Universal access to reliable healthcare information:

A global consultation

Global Healthcare Information Network CIC:
A report for the World Health Organization

Contents

Subgroup analyses are available as a separate document.

Summary

Introduction: Reliable healthcare information saves lives. Universal access to reliable healthcare information is implicit in the World Health Organization's (WHO) Constitution. [1] In practice, however, there is a lack of high-level political and financial commitment to this goal. Lack of availability and use of reliable healthcare information continues to be a neglected global health issue and a major cause of avoidable death and suffering.

Healthcare Information For All (HIFA) is a global community of practice campaigning for universal access to reliable healthcare information. [2] It is administered by Global Healthcare Information Network (GHIN), a UK-based NGO in official relations with WHO since 2022. HIFA and WHO have agreed on a 3-year collaboration plan. [3] The first activity under this plan is a global online consultation with key stakeholders, reported here.

Objectives: To assess stakeholder views on:

1. How important is the availability and use of reliable healthcare information?
2. What should be done to improve the availability and use of reliable healthcare information?
3. What more can WHO and HIFA do to accelerate progress towards universal access to reliable healthcare information?

Methods: A validated, mixed-methods, online survey was developed with 21 questions, available in 10 languages, using Qualtrics. The survey targeted professionals in the global evidence ecosystem. Respondents were invited to answer questions (using 5-point Likert scales) and provide optional comments on statements relating to objective 1 (4 statements) and objective 2 (7 statements). The latter were based on the seven recommendations to improve the availability and use of reliable healthcare information as proposed by the World Medical Association (WMA) in their Healthcare Information For All Policy Statement (2019). [4] For Objective 3 we invited respondents to answer multiple choice questions and provide comments.

Results: There were 2410 respondents from 135 countries, representing all six stakeholder groups in the global evidence ecosystem (generation, publishing, synthesis, packaging, finding, and application of evidence).

Objectives 1 and 2: There was strong agreement on all 11 statements. Objective 3: Respondents overwhelmingly called for WHO to explicitly champion universal access to reliable healthcare information and for WHO and HIFA to convene stakeholders to develop a global strategy.

Discussion: These findings confirm strong support among key stakeholders for the vision of universal access to reliable healthcare information and for the seven WMA recommendations. WHO is uniquely placed to lead on universal access and convene stakeholders to develop a global strategy. HIFA is uniquely placed to support WHO by promoting communication, understanding and advocacy across the global evidence ecosystem.

Conclusion: HIFA stands ready to collaborate with WHO for a world where every person, every health worker and every policymaker will have access to the information they need to protect their own health and the health of others, and will be protected from misinformation.

Acknowledgements: Main funders: Elsevier Foundation, Oxford PharmaGenesis, UK National Institute for Health Research. Technical support: Costello Medical, Digital Medic, International Federation of Library Associations' Evidence for Global and Disaster Health special interest group (IFLA E4GDH), and JBI.

Introduction

Reliable healthcare information saves lives.

Every day more than 20,000 people die in low- and middle-income countries (LMICs) because of poor quality health care in health facilities. [5] Countless others die because of poor care in the home and community, even before reaching a health facility. Quality of care is defined as that which will increase the likelihood of desired health outcomes. [6] For any given clinical situation, quality of care is dependent on the ability of the parent, caregiver or health worker to make evidence-informed decisions and take appropriate action, thereby ensuring the best possible care with available resources. Quality health care is centrally dependent on the availability and use of reliable healthcare information.

The World Health Organization's (WHO) Constitution notes that 'The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health' [1] and WHO's 13th General Programme of Work states 'WHO's quintessential function is to ensure access to authoritative and strategic information on matters that affect peoples' health'. [7]

Healthcare Information for All (HIFA) is a global social movement, launched in 2006, with the vision of a world where every person, every health worker and every policymaker has access to the reliable healthcare information they need to protect their own health and the health of others. HIFA is administered by Global Healthcare Information Network (GHI-Net), a UK-based NGO in official relations with WHO since 2022. For the purpose of this report, we use the term HIFA throughout unless there is a need to specify GHI-Net as an organisation. HIFA argues that universal access to essential health information is a prerequisite for universal health coverage [8], which has been echoed by WHO and others. [9]

Despite the above, access to reliable healthcare information is widely ignored in health development frameworks and is only mentioned once (and then only in relation to sexual and reproductive health information) in the United Nations Sustainable Development Goals. [10]

Objectives

HIFA and WHO have agreed on a three-year collaboration plan to accelerate progress towards universal access to reliable healthcare information. The plan comprises 10 activities, grouped in five priority areas. This report describes the first activity: 'To identify best practices, opportunities and challenges from relevant health related stakeholders, towards pursuing universal access to reliable healthcare information.'

The HIFA steering group and partners have interpreted this activity, in consultation with WHO, as a global consultation to identify stakeholders' views on three key questions:

1. How important is the availability and use of reliable healthcare information?
2. What should be done to improve the availability and use of reliable healthcare information?
3. What more can WHO and HIFA do to accelerate progress towards universal access to reliable healthcare information?

