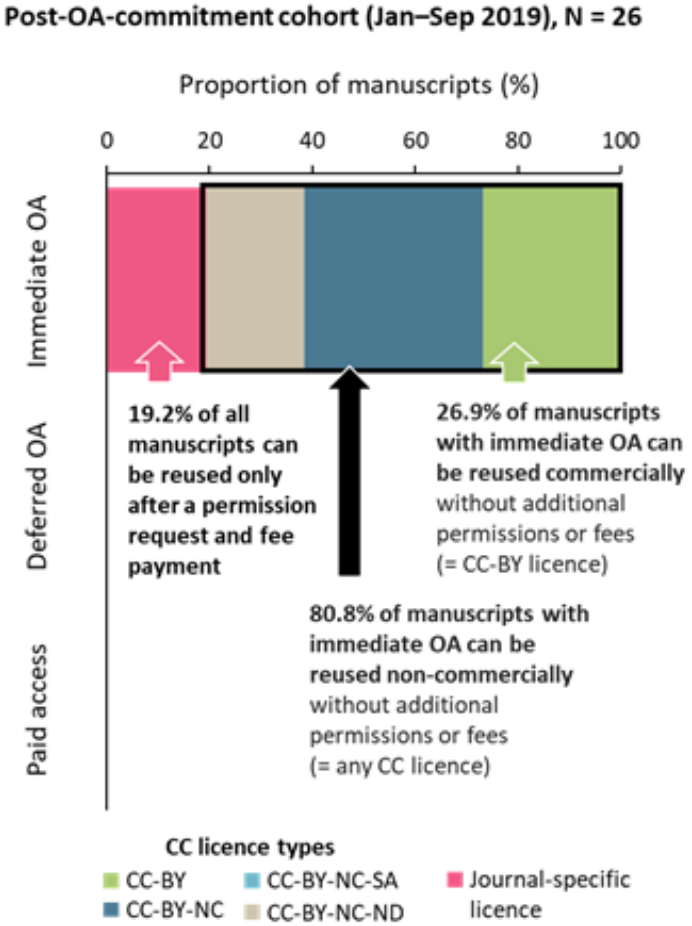
Lang *et al*. Open access publishing of research affiliated to Ipsen, 2013–2017: a baseline assessment. Curr Med Res Opin 2019;35(Suppl 2):39

IPSEN Innovation for patient care

Benchmarking

The 2019 Open Access record for Ipsen





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

IPSEN
Innovation for patient care

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

IPSEN
Innovation for patient care

Update on the Open Pharma position statement on open access

Chris Winchester, Oxford PharmaGenesis

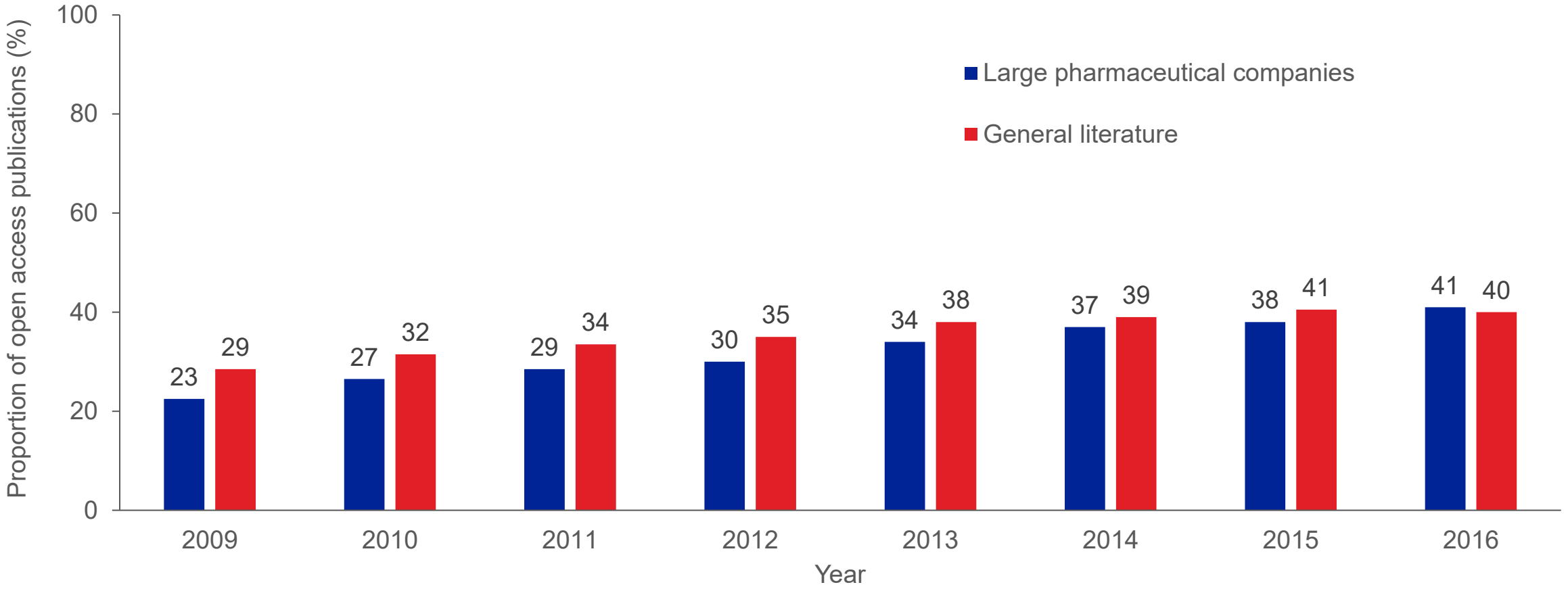
OpenPharma

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

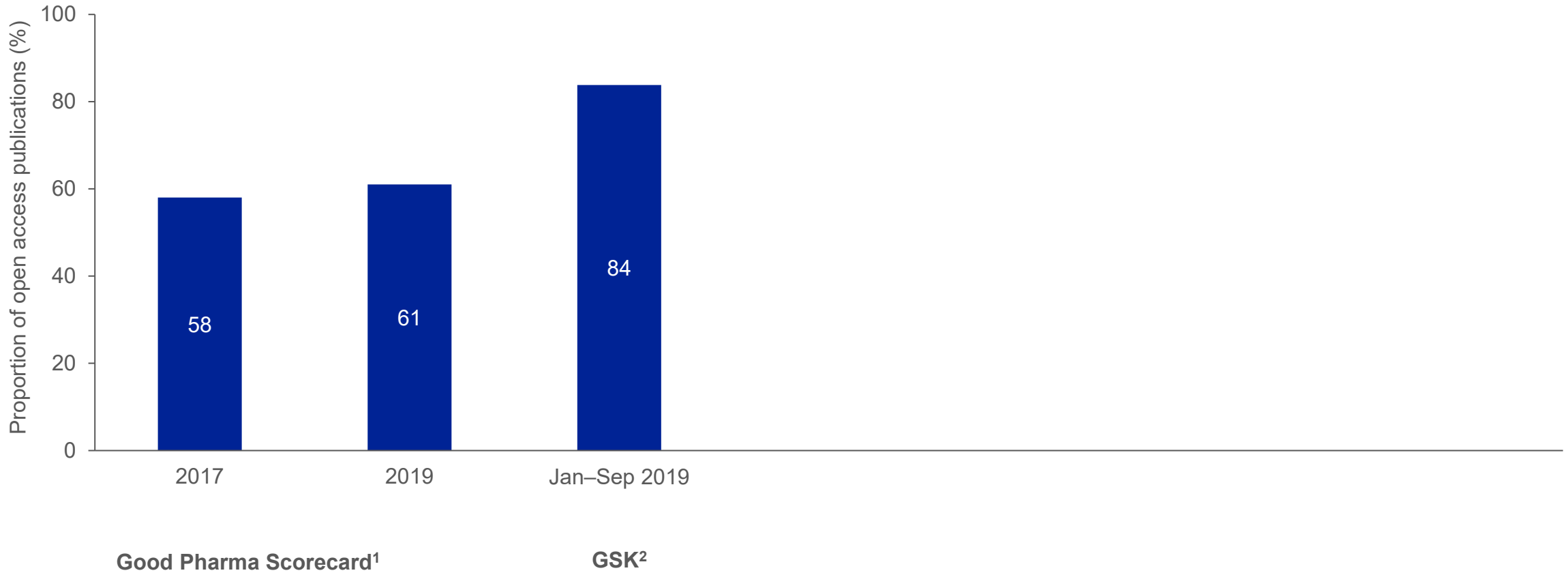
Pharma was lagging but is starting to take the lead

