













HIFA Photo Award Winner 2018: © 2016 Leyla Emektor, Courtesy of Photoshare

HIFA in 2018 The Year in Review and Objectives for 2019

Healthcare Information For All www.hifa.org

What is HIFA?

HIFA is a dynamic global campaign and knowledge network with a shared vision:

"A world where every person and every health worker has access to the healthcare information they need to protect their own health and the health of others."

Why we need to achieve the HIFA vision

Every day thousands of children and adults die needlessly because they do not receive basic life-saving interventions - interventions that are often locally available but are simply not provided due to indecision, delays, misdiagnosis, and incorrect treatment. Many would still be alive today if those responsible for their care had access to basic healthcare information. For example, 6 in 10 parents of children with diarrhoea in India believe they should withhold fluids, contributing to hundreds of unnecessary deaths every day in India alone. HIFA members report a similar picture of unnecessary deaths in all low- and middle-income countries (LMICs), not only for childhood diarrhea but for all life-threatening diseases and injuries of children, women and men.



Membership growth during 2018 (all forums)

How is HIFA working to end this crisis?

At the heart of HIFA is a virtual 'think-tank' of over 19.000 members from 180 countries, interacting across 6 forums in 4 languages (English, French [http://www.hifa.org/ forums/hifa-french], Portuguese [http://www.hifa.org/ forums/hifa-portuguese], Spanish [http://www.hifa.org/ forums/hifa-spanish]). They represent the full range of providers and users of health information (health workers, publishers, librarians, researchers, policymakers, social human rights advocates, representatives...). HIFA members communicate about how to improve the availability and use of reliable healthcare information in LMICs, sharing expertise and experiential knowledge unavailable elsewhere. This helps build a collective **understanding** of the issues from global to local level, and shapes our advocacy for the political and financial support needed to accelerate progress towards the HIFA vision.



HIFA Community

In 2018 we increased our total membership by 7% to 19,062 in 180 countries. [http://www.hifa.org/news/membership-hifa-forums-jan-dec-2018]

- Membership of HIFA (English) increased by 10% to 11,380
- Membership of CHIFA (Child Health and Rights) increased by 7% to 3,705, as a result of the combined efforts of the CHIFA moderators, International Child Health Group, and International Society for Social Paediatrics and Child Health.
- Membership of HIFA-French increased by 9% to 860, under the leadership of Isabelle Wachsmuth (Head of Linguistic Collaborations, WHO)
- HIFA-Portuguese increased by 3% to 2,192
- HIFA-Spanish grew from zero to 431 in the last 2 months of 2018
- Our work with the Zambia UK Health Workforce Alliance helped increase the membership of HIFA-Zambia by 5% to 506

2019 OBJECTIVES

- Increase total membership to >20,000 members
- Increase membership from underrepresented regions (Central Asia, China, Eastern Europe Eastern Mediterranean, Russia)

HOW YOU CAN HELP:

Join HIFA today and interact on the forums!

HIFA Voices

HIFA members share their experiential knowledge and expertise across the HIFA forums to create an evolving picture of health information needs and, crucially, how to meet them. Key points are uploaded to HIFA Voices, a searchable openaccess database.

2019 OBJECTIVES

 Explore options to increase value to HIFA community and ensure sustainability

HIFA Advocacy

"Healthcare Information For All is an ambitious goal but it can be achieved if all stakeholders work together."

World Health Organization

Achieving and sustaining the HIFA Vision requires the support of decision makers. That is why HIFA has evolved a multi-level advocacy strategy, harnessing the full range of resources across our community: individuals, organisations, and networks.

HIFA Country Representative Programme

"I am delighted to be recognised as Country Representative of the Year 2018. All the work from Honduras has been possible thanks to the support of other HIFA Country Representatives. HIFA helps me to build bridges with health organisations worldwide. We are happy to now have HIFA-Spanish and



we will continue promoting HIFA's vision in our daily work."

Jackeline Alger, University of Honduras

HIFA Country Representatives (CRs) help to grow our membership in each country, and raise awareness about the importance of access to healthcare information.

