

Concept Note: HIFA SMART Goal #1

Mobile Health Information For All by 2015

1st June 2013

The HIFA Community involves more than 10,000 professionals in 167 countries, working together towards our shared vision of a world where people are no longer dying or suffering as a result of lack of basic healthcare knowledge. This project will leverage the power of the HIFA Community to catalyse and advocate for action at scale to make basic healthcare knowledge available to all citizens, when and where it is needed.

Our goal is that, by 2015, at least one telecoms provider, in at least one country, will endorse the vision of Health Information For All, and will provide free access to essential healthcare knowledge in the local language, preloaded on all new mobile phones they may sell *and* freely downloadable to all those who already have mobile phones.

The Problem

Everyone needs healthcare knowledge and timely access to healthcare information to protect their own health and the health of others. Basic healthcare knowledge can and must be made available, when and where it is needed, for all citizens. This is especially important in low-income countries, where health workers may not be available. Thousands of lives could be saved every day if all mobile phones had basic healthcare knowledge (including and especially first aid information, and maternal and child health information).

In low-income countries, and especially among those who are poor and marginalised, the fate of people who become ill or injured is highly dependent on the decisions and actions of their fellow citizens or family members. Every citizen and family member is at some stage the main healthcare provider for another human being. The decisions and actions they take often mean the difference between life and death, or between full recovery and permanent disability. These decisions and actions are largely dependent on the level of basic healthcare knowledge and the availability, or otherwise, of basic healthcare information.

Examples

1. Childhood diarrhoea. A major study from India in 2006 indicated that 4 in 10 mothers would **withhold** fluids from a child with diarrhoea, thereby tragically and **unknowingly** increasing the risk of death of the child¹. It is vital that parents and carers provide adequate fluids, correctly prepared. Basic information on how to mix a simple oral rehydration solution (ORS) can mean the difference between the child living and dying. Diarrhoea kills an estimated 1.5 million children each year. Inexpensive and effective treatments for diarrhoea exist, but in developing countries only 39 per cent of children with diarrhoea receive the recommended treatment. Correct use of ORS could avoid millions of deaths from dehydration caused by diarrhoea.

¹ Wadhwani N. 2005. An integrated approach to reduce childhood mortality and morbidity due to diarrhoea and dehydration.

2. Childhood malaria. 'More than half of the children who die of malaria die within the first 48 hours. Choice between aspirin and antimalarials to treat the fever can make a difference in terms of life and death. Fast and appropriate diagnosis and treatment of malaria is extremely important in reducing child mortality and achieving two of the major millennium development goals. Quite often symptoms of malaria go unrecognized or untreated. According to the Multilateral Initiative on Malaria, 70% of the malaria cases that are treated at home are mismanaged.' ² A study in Karachi. Pakistan, showed that the majority of family doctors had insufficient knowledge of the diagnosis and management of malaria. This is despite the disease being common in the country and in Karachi itself, killing more than 50,000 people each year. In Uganda, The respondents in childheaded households had less knowledge on signs and symptoms of simple and severe malaria and receive too little or late health care from health professionals compared to the adult heads of households probably due to lack of knowledge and money. Information Communication and Education programs should be designed and target the child-headed households and supply home packs.³ In Kenva, the International Federation of Red Cross and Red Crescent Societies (IFRC) recommends that training and communication materials on home management of malaria are made available to community members, taking account of literacy levels, local languages, and an adequate supply to meet needs.4 'Studies of care seeking in Nigeria show that a tremendous amount of treatment for malaria takes place at home and, in most instances, such treatments are incorrect. This deficiency is attributed to caregivers' poor knowledge of treatment.'5 'People who seek treatment for P vivax symptoms often stop treatment after a few days, allowing the parasite to remain untreated in the phase in which it infects the liver.'6 In sub-Saharan Africa, 'presumptive treatment of febrile illness with an antimalarial drug is common. This practice has contributed to resistance to all common antimalarials.'7 'For every billion dollars in subsidy for antimalarial drugs, around \$500m to \$960m will be spent on treatment for people who do not have malaria.¹⁸ 'In Kenya, the largest homeopathic supplier, the Abha Light Foundation sells homeopathic medicines for malaria.'9 'Standing in the paediatric ward at Kongwa District Hospital, Temba Nazar, the doctor in charge, says that there is a lot of ignorance about malaria among the population. "People don't know the first signs of malaria. They may try local traditional medicine or paracetamol for a fever first.""10 'Over-diagnosis of malaria in the formal healthcare sector coexists with under-diagnosis of malaria in the community, with the result that antimalarials are given to people who do not need them and not given to children who do.'11 Children and adults with diabetic coma are often misdiagnosed with malaria, and subsequently die or suffer brain damage. 'In one study in Tanzania, 21 of 199 patients diagnosed as having cerebral malaria actually had precoma or coma precipitated by uncontrolled diabetes. 12 Pregnant women with malaria have a high risk of death,