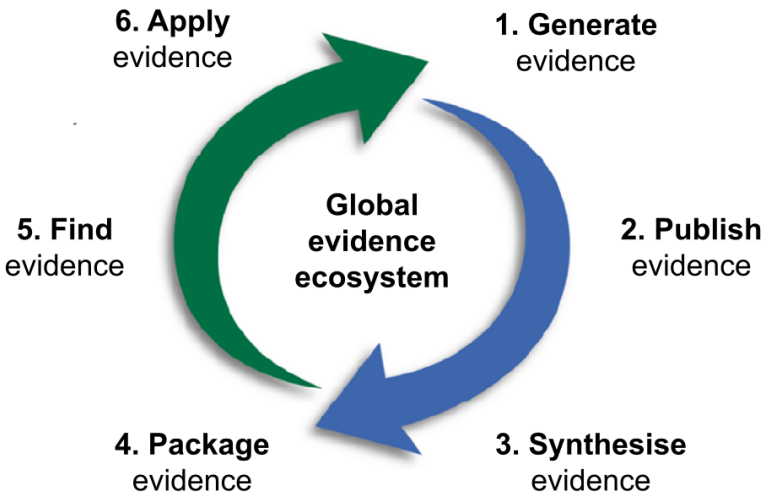
In particular, this consultation aimed to assess support for each of the seven recommendations for action in the unanimous policy statement by the World Medical Association (WMA, representing around 10 million doctors) on universal access to reliable healthcare information [4].

The global evidence ecosystem

The survey sought views across all stakeholder groups in the global evidence ecosystem (especially those who are professionally involved in the generation, publishing, synthesis, packaging, finding and application of evidence), across all countries worldwide.

The target audience was therefore mainly professional, but the component 'Apply evidence' includes, importantly, not only health workers but also the general public, patients and policymakers. There were therefore no restrictions on who could complete the survey.

Figure 1: The global evidence ecosystem, adapted from *The Lancet* 2004 [11]



Definition of reliable healthcare information

HIFA's definition of 'reliable healthcare information', as used throughout this report, has a wider meaning than it may suggest, namely: 'Reliable healthcare information is the information people need to protect their own health and the health of others. By definition, such information should not only be accurate and up to date, it should also be unbiased and reflect, as far as possible, the cumulative evidence based on robust research; it should be in the right language, technical level, and format; it should be relevant and applicable to the person's immediate situation (which is always changing); and the person should be empowered to differentiate it from the barrage of misinformation that does not fulfil these criteria'. [12]

Methods

The consultation was coordinated by the HIFA-WHO Collaboration Group [13], comprising HIFA Steering Group members, WHO staff and others, and reporting to the main HIFA Steering Group [14]. Subgroups were formed for successive tasks: survey development; survey testing; publicity and dissemination; results analysis; and report writing.

Survey development

The survey was created iteratively by the survey development team in liaison with the wider group. The starting point for the survey was the WMA policy statement and its seven recommendations. During the process of writing, pre-testing, and validating the survey instrument, further questions were added to assess the survey respondents' views on the importance of access to reliable healthcare information and the roles of WHO and HIFA in working toward that goal.

A prototype of the survey was initially developed on Google Forms and then migrated to Qualtrics, provided pro bono through the institutional account of one of the team. Qualtrics was selected for its superior functionality including language translation, data security, tracking of IP addresses, and greater inclusivity.

The survey testing process included both pilot testing and expert review. Following an iterative review process, the survey development team finalised a draft survey. This draft was then administered by the testing team to eight volunteers, self-selected from the wider HIFA community, to evaluate for question comprehension and to check that each question was clear and understood as intended. The testing was facilitated by a Zoom workshop, where volunteers were briefed and invited to complete the questionnaire live, and then reconvene for questions and discussion.

On the basis of the test findings, the wider group approved the final survey and used Qualtrics to translate this into ten different languages, selected for maximum inclusivity. In order to ensure that the translations were valid, native speakers available on the HIFA steering group (Arabic, French, Portuguese, Spanish) reviewed the translations. Once all final edits were made, the survey was made openly available online for self-administration.

Survey instrument

The final survey was a 21-question, mixed-methods instrument with five distinct sections (see Appendix for a copy of the survey itself). None of the questions were obligatory.

1. **Introduction:** introduces the purpose of the survey and how the information would be used.
2. **About you:** Respondents were able to self-identify or remain anonymous. The survey invited respondents to identify their roles within the global evidence ecosystem. The intention was to categorise respondents and also raise awareness of the global evidence ecosystem concept.
3. **How important is reliable healthcare information?** We presented four statements and invited respondents to indicate their level of agreement or disagreement using 5-point Likert scales. We also provided optional text fields for additional comments.
4. **What should be done to improve access to reliable healthcare information?** This included questions based on the WMA statement. Question 8 was in multiple-choice format, inviting people to select the two recommendations they felt were most important. Questions 9–15 explored stakeholder perspectives on each of the seven recommendations in the statement, using 5-point Likert scales and comment boxes.
5. **What more can WHO and HIFA do to accelerate progress towards universal access to reliable healthcare information?** This was a multiple-choice format, inviting people to select the two options they felt were most important. Finally there were questions asking respondents to prioritise action areas in the HIFA-WHO Collaboration Plan and to indicate their willingness to be contacted (a) in relation to the survey and/or (b) to discuss possibilities to support future efforts.

Participant recruitment

The survey aimed to present the perspectives of all six stakeholder groups in the global evidence ecosystem. This includes especially those who are professionally involved in the generation, publishing, synthesis, packaging, finding and application of evidence. All participants were invited to contribute from a personal perspective.