In 2018, we:

- Expanded our HIFA CR programme by 15% to 210 CRs in 85 countries.
- Expanded our CHIFA CR programme by 25% to 60 CRs in 44 countries.
- Maintained two dedicated Communities of Practice (CoPs) to support CR communication and coordination.

We provided technical support to a number of CRs, including: Gladys Dadzie (Ghana), who represented HIFA at the Nurse Leadership Conference, Lagos (April 2018) and presented HIFA on Ghana Television (May 2018). Jennifer Kizza and David Musoke (Uganda) gave a presentation on HIFA at Makerere University, Kampala (April 2018). Poorva Patil presented HIFA at the Implementing Best Practice conference in Delhi, India.

Our country representative of the year 2018 is **Jackeline** Alger, Honduras.

2019 OBJECTIVE

Expand HIFA (and CHIFA) CR programmes to at least 250 in 90 (CHIFA: 70 in 50) countries, respectively.

HOW YOU CAN HELP:

Already a HIFA member? Become a HIFA Country Representative!



HIFA Supporting Organisation Programme

By the end of 2018, 326 health and development organisations worldwide had declared their support for the HIFA vision. 40 SOs also gave a financial contribution in 2018. Financial SOs are prominently recognized on our home page, conference presentations, and publications (see back page).

In 2018 we achieved the following

- Ratified 16 new HIFA SOs, bringing the total to 326 in 64 countries
- Ratified 10 new CHIFA SOs, total 27 SOs in 15 countries.

2019 OBJECTIVE

Ratify at least 30 and 20 new HIFA and CHIFA SOs, respectively

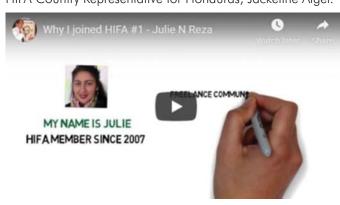
HOW YOU CAN HELP:

Apply for membership of HIFA as a Supporting Organisation (without financial obligation)

Social media

The HIFA Social Media Group expanded to 9 volunteers, with leads in place for Twitter (@hifa_org), Facebook (HIFAdotORG), LinkedIn and YouTube. During 2018 Twitter followers increased by 20% to 3006. Likes on HIFA Facebook increased by 18% to 1650. HIFA produced 3 YouTube videos, 21 news articles and 10 HIFA Blogs.

In 2018 we launched the "Why I joined HIFA" video series, with a video from HIFA Steering Group member Julie Reza http://www.hifa.org/news/why-did-i-join-hifa-julie-n-reza followed by two videos (one in English, one in Spanish) by HIFA Country Representative for Honduras, Jackeline Alger.



2019 OBJECTIVE

Continue to build our Social Media presence through Twitter, Facebook, LinkedIn, YouTube and other media.

HOW YOU CAN HELP:

Connect with HIFA on Twitter, Facebook, LinkedIn and YouTube!

www.twitter.com/hifa_org
www.facebook.com/HIFAdotORG
https://www.linkedin.com/company/healthcareinformation-for-all-hifa-/

https://www.youtube.com/HIFAGlobalHealth

HIFA Photographer of the Year Award

HIFA was proud to continue our collaboration with Photoshare, a service of the Knowledge for Health (K4Health) project, based at Johns Hopkins Bloomberg School of Public Health Center for Communication Programs (CCP), helping international nonprofit organisations communicate health and development issues through photography. The winner of the HIFA Photographer of the Year in 2018 is Leyla Emektar from Turkey. Her photo (see front cover) captures a poignant moment of crossgenerational care provided by a new generation of professional health worker.