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² Mozumder P & Marathe A. Role of information and communication networks in malaria survival. Malaria Journal 2007;6:136

http://www.malariajournal.com/content/6/1/136

³ Health-seeking behavior for malaria among child and adult headed households in Rakai district, Uganda Beatrice Amuge,1 Fred Wabwire-Mangen,2 Chilunga Puta,4 GW Pariyo,2 Nathan Bakyaita,5 Sarah Staedke,3 Moses Kamya,3 and Olico-Okui, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2141622/

⁴ IFRC. 2010. Beyond prevention: home management of malaria in Kenya. http://www.ifrc.org/docs/pubs/health/malaria/Beyond_Prevention_HMM%20Malaria-EN.pdf

⁵ O. A. Ikeoluwapo, O. K. Oladele, O. Kale, O. Oladimeji and E. Afolabi. Using "Mother Trainers" for Malaria Control: The Nigerian Experience. International Quarterly of Community Health Education (2006-2007) 27 (4) 351-369 Document: http://baywood.metapress.com/openurl.asp?genre=article&id=doi:10.2190/IQ.27.4.f

⁶ PAHO's carter, quoted in Barbara Fraser. Taking on malaria in the Amazon. Lancet 2010:376:1134

⁷ Baiden F et al. Lancet 2010;375:637

⁸ Heidi Hopkins, Caroline Asiimwe and David Bell. Access to antimalarial therapy: accurate diagnosis is essential to achieving long term goals. British Medical Journal 2009;339:324-6.

⁹ News: WHO slow to respond over homeopathy for TB and HIV. Voice of Young Science (VOYS), STOP-TB, 24 June 2009

¹⁰ 'Drug subsidy could help Tanzania tackle malaria', <u>Udani Samarasekera</u>; *The Lancet* 2008; **371**:1403-1406 (26 April 2008) http://www.thelancet.com/journals/lancet/article/PIIS014067360860611X/fulltext

¹¹ Hugh Reyburn et al, 'Rapid diagnostic tests compared with malaria microscopy for guiding outpatient treatment of febrile illness in Tanzania: randomised trial'; BMJ 2007;334:403 (24 February 2007)

¹² David Beran & John Yudkin. Diabetes care in sub-Saharan Africa. The Lancet 2006; 368:1689-1695 (Review)

prompt and effective treatment depends on illness recognition. However, malaria-related symptoms can be easily confused with pregnancy-related symptoms. No publication was found that explores the way pregnant women distinguish malaria signs from general malaise and other common symptoms (e.g., nausea, vomiting, weakness, etc.) during pregnancy. Furthermore, it is necessary to determine whether pregnant women's susceptibility to anaemia is commonly known. and if people realize the link between anaemia during pregnancy and malaria. 13 'Only 56% of the respondents [health workers] knew that the mosquito transmits malaria in a community where malaria is endemic.'14 'Often people do not take the correct dose, stopping the treatment when they feel better and keeping tablets from one course for the next time someone is ill. This increases the likelihood of drug resistant malaria developing¹⁵ It is important to use bed nets and to identify and treat fevers. This can help prevent the death of children and prevent complications and death in women who are pregnant. One million deaths a year – most of them children under five in Africa - could be prevented by using mosquito nets and by correct diagnosis and treatment of fevers. In Africa, a child in Africa dies every 30 seconds from malaria. These deaths are almost always preventable: children are not adequately protected with bed nets and, when they become ill, they are not provid ed timely, life-saving treatment.