Large pharmaceutical companies have been publishing an increasing proportion of their scientific papers in open access journals[1]



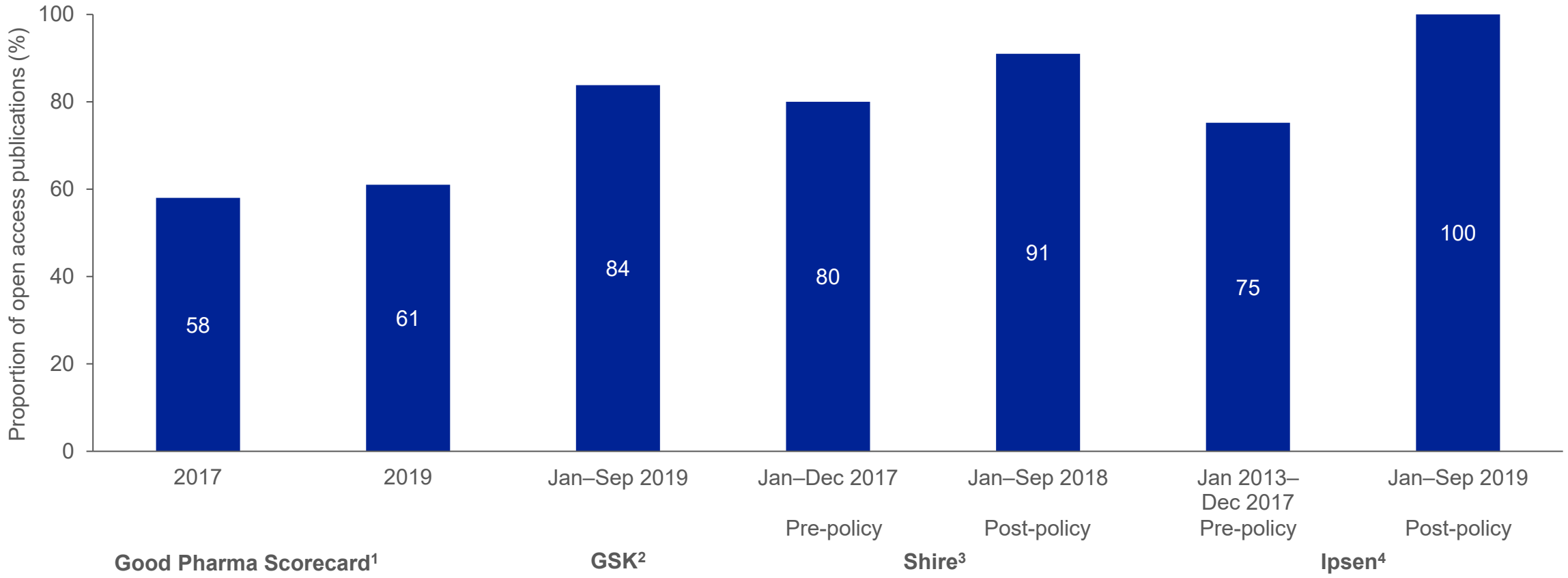
1. Yegros-Yegros A, van Leeuwen TN. *SocArXiv* 2019; https://doi.org/10.31235/osf.io/zt6kc (Accessed 20 April 2020).

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



1. Macdonald S, Koder T. Presented at ISMPP, January 21–22, 2020, London, UK; 2. Mysore S *et al.* Poster presented at ISMPP, January 21–22, 2020, London, UK;

And up to 100% by mandating open access



1. Macdonald S, Koder T. Presented at ISMPP, January 21–22, 2020, London, UK; 2. Mysore S *et al.* Poster presented at ISMPP, January 21–22, 2020, London, UK; 3. Philippon V *et al.* Poster presented at ISMPP, January 21–22, 2020, London, UK; 4. Page S *et al.* Poster presented at ISMPP, January 21–22, 2020, London, UK;

Position statement on open access

OpenPharma

> 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

Our objectives

OpenPharma

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**

BY, Attribution; CC, Creative Commons

Endorsements from individuals, organizations, pharmaceutical companies and publishers

OpenPharma

152 endorsements

8 publisher endorsements

- Betasciencepress Publishing
- ecancer
- F1000 Research Ltd
- Frontiers Media SA
- Future Science Group
- MDPI
- PLOS
- Wiley

27 endorsements from other organizations

- Ataxia and Me
- Autoinflammatory UK
- Cambridge Rare Disease Network
- Canadian Organization for Rare Disorders
- Centro Español de Investigación Farmacoepidemiológica
- Cinclus Pharma Holding AB
- DSL Consulting, LLC
- Epi-Fit
- Galápagos NV
- International Kidney Cancer Coalition
- Ipsen
- KAN Consulting MON. I.K.E
- Kidney Research UK
- Observational and Pragmatic Research Institute Pte Ltd
- Outcomes Positive, Inc
- Oxford Health Policy Forum
- Oxford PharmaGenesis
- Pedalling4ACure
- SCN2A Australia
- Scott Pharma Solutions
- Scriva medical Communications
- Sequoia Medical Communications Ltd
- Solanum Medical Communications Ltd
- SUDEP Action
- The Aarskog Foundation
- ThinkSCIENCE, Inc.
- Zimbabwe Evidence-Informed Policy Network

1–2 endorsements 3–5 endorsements 6–30 endorsements 31+ endorsements

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

Contributors

We thank all Members, Supporters and Followers of Open Pharma for their valuable input

Catherine Skobe
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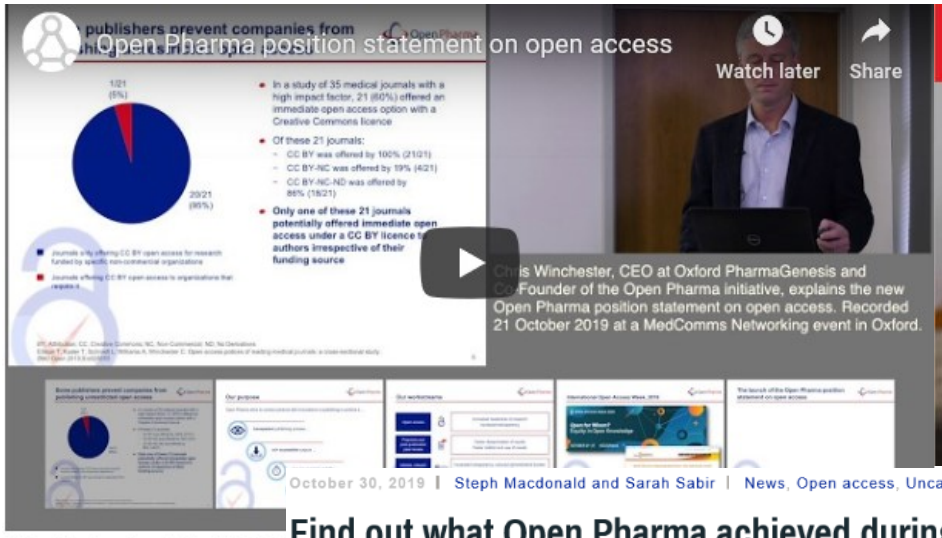
Associate Director, HIV, Gilead

