

HIFA Thematic Discussion on Improving Access to Health Research in Low- and Middle-Income Countries

Compilation of messages (Edited)

7 November - 2 December 2016

Note: For background info see: http://www.hifa.org/news/new-hifa-thematic-discussion-how-can-published-research-be-made-more-accessible-users-low-and

HIFA is grateful for sponsorship of this discussion from Elsevier and The Lancet

Participants

There were 43 messages from 15 participants in 9 countries (Australia, Bangladesh, Belgium, Canada, Honduras, India, Kenya, Nigeria, UK):

Barbara Kirsop (UK) 2 Chris Zielinski (UK) 3 Claire Allen (UK) Jackeline Alger (Honduras) James Heilman (Canada) Jan De Maeseneer (Belgium) Joseph Ana (Nigeria) 4 Katie Foxall (UK) Moderator (Neil PW) 19 Nasra Gathoni (Kenya) Noor Elahi (Bangladesh) Pamela Sieving (USA) 4 Sandeep Saluja (India) Sian Williams (UK) 2 Virginia Barbour (Australia)

Introduction

The Manila Declaration, which was strongly influenced by HIFA discussions in 2015, noted that 'despite a growing momentum towards free and open access to research literature, and important initiatives such as HINARI Access to Research In Health Programme and IRIS (Institutional Repository for Information Sharing) ... there continue to be many challenges, limitations and exclusions that prevent health research information from becoming freely and openly available to those who need it'.

http://www.hifa.org/sites/default/files/publications_pdf/Manila_Declaration_2015_FINAL_A ugust_242.pdf

There is a growing consensus that open access (OA) (via both journals and repositories) is the way forward for long term sustainable access, and to enable the use and reuse of published research. Bibliometric research shows strong advantages for those whose work is made available OA and many people also see OA as an ethical imperative which promotes equity

globally. More and more publishers, funding agencies, universities and governments are supporting, and in some cases requiring, OA publishing of research.

Definitions of access

NPW: I note that the Wikipedia entry on open access has evolved over the past year (I was involved in editing it)

The first part of the entry for Open Access in Wikipedia was (in September 2015):

'Open access (OA) means unrestricted online access to research outputs... Open access comes in two degrees: gratis open access, which is online access free of charge, and libre open access, which is online access free of charge and with some additional usage rights' I edited this in October 2015 to:

'Open access (OA) means unrestricted online access to research outputs, free of most copyright and licensing restrictions.'

The entry has further evolved since then to:

'Open access (OA) refers to online research outputs that are free of all restrictions on access (e.g. access tolls) and free of many restrictions on use (e.g. certain copyright and license restrictions).'

Gratis is still included further down the page, but is now effectively a historical footnote relating to 'two of the co-drafters of the original BOAI definition'. The current BOAI definition removes any confusion:

NPW: 1. Restricted-access (whereby published research is available only to those who pay for it - this has been the predominant model of journal publishing, but things are rapidly changing)

- 2. LMIC access initiatives. A range of initiatives aim to increase access to restricted-access research within low- and middle-income countries. They are responses by WHO (notably the HINARI programme) and NGOs such as eIFL and INASP to address the unaffordability of access to research in LMICs.
- 3. Hybrid access. Many of the major traditional publishers are publishing some papers 'restricted' and some papers 'open' access, with the aim to secure additionl income for the latter.
- 4. Free access. This describes published research that is freely accessible to anyone with an internet connection, but where sharing and adaptation of the content is not permitted or is restricted.
- 5. Open access. This describes free-access content that may be freely reproduced and adapted, ususally with attribution to the source.

NPW: 'By "open access" to this literature, we mean its free availability on the public internet, permitting any users to read, download, copy, distribute, print, search, or link to the full texts of these articles, crawl them for indexing, pass them as data to software, or use them for any other lawful purpose, without financial, legal, or technical barriers other than those inseparable from gaining access to the internet itself. The only constraint on reproduction and distribution, and the only role for copyright in this domain, should be to give authors control over the integrity of their work and the right to be properly acknowledged and cited.' https://en.wikipedia.org/wiki/Budapest_Open_Access_Initiative

NPW: I think it is finally time to stop talking about free access as open access, as some publishers still do.