Conferences and collaborations

HIFA gave several presentations during 2018, including United Nations Association, Lymington (February, Dgroups webinar (March), Makerere University, Uganda (March) [http://www.hifa.org/news/jennifer-kizza-and-davidmusoke-bring-hifa-makerere-university-uganda], Oxford Global Health Group (May), mHealth Conference, Oxford University (May), Ghana Television [http://www.hifa.org /news/hifa-country-representative-year-gladys-dadzieghana-television] (May), Dgroups webinar [http://www. hifa.org/news/how-does-hifa-work-using-dgroups-platformsupport-community-purpose] (May), Implementing Best practice, London (June), International Health Congress, Oxford http://www.hifa.org/news/hifa-presents-universalaccess-healthcare-information-international-health-congress -oxford-uk (June), Health Systems Research symposium, http://www.hifa.org/news/hifa-presentationhealth-systems-research-symposium-universal-access-health care-information (October), HIFA-Spanish (November). http://www.hifa.org/news/hifa-spanishlaunches-7-november-2018-hifa-espanol-se-lanza-el-7-denoviembre-de-2018

Publications

In December 2018 we published an editorial in *BMJ* Paediatrics Open: Why health information needs to be accessible to all

http://www.hifa.org/news/bmj-paeds-open-editorial-why-health-information-needs-be-accessible-all

HIFA and WHO

"HIFA facilitates networking across the full range of stakeholders in global health."

World Health Organization

In October 2018 HIFA, WHO and PAHO celebrated the launch of our sixth HIFA forum, HIFA-Spanish, in collaboration with the WHO Collaborating Centre at the Andalucian School of Public Health.

http://www.hifa.org/news/hifa-spanish-launches-7-november-2018-hifa-espanol-se-lanza-el-7-de-noviembre-de-2018

HIFA continues to collaborate closely with WHO and PAHO on HIFA-French and HIFA-Portuguese.

 The HIFA Steering Group has four WHO staff members (two at HQ; one at PAHO; one at WHO Africa Regional Office) as well as two recently retired senior staff members and one WHO consultant. We also have WHO representation among our Country Representatives and on seven HIFA Project working groups (below).



HIFA and WHO are exploring possibilities for development and launch of new HIFA Forums as part of a Memorandum of Understanding for continued collaboration in 2019 and beyond.

2019 OBJECTIVES

We shall continue to expand our collaborative activities with WHO during 2019, with a view to reassess our potential to apply for NGO in Official Relations in late 2019/20.

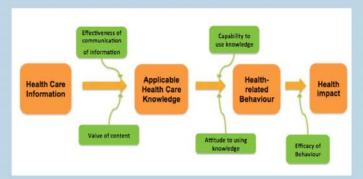
We shall work with WHO to assess potential for a HIFA forum in a fifth language (?Arabic,?Chinese...)



Accelerating Universal Health Coverage through Universal Access to Essential Healthcare Information

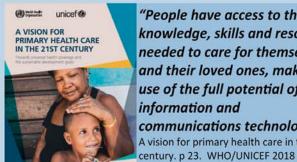


Healthcare starts with people knowing how to look after their & their families' health



But most citizens in low- and middle-income countries lack essential healthcare information (actionable information about protecting their own health and the health of others and about what to do in a healthcare situation): a lack of reliable, timely, practical healthcare information is a major obstacle to health.

The WHO vision for primary care entails wider access to healthcare information



"People have access to the knowledge, skills and resources needed to care for themselves and their loved ones, making use of the full potential of information and communications technologies" A vision for primary health care in the 21st

Modern communication methods make this achievable

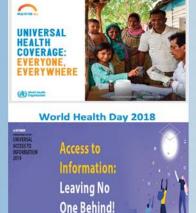
For example mobile devices can now provide wide access, even without a permanent network connection, to essential healthcare information when and where it is required and in formats, such as audio or short video clips, that can be understood by everyone regardless of literacy level¹.

Such access is of proven effectiveness, for instance a systematic review² of mobile phone applications related to HIV in Africa found numerous examples of improved adherence to medication and attendance to scheduled appointments through text messaging and voice calls.

Wider access to healthcare information will accelerate Universal Health Coverage

"Universal health coverage and sustainable development goals are empty shells without timely access to and availability of health information."

Dr Najeeb Al-Shorbaji, former Director, Knowledge, Ethics and Research Department, World Health Organization, Geneva



Access to essential healthcare information is a prerequisite for UHC and an accelerator for many of its components which are monitored as part of the health Sustainable Development Goal (SDG 3.8.1).