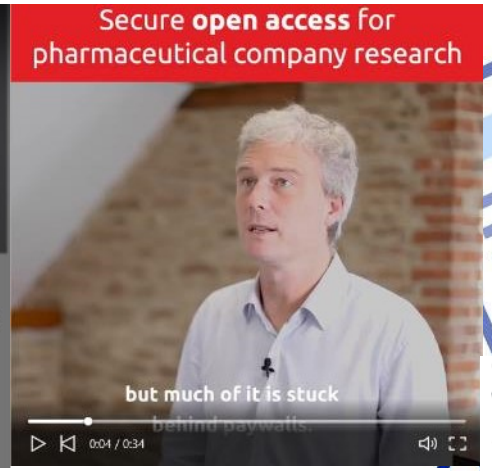
Lise Baltzer
Director Global Publications, Novo Nordisk

Sarah Sabir
Medical Writer, Oxford PharmaGenesis

Valérie Philippon
Head, Global Publications, Takeda

Coverage from Open Pharma





Chris Winchester, CEO at Oxford P
Open Pharma position statement on

October 30, 2019 | Steph Macdonald and Sarah Sabir | News, Open access, Uncategorized | Edit

Find out what Open Pharma achieved during Open Access Week 2019

November 7, 2019 | sarahsabir | Open access | Edit

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.

October 28, 2019 | Steph Macdonald | News | Edit

Weekly digest: what's happening in open science?

Featuring the launch of the Open Pharma position statement on open access, an introduction to the Open Science in Action Inaugural Symposium and a call to action for the UK government to do more to ensure transparent clinical trial reporting.

To open access and beyond via *Open Pharma*

Open Access Week 2019 kicked off with a bang for Open Pharma with the launch of our position statement on open access at the NetworkPharma MedComms Branch Meeting

Subscribe

Join 283 oth

You Retweeted

Chris Winchester @ChrisW_PharmaG · 14 Nov 2019

To help ensure that research funded by pharmaceutical companies is available to anyone who needs it, anywhere in the world, please join us in signing the @_OpenPharma position statement on #openaccess. openpharma.blog/position-state...

Chris Winchester @ChrisW_PharmaG

Over 40% of researchers from Africa, Asia and South America cannot access most or all of the academic research they need, say @andy_nobes and @SianHarris8 in their article posted on @EmeraldGlobal [awaiting peer review]. #openaccess

nt, which has already featured in an ar
l medical publishers to allow pharma th
ed to other funders. This would make
e of publication, for anyone, anywhere i

sday 23 October, the position statemer
iduals and 10 organizations, namely A
al & Pragmatic Research Institute, Oxfo
esis, SUDEP Action, ThinkSCIENCE In

Ataxia and Me CIO 1184030 and 1 other Retweeted

Sarah Sabir @SarahRSabir · 23 Oct 2019

Did you miss the launch of the **Open Pharma position statement** on **open** access? Watch @ChrisW_PharmaG share why we are pushing for **open** access. #OpenAccessWeek #OAWeek #OAWeek19 #OAWeek2019

peter llewellyn @networkpharma

#MedComms #ISMPP #EMWA #Openpharma #pubplan - Open access ensures that the highest quality, peer-reviewed evidence is available to anyone who needs it, anywhere in the world >> see youtu.be/UgG26ZioGn0

Show this thread

Reach of the position statement

OpenPharma

You Retweeted

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

You Retweeted

ecancer @ecancer · 7 Nov 2019

ecancer is proud to endorse @_OpenPharma's position statement on open access - by breaking down barriers to the published results of research we can narrow the gap between those who have access to adequate cancer prevention, treatment and care and those who do not. #openaccess

The Telegraph

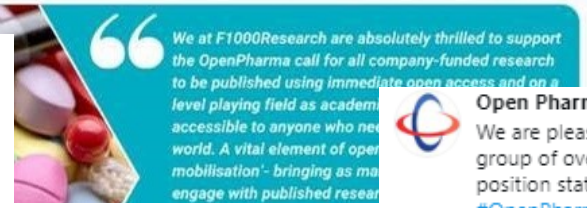
News › Global Health Security › Science & Disease

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

share Save

F1000 @F1000 · 1h

Supporting @_OpenPharma to make pharma-funded research accessible to anyone who needs it, anywhere in the world. @rnl_s, Managing Director @F1000, shares her thoughts on this goal & the benefit of immediate #OpenAccess #OAWeek #OpenScience openpharma.blog/position-state...



New organizational endorsements and 150 individual endorsements via *Open Pharma*

Open Pharma is pleased to announce that we have now gained 150 individual endorsements on our position statement on open access. We also have new endorsements from the Canadian Organization for Rare Disorders and Outcomes Positive, Inc., which brings us to a total of 37 organizational endorsements!

Chris Banks @ChrisBanks · 24 Oct 2019

Things I didn't know:
1) Pharmaceutical companies fund ½ of biomedical #research
2) Some companies are comitted to publishing #OA
3) They are often prevented from publishing #OA by #Publishers - no ev
playing field with other funded research
#OAWeek19

Position statement on open access

Pharmaceutical companies, which fund approxima
half of all biomedical research,1 are now leaders i
publication and disclosure of research.2,3 Howev

openpharma.blog

13 15

The MAP NEWSLETTER Highlights Leadership Message News & Trends Whe

Open Pharma Releases Position Statement on Open Access

Nov 13, 2019 | Highlights

Open Pharma @_OpenPharma · May 21

We are pleased to welcome @raredisorders 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.

You Retweeted

Chris Winchester @ChrisW_PharmaG · 28 Oct 2019

In the spirit of the @_OpenPharma position statement, @tandfmedicine offer #openaccess to all authors, regardless of their funding source or affiliation. 👏👏👏

To read the position statement in full, and sign up, see openpharma.blog/position-state... #OAweek #openaccessweek #pubplan

Taylor & Francis Medicine and Health @tandfmedicine

We welcome further discussion led by @_OpenPharma around making research more accessible and @tandfmedicine offer open access options to all of our authors irrelevant of funding/affiliation. #openaccess #openscience #openforall #OAWeek #pubplan #ISMPP

8 7

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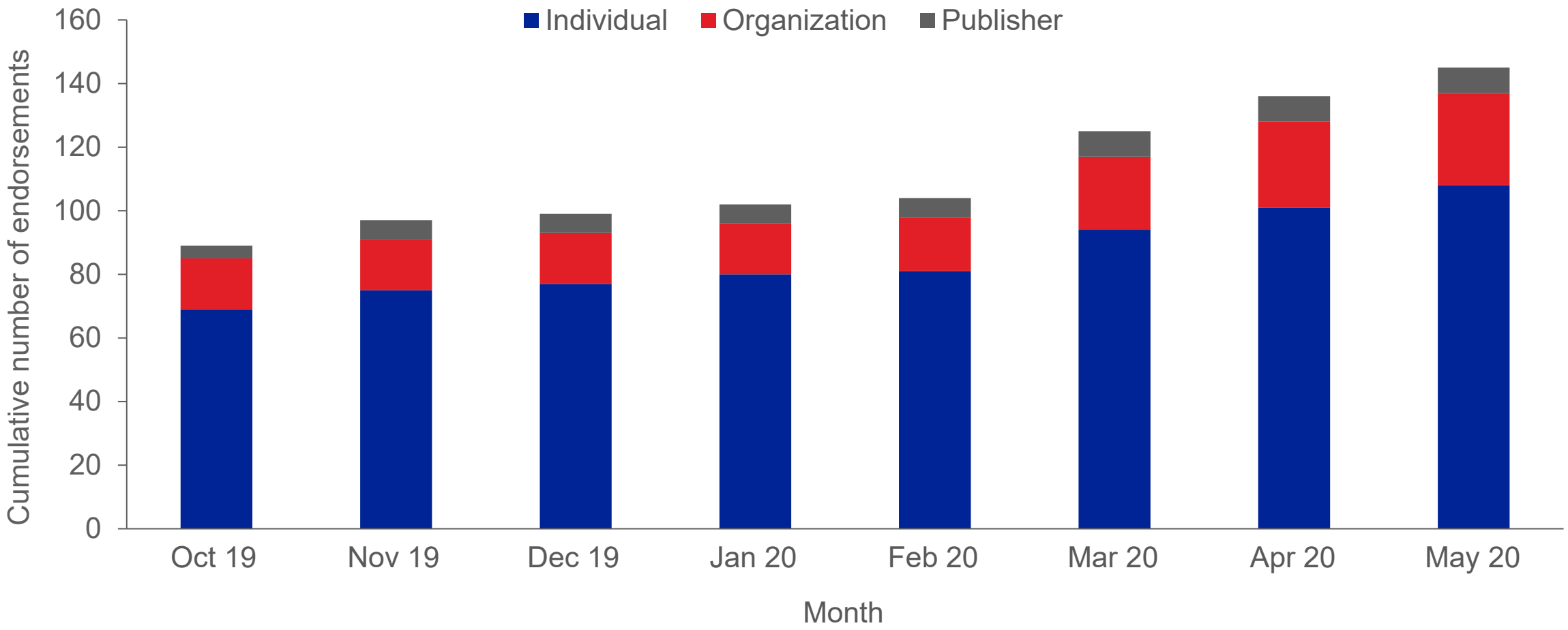
ation and disclosure...