Open access

NPW: Open access to all health research (ie free access content that may be freely reproduced and adapted, usually with attribution to the source) is the ideal that we should all be aiming for. Everything we do as stakeholders in the global healthcare information system should include the question: "Is this supporting/promoting the emergence of open access to health research?"

NPW: I think all major medical publishers are now including some aspect of open access in their publishing models - this represents a huge change over the past 10-15 years. There are, however, many questions about how this revolution in open-access publishing can best be managed in ways that promote sustainability and equity; and that maintain quality. There are questions also on how to promote open access publishing for national journals - I note that many African journals are indeed now available open-access, some of them apparently thanks to the African Journals Partnerships Programme - what can we learn from them?

NPW: What can be done to increase access to the vast majority of the health literature which remains restricted-access? Should we encourage more people to take advantage of HINARI? How?

NPW: It could be argued that open-access (the freedom to reproduce, adapt, translate and so on) has benefits for primary research, but has even greater potential benefits when applied to secondary materials (eg learning and reference materials, commentary, editorials, textbooks and manuals) than it does when applied to primary research. Paradoxically, open-access is more developed for journals and primary research than for educational/reference materials. Indeed some journals (eg BMJ) have made their primary research available open-access but maintain restricted-access to their educational and analysis content.

I wonder how appropriate open access is for journals which make most of their production money out of sales of paper copies - in other words, many developing country journals. Giving away their work online surely kills their paper versions and cuts off any revenue stream whatsoever. The journals still need to pay for an office, an editor, a web person, and the like, while the income dwindles to zero. Small low-impact-factor developing country journals have little prospect of successfully applying publication charges (pay to publish) - so what do they do?

Chris Zielinski, UK

Roadmap.eprints.org provides a directory of OA mandates which includes information for each mandate as to OA Gold fees and APCs being payable from funds.

Pam Sieving

There are hosting platforms that are freely avaliable. We for example host and run the Wiki Journal of Medicine on Wikiversity as seen here

<u>https://en.wikiversity.org/wiki/WikiJournal_of_Medicine</u> We would be happy to see further journals in different topic domains and in different languages begin.

While there are no associated costs and no advertising one is required to use an open license. One could co publish on a plateform such as this just in case ones other option went down aswell. Not sure if charging for publishing would be allowed such as most OA publishers do. James Heilman, Canada

The rise of open access in LMICs

I think the African Journal for Primary Health Care and Family Medicine, started in 2008 with a Seed money from Belgium Development of 12000 Euro, and actually with Prof Bob Mash as Editor, provides an excellent example of what can be realised with vision, enthousiasm and skills. It is free accessible at:

Prof Jan De Maeseneer

www.phcfm.org

NPW: I find it hugely encouraging to read about the growing success of journals such as the African Journal for Primary Health Care and Family Medicine. It seems to me that an increasing number of African medical journals are flourishing, and indeed are doing so with an open-access business model. I would be interested to better understand this success and what has supported it. In the case of the African Journal for Primary Health Care and Family Medicine, it seems this has been seeded with a relatively modest amount of money (12,000 Euros). Other African journals are in twinning partnerships with journals in high-income countries in the African Journals Partnership Programme. Many (most?) African medical journals are also part of the African Journals OnLine (AJOL) programme, which was started by INASP and which is now run independently from South Africa. INASP has since replicated the AJOL approach in other regions and countries, including Bangladesh, Nepal and Sri Lanka. I pay tribute to all these initiatives. Financially, their cost is (I think) minimal and yet they have had such a huge impact on the availability of local health research. And yet I suspect that the success of many individual journals is precarious. So what can be done to further strengthen local publishing in Africa and other regions worldwide?

NPW: Thanks again to AJOL, I was alerted to the latest issue of the African Journal of Reproductive Health.

http://www.ajol.info/index.php/ajrh/issue/view/15023

This issue is dedicated to the Sustainable Development Goals and all papers are open-access. I also learned from AJOL that it hosts 520 African journals (all disciplines) of which more than half (213) are open-access.

I would invite HIFA members to access the web site of Bioline at http://www.bioline.org.br where the following can be found: full text of articles in all the peer-reviewed journals from 16 LMICs... Barbara Kirsop, UK

Financing open access

NPW: I understand that some open-access journals do not charge APCs at all. Can anyone on HIFA describe how this works?

