

Why health information needs to be accessible to all

Tony Waterston,¹ Neil Pakenham Walsh²

To cite: Waterston T, Pakenham Walsh N. Why health information needs to be accessible to all. *BMJ Paediatrics Open* 2018;**2**:e000352. doi:10.1136/bmjpo-2018-000352

Received 31 July 2018
Revised 11 September 2018
Accepted 12 September 2018

In this editorial, we shall discuss problems with the provision of health information to healthcare providers around the world and the work of CHIFA¹ (Child Healthcare Information for All).

THE CHIFA VISION

A world where every child, every parent and every health worker has access to the health information they need to protect their own health and the health of children for whom they are responsible.

WHAT IS 'HEALTH INFORMATION', AND WHY IS IT NEEDED?

Health information can be described as the information that citizens, health workers and others need to protect their own health and the health of others. In this context, it is information that is needed for all aspects of child health: for the prevention of disease and the maintenance of health; for screening, diagnosis and appropriate management of disease; and for rehabilitative and palliative care. More specifically, this refers to the information needed to promote healthy lifestyles, appropriate healthcare seeking, decision-making, accurate diagnosis, rational prescribing, appropriate management and referral. This information can be found through a wide variety of sources; from scholarly journal articles to patient leaflets and mass media, from well-conducted systematic reviews to global and national policy and practice guidelines, from decision-support tools to textbooks, manuals and drug formularies.

Improving access to relevant, reliable and evidence-based healthcare information has enormous potential to radically improve healthcare and outcomes worldwide. The Alma Ata Declaration on Primary Health Care² states that: 'Primary Healthcare includes at least: education concerning prevailing health problems and the methods of preventing and

controlling them'. It is essential that all users of healthcare information can find information that is in their preferred language and at the correct technical level, and presented in the optimal format (electronic, print, visual and oral) so that it can be utilised effectively.

WHERE ARE WE NOW?

There are thousands of 'healthcare information providers' in existence, from the WHO to convenors of participatory women's groups. We would like to acknowledge the pioneering work of one such provider, Teaching Aids at Low Cost (TALC), which was set up by Professor David Morley in 1965 in response to requests from overseas students for teaching aids. TALC (recently relaunched as Health Books International³) proved extremely successful in the pre-internet age and has distributed millions of books, slides and accessories to numerous health workers throughout the developing world.

Much progress has been made in child health and survival over the past few decades, however, there were 5.6 million child deaths under 5 in 2016; more than half (16 000 per day) were due to conditions that could have been prevented or treated with access to simple, affordable interventions.⁴ A literature review in 2009⁵ on papers looking at healthcare workers' needs, knowledge and practice demonstrated multiple examples of inadequate basic knowledge of common childhood diseases, ranging from inappropriate withholding of fluids from children with diarrhoea (thereby increasing dehydration), inappropriate use of antibiotics for these children, failure to recognise pneumonia and failure to recognise life-threatening signs.

Increasing access to internet and mobile phones even in low-income settings could revolutionise healthcare information availability and use; however, this also comes with dangers, especially if the quality of the



© Author(s) (or their employer(s)) 2018. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK

²HIFA, Oxford, UK

Correspondence to

Dr Tony Waterston; tony.waterston@newcastle.ac.uk

content is poor and unregulated. For example, in the Ebola crisis of West Africa in 2014–2015, the ubiquity of mobile phones allowed misinformation to circulate widely regarding false advice on how to prevent and treat Ebola. Globally, the antivaccine movement continues to cause widespread harm through misinformation spread on the internet. The majority of information on the Internet is in the English language, but only 1 in 20 of the world's population speak English as their first language, and only 1 in 5 can understand even basic English. People with low literacy levels and those with disabilities may also be restricted in their access to healthcare information.