Publicity was designed mainly to reach professional stakeholders in the global evidence ecosystem. We were supported by complimentary publicity on the *BMJ* and *Lancet* websites, and by a WMA mailing to its constituent national medical associations. We publicised the survey on several professional discussion forums. We invited HIFA members to complete the survey themselves and distribute it to their networks.

Recruitment was further supported by a number of virtual and in-person events:

1. Evidence Based Health Care Day 2023. HIFA was invited as an operational partner for Evidence Based Health Care Day 2023, alongside Cochrane, JBI and others. [15]
2. HIFA partnered with the International Federation of Library Associations' Evidence for Global and Disaster Health special interest group (IFLA E4GDH) to host a hybrid event at the World Library and Information Congress, Rotterdam, Netherlands, 24 August 2023. [16]

3. HIFA partnered with *The Lancet* to hold a webinar on Research for Health on 9 November 2023, to celebrate 200 years of *The Lancet*. The recording is freely available [17] This raised the visibility of the consultation, although the event postdated the online survey.

Data analysis

The survey could be classified as a voluntary response sample, with the relevant underlying population being people with particular interest (and often expertise) in issues concerning healthcare information. It was not designed as a random sampling exercise, i.e. selection of a random sample of a larger (global) population, whether of the public or of healthcare workers. So, formally, analysis using statistical tests based on assumptions of random sampling would not be valid.

However, it seems more appropriate to consider the survey not as a sampling exercise at all but to consider the responders as a sizeable relevant population (largely those professionally involved in the generation, publishing, synthesis, packaging, finding and application of evidence) in their own right, allowing the survey results to simply be taken at face value.

To examine attitudes about the importance of access to reliable healthcare information and level of agreement across a series of statements, we present responses on a 5-point Likert scale (1=strongly disagree, 5=strongly agree).

None of the questions were obligatory. As a result, the total number of respondents who answered any given question was slightly less than the total number of respondents. Results are presented in absolute numbers and percentages, with the latter relating to the number who responded to the corresponding question rather than the total number of respondents.

For qualitative analysis of comments, contributions were reviewed by at least two authors and categorised under subheadings, from which we derived a short overview paragraph for each question and selection of illustrative quotes.

Subgroup analyses were done to investigate possible differences in responses among the six different WHO regions, six major stakeholder groups in the global evidence ecosystem, and English-speakers versus Other-language-speakers.

Results

The responses demonstrated strong agreement on all four questions relating to the importance of reliable healthcare information, and strong agreement on all seven recommendations of the WMA Statement. There was strong support for WHO to make a public commitment to accelerate progress towards universal access to reliable healthcare information; support stakeholders to develop a strategy for universal access to reliable healthcare information; and promote access to reliable healthcare information in languages other than English.

The results are presented below. For interpretation and implications, see Discussion.

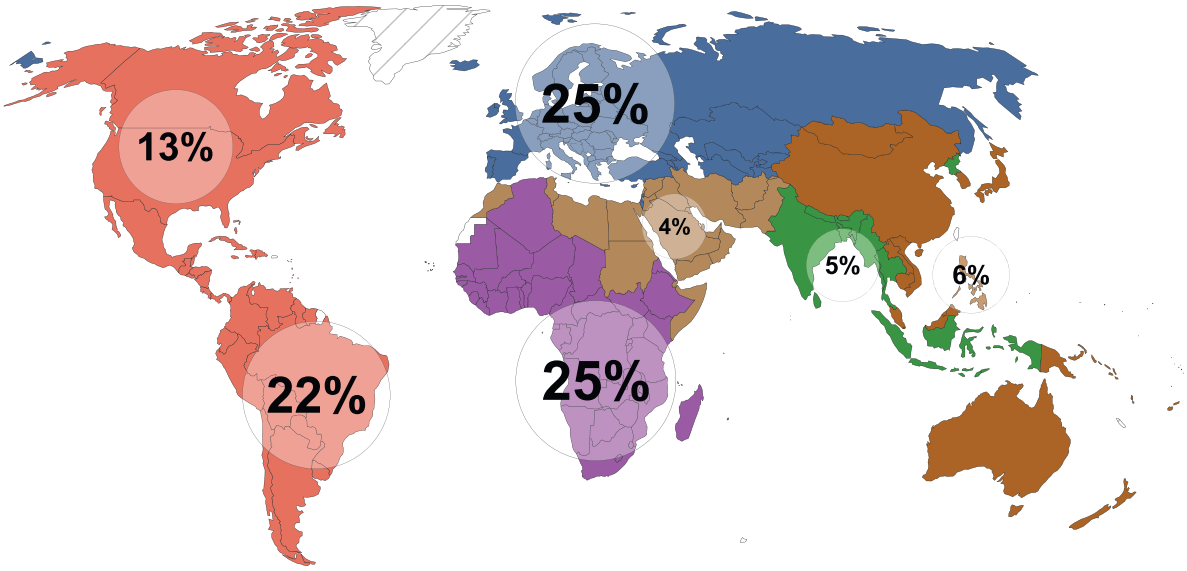
Participants

There were 2410 responses from 135 countries.

Representation by WHO region

Representation by WHO region is shown below. There was strong representation from Africa, Europe, and the Americas (especially Latin America), as compared with the Eastern Mediterranean, South East Asia and Western Pacific.