Sian Williams: "The way forward for the first is to ensure that all research budgets include sufficient for article processing charges. If the research is funded, so should dissemination of the findings. Is the way forward on reviewing is to consider capacity building in reviewing? Any suggestions for translation budgets?"

NPW: There is a very strong case for inclusion of APCs (including translations) in research budgets. How can this be promoted? Are there examples of research funders who insist on inclusion of a budget line for publishing in an OA journal?

The model which we have adopted at ecancer is to support the activities of the journal with income derived from other areas of the organisation (events management, sponsored filming,

elearning etc). .. We also have a Pay What You Can Afford model so that only authors who have funding specifically earmarked for dissemination of their results need to pay towards publication. More detail here: http://onlinelibrary.wiley.com/doi/10.1002/leap.1023/full Katie Foxall, UK

Perceptions of Open Access

In general the credibility of OA journals tends to be lower. The review and editorial process gives an impression of being less stringent. [*see note below] Sandeep Saluja, India

[*Note from HIFA moderator (Neil PW): Open access per se is not an indicator of quality. The Wiki Journal of Medicine is a member of the Directory of Open Access Journals, which 'proves a commitment to quality, peer-reviewed open access'. https://doaj.org/about]

It is incorrect to suggest OA journals are poor quality - some may be, as are some from commercially available journals.

Barbara Kirsop, UK

Predatory journals

NPW: The rise of predatory publishers is especially worrying. They not only cause misery to unsuspecting researchers. They also contribute to misconceptions about open-access publishing. What more can be done to promote and uphold high-quality OA publishing while stamping out predatory publishers?

Access initiatives

NPW: Even if some of us consider that open access is 'the future', we have to deal with the realities of the present. And this is where initiatives such as HINARI, EIFL and INASP remain important. How can these initiatives be made more effective? We know, for example, that HINARI is not used by the vast majority of institutions that are eligible to use it, especially small and medium sized facilities. Is there perhaps a role for HIFA and others to raise awareness about these initiatives?

The biggest challenge we now have is how to enable access to the journal and its services - peer review, support to publicity for authors - to authors from middle income countries or institutions who do not meet Hinari criteria.

Sian Williams, UK

Restricted-access journals

NPW: Thanks to AJOL (African Journals OnLine) I was alerted to the latest issue of the East African Medical Journal. The list of contents is available here:

http://www.ajol.info/index.php/eamj/issue/view/15010

The East African Medical Journal is one of the oldest, most established, and highly regarded medical journals in Africa. I note, however, that the journal remains restricted-access, which means that it is not currently available to many of those who would benefit. By contrast, many other leading African medical journals are now open-access.

This leads me to ask: What are the business plans for the EAMJ? What would it take to allow it to become open-access? What can be learned from other Africa journals that are already open-access?

I note also that 'The EAMJ has a 3 year embargo period/moving wall on its published content. Therefore all content older than 3 years will be freely available for download.'

Opening up the archives of restricted-access journals

NPW: Retrospectively, there is the potential to open up more of the health research literature from the past 10 years. Anyone who has done a review will have been frustrated by the inability to access past papers. Ethically, I believe there is a case that all health research after an embargo period (of, say, 1 year) should be made publicly accessible for free.

Neil PW: Access to the full text of research is especially important for those who undertake systematic reviews. I would be interested to hear from systematic reviewers, whether in HICs or LMICs, about their experience of identifying relevant papers and retrieving the full text of those papers. I suspect that a lot of research time is wasted trying to track down subscription-based content. This is another reason why it would make sense for all subscription-based publishers to be encouraged to release content after an embargo period of, say, 1 year. Some publishers do this already - why not others?

NPW: As we have discussed previously on HIFA, there is a strong case for all subscription-based journals to have a similar (and preferably shorter) embargo period. What would it take to persuade more journals to release 'old' content in this way? It is increasingly accepted that no new research should be undertaken without a synthesis of existing research, and it is therefore all the more important that researchers and reviewers have unfettered access to the medical literature.

Indexing

NPW: I would also like to bring in the question of indexing and the role of the Global Health Library and its regional Index Medici. These indexes were (I think) intended to complement Medline, and index all (or nearly all) non-Medline journals published in the different WHO regions. For example, there is the African Index Medicus. We don't hear much about these indexes on HIFA and I'm not sure why. Are they underresourced and/or underutilised? How can they be strengthened?