- **3. Childhood pneumonia.** Pneumonia is the biggest cause of child deaths in the world, killing 1.6 million children under 5 years of age every year, more than 98% of which occur in developing countries. Almost all of these deaths would have been avoided if the child was provided with timely antibiotics. 8 in 10 caregivers in developing countries do not know the two key symptoms of childhood pneumonia fast and difficult breathing which indicate the need for urgent treatment (only 20% of children with pneumonia receive antibiotics despite wide availability, and 1.6 million die each year). Misdiagnosis of illness by health workers is common: 'a study in Kenya showed that only 8% correctly diagnosed severe pneumonia'. ¹⁶
- **4. Road traffic accidents.** The first advice of the British Red Cross is "Stop! You can help Knowing just a few basics could help keep someone alive until an ambulance arrives." A few basic pieces of knowledge can mean the difference bewteen life and death, and full recovery or permanent disability. This is especially important in low-income countries, where ambulances are often absent. Victims of road traffic accidents in low-income countries are frequently (mis) handled by fellow citizens, and are often taken to hospital in pick-up trucks. Citizens will often have no idea about the possibility of neck injury, whereby inappropriate movement can result in permanent quadriplegia. Injured people may die at the roadside from uncontrolled haemorrhage, crush injury, burns or other injuries, and their chances to survive are greatly reduced if by-standers do not provide appropriate first aid.
- **5. Choking on food.** A child or adult who chokes on food is at risk of death due to airway obstruction. Simple actions such as the Heimlich manoeuvre (in adults), or holding upside down and striking between the shoulder blades (in small children) can be life-saving. The time for action here is so short that the person will only be saved if the by-stander has previously read and understood what to do, or can find the information on their phone within seconds. Preloaded information can provide such information.

http://www.thelancet.com/journals/lancet/article/PIIS0140673606697043/fulltext

¹³ Malaria in Pregnancy: What Can the Social Sciences Contribute? Ribera JM, Hausmann-Muela S, D'Alessandro U, Grietens KP PLoS Medicine, April 2007

¹⁴ Towards malaria control: the knowledge of health care providers about mosquito and malaria transmission. V.A. Wagbatsoma et al. Central African Journal of Medicine vol. 45, No. 1, 1999.

¹⁵ Alison Dunn 2006 Participatory communication in malaria control: why does it matter? Findings No4 (publication of Exchange). http://www.healthcomms.org/pdf/findings4.pdf

¹⁶ Olumole D, Mason E, Costello A. Management of childhood illness in Africa BMJ 2000; 320: 594-5

6. Complications of pregnancy and childbirth.

Every day, approximately 800 women die from preventable causes related to pregnancy and childbirth. 99% of all maternal deaths occur in developing countries. Almost all of these deaths occurred in low-resource settings, and most could have been prevented. The major complications that account for 80% of all maternal deaths are: severe bleeding (mostly bleeding after childbirth); infections (usually after childbirth); high blood pressure during pregnancy (pre-eclampsia and eclampsia); unsafe abortion. Severe bleeding after birth can kill a healthy woman within two hours if she is unattended. Injecting oxytocin immediately after childbirth effectively reduces the risk of bleeding. Infection after childbirth can be eliminated if good hygiene is practiced and if early signs of infection are recognized and treated in a timely manner. Pre-eclampsia should be detected and appropriately managed before the onset of convulsions (eclampsia) and other life-threatening complications. Administering drugs such as magnesium sulfate for pre-eclampsia can lower a woman's risk of developing eclampsia.¹⁸

7. Top ten causes of death

The top 10 causes of death in low-income countries are: Lower respiratory infections; Diarrhoeal diseases; HIV/AIDS; Ischaemic heart disease; Malaria; Stroke and other cerebrovascular disease; Prematurity and low birth weight; Birth asphyxia and birth trauma; and Neonatal infections. All of these can be prevented and/or managed more effectively if the parent, family member, citizen or health worker knows what to do, and when and where to seek help.¹⁹

Again and again, the knowledge, decisions and actions of citizens have the potential to save millions of lives every year. For more examples, see http://www.hifa2015.org/about/why-hifa2015-is-needed/

The Solution

In all these cases the missing element is *timely and affordable access to relevant, reliable, easily assimilable and actionable healthcare knowledge*. Mobile phones, for which there are now over 6 billion subscriptions globally, of which over 4 billion (and growing fast), are in developing countries, and which are used widely even by the poor (who often share use of a phone), can provide the means to fill this gap.