Figure 2: Representation by WHO region (PAHO disaggregated)

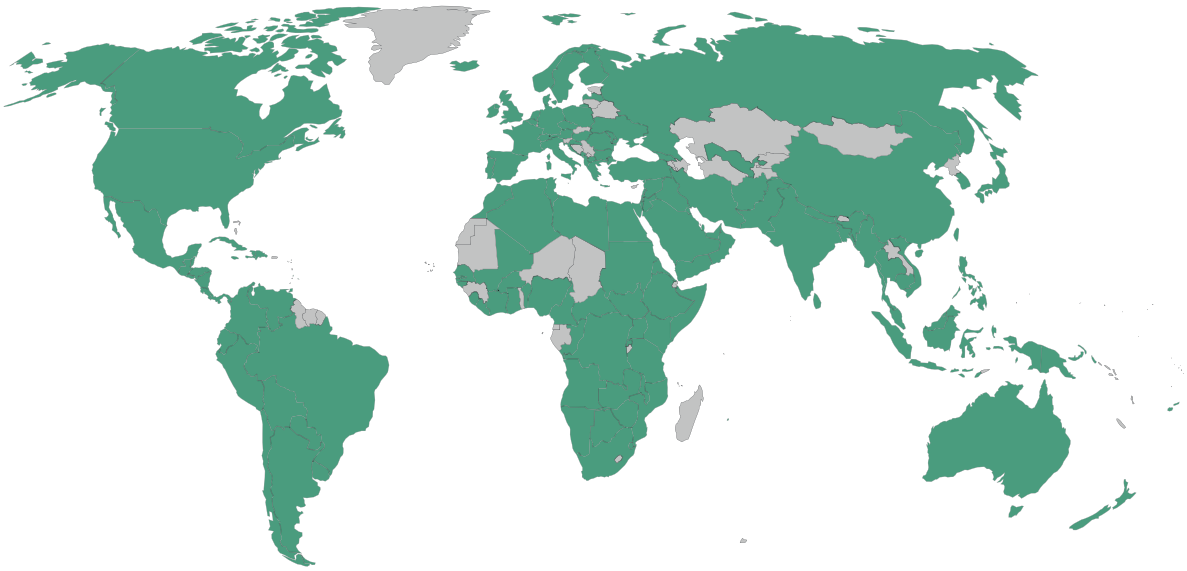


Absolute numbers of respondents in each region were: Africa 599; Eastern Mediterranean 99; Europe 594; Latin America 510; North America 315; South-East Asia 124; Western Pacific 138.

Representation by country

Respondents self-identified as resident in 135 countries.

Figure 3: Self-identification by country. Respondents represented 135 countries (shaded green)



Representation was strongest in the following six countries: United Kingdom (194), United States (193), Brazil (182), Nigeria (158), Greece (125), Ethiopia (121), Canada (111). By contrast, China and Russia were underrepresented.

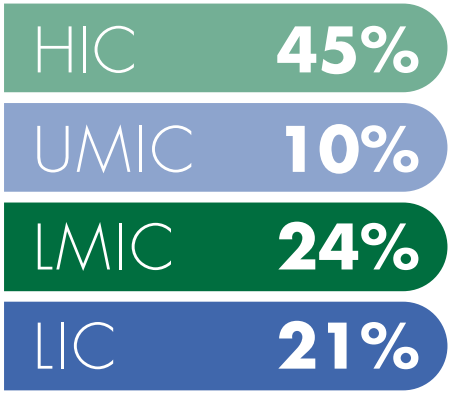
Table 1: Number of respondents from each country

Africa	Americas	Eastern Mediterranean	Europe	South-East Asia	Western Pacific
Algeria 1	Argentina 16	Afghanistan 1	Albania 1	Bangladesh 11	Australia 72
Benin 3	Barbados 1	Egypt 6	Austria 28	India 62	Brunei 1
Botswana 2	Belize 1	Iraq 6	Belgium 21	Myanmar 7	Cambodia 1
Burkina Faso 9	Bolivia 5	Israel 1	Bulgaria 2	Nepal 24	China 14
Cameroon 34	Brazil 182	Lebanon 18	Croatia 5	Sri Lanka 3	Fiji 2
Central African Republic 1	Canada 111	Iran 4	Czech Republic 1	Thailand 1	Indonesia 13
Côte d'Ivoire 4	Chile 8	Jordan 22	Denmark 4		Japan 14
Democratic Republic of the Congo 5	Colombia 37	Kuwait 1	Finland 13		Malaysia 5
Eritrea 1	Costa Rica 6	Morocco 2	France 14		New Zealand 9
Ethiopia 121	Cuba 13	Occupied Palestinian territory 2	Georgia 1		Papua New Guinea 3
Gambia 3	Dominican Republic 25	Oman 2	Germany 22		Philippines 9
Ghana 15	Ecuador 9	Pakistan 12	Greece 125		Singapore 1
Guinea-Bissau 1	El Salvador 8	Qatar 7	Hungary 1		South Korea 1
Kenya 32	Guatemala 5	Saudi Arabia 3	Iceland 2		Viet Nam 1
Liberia 1	Haiti 1	Sudan 3	Ireland 9		
Libya 2	Honduras 87	Syria 2	Italy 15		
Malawi 9	Jamaica 1	Tunisia 2	Latvia 5		
Mali 1	Mexico 20	United Arab Emirates 4	Macedonia 1		
Mauritius 1	Nicaragua 3	Yemen 1	Malta 2		
Mozambique 12	Panama 8		Moldova 2		
Namibia 3	Paraguay 3		Montenegro 1		
Nigeria 158	Peru 13		Netherlands 16		
Republic of the Congo 3	Saint Kitts and Nevis 2		Norway 12		
Rwanda 14	Saint Lucia 1		Poland 5		
Senegal 9	Trinidad and Tobago 2		Portugal 29		
Sierra Leone 5	United States 193		Romania 2		
Somalia 6	Uruguay 48		Russia 2		
South Africa 61	Venezuela 6		Spain 28		
South Sudan 3			Sweden 7		
Swaziland 1			Switzerland 14		
Tanzania 8			Turkey 4		
Uganda 25			Ukraine 1		
Zambia 11			United Kingdom 194		
Zimbabwe 25			Uzbekistan 1		