NPW: Should Medline remain US- and anglophone-centric, or should it expand its scope to index more journals from LMICs and in other languages? What is the role of the regional index medici (such as Africa Index Medicus) and how can this role be better supported?

While I would love to see Medline expand its journal coverage, I suggest that the election yesterday makes me skeptical that this is possible any time soon. Indexing actually costs money; the National Library of Medicine, which manages this, is one of the 27 institutes and centers at NIH. For several years there have been reductions in the NIH budget, or small increases that do not cover increases in costs of current operations. My only reason for this post is to make sure the reality is recognized. Continue to explore this with NLM, but also look elsewhere.

Pamela C. Sieving

NPW: Pamela Sieving: "While I would love to see Medline expand its journal coverage, I suggest that the election yesterday makes me skeptical that this is possible any time soon." This makes it all the more important to ensure support for the WHO's Global Health Library and its constituent Regional Index Medici (African index Medicus etc). 'The Global Index

Medicus (GIM) provides worldwide access to biomedical and public health literature produced by and within low- and middle- income countries. The main objective is to increase the visibility and usability of this important set of resources.' http://www.globalhealthlibrary.net/php/index.php

I would like to bring to your attention the African Index Medicus (AIM). This is a project initiated by World Health Organization, in collaboration with the Association for Health Information and Libraries in Africa (AHILA), with a purpose to "give access to information published in or related to Africa and to encourage local publishing" (http://indexmedicus.afro.who.int/). This initiative has made great strides in producing an index to African health literature and information sources and it is important that such initiatives are supported and capacity is expanded so as to ensure its sustainability. Nasra Gathoni, Kenya

Publisher associations

In Nigeria, four years ago, we formed the Association of Scholarly Publications in Nigeria (AESPN), essentially to address many business of scholarly journals in the country were already in the 'precarious' realm. Running costs were sky rocketing from the cost of paper, production/printing - most of it overseas / foreign exchange, drying up of subscription, drying up of adverts, etc etc.

Joseph Ana, Nigeria

Geographical disconnect in medical journal publishing

NPW: Thanks to AJOL (African Journals OnLine) I was interested to see the new issue of the Central African Journal of Medicine.

http://www.ajol.info/index.php/cajm

The Central African Journal of Medicine describes itself as 'a refereed journal which seeks to promote the practice and science of medicine in Zimbabwe, in other parts of Africa, and the rest of the world in general.'

Indeed, all five of the papers are from Zimbabwe (southern Africa). The papers are restricted-access.

We have discussed previously on HIFA about the geographical disconnect that sometimes exists between a journal's title and its content. A title with country/region A often contains content from country/region B, and vice versa. Given that the main value of 'local content' to readers is that it is indeed 'local' (from the same country, or at least region, as the reader), and given that readers and libraries have to make choices on which journals to subscribe to (and even, if they are open access, on which journals to follow), it seems that a realignment of titles and content would be desirable?

It would be interesting to hear more about this journal's development and plans. Is it perhaps in a stage of transition towards becoming a national journal for Zimbabwe? Or is this a reflection of a transfer of ownership to a Zimbabwe-based editorial team?

I look forward to comments and suggestions from HIFA readers. Is it important that the title of a journal reflects its content? What are the reasons for disconnect and how can these be addressed?

NPW: The new issue of Central African Journal of Medicine is now available on AJOL (African Journals OnLine)

http://www.ajol.info/index.php/cajm

The papers are restricted-access and from Zimbabwe and Nigeria.

I have invited the editor Prof IT Gangaidzo (Zimbabwe) to join us and share their experiences, challenges, and plans for the future.

Email: cajm@medsch.uz.ac.zw

Peer review

Sian Williams: "A second challenge will, inevitably, be the competition for reviewers, as more journals move to author-pays."

NPW: I'm not sure how open-access in itself would lead to greater competition for reviewers? Sian Williams: Response: Because journals are now marketing themselves to authors not readers. And good quality peer review is therefore more important.

Language

Sian Williams: "The third will be translations - it simply isn't true that the "medical language is English" which we have been told time and time again. Not in primary care." This is an important point. The lingua franca of medical publishing is English and yet English is not understood by the majority of the health professionals worldwide, including many medical doctors.