7 7

Cumulative monthly endorsements



Cumulative monthly figures do not include the endorsements of the six authors of the position statement

Comments from individual endorsers

OpenPharma

"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

"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

"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

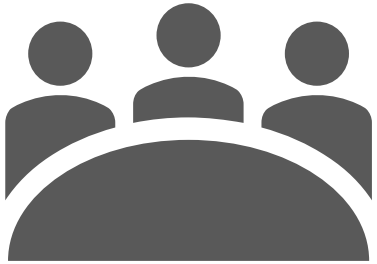
"Important step in enabling patient groups and charities to share relevant information with the community and build an informed society."

–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?

For later discussion



Update to the ICMJE recommendations (December 2019)

"Policies that dictate where authors may publish their work violate the principle of academic freedom"

ICMJE, International Committee of Medical Journal Editors

OpenPharma

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

OpenPharma

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

OpenPharma

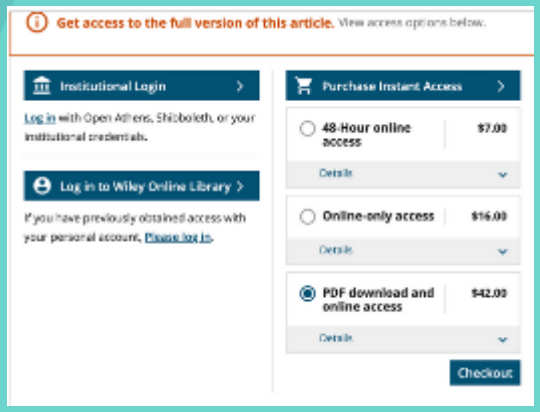
Should pharma provide scientific information to patients?

- 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

TERRIFYING COMPUTER NOTIFICATIONS



FEES TO ACCESS

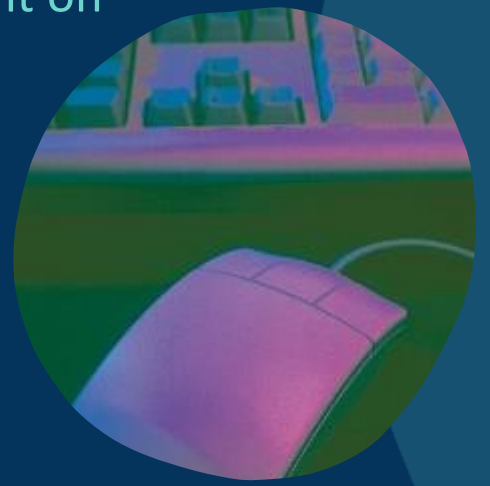
WHY PATIENTS NEED ACCESS TO PUBLISHED PRIMARY RESEARCH

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%

ARTICLES ARE ACCESSIBLE (DEPENDING ON TOPIC)

CASE: PATIENT AND PATIENT GROUP ACCESS (OR NOT)

MARTIN EVE

Humanities researcher, open access innovator and cerebral vasculitis patient

- I was dealing with four team: 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 do 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

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Improving the use of ORCID during the manuscript publication process

Sarah Sabir, Oxford PharmaGenesis

What is an ORCID iD?

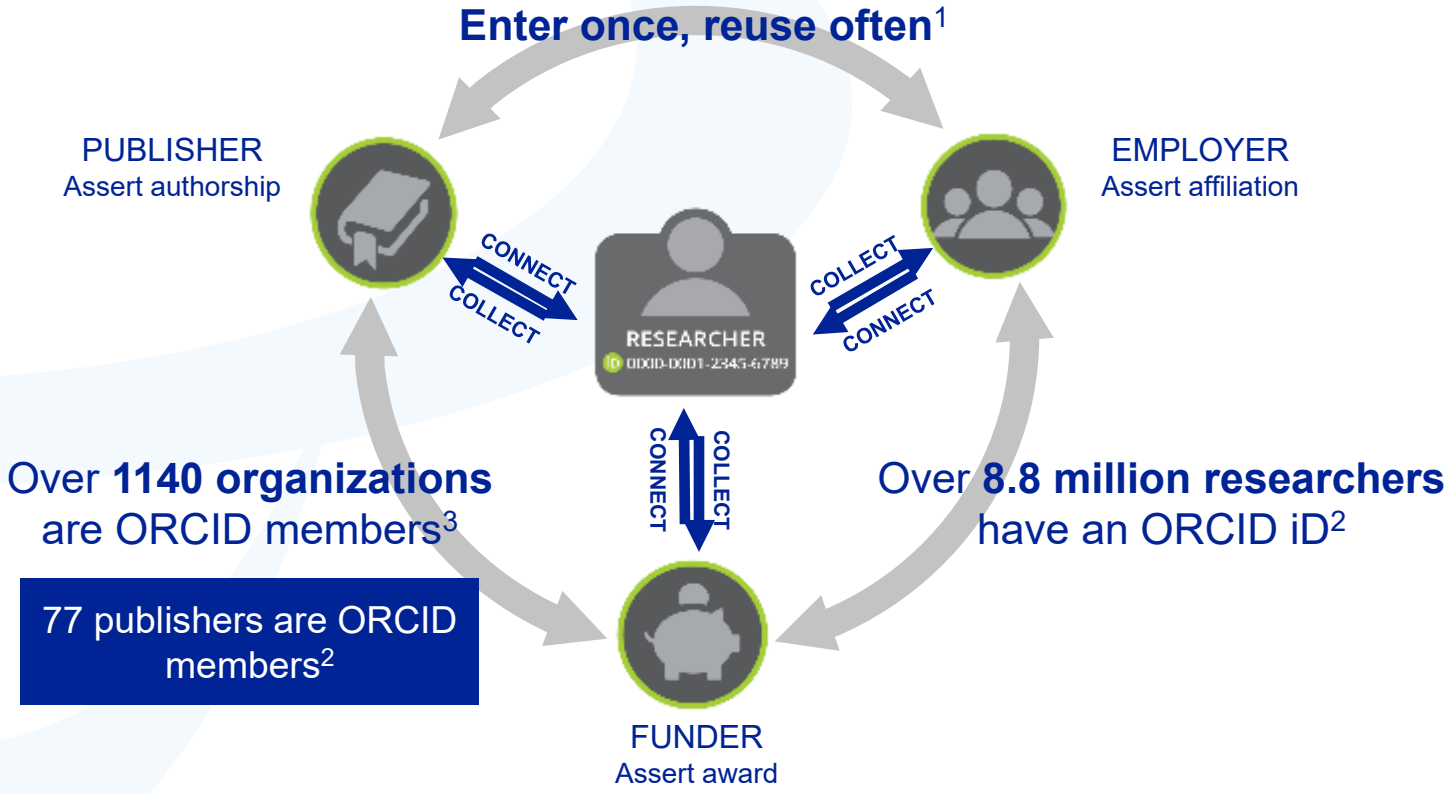
- A **persistent digital identifier** that distinguishes an account holder from every other researcher
- An ORCID iD can be **connected** with the researcher's professional information