Representation by country income group

Country data were categorised according to country income group: low-income countries (LIC), lower-middle-income countries (LMIC), upper-middle-income countries (UMIC) and high-income countries (HIC). 21%, 24%, 10%, 45% of respondents were based in LIC, LMIC, UMIC, and HIC, respectively.

Figure 4: Representation by country income group



Representation by stakeholder group

The survey asked: How would you describe yourself in relation to the global evidence ecosystem? 94% self-identified with one of the six parts of the ecosystem, with almost half identifying as "I apply healthcare evidence (e.g. patient, health worker, policymaker)". All parts of the ecosystem were represented:

Figure 5: Representation by role in the global evidence ecosystem

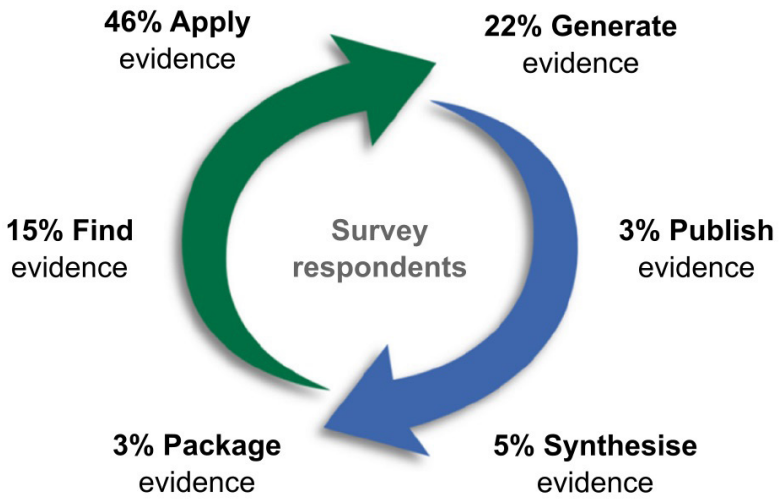


Table 2: Representation by role in the global evidence ecosystem

I **generate** healthcare evidence (e.g. researcher)	511	22%
I **publish** healthcare evidence (e.g. journal editor)	81	3%
I **synthesise** healthcare evidence (e.g. systematic reviews, guidelines)	121	5%
I **package** healthcare evidence (e.g. manuals for health workers)	73	3%
I **find** healthcare evidence (e.g. library and information professional)	350	15%
I **apply** healthcare evidence (e.g. patient, health worker, policymaker)	1096	46%
Other	144	6%

6% of respondents selected 'Other', some noting they were active in more than one area of the ecosystem, and others identifying as teachers, students, funders, data analysts, patients, or retired persons.

Representation by language

The survey was offered in 10 languages, with English as the default. Most responded in English, but a substantial number responded in Spanish and Portuguese.

Table 3: Representation by language

English	1730	72%
Spanish	329	14%
Portuguese	221	9%
French	83	3%
Arabic	30	1%
Chinese	13	<1%
Russian	3	<1%
Bengali	1	<1%
Persian	0	0
Hindi	0	0

How important is access to reliable healthcare information?

Respondents were invited to indicate their level of agreement with four statements. The results are shown in the table below. There was strong agreement on all four statements, with 87–98% of participants agreeing or strongly agreeing with each statement. The median response for every statement was "strongly agree".

Table 4: How important is access to reliable healthcare information?

	Responses by number and %						
How much do you agree with the following statements?	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	**Agree + Strongly agree**	Total
Q4: Access to reliable healthcare information is (or should be) a human right	17 <1%	14 <1%	58 2.4%	268 11%	2013 85%	**96%**	2370
Q5: Improving the availability and use of reliable healthcare information would lead to substantial improvements in quality of care and health outcomes	14 <1%	26 1.1%	96 4.1%	392 17%	1835 78%	**95%**	2363
Q6: Universal health coverage cannot be achieved without universal access to reliable healthcare information	18 <1%	57 2.4%	231 9.8%	572 24%	1478 63%	**87%**	2356
Q7: More support is needed for health literacy	15 <1%	13 <1%	65 2.7%	392 17%	1879 80%	**97%**	2364

Q4 Access to reliable healthcare information is (or should be) a human right

96% of respondents agreed or strongly agreed with this statement.

325 respondents wrote comments on this question. The vast majority emphasised the importance of reliable healthcare information and that it is, or should be, a human right. Several said it should be recognised in national legislation and policy. A few noted that, while access to reliable healthcare information is very important, the term 'right' should be reserved for what is already internationally agreed.