For example, a randomised trial³ of a child health radio campaign in Burkina Faso indicated increases of consultations for pneumonia of 39% and for diarrhoea by 73% and an expected average reduction in under-5 mortality of 7% per year.

Providing essential healthcare information for everyone, everywhere offers an early and affordable win in accelerating Universal Health Coverage



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- 2. Linguissi LSG, Ouattara AK, Ntambwe EK, Mbalawa CG and Nkenfou CN. Mobile applications: effective tools against HIV in Africa. Health and Technology, 2017; (4): 1-8
- 3. Murray J, Head R, Sarrassat S, et al. Modelling the effect of a mass radio campaign on child mortality using facility utilisation data and the Lives Saved Tool (LiST): findings from a cluster randomised trial in Burkina Faso. BMJ Glob Health, 2018: 3:e000808.

ACKNOWLEDGEMENTS

Dr Neil Pakenham-Walsh, Co-ordinator, Contact Dr Geoff Royston Healthcare Information for All (HIFA) & HIFA Steering Group members.

FURTHER DETAILS

geoff.royston@gmail.com See www.hifa.org



HIFA Projects

HIFA Projects are delivered by HIFA members through working groups which lead the wider HIFA community in focused discussion, increasing understanding and advocacy around the Project theme. In 2018 we supported 12 Projects:

1. Access to Health Research

http://www.hifa.org/working-groups/access-health-research

Vision: A world where every person will have access to the health research literature they need to protect their own health and the health of others

In 2018 we launched a programme to address Seven Priority Areas for Action identified by HIFA members in 2017. We hosted global discussions on Open Access, predatory journals, support for journals from LMICs, author processing charges; Cochrane and open access; WHO and open access; African journals and open access; self-archiving; and plagiarism.

2. Astana Declaration http://www.hifa.org/projects/astana-declaration

Objective: To contribute inputs to the Declaration of Astana 2018, a new declaration emphasizing the critical role of primary health care around the world

In 2018 we collaborated with WHO to host discussions on the future of primary health care, which helped to inform the Astana Declaration.

3. Citizens, Parents and Children http://www.hifa.org/projects/citizens-parents-and-children

Vision: A world where every citizen, parent and child will have access to the information they need to prevent illness and injury, to recognise serious illness, to provide basic care, and to seek timely medical help

In 2018 we supported discussions on high priority issues, including perspectives on traditional medicine [http://www.hifa.org/news/hifa-blog-month-review-january-2018-traditional-medicine-and-universal-health-coverage]; addiction to tramadol in West Africa [http://www.hifa.org/news/hifa-blog-month-review-march-2018-tramadol]; and Ebola.

4. Community Health Workers

http://www.hifa.org/projects/community-healthworkers

Vision: A world where every community health worker will have access to the information they need to prevent and manage illness and injury.

In 2018 we supported more than 200 substantive messages relating to high priority CHW issues and helped prepare a session on CHWs at the Health Systems Research Symposium, UK.

http://www.hifa.org/news/hifa-presentation-health-systems-research-symposium-universal-access-healthcare-information In 2018 (20 January) we published a blog 'Using WhatsApp to connect Community Health Workers in Uganda with the global HIFA community' http://www.hifa.org/news/using-whatsapp-connect-community-health-workers-uganda-global -hifa-community-0

by Carol Namata, Environmental Health Officer at Makerere University School of Public Health in Uganda.

5. Evaluating Impact

http://www.hifa.org/projects/evaluating-impacthealthcare-information

Objectives: Objectives: identify what works and what doesn't in different contexts; enable providers and users of healthcare information to continually improve their effectiveness; persuade funders, governments and others to invest in future healthcare information activities

During 2018 we advocated with WHO and the Inter-Agency and Expert Group on Sustainable Development Goal Indicators for indicators on healthcare information to be included in the SDGs. On World Health Day (7 April), we called on the United Nations Development Programme to officially recognise universal access to healthcare information as a prerequisite for UHC. [http://www.hifa.org/news/hifamarks-world-health-day-call-target-and-track-progress-univer sal-access-essential]

6. Evidence-Informed Policy and Practice

http://www.hifa.org/projects/evidence-informed-policy-and-practice

Vision: A world where every policymaker and every health professional has access to the evidence they need to provide high-quality health care and services

In 2018 we exchanged 140 substantive messages on the HIFA forums and published a blog on 'What do we mean by evidence-informed humanitarian action?' [http://www.hifa.org/news/what-do-we-mean-evidence-informed-humanitarian-action]

7. Family Planning and Reproductive Health

http://www.hifa.org/projects/family-planning

Vision: A world where every person will have access to the sexual and reproductive health information they need to protect their own health and the health of others.