Affiliations

Publications

Grants

Peer review



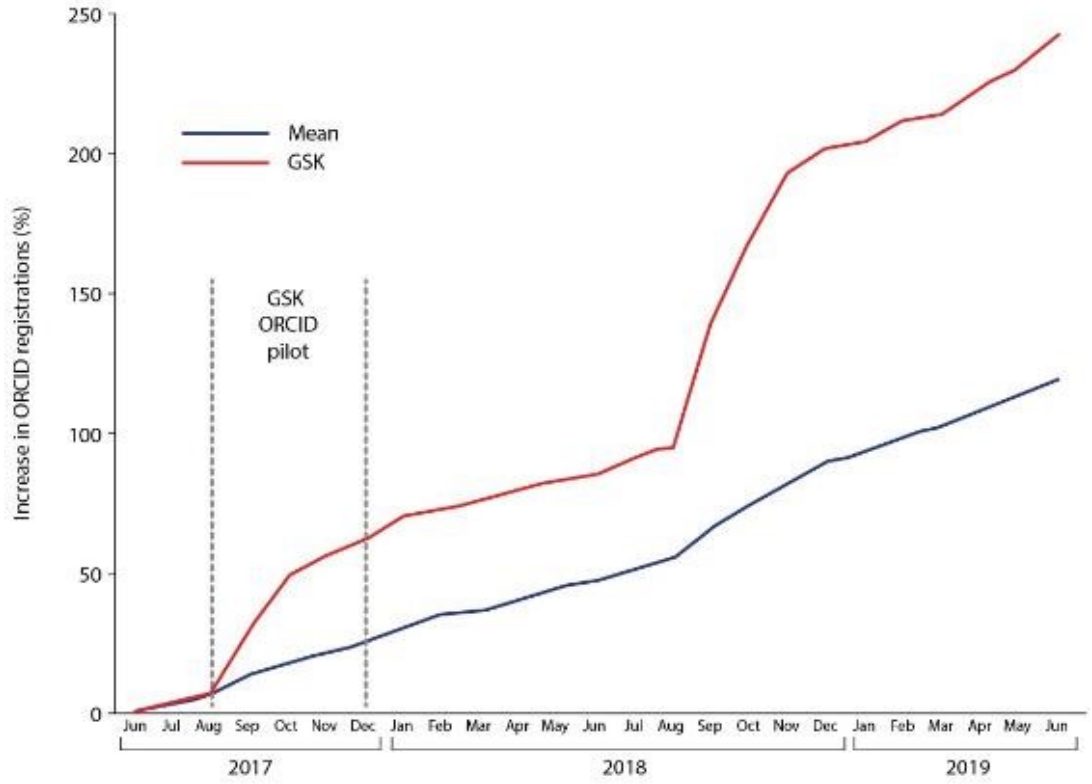
ORCID, open researcher and contributor ID

1. https://orcid.org/blog/2018/05/24/enter-once-reuse-often (Accessed 14 June 2020); 2. https://orcid.org/statistics (Accessed 14 June 2020); 3. https://orcid.org/members (Accessed 14 June 2020)

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

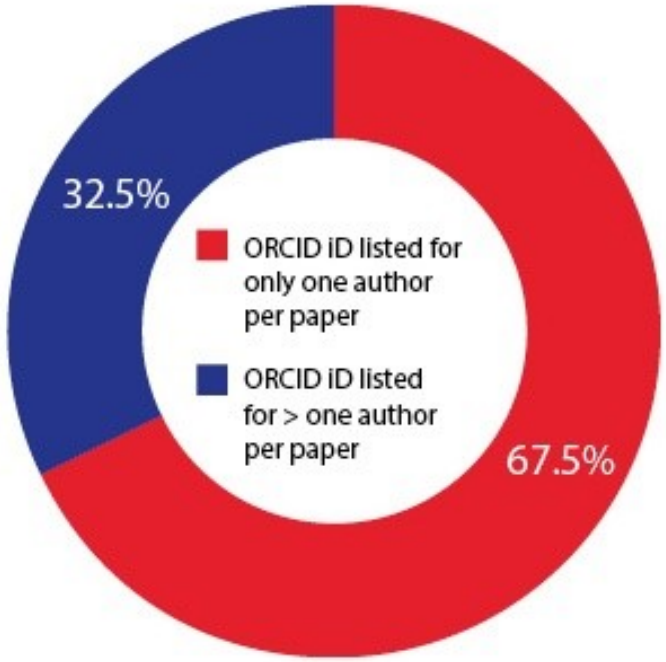
- PubMed data were extracted for **843** papers from **346** journals, listing **10 091** internal employees and external collaborators

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



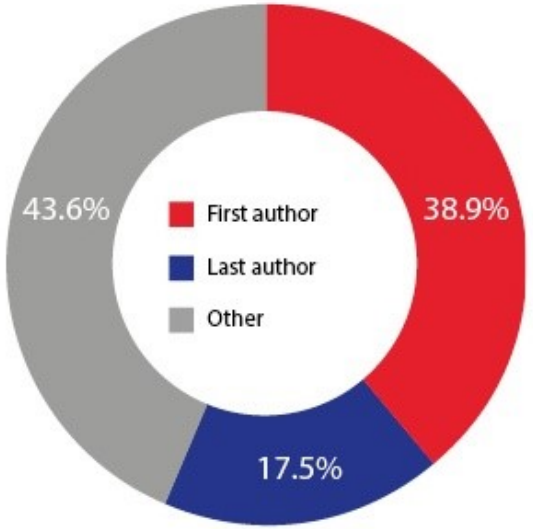
Use of ORCID in publications

4% **of**

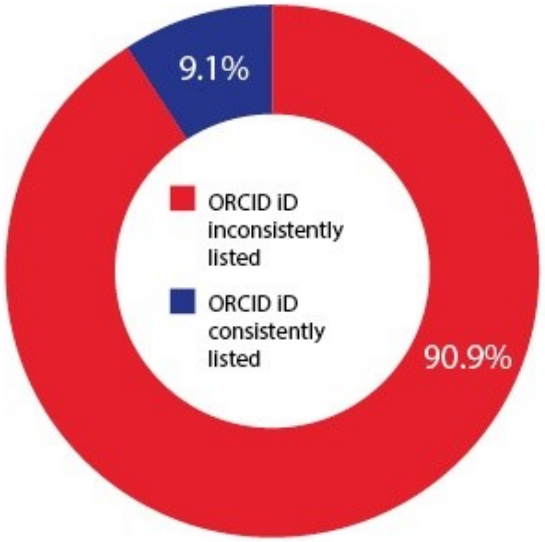
authors were listed with an ORCID iD

(388 out of **10 091)**

ORCID iDs were often provided for the first author[a]



For authors listed with an ORCID iD and who authored multiple publications, ORCID iDs were mainly inconsistently listed[b]



[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

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- 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

OpenPharma

- 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

OpenPharma

Accessibility

Accessibility

- **Publication plain language summaries** – Avishek Pal, Novartis
- **Preprints in the time of COVID-19** – Steph Macdonald, Oxford PharmaGenesis
- **Discussion** – All

Scientific Engagement & Communications | Novartis

Publication Plain Language Summaries (PPLS)

Open Pharma Meeting – June 15, 2020

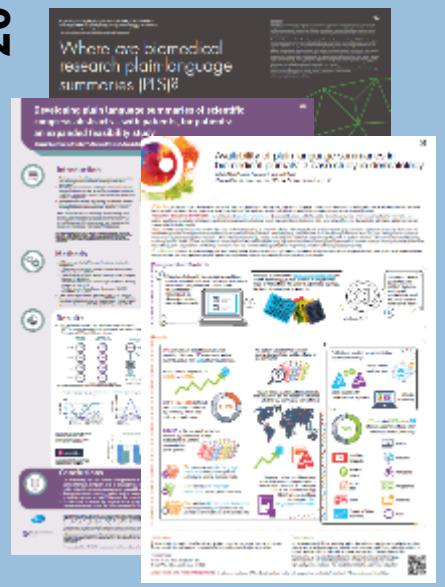
Avishek Pal

NOVARTIS | Reimagining Medicine

What propelled our PPLS journey?