Q4 Illustrative quotes:

"Without reliable healthcare information, we cannot make informed decisions about our health and wellbeing."
I find evidence, United Kingdom

"There is no way to involve the patient if they don't have access to knowledge."
(translated from Portuguese)
I apply evidence, Brazil

"I don't know if 'right' is the correct word, but everyone should have access to reliable information."
I generate evidence, Brazil

"I was surprised to see that this is not already in the Declaration of Human Rights."
I publish evidence, United Kingdom

Q5 Improving the availability and use of reliable healthcare information would lead to substantial improvements in quality of care and health outcomes

95% of respondents agreed or strongly agreed with this statement.

276 respondents added comments on this question, which showed overwhelming support for the statement. Most emphasised that reliable healthcare information, both for health workers and the public, is essential for quality care and positive health outcomes. Several stressed the importance of 'use' as well as availability of information. Others noted that information needs to be understandable and relevant to the end-user. Many pointed out that the availability of reliable information is vital but other factors are also needed for positive health outcomes.

Q5 Illustrative quotes:

"The more information an individual has about their health, the better they can make conscious and informed decisions."
(translated from Portuguese)
I apply evidence, Mozambique

"Health information helps individuals to make better choices in seeking healthcare and maintaining their health and that of community."
I apply evidence, South Sudan

"It is important that health personnel have updated, reliable and safe information to offer services to the population."
(translated from Spanish)
I generate evidence, Guatemala

"I think reliable healthcare information is the key but not the only thing for quality improvement."
I generate evidence, Ethiopia

Q6 Universal health coverage cannot be achieved without universal access to reliable healthcare information

87% of respondents agreed or strongly agreed with this statement.

208 respondents wrote comments on this question. Most were equally divided between those who emphasised their agreement with the statement, and those who pointed out that information is one of many factors needed for the achievement of UHC.

Q6 Illustrative quotes:

"Definitely I agree because there is no way to achieve UHC without valid and contemporary information and evidence."
I apply evidence, Ethiopia

"Universal health coverage begins with access to reliable health information."
I generate evidence, Tanzania

"Although access to reliable and quality information is essential to achieving quality care, universal health coverage is above all dependent on political and societal choices."
(translated from French)
I find evidence, Canada

"Besides health information, there needs a push in improving equitable access to health care, financial investments and political will."
I generate evidence, India

Q7 More support is needed for health literacy

97% of respondents agreed or strongly agreed with this statement.

243 respondents wrote comments on this question. Most emphasised the importance of health literacy, particularly for those in low-income countries, those who are living with disabilities and those who are marginalised. Several respondents stressed that health workers and healthcare information providers have a responsibility to use language that is readily understandable to their patients and the public. Ten respondents highlighted the role of librarians in supporting health literacy, and a few others noted that health literacy starts with (primary) school education.

Q7 Illustrative quotes:

"This is so important, people often don't know what they should be looking for, which sites to check, and what might be misleading."
I find evidence, United Kingdom

"Yes. In understandable languages, not in languages that people do not understand."
(translated from Arabic)
I find evidence, Jordan

"Healthcare literacy should start with children learning about health and care."
I apply evidence, United Kingdom

"Health information needs to be understandable for all reading levels."
I find evidence, Canada

"This should also incorporate elimination of misinformation and gaining trust of healthcare providers and systems."
I apply evidence, United States

What should be done to improve access to reliable healthcare information?

Q8 Ranking of the seven WMA Recommendations

The seven WMA recommendations were presented as seven statements:

- There should be more support for initiatives that improve access to reliable healthcare information
- There should be higher standards of practice and ethics among information providers
- There should be more support for research on the availability and use of reliable healthcare information
- More should be done to ensure that health workers have access to reliable healthcare information
- More should be done to protect people from misinformation
- Governments should recognise their obligation to improve the availability and use of reliable healthcare information
- Governments should provide more support for WHO to 'extend to all peoples the benefits of medical, psychological and related knowledge' as described in the WHO Constitution (1948)

Participants were invited (Q8) to select which two WMA recommendations they thought were most important, and these were ranked as follows.

Table 5: Respondents' ranking of the importance of the seven WMA recommendations

WMA Recommendation	Ranking	Number of selections
Support initiatives to improve access to reliable healthcare information	**1**	1289
Ensure health workers have access to reliable healthcare information	**2**	1233
Protect people from misinformation	**3**	838
Promote higher standards of good practice and ethics	**4**	782
Support research on the availability and use of reliable healthcare information	**5**	708
Urge governments to recognize their obligation to improve availability and use	**6**	493
Urge governments to provide more support for WHO constitutional mandate	**7**	394

100 (4%) of respondents selected 'Other' in response to the above question. Their responses highlighted training of health workers, open access, reliable information for the general public, health literacy, and support for libraries.