In 2018 we exchanged more than 500 substantive messages

on FP and RH. We held a major discussion on Empowering health workers to provide better family planning [http://www.hifa.org/news/join-global-hifa-discussion-empowering-health-workers-better-family-planning], supported by the Johns Hopkins' K4Health (Knowledge for Health) project.

In July-August we held a second major thematic discussion on Addressing the reproductive health and family planning (RH/FP) information and service needs and rights of children (0-17) and youth (15-24)

http://www.hifa.org/news/join-hifa-global-discussion-addressing-reproductive-health-and-family-planning-rhfp-information

In June we had a discussion on addressing myths and misconceptions about vasectomy http://www.hifa.org/news/hifa-blog-month-review-june-2018-vasectomy

8. Library and Information Services

http://www.hifa.org/projects/library-and-information-services

In 2018 we published Libraries and Global Health in collaboration with Public Health England http://www.hifa.org/sites/default/files/publications_pdf/HIF A PublicHealthEngland Librariesandglobalhealth.pdf

We presented our work at the European Association for Health Information and Libraries, Cardiff, July 2018. http://www.hifa.org/sites/default/files/publications_pdf/EAH IL HIFA LIS Project 2018 PPT.pdf

We worked with Public Health England to produce an Evidence Briefing, "What is the evidence around knowledge and library service provision and knowledge management to support global health, and disaster and emergency preparedness?"

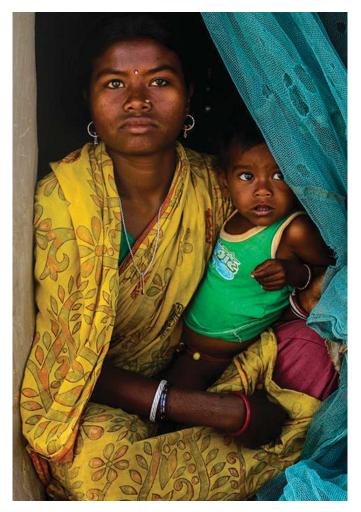
- Hosted a session on LIS for Global Health at the International Congress of Medical Librarians in Dublin (June 2017).
- Led the HIFA community in two 6-week thematic discussions: 1. Library and Information Services for Disasters, Emergencies, Disease Outbreaks; and 2. Evidence-Informed Humanitarian Action (Oct-Nov 2017).

Mobile Healthcare Information For All (mHIFA)

http://www.hifa.org/projects/mobile-hifa-mhifa

Vision: Thousands of lives could be saved every day if every mobile phone had basic healthcare information

In 2018 we presented our work at the mHealth Conference, Oxford, and the Oxford International Health Congress; prepared a research brief for collaboration with leading mHealth researchers; attended the SDG Indicators conference in Vienna; prepared a briefing for senior WHO staff 'Filling a gap in the SDG indicator for monitoring progress on Universal Health Coverage: access to essential healthcare information.



10. Multilingualism

http://www.hifa.org/projects/multilingualism

Vision: A world where every person can access the healthcare information they need and participate fully in global and local health communication, in their own language

In 2018 we:

- developed and advocated the concept of translation of selected abstracts in language appropriate to target audience;
- published article in *The Lancet Global Health*: Improving the availability of health research in languages other than English
- https://www.thelancet.com/journals/langlo/article/ PIIS2214-109X(18)30384-X/fulltext
- signed MOUs with WHO to work together towards shared goals
- worked with WHO to create a new page on Linguistic Collaborations on the WHO website
- collaborated with WHO, PAHO and EASP to launch HIFA-Spanish (October 2018)

11. Newborn Care

http://www.hifa.org/projects/newborn-care

Vision: A world where every person will have access to the information they need to protect the health of newborn children.