Envision PFMD PLS workshop 2018

ISMPP Annual Meeting 2019



Open Pharma 2020 / ISMPP EU 2020

Virtual conferences 2020

ASCO AMERICAN SOCIETY OF CLINICAL ONCOLOGY

eular

AMERICAN ACADEMY OF NEUROLOGY

NOVARTIS | Reimagining Medicine

How did we approach it?

PPLS CTLS

Nomenclature finalization

Cross-divisional working group

Endorsement from Legal and Compliance

PPLS toolkit rollout

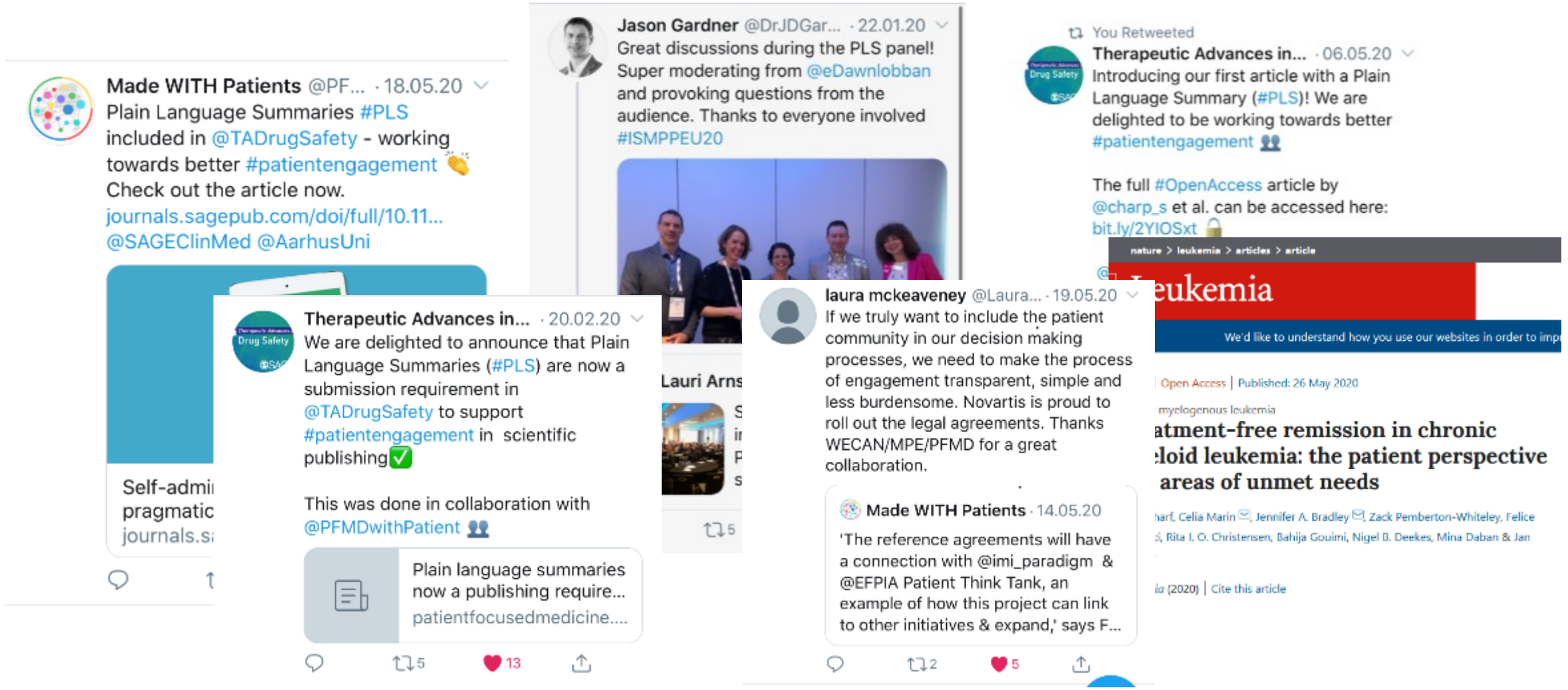
Discussion with Comms, Patient Relations/Advocacy

Phase-wise implementation

Internal advocacy and championing

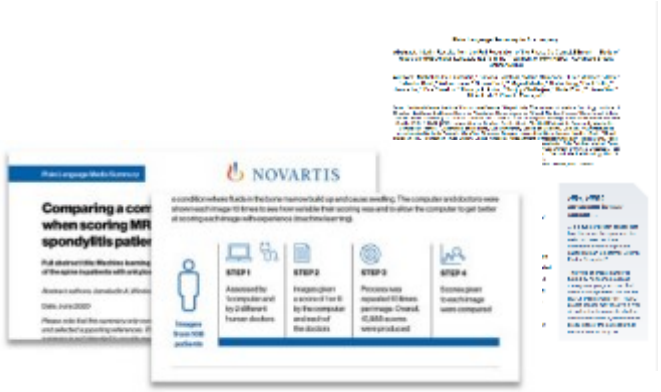
NOVARTIS | Reimagining Medicine

A more enabling external landscape!

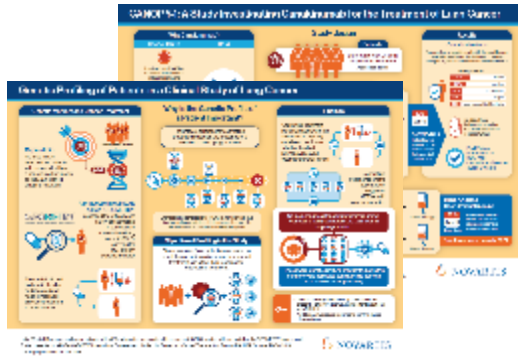


NOVARTIS | Reimagining Medicine

What have we dabbled in?