Q8 Illustrative quotes:

"All [seven recommendations] should be applied."
I apply evidence, United States

"Ensuring health information meets the requirements of end users in all their diversity."
I apply evidence, Italy

"Ensure patients and families have access to reliable healthcare information in simple, accessible formats."
I apply evidence, United States

"Free access for health workers to reliable health care information."
I apply evidence, Greece

Level of agreement with each WMA recommendation

The seven WMA recommendations were then presented as seven separate statements, and respondents were invited to indicate their level of agreement on a 5-point Likert scale. There was overwhelming agreement for each of the WMA recommendations, with 88–95% of participants agreeing or strongly agreeing with each statement. The median response for every statement was "Strongly agree":

Table 6: Level of agreement with each WMA recommendation

	Responses by number and %						
How much do you agree with the following statements?	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	**Agree + Strongly agree**	Total
Q9: Support initiatives to improve access to reliable healthcare information	17 <1%	14 <1%	101 4.3%	474 20%	1765 74%	**94%**	2371
Q10: Promote higher standards of good practice and ethics	20 <1%	25 1.1%	210 8.9%	538 23%	1570 66%	**89%**	2363
Q11: Support research on the availability and use of reliable healthcare information	15 <1%	33 1.4%	232 9.8%	586 25%	1495 63%	**88%**	2361
Q12: Ensure health workers have access to reliable healthcare information	12 <1%	17 <1%	99 4.2%	448 19%	1780 76%	**95%**	2356
Q13: Protect people from misinformation	17 <1%	22 <1%	130 5.5%	410 17%	1772 75%	**92%**	2351
Q14: Urge governments to recognize their obligation to improve availability and use	16 <1%	21 <1%	122 5.2%	517 22%	1672 71%	**93%**	2348
Q15: Urge governments to provide more support for WHO constitutional mandate	25 1.1%	66 2.8%	363 16%	668 29%	1217 52%	**81%**	2339

Below are the results for each of the seven WMA recommendations, including an overview and examples of respondents' comments.

Q9 There should be more support for initiatives that improve access to reliable healthcare information

94% agreed or strongly agreed with this statement

156 (7%) respondents added comments on this question. There was a diverse range of comments. Respondents emphasised the importance of funding, governments, and WHO. Cross-cutting issues included health literacy, better health communications for the general public, reaching special needs and marginalised groups, and access to reliable information for health workers. health literacy, and a few others noted that health literacy starts with (primary) school education.

Q9 Illustrative quotes:

"Undoubtedly! This is the basis for practising quality medicine."
(translated from Portuguese)
I apply evidence, Brazil

"We must support all initiatives wherever they come from to facilitate access to reliable information for all people on earth."
(translated from French)
I apply evidence, Haiti

"Access for all, from community to physicians, all the way through patients, admin staff, tech staff, and nurses/caregivers."
I generate evidence, Brazil

"This should be targeted towards groups who are most at risk of being left behind, such as people with disabilities, people on the move, etc."
I apply evidence, Italy

Q10 There should be higher standards of practice and ethics among information providers

89% agreed or strongly agreed with this statement.

192 (8%) respondents added comments on this question. Several believed that most information providers already have high standards and ethics, while others highlighted commercial conflicts of interest and the rising tide of poor-quality information online.

Q10 Illustrative quotes:

"If existing standards are met, higher standards are not required."
(translated from Spanish)
I synthesise evidence, Honduras

"There is too much false information and poor quality information that is easily published and accessed online."
I apply evidence, South Africa

"Articles published in tabloid newspapers giving misleading information need to be stopped."
I find evidence, United Kingdom

"Endorsement of websites that provide accurate health information by credible institutions should be clearly visible."
I apply evidence, South Africa

"Ethical considerations, such as transparency about sources and potential conflicts of interest, are essential to maintain the credibility and authenticity of healthcare information."
I generate evidence, Croatia

Q11 There should be more support for research on the availability and use of reliable healthcare information

88% agreed or strongly agreed with this statement.

143 (6%) respondents added comments on this question. Many people appear to have misunderstood the question as their responses referred to health research rather than health information research. Others noted that health research is relatively strong but translation of research into policy and practice is weak. About 20 responses referred specifically to health information research and these were overwhelmingly supportive of the statement.

Q10 Illustrative quotes:

"I strongly agree… Robust research in this area is essential to comprehensively understand the challenges individuals face in accessing accurate health information and to identify effective strategies to overcome such challenges."

I generate evidence, Croatia

"Countries should work with the Global Evidence Commission Implementation Council to ensure consistency in the production of reliable healthcare information."

I find evidence, United Kingdom

Q12 More should be done to ensure that health workers have access to reliable healthcare information

95% agreed or strongly agreed with this statement.

187 respondents (8%) provided comments. Most agreed that improving the access of health workers to reliable healthcare information is essential and would empower them to provide quality services to end users. Several noted that health workers are also a primary source of health information for patients, so ensuring health workers are fully informed is especially important. Others indicated that health workers may have access to information but do not always have the skills to find reliable information and to understand and practise evidence-informed decision making. A few noted that some health professionals are vulnerable to misinformation. Several said there should be more attention to the needs of community health workers and other primary care professionals, where information access is often limited. Some highlighted the importance of open access and libraries.

Q12 Illustrative quotes:

"Providing healthcare workers with reliable information contributes not only to their professional growth and expertise but also directly impacts patient safety and positive health outcomes."
I generate evidence, Croatia

"Health workers have strong influence on the community and the public. What they say carries a lot of weight and if they say and perpetuate inaccurate information then the impact is huge"
I apply evidence, Zimbabwe

"Ensure that health workers know what reliable healthcare information means."
I find evidence, UK

"I cannot count the number of situations where I have been witness personally of the lack of reliable healthcare information to inform and improve treatment outcome. It is crucial that health workers everywhere and mostly in low resource settings be supported to access reliable healthcare information."
I apply evidence, Cameroon

Q13 More should be done to protect people from misinformation

92% agreed or strongly agreed with this statement.