In February/March 2018 we implemented a major thematic discussion on our child health forum CHIFA, inspired by The Lancet Every Newborn series: Who is caring for the newborn? Looked at training, infrastructure, equipment, family-centred care, measurement and accountability, and the global health architecture for newborn care.

The Project is supported by the Every Newborn Action Plan (ENAP), which aims to end preventable newborn deaths and stillbirths by 2030, with technical support from ENAP, London School of Hygiene and Tropical Medicine, Makerere University, Save the Children, USAID and others.

http://www.hifa.org/news/join-chifa-global-discussion-newborn-care-low-and-middle-income-countries

We also held a thematic discussion on How can we improve the care of small and sick newborns in low- and middleincome countries?

http://www.hifa.org/news/how-can-we-improve-care-small-and-sick-newborns-low-and-middle-income-countries-summ ary-global

12. Prescribers and Users of Medicines

http://www.hifa.org/projects/prescribers-andusers-medicines

Vision: A world where every prescriber and user of medicines will have access to independent, reliable, actionable information on commonly used medicines.

In 2018 we collaborated with researchers from Nagasaki University and the London School of Hygiene and Tropical Medicine to conduct a systematic review to learn about how primary healthcare workers in low and middle-income countries (LMICs) obtain information during consultations to aid prescribing. http://www.hifa.org/news/call-volunteers-systematic-review-how-primary-healthcare-workers-lmics-obt ain-information The protocol was published in *BMJ Open* https://bmjopen.bmj.com/content/9/1/e023015

In May 2018 we held a thematic discussion on Antimicrobial Resistance, summarized here:

http://www.hifa.org/news/hifa-blog-month-review-may-2018-antimicrobial-resistance hifa-blog-month-review-june-2018-vasectomy

2019 OBJECTIVE

Discussions are ongoing about potential new Projects, including Mental Health, Non-Communicable Diseases, and Palliative Care.

HOW YOU CAN HELP:

Join a Project working group; suggest a new Project; provide technical and financial support:

Contact the HIFA Coordinator

Staff and volunteers

Current staff

1 full-time professional staff member, 1 part-time office manager.

Volunteers

We could not have achieved this work without our volunteers. They are critical to our success and in 2018 we increased their number substantially from **248** to more than **350**. Volunteers provide time and expertise for our growing number of Projects, the HIFA and CHIFA Country Representative programmes, HIFA Steering Group, HIFA Social Media Group, and a wide range of supportive and administrative tasks. Details of our volunteers can be found on the HIFA website.

The HIFA Steering Group has conservatively estimated that HIFA's volunteer base is equivalent to at least £120,000 per year in terms of donated time and expertise.

The pace and scale of growth described above could not have been achieved without the continued support of the BMA, The Lancet, and Elsevier which provided £10k, £7.5k and £5k, respectively, in 2018, together with financial contributions from 49 Supporting Organisations worldwide and personal donations from HIFA members, providing a total income of nearly £50,000 in 2018.

2019 OBJECTIVES

- Recruit a part-time Deputy Coordinator
- Increase our annual turnover to £75,000.

HOW YOU CAN HELP:

Contact the HIFA Coordinator (Dr Neil Pakenham-Walsh: neil@hifa.org) for further information and to discuss opportunities for sponsorship and collaboration.



Thank you to our supporters

We would like to thank the following 49 organisations who provided a financial contribution for HIFA's work in 2018 (total = £49k). We are proud of the breadth of our support, including many organisations based in low- and middle-income countries.



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HIFA and CHIFA are part of HIFA Global Forums, which also include HIFA-French, HIFA-Portuguese, and HIFA-Spanish (in collaboration with WHO) and HIFA-Zambia (with the Zambia UK Health Workforce Alliance)

HIFA is administered by the Global Healthcare Information Network, a non-profit organisation registered in the UK.

Contact: Dr Neil Pakenham-Walsh, HIFA Coordinator: neil@hifa.org