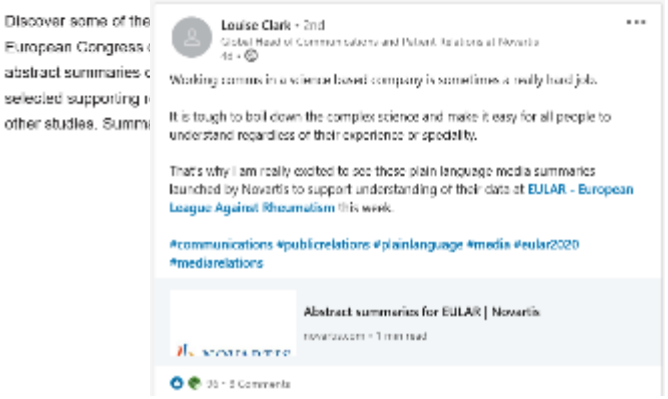


Conference abstract summaries

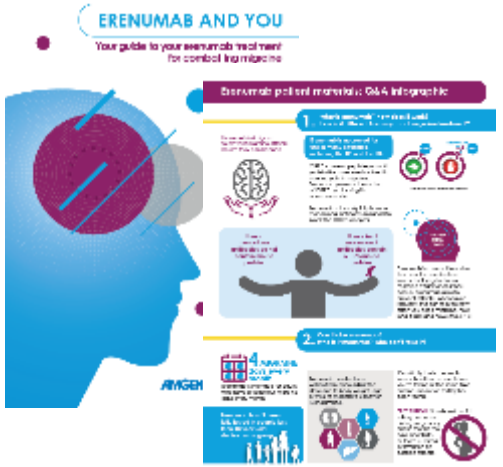


Plain language conference posters

Classic PPLS



External comms about
Conference abstract summaries

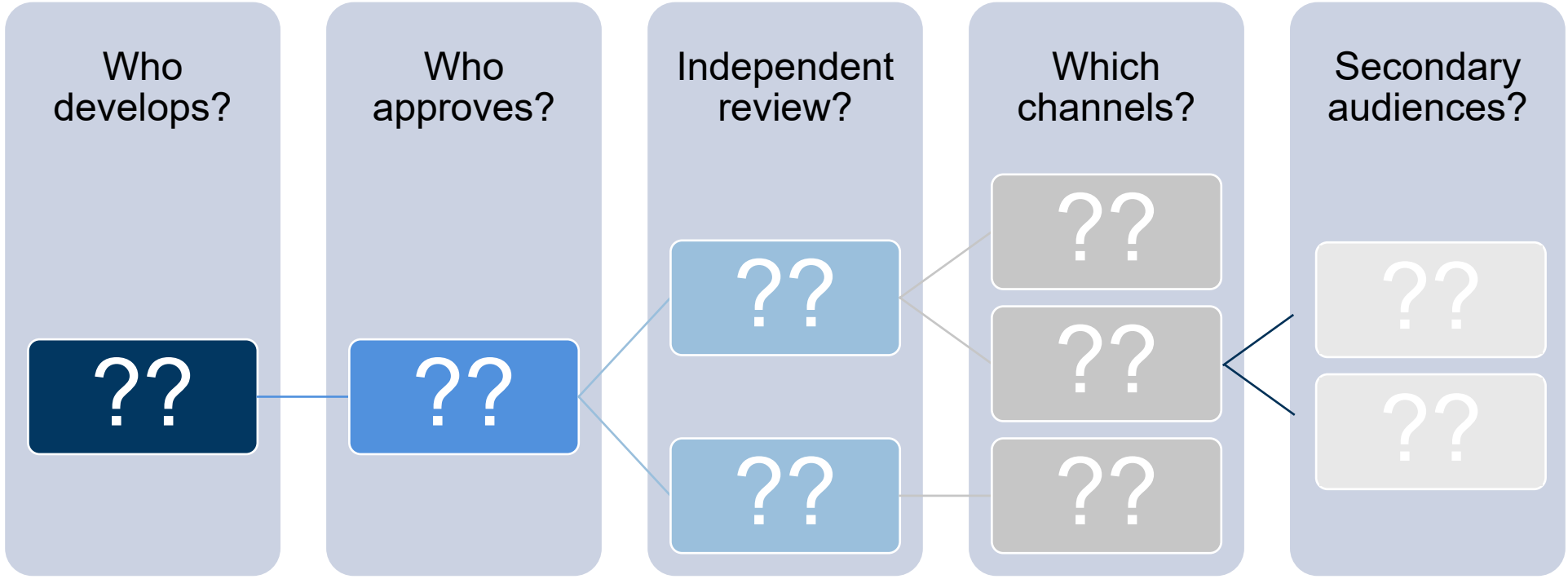


Plain language FAQs

NOVARTIS | Reimagining Medicine

Where are we headed?

- Expanding dissemination channels
- Exploring secondary use of PPLS



Thank you

NOVARTIS | Reimagining Medicine

Preprints in the time of COVID-19

Steph Macdonald, Oxford PharmaGenesis

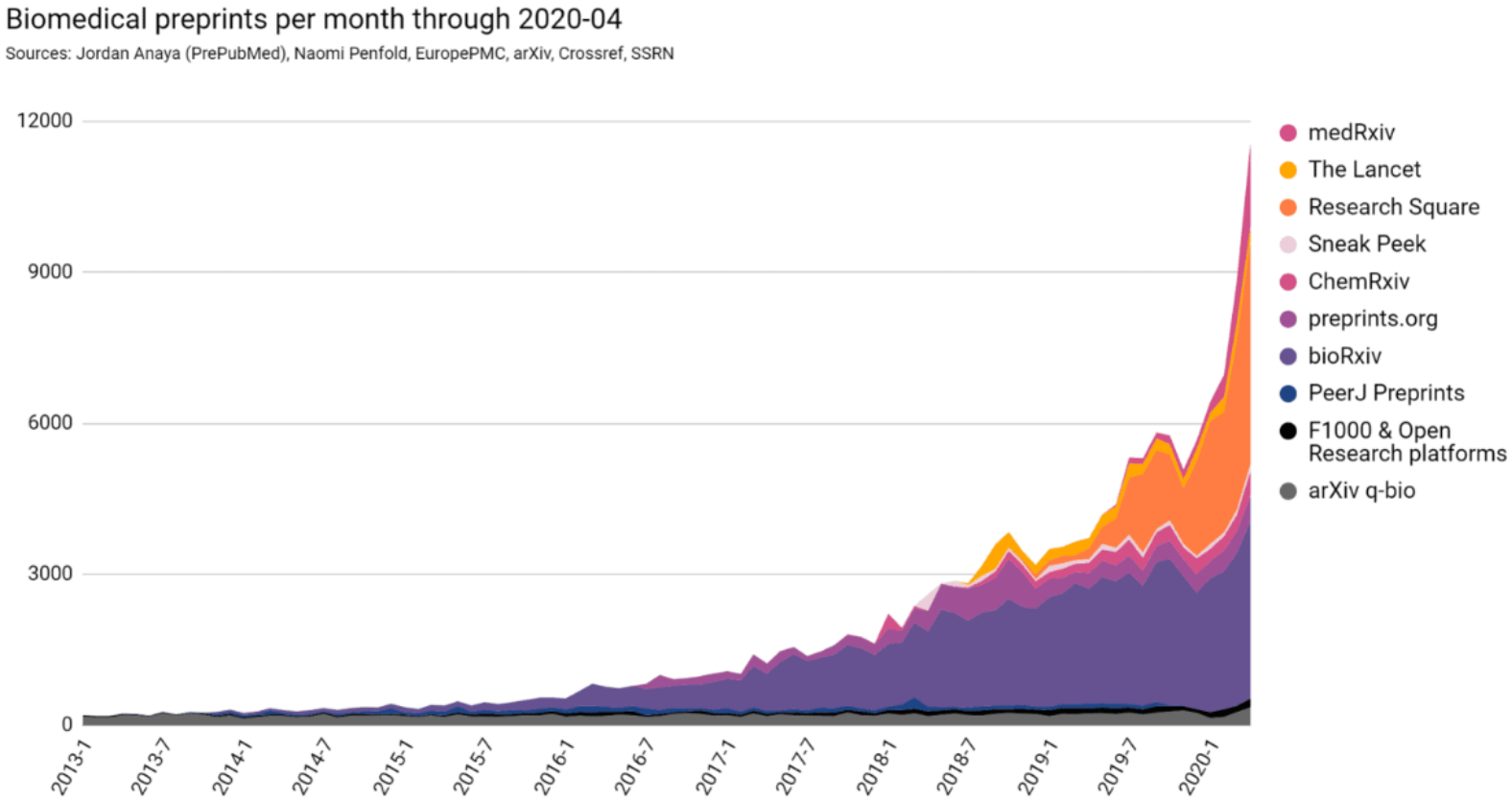
Rapid communication is key in medicine

> A preprint is a version of a scientific manuscript posted on a public server prior to formal peer review.
>
> PLOS[1]

- 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

DOI, digital object identifier

The rise of biomedical preprints[a]



[a]does not include 6000 preprints on relevant OSF platforms
Available from https://asapbio.org/preprint-info/biology-preprints-over-time. Accessed 13 May 2020

What constitutes a preprint server?