HIFA will campaign for a health app on every new mobile phone, preloaded before sale, plus the ability for anybody with an old phone to download the app free of charge. We aim to persuade at least one major supplier to commit to this as standard, in at least one country, by the end of 2014.

It will be important to mobilise and engage the HIFA members as a whole, and to make this one of HIFA's main objectives. We are also cognisant that HIFA is (and needs to remain) a neutral player and convenor rather than become yet another health information provider - thus our role is to provide the impetus and enabling environment for HIFA members and others to come together and form independent collaborations and health information delivery projects. So, new health apps would not be branded as HIFA (HIFA is a convenor rather than a health information provider - we do not want HIFA to be in competition with any of our individual members), although of course we would welcome and encourage the developers to use and acknowledge HIFA as a learning network as they progress from concept to implementation.

¹⁸ World Health Organization. Maternal mortality. Fact sheet N°348. May 2012. http://www.who.int/mediacentre/factsheets/fs348/en/

¹⁹ World Health Organization. The 10 leading causes of death by broad income group (2008). Fact sheet 310. May 2012 http://www.who.int/mediacentre/factsheets/fs310/en/index.html

Questions to explore

- 1. Preloaded or On-Demand?
- 2. How would Telecoms companies benefit?
- 3. Which country?
- 4. What would be the basis for the content? How to ensure reliability?
- 5. What would be the scope of the content? MCH? First Aid? Health education messages?
- 6. For what applications can phone-mediated knowledge be deployed without requiring supplementary skills that may require training and/or practice?
- 7. How would the content be made accessible for those with low literacy skills?
- 8. What are the implications of shared (e.g a village phone) use for applications?
- 9. Text? Pictures? Video? Audio?
- 10. How much would it cost?
- 11. What expertise and effort (time) would be required (a) to set up (b) to develop (c) to maintain mHIFA globally?
- 12. What is the role of Global Healthcare Information Network and HIFA?

1. Preloaded versus On-Demand

The original concept, as described on Reuters AlertNet's "Top 20 Big Ideas That Will Not Cost the Earth", is that all new mobile phones should be sold with a **preloaded** app(s) with basic healthcare information content, in the local language. This would therefore be available, as and when needed, to provide basic healthcare information such as first aid and Mother and Child Health information (eg what to do if snake bite? what to do if child has diarrhoea?). Preloaded health info would sit side by side with existing preloaded content on mobile phones (such as preloaded games), and would be available on basic SMS phones. Also, preloaded health info will be more readily available in an emergency, when it is most urgently needed, including situations where there is no mobile signal.

It is envisaged that the impact of this mHealth intervention would be greater as the proportion of mobile phones that have basic healthcare knowledge increases. Thus, we think it is important that the app(s) should not only be sold on all new phones, but should also be available for download to anyone, free of charge, on any mobile phone that they may already own.

2. How would Telecoms companies benefit?

The main perceived benefit to Telecoms companies is enhancement of their Corporate Social Responsibility. This would be particularly important to them if they see this as an opportunity to be the FIRST Telecoms company to endorse and implement the concept. If the concept is implemented in collaboration with (or endorsement by) the country's Ministry of Health, WHO/UNICEF, or other high-profile agency, this will further boost the CSR value to the company.

3. Which country?

At this time, we would be keen to see this implemented in any low- or middle-income country. It would make sense to identify a country that has a high penetration and growth rate of mobile phones, and that also has a great need - a country where people currently do not have access to basic healthcare knowledge. A country with a relatively high literacy level may be useful if the messages are text-based. A country which is monolingual, and perhaps one where English is widely spoken, would make things easier but this is not critical.

4. What would be the basis for the content? How to ensure reliability?

The content must be **reliable** and endorsed by recognised authorities such as WHO and UNICEF. We could perhaps explore the possibility of using/adapting existing "flagship" content such as Facts for Life or Where There is No Doctor.

