



Statement from HIFA on the draft High Level Declaration on Universal Health Coverage

On 23 September 2019 a high-level meeting on universal health coverage will be held at the United Nations General Assembly. The meeting, 'Universal Health Coverage: Moving Together to Build a Healthier World', will bring together heads of state, political and health leaders, policy-makers, and universal health coverage champions to advocate for health for all. It will focus on accelerating progress towards universal health coverage, a skilled health workforce, financial risk protection and access to safe, quality, effective and affordable medicines and vaccines for all. The meeting will result in a Political Declaration on Universal Health Coverage, negotiated by Member States and endorsed by Heads of State.

We welcome the development (for agreement at this meeting) of this Declaration, now in its final draft (<https://www.un.org/pga/73/wpcontent/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf>)
However we are concerned that it barely acknowledges the importance of access to essential healthcare information for achieving UHC.

The parts of the draft Declaration that say most about health communication, health literacy and healthcare decision-making, paragraphs 27 and 65, discuss information largely in terms of data analysis and patient records. **The draft Declaration omits mention of generic, reliable, actionable, healthcare information, in a language and format that is accessible to the patient, which is critical in strengthening patient involvement in clinical decision making.**

In this respect it appears seriously out of step with the latest WHO declared policies and guidelines, in particular the WHO/UNICEF Vision for Primary Care (2018), the Declaration of Astana (2018); and the WHO Guideline on Self-Care Interventions for Health (2019), which all clearly indicate the role of healthcare information as a key enabler for patient-centred care and the need therefore to support wide access to it. (See Annex for details.)

The Declaration could be made more consistent with the above WHO policies and guidelines by adding just six words: **“timely access to essential healthcare information”** to either or both of paragraphs 27 and 65. Alternatively, to follow paragraph 65, it could add wording drawn from the recent

statements from WHO on this topic e.g. “Ensure people have access to the knowledge, skills and resources needed to care for themselves and their loved ones, empowering people through improved education and health information and making use of the full potential of information and communications technologies. Individuals – as the people experiencing the impact of their health and as decision-makers – have a central role to play in co-creating their own health and well-being and in providing informal care to their peers and loved ones. Health information and services must be available and accessible at the time and place they are needed, and they must also be acceptable and of high quality. With self-care interventions available outside the health system, potential users must have access to reliable, useful, quality information that is consistent with the needs of the individual and the community”.

*Geoff Royston, Chris Zielinski, Neil Pakenham-Walsh
11 September 2019*

on behalf of the HIFA Steering Group:

Tara Ballav Adhikari, Aarhus University, Denmark
Grace Ajuwon, Association for Health Information and Libraries in Africa, Nigeria
Najeeb Al-Shorbaji, former Director, Knowledge, Ethics and Research, World Health Organization, Switzerland
Joseph Ana, Africa Centre for Clinical Governance Research and Patient Safety, Nigeria
Frederick Bukachi, Global Healthcare Information Network, UK/Kenya
Martin Carroll, Independent, UK
Martin Davies, Head, British Medical Association, UK
Tracy Eastman, BMJ and University of Cape Town, UK/South Africa
Alberto Fernández Ajuria, Andalucian School of Public Health, Spain
Liz Grant, Global Health Academy, University of Edinburgh, UK
John Liebhardt, American University of Sharjah, UAE
Wendie Norris, CABI, UK
Oluwatosin (Tosin) Ogunmoyero, Marshfield Clinic Research Institute, USA
Onikepe Oluwadamilola Owolabi, Guttmacher Institute, USA
Neil Pakenham-Walsh, Global Healthcare Information Network, UK (HIFA Coordinator)
Jonathan Parker, Global Healthcare Information Network, UK
Karah Pedersen, IntraHealth International, USA
Julie N Reza, Independent, UK
Geoff Royston, Independent, UK
Rachel Stancliffe, Global Healthcare Information Network, UK
Arjun Thandi, Independent, UK
Nand Wadhvani, Mother and Child Health and Education Trust, Canada
Tony Waterston, International Society for Social Paediatrics and Child Health, UK
Chris Zielinski, Partnerships in Health Information, University of Winchester, UK
<http://www.hifa.org/people/steering-group>

Note that endorsement by individual Steering Group members does not necessarily imply endorsement by the organisations with which they are affiliated.

Annex

The **WHO/UNICEF publication 'A vision for primary health care in the 21st Century'** (<https://www.who.int/docs/default-source/primary-health/vision.pdf>) states:

“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.”

In more detail, section 5.3 “**Empowered people and communities**” states: “In the PHC approach, the health system (along with other sectors) contributes to empowering people through improved education and health information. Particular attention should be given to populations in situations of vulnerability, seeking to meet their information needs and provide guidance towards improved health.”

“Individuals – as the people experiencing the impact of their health and as decision-makers – have a central role to play in co-creating their own health and well-being and in providing informal care to their peers and loved ones. The possibilities for this have been revolutionized over the past 40 years as a result of technological changes, in particular the rapid expansion of new health technologies and information and communication technologies. At the time of the International Conference on Primary Health Care in Alma-Ata in 1978, access to health information was often quite limited and typically required access to a health professional. Today, in contrast, the first thing that many people across the world do when faced with a health problem is to use their mobile phone to seek more information, from the Internet or another source of information that previously would not necessarily have been accessible. Even newer technologies, such as point of care diagnostics that can be used by health care workers as well as patients, artificial intelligence and low-cost genetic testing, are also starting to create new possibilities for self-care, the potential of which is only beginning to emerge. Measures will be needed to ensure equitable access as well as reliable information and support for the interpretation of complex information.”

In the **WHO/UNICEF publication Declaration of Astana** (https://www.who.int/docs/default-source/primary-health/declaration/gcphc_declaration.pdf) , item VI “**Empower individuals and communities**”, includes the statement:

“We will promote health literacy and work to satisfy the expectations of individuals and communities for reliable information about health. We will support people in acquiring the knowledge, skills and resources needed to maintain their health or the health of those for whom they care, guided by health professionals.”

In the latest **WHO Consolidated Guideline on Self-Care Interventions for Health** (<https://www.who.int/reproductivehealth/publications/self-careinterventions/en>) para 2.2.3, “**Health Information**” states:

“Health information and services must be available and accessible at the time and place they are needed, and they must also be acceptable and of high quality. With self-care interventions available outside the health system, potential users must have access to reliable, useful, quality information that is consistent with the needs of the individual and the community. Additionally, pictures and visuals are useful in overcoming language barriers and literacy issues. Mobile phones, tablets and other information and communications technologies (ICTs) are providing new opportunities to deliver health information. There may be a need to devise different ways of providing information to populations with diverse needs and different levels of literacy that connects them back to the health system as appropriate. Health information should be available to and used by health workers to address clinical and non-clinical aspects of self-care for SRHR. Information should be reliable and accurate, and it needs to be trusted by individuals, who rely on it to support their informed decision-making about their personal health and well-being and about their interactions with the health system. For example, patient information leaflets are a legal requirement in many countries, and they must be designed to ensure that patients who rely on the information provided can make informed decisions about the safe and effective use of the products and interventions described.”