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1991 arXiv.org

1994 SSRN Tomorrow's Research Today

2013 bioRxiv THE PREPRINT SERVER FOR BIOLOGY

PeerJ Preprints

2019 medRxiv THE PREPRINT SERVER FOR HEALTH SCIENCES

figshare

zenodo

Assign DOIs and take all types of data

Expose some or all of the peer-review process

CellPress Sneak Peek A PREVIEW OF PAPERS UNDER REVIEW

F1000Research Open for Science

Praise for preprints

OpenPharma

THE WORLD UNIVERSITY RANKINGS

PROFESSIONAL JOBS EVENTS RANKINGS STUDENT

The Covid-19 outbreak highlights the potential of preprints

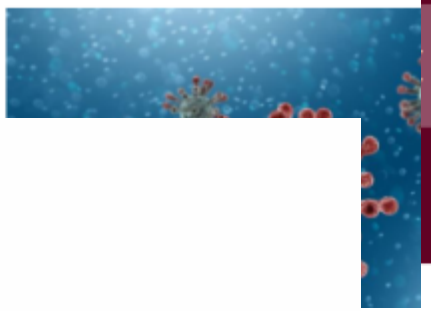
A recent posting on bioRxiv may have been erroneous, but the mistakes picked up within hours, notes Kristen Sadler

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



FEATURES / ISSUE: APR/MAY20 / GROWING SHARE FOR...

Growing share for preprints

2 April 2020

issue: APRIL/MAY 2020

topic tags: PREPRINTS, COVID-19

Five organisations define, describe, and share their thoughts on a subject that has become something of a hot topic in recent times

FIRST OPINION

Covid-19 is reshaping the world of bioscience publishing

By JEFFREY S. FLIER / MARCH 23, 2020

THE LANCET Global Health

COMMENT | ONLINE FIRST

PDF [192 KB]

Early in the epidemic: impact of preprints on global discourse about COVID-19 transmissibility

Maimuna S Majumder • Kenneth D Mandl

Open Access • Published: March 24, 2020 • DOI: https://doi.org/10.1016/S2214-109X(20)30113-3 •

Check for updates

Supplementary Material

Since it was first reported by WHO in Jan 5, 2020, over 80 000 cases of a novel coronavirus disease (COVID-19) have been diagnosed in China, with exportation events to nearly 90 countries, as of March 6,

Preprint to peer-reviewed publication: genomics

OpenPharma

27 January 2020

medRxiv

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

Now published in *Infection, Genetics and Evolution* doi: 10.1016/j.meegid.2020.104212

Posted January 27, 2020.

Download PDF

Data/Code

April 1 2020

Infection, Genetics and Evolution

Journal of Molecular Epidemiology and Evolutionary Genetics of Infectious Diseases (MEEGID)

ELSEVIER

Infection, Genetics and Evolution

Volume 79, April 2020, 104212

Short communication

Full-genome evolutionary analysis of the novel corona virus (2019-nCoV) rejects the hypothesis of emergence as a result of a recent recombination event

Risk mitigation at medRxiv

OpenPharma

Launched in June 2019, medRxiv is a HealthScience-specific preprint server

Performed at medRxiv and bioRxiv

Performed at medRxiv only

Author undertakings	Automated check	CSHL check	medRxiv affiliate check	**Escalation 1** experienced clinician editors	**Escalation 2** medRxiv leadership

CHSL, Cold Spring Harbour Laboratory

Quality control

Withdrawn

This article has been withdrawn. Click here for details

Previous

126 comments

Posted January 31, 2020.

Uncanny similarity of unique inserts in the 2019-nCoV spike protein to HIV-1 gp120 and Gag

Prashant Pradhan, Ashutosh Kumar Pandey, Akhilesh Mishra, Parul Gupta, Praveen Kumar Tripathi, Manoj Balakrishnan Menon, James Gomes, Perumal Vivekanandan, Bishwajit Kundu

doi: https://doi.org/10.1101/2020.01.30.927871

Abstract

This paper has been withdrawn by its authors. They intend to revise it in response to comments received from the research community on their technical approach and their interpretation of the results. If you have any questions, please contact the corresponding author.

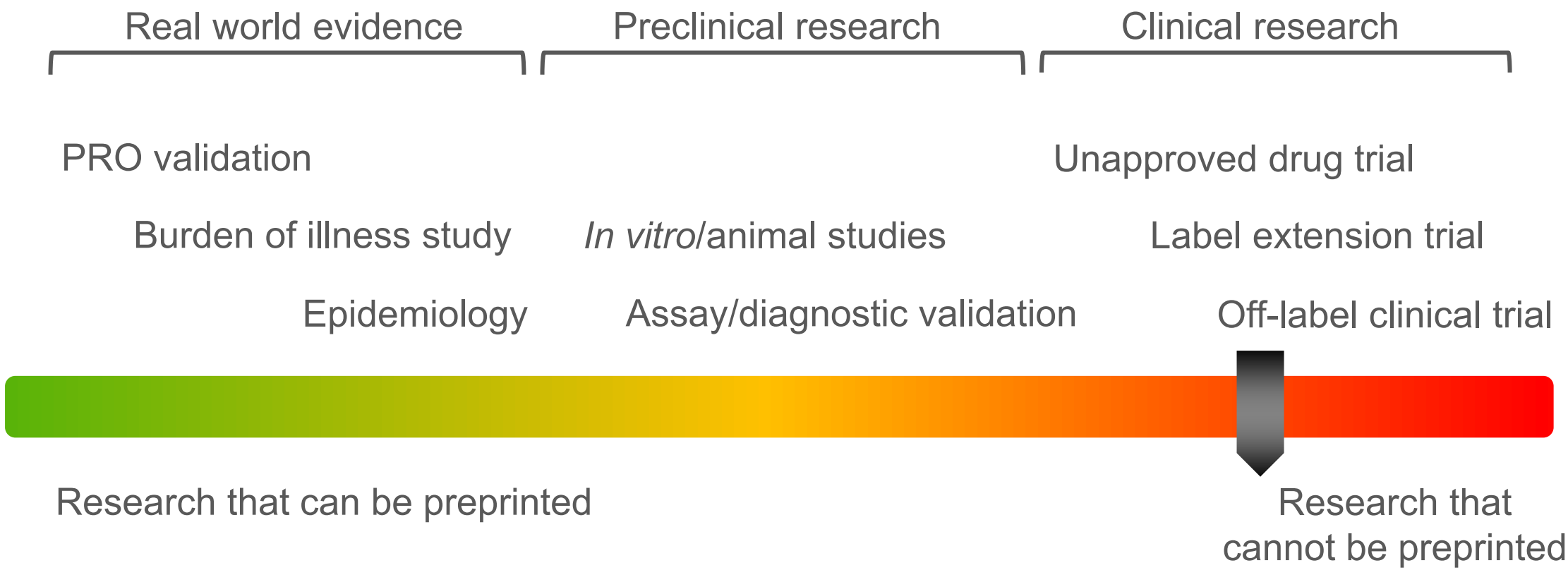
THE WATCHDOGS

Quick retraction of a faulty coronavirus paper was a good moment for science

By IVAN ORANSKY *and* ADAM MARCUS / FEBRUARY 3, 2020

What research should be shared as a preprint?

OpenPharma



Over 90% of research can be made available as a preprint

Summary of journal policies

OpenPharma

Journal	Accepts articles published as preprints
The NEW ENGLAND JOURNAL of MEDICINE	✓
JAMA Network™	Posting as a preprint will necessitate the decision as to whether publication will bring new/meaningful insight
Journal of Clinical Oncology® An American Society of Clinical Oncology Journal	✓
Annals of Internal Medicine®	No mention of preprints
THE LANCET	✓

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

OpenPharma

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

OpenPharma

Summary and close

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Thank you!