As mobile phone ownership increases, so too does the risk of commercially biased information that may harm rather than protect health. We need to make it known loudly what is truly needed and what we primarily want (to reduce maternal, infant and young child mortality and morbidity). The danger in that is that the whole 'health education using mobile phones' agenda will be hijacked by people with self-interest, eg a pharmaceutical company and then we will have the same problem as we have with Nestle and breastfeeding; spending time and resources to undo the damage.

5. What would be the scope of the content?

The content may include any or all of the following:

- First aid Maternal and Child Health (including Nutrition)
- Reproductive Health and Family Planning
- Health education messages

6. For what applications can phone-mediated knowledge be deployed without requiring supplementary skills that may require training and/or practice?

[Expert advice required here - this could be basis for a HIFA thematic discussion]

9. Text? Pictures? Video? Audio?

The content may be produced as text, pictures, and/or video. Each of these has different advantages and disadvantages. The app may be developed for ordinary low-cost SMS phones and/or for smartphones.

Text-based information on old-style phones may be useful and more universally available. However, the usefulness of such information would depend on the presence of someone who can read. Text could be supplemented by pictures for better understanding, especially among those with low literacy. Video clips would be especially useful for those with smartphones. Videoclips are potentially especially useful to convey health education messages.

Once a video is created: an audio file can be extracted. a text message created from the script, still frames used as photos.

The project will aim to get a better understanding of what format works in what contexts.

10. How much would it cost?

It is anticipated that the costs of establishing a health app for free download on existing mobile phones, and the costs of introducing the health app as standard on every new mobile phone, would both be small as compared with the CSR value and, indeed, the potential impact on health outcomes of the population.

Using *Facts for Life* as an example; there are a total of 123 messages for the 14 health topics. Depending on the style of the videos (straightforward narration or drama or animation) cost would vary widely. Also, the number of languages the video is dubbed/subtitled in would need to be taken into consideration.

The overall HIFA campaign requires additional income and we would request a modest financial contribution for general HIFA costs, from the collaborating Telecoms company.

11. What expertise and effort (time) would be required (a) to set up (b) to develop (c) to maintain mHIFA globally?

[Expert advice required here - this could be basis for a HIFA thematic discussion]

12. What is the role of Global Healthcare Information Network and HIFA?

GHI-net/HIFA would be the catalyst rather than the implementer of the project, and our role is to mobilise policymakers, health professionals and others in the "health information community" to support the principle of "preloaded health information on mobile phones" and help bring parties

together to make it happen (eg WHO and telecoms). We would also have an important role in stimulating public debate about how the project might be implemented, including literature review of what has or hasn't worked in the past. It's important for GHI-net/HIF not to be (or perceived to be) a "health information provider", because that would potentially put us in competition with the members of our network. Our strength is our perceived neutrality and purpose as a platform for all providers and users of health information worldwide to interact, explore issues, and form connections/collaborations to implement health information activities (independently of HIFA).

Discussion is needed on whether the product could/should include the HIFA logo.

Operational Plan

The project is envisaged to have four phases:

1. Collect baseline information

We would look at existing frameworks for using mobile phones for providing health information; collect information on what already exists that is relevant to the HIFA SMART goal. As we receive comments from experts and general HIFA members, we would start with a scoping exercise to describe what already exists and what is already in planning, with regards to free first aid/MCH info in local languages, either preloaded and/or downloadable apps. One of the members of the HIFA 2013 Challenge Group (Nand Wadhwani) has collected relevant information (mostly pdf files of reports and papers) relating to mobile health.

2. Information gathering, consultation, awareness raising

We aim to **engage** the 10,000 members of the HIFA Forums around the concept of Health Information for All, preloaded on mobile phones. We would explore the above questions (and others) on the HIFA Forums. This would help us to ask and explore the right questions to make it happen, and would also create a major hook for a telecoms company to bite and be part of the solution.

We shall publicise the concept widely, and explore the concept and various options with key players such as GSMA, WHO, and individual telecoms companies.

HIFA Forums: We aim to stimulate discussion on the forums on a range of topics, including:

- 1. Importance of health videos in local languages
- 2. The role of national and regional governments in mHealth programmes
- 3. What content is available in the public domain for parents, children and citizens?

There are various health apps e.g. for first aid already out there, and some are free. Working with HIFA members, we shall explore these and assess whether any of these are coming close to providing what is being sought. If no, then the gap is clear, if yes, then these could provide a good starting point for further development.