CHIFA: CHILD HEALTHCARE INFORMATION FOR ALL

CHIFA was officially launched with its sister forum HIFA (general adult health) in Mombasa, Kenya in October 2006, at the 10th Congress of the Association for Health Information and Libraries in Africa. Prior to this in 2004, the WHO had commissioned a global review on access to healthcare information, leading to a paper in *The Lancet*⁶. The authors called for all stakeholders to work together to improve the availability and use of healthcare information, and HIFA and CHIFA are a direct response to that challenge. Working entirely via the internet, CHIFA brings together all those with an interest in global health (focusing mainly on low-income and middle-income countries) including doctors, nurses, auxiliaries, academics, librarians, health journalists, publishers, policy-makers and researchers to exchange experience and expertise on how to improve the availability and use of healthcare information, and therefore health outcomes. As well as healthcare information, CHIFA also aims to highlight advocacy and child health rights—since so

often health workers require skills in these fields to bring about change.

HIFA and CHIFA now have >18 500 members in 177 countries, and 320 supporting organisations, interacting on five forums in three languages (English, French, Portuguese–Spanish to be launched soon). CHIFA has >3500 members in over 140 countries (Figure 1).

CHIFA is administered by the International Child Health Group (affiliated with the Royal College of Paediatrics and Child Health, UK), the International Society for Social Paediatrics and Child Health (ISSOP) and Global Healthcare Information Network (the non-profit organisation that administers HIFA).

CHIFA IN ACTION

Discussions on CHIFA forums are wide ranging and include contributions from grassroots healthcare workers, academics, WHO and other health agency members, policy-makers, pharmacists, journalists, publishers and media experts. There has been limited participation from parents and other caregivers. Examples of message threads include forced genital mutilation, violence against children, breastfeeding and the role of formula manufacturers, children's rights to universal healthcare, role of traditional healers, Plumpy'nut in malnutrition management, overuse of antibiotics and much more. Messages are circulated through daily email compilations and are available for review on the CHIFA RSS feed.⁷

Recently, a new project on newborn care⁸ has been launched on CHIFA, in collaboration with a team at the London School of Hygiene and Tropical Medicine. It comprises a series of thematic discussions (discussions stimulated around preset questions) focusing on



Figure 1 CHIFA member distribution. CHIFA, Child Healthcare Information for All.

exploring how to improve the quality of care for newborns within the overall care continuum, particularly for those born small and sick.

CHIFA has also organised webinars (on child abuse, corporal punishment by parents, vaccination and child rights). These have been valuable though the reach needs to be increased and there is discussion ongoing on working with other organisations.

FUTURE OPPORTUNITIES

The achievement of CHIFA to date is remarkable considering the low level of resources and the reliance on volunteer input. As funding becomes more available, there is great scope to expand the network and broaden its work in the following ways:

- ▶ Strengthen the role of country representatives
- ▶ Expand the role of supporting organisations
- ▶ Develop specific topics for project work similar to the Newborn Care project
- ▶ Evaluate the benefits to users
- ▶ Host a regular programme of webinars
- ▶ Collaborate more closely with WHO and other agencies.

We invite readers of *BMJ Paediatrics Open* (already a supporting organisation) to join CHIFA and contribute your valuable experience and opinions to our online discussions.

Acknowledgements The authors thank Samantha Sadoo for drafting assistance, and members of the CHIFA working group [<http://www.hifa.org/forums/chifa-child-health-and-rights/steering-group/10>] for their comments.

Contributors The two authors contributed equally to the paper.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Provenance and peer review Commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

REFERENCES

1. HIFA.org. CHIFA (child health and rights). www.CHIFA.org.
2. WHO. *Declaration of Primary Health Care*. Geneva: World Health Organisation, 1978. http://www.who.int/publications/almaata_declaration_en.pdf.
3. Health Books International. <https://healthbooksinternational.org>.
4. WHO. *Children: reducing mortality*. Geneva: World Health Organisation, 2017. <http://www.who.int/news-room/fact-sheets/detail/children-reducing-mortality>.
5. Pakenham-Walsh N, Bukachi F. Information needs of health care workers in developing countries: a literature review with a focus on Africa. *Hum Resour Health* 2009;7:30.
6. Godlee F, Pakenham-Walsh N, Ncayiyana D, *et al*. Can we achieve health information for all by 2015? *Lancet* 2004;364:295–300.
7. HIFA.org. Latest HIFA forum messages. <http://www.hifa.org/rss-feeds/10>.
8. HIFA.org. Newborn Care. <http://www.hifa.org/projects/newborn-care>.