We provide free translation into English of Spanish and Portuguese submissions (in conjunction with Translators without Borders) and publish both versions open access. Katie Foxall, UK

Technology issues

NPW: I would like to make a comment and ask two questions particularly for those in low-bandwidth settings:

Comment: There exist organisations that specialise in this question (and others). One such organisation is Aptivate, which is UK-based and describes itself as 'The Digital Agency for International Development'. It has been a HINARI partner since 2006.

NPW: Question 1: Since September 2016 HIFA has a new website: www.hifa.org - It's important that this works well in low-bandwidth settings and I would welcome feedback from HIFA colleagues on the accessibility of the site. You can send your feedback to hifa@dgroups.org or direct to me at neil@hifa.org

NPW: Question 2: Which websites work well for you, and which could be better (in terms of download speeds)? I would be especially interested to hear about leading sites such as WHO (HQ, regional and country offices), MoH websites, medical journal websites, Wikipedia, HINARI, AJOL and other health websites that are used by citizens, health workers, researchers, policymakers...

Other issues

How can research waste be minimised?

NPW: We have discussed previously on HIFA how 85% of spending on global health research is wasted for many reasons, including failure to appraise the pre-existing evidence (thereby leading to unnecessary and/or duplicative research) and failure to publish (which may or may not be driven by commercial interests). These are global issues, but it seems likely that they are even more acute in low- and middle-income countries - there are many examples of unethical clinical research in LMICs, eg

https://en.wikipedia.org/wiki/Medical_experimentation_in_Africa

Profiles

HIFA profile: Jackeline Alger works in the Parasitology Service, Department of Clinical Laboratories, Hospital Escuela Universitario, and at the Faculty of Medical Sciences, Universidad Nacional Autonoma de Honduras, Tegucigalpa, Honduras. She is a Country Representative for HIFA and CHIFA and is the current holder of HIFA Country Representative of the Year

(2015). http://www.hifa.org/support/members/jackeline jackelinealger AT gmail.com

HIFA profile: Claire Allen is Operations Manager at Evidence Aid, UK. Professional interests: Evidence Aid (www.evidenceaid.org) provides evidence for people in disaster preparedness and response to make better decisions. Areas of interest = humanitarian crises, natural disasters and major healthcare emergencies (disaster = when a country is unable to cope with the disaster/crisis or emergency). She is a member of the HIFA Working Group on Access to Health Research. callen AT evidenceaid.org

HIFA profile: Joseph Ana is the Lead Consultant and Trainer at the Africa Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria. In 2015 he won the NMA Award of Excellence for establishing 12-Pillar Clinical Governance, Quality and Safety initiative in Nigeria. He has been the pioneer Chairman of the Nigerian Medical Association (NMA) National Committee on Clinical Governance and Research since 2012. He is also Chairman of the Quality & Performance subcommittee of the Technical Working Group for the implementation of the Nigeria Health Act. He is a pioneer Trustee-Director of the NMF (Nigerian Medical Forum) which took the BMJ to West Africa in 1995. He is particularly interested in strengthening health systems for quality and safety in LMICs. He has written Five books on the 12-Pillar Clinical Governance for LMICs, including a TOOLS for Implementation. He established the Department of Clinical Governance, Servicom & e-health in the Cross River State Ministry of Health, Nigeria in 2007. Website:

www.hriwestafrica.com
Joseph is a member of the HIFA Steering Group:

http://www.hifa.org/people/steering-group
jneana AT yahoo.co.uk

HIFA profile: Virginia (Ginny) Barbour is Executive Director of the Australasian Open Access Strategy Group, a position she has held since 2015. In 2004, she was one of the three founding editors of PLOS Medicine, finally becoming Medicine and Biology Editorial Director of PLOS from 2014 until 2015. She has a part time position split between the Library and as Professor in the Office of Research Ethics & Integrity at Queensland University of Technology (QUT). She is Chair of COPE (Committee on Publication Ethics). She has a medical degree from Cambridge University, and a DPhil from the University of Oxford. She has been involved in the development of a number of reporting guidelines including CONSORT, PRISMA and TIDieR statements. She has been and is currently involved with a number of Open Access, publishing, and ethics initiatives. She has an academic title as Professor in the School of Medicine at Griffith University, Queensland and is also an honorary Professor at the University of Queensland. She is based in Brisbane, Australia. Her ORCID ID is: 0000-0002-2358-2440