3. Assist one (or more) implementing groups with planning and implementation.

4. Encourage feedback of lessons learned throughout.

We want to encourage the implementing group to develop the project in full consultation with the HIFA community, to tap into other HIFA members' experience, and to share lessons learned on HIFA and beyond.

HIFA 2012 Challenge Group

This project will be led by the HIFA 2012 Challenge Group. The Group will have an **Advocacy** and **Catalyst** function, and a role as a **Convenor**. The development and implementation of apps will be done *independently* of the Group.

The HIFA 2012 Challenge Group will take lead responsibility for the project *in addition to* its current role in promoting discussion on HIFA on the theme of the 2012 Challenge (addressing the health information needs of parents, families, children and citizens). The current members of the group are:

Oluwatosin Ogunmoyero is a Nigerian trained medical doctor currently studying for an MSc in global health science at the University of Oxford, UK. She has strong interests in maternal and child health, adolescent health and NCDs. She believes a lot can be achieved if women and caregivers are able to recognize early danger signs, know the right thing to do and the right place to seek help. Healthcare workers including doctors and nurses but most importantly community health workers (especially in resource poor settings) have a great role to play. She is the coordinator of the HIFA 2012-2015 Challenge team: Meeting the health information needs of citizens, mothers and families. oreogunmoyero@yahoo.co.uk

Clare Hanbury qualified as a teacher in the UK and then worked in schools in Kenya and Hong Kong. After an MA in Education in Developing Countries and for many years, Clare worked for The Child-to-Child Trust based at the University of London's Institute of Education where, alongside Hugh Hawes and Professor David Morley she worked to help embed the Child-to-Child ideas of children's participation in health - into government and non-government child health and education programmes in numerous countries. Clare has worked with these ideas alongside vulnerable groups of children such as refugees and street children. Since her MSc in International Maternal and Child Health, Clare has worked freelance and focuses on helping government and non-government programmes to design and deliver child-centred health and education programmes where children are active participants. Clare has worked in many countries in East and Southern Africa and in Pakistan, Cambodia and the Yemen. Her current passion is for distilling health information for teachers, health workers and others - into simple practical health messages actionable by children. clare.hanbury AT zen.co.uk

Neil Pakenham-Walsh is the coordinator of the HIFA2015 campaign and co-director of the Global Healthcare Information Network. He is also currently chair of the Dgroups Foundation (www.dgroups.info), a partnership of 18 international development organisations promoting dialogue for development. He started his career as a hospital doctor in the UK, and has clinical experience as an isolated health worker in rural Ecuador and Peru. For the last 20 years he has been committed to the global challenge of improving the availability and use of relevant, reliable healthcare information for health workers and citizens in low- and middle-income countries. He is particularly interested in the potential of inclusive, interdisciplinary communication platforms to help address global health and international development challenges. He has worked with the World Health Organization, the Wellcome Trust, Medicine Digest and INASP (International Network for the Availability of Scientific Publications). He is based near Oxford, UK.

Nand Wadhwani is a Founding Trustee of The Mother and Child Health and Education Trust (MCHET) http://motherchildtrust.org/ . Over the past 15 years he has launched several programmes to address the challenge of improving health education in underdeveloped countries. MCHET works primarily in the areas of mother and child nutrition, water, hygiene, sanitation and diarrhoea prevention and management. Nand firmly believes that the most effective and efficient way to advance health education is by employing a mix of established and newer communication technologies to deliver contextually-appropriate messages directly to the people who need it most. He is presently working on the development of HealthPhone, an illiterate-friendly mobile phone app. with preloaded, reliable, relevant health and nutrition material in various formats and that will initially be offered in English and several other languages. Using rich multimedia, HealthPhone will put life-saving and life-changing content directly in the hands of those who can use it in an accessible format and with 24x7 availability, everywhere. He is a HIFA2015 Steering Group member. nand AT motherchildtrust.org

Contacts:

Oluwatosin Ogunmoyero (HIFA 2012-15 Challenge Working Group Coordinator) <u>oreogunmoyero@yahoo.co.uk</u>

Neil Pakenham-Walsh (HIFA2015 Coordinator) neil.pakenham-walsh@ghi-net.org