HIFA profile: Jan De Maeseneer is Secretary General of the Network Towards Unity for Health. The Network: TUFH is a global association of individuals, groups, institutions and organisations committed to improving and maintaining health in the communities they have a

mandate to serve. The Network: TUFH is a Non-Governmental Organisation in official relationships with the World Health Organization (WHO). Jan is a working family physician (part time) in the Community Health Centre Ledeberg-Ghent (Belgium). He is Head of Department of Family Medicine and Primary Health Care of Ghent University (Belgium). He is the Chairman of the European Forum for Primary

Care: <u>www.euprimarycare.org</u> <u>www.the-networktufh.org</u> jan.demaeseneer AT UGent.be

HIFA profile: Noor Elahi, Bangladesh Assistant Librarian Rajshahi University Central Library Rajshahi, Bangladesh email: jami_elahi_noor@yahoo.com

HIFA profile: Katie Foxall is Head of Publishing at eCancer, Bristol, UK. katie AT ecancer.org

HIFA profile: Nasra Gathoni is past President of the Association for Health Information and Libraries in Africa (AHILA). She is a librarian at the Aga Khan University, KENYA and her areas of interest include: information literacy, evidence based medicine, access to online resources. nasra.gathoni AT aku.edu

HIFA profile: Barbara Kirsop is the Co-founder of Bioline International (http://www.bioline.org.br), that was established 20 years ago. Bioline is a platform for bioscience articles published in developing countries and made available on an open access basis. Barbara is an advocate of the movement towards free and open access to all published research papers through the global Open Access movement. This interest is shared by her colleagues at the Electronic Publishing Trust for Development, www.epublishingtrust.org

HIFA profile: Neil Pakenham-Walsh is the coordinator of the HIFA campaign (Healthcare Information For All - www.hifa.org) and current chair of the Dgroups Foundation (www.dgroups.info). Twitter: @hifa_org FB: facebook.com/HIFAdotORG neil@hifa.org

HIFA profile: Sandeep Saluja is an Internist at Saran Ashram Hospital, Dayalbagh, Agra, India. He is also a Rheumatologist and was earlier with the All India Institute of Medical Sciences. He has volunteered to work in remote inaccesible parts of India for no personal or commercial reasons. He is a member of the HIFA working group on Information for Prescribers and Users of Medicines. www.hifa.org/projects/prescribers-and-users-medicines Twitter @doctorsaluja Email: doctorsaluja AT gmail.com

HIFA profile: Pamela Sieving is a special volunteer at the National Eye Institute/National Institutes of Health, and an independent consultant in biomedical information access; she works primarily in the vision community to increase access to information needed to preserve and restore vision. pamsieving AT gmail.com

HIFA profile: Sian Williams is Executive Officer at the International Primary Care Respiratory Group in the UK. Professional interests: Implementation science, NCDs, primary care, respiratory health, education, evaluation, value, breaking down silos. sian.health AT gmail.com

HIFA profile: Chris Zielinski is the Director of Partnerships in Health Information (Phi), formerly an NGO, and now a programme of the Centre for Global Health, RKE, University of Winchester, UK, where Chris is a Senior Fellow. Phi supports knowledge development and brokers healthcare information exchanges of all kinds. He has held senior positions in publishing and knowledge management with WHO in Brazzaville, Geneva, Cairo and New Delhi, and with FAO in Rome and UNIDO in Vienna. Chris also spent three years in London as Chief Executive of the Authors Licensing and Collecting Society. He was the founder of the ExtraMED project (Third World biomedical journals on CD-ROM), and managed the Gates Foundation-supported Health Information Centres project. He served on WHO's Ethical Review Committee, and was an originator of the African Health Observatory. Chris has been a director of the World Association of Medical Editors, UK Copyright Licensing Agency, Educational Recording Agency, and International Association of Audiovisual Writers and Directors. He has served on the boards of several NGOs and ethics groupings (information and computer ethics and bioethics). UK-based, he is also building houses in Zambia. His publications are at www.ResearchGate.net and his blog is http://ziggytheblue.wordrpress.com chris AT chriszielinski.com