211 respondents (9%) provided comments on this question. Most emphasised the importance of misinformation as a global health challenge. Some highlighted the importance of health literacy and making it easier for people to differentiate reliable information from misinformation. Others suggested there needs to be tighter regulation, especially of social media, as well as increased penalties for those who spread disinformation. Conversely, a few respondents were concerned about the possibility of overregulation.

Q13 Illustrative quotes:

"Misinformation and outright false information is one of the greatest challenges in our present information age."
I apply evidence, South Africa

"This all starts with increasing trust in government and science."
I apply evidence, Rwanda

"We should make it easier for people to find out if information is fact or fiction."
I find evidence, Australia

"As it is impossible to eliminate misinformation the key priority is developing health literacy."
I find evidence, United Kingdom

"The so-called social media platforms are the worst and must be controlled."
(translated from Arabic)
I find evidence, Jordan

"I think this needs to be approached with caution. I worry about heavy-handed regulation backfiring."
I synthesise evidence, United Kingdom

Q14 Governments should recognise their obligation to improve the availability and use of reliable healthcare information

93% agreed or strongly agreed with this statement.

165 respondents (7%) provided comments on this question. The vast majority emphasised that governments have a moral and/or legal obligation to ensure the availability of reliable healthcare information for their population. A few said that this is already recognised under international human rights law, but not put into practice. Others noted that governments can politicise healthcare information, citing examples of COVID-19 misinformation by heads of state. Several respondents called for tougher regulation and penalties for deliberate misinformation. Several noted popular mistrust in governments and public institutions.

Q14 Illustrative quotes:

"It is not just a MORAL obligation – it is a LEGAL one too; at least for those states – which is most of them – who are signatories to the International Covenant on Economic, Social and Cultural Rights. A few test class action court cases might concentrate their minds!"
I synthesise evidence, United Kingdom

"Actively spreading misinformation regarding health should be criminalized."
I find evidence, Canada

"By clear legislation and sufficient and continuous public funding for info producers."
I synthesise evidence, Finland

Q15 Governments should provide more support for WHO to 'extend to all peoples the benefits of medical, psychological and related knowledge' as described in the WHO Constitution (1948)

81% agreed or strongly agreed with this statement.

152 respondents (7%) provided comments. Many said that governments should provide financial support to WHO to deliver its mandate. A few emphasised the importance of building trust in institutions, including WHO. Several made non-specific and unsubstantiated comments that were critical of WHO, relating to trust, accountability, cost, conflicts of interest due to industry interference, and political influences. Others suggested that such criticisms were politically motivated.

Q15 Illustrative quotes:

"Yes, in terms of WHO as an advocate of the importance of access to information for all, but not sure the WHO is necessarily the best organisation to actually carry out the communications work itself."
I package evidence, United Kingdom

"The public needs to recover TRUST in current scientific and public health institutions and that's the most difficult thing to do these days, and before any misinformation is effectively tackled."
I apply evidence, Switzerland

"WHO is facing challenges to its credibility post Covid. Whether these are fair or not it needs to review and rebuild its credibility before seeking increased support for other initiatives."
I apply evidence, United Kingdom

Q16: What more can WHO do to accelerate progress towards universal access to reliable healthcare information?

Respondents were offered four options and invited to select the two options they thought were most important. The most popular option was: 'Support stakeholders to develop a strategy for universal access to reliable healthcare information', followed closely by 'Promote access to reliable healthcare information in languages other than English.' There was also very strong support for WHO to make a public commitment to accelerate progress towards universal access to reliable healthcare information.

Table 7: What more can WHO do to accelerate progress towards universal access to reliable healthcare information?

Option	Ranking	Number
Support stakeholders to develop a strategy for universal access to reliable healthcare information	**1**	1638
Promote access to reliable healthcare information in languages other than English	**2**	1520
Make a public commitment to accelerate progress towards universal access to reliable healthcare information	**3**	1436
Increase investment in WHO publications	**4**	432

This question included an 'Other' option with a text box. 139 respondents (6%) selected this option and provided comments, which emphasised the importance of: high-level political support for universal access to reliable healthcare information; meeting information needs in languages other than English and for people with disabilities; health literacy; open access; support for initiatives that provide reliable information; combating misinformation; and improving the WHO website. There were a few non-specific criticisms of WHO.

> **"WHO should support stakeholders to develop a strategy for universal access to reliable healthcare information"**

Q16 Illustrative quotes:

"Co-design a strategy on universal access to reliable healthcare information with the groups who don't currently have good access."
I find evidence, Australia

"Promote the dissemination of information in language accessible to the general public"
(translated from Portuguese)
I find evidence, Portugal

"Support open access so health research is accessible to all."
I find evidence, Fiji

Q17: What more can HIFA do to accelerate progress towards universal access to reliable healthcare information?

Respondents were offered four options and invited to select the two options they thought were most important. The most popular option was: 'Support stakeholders to develop a strategy for universal access to reliable healthcare information', followed closely by 'Harness the collective expertise of stakeholders to accelerate progress towards universal access'.

Table 8: What more can HIFA do to accelerate progress towards universal access to reliable healthcare information?

Option	Ranking	Number
Support stakeholders to develop a strategy for universal access to reliable healthcare information	**1**	1525
Harness the collective expertise of stakeholders to accelerate progress towards universal access	**2**	1365
Promote access to reliable information in languages other than English	**3**	1117
Use the HIFA forums to explore key healthcare information issues	**4**	746

56 respondents (2.5%) selected 'Other' and provided comments. There were several suggestions to strengthen advocacy for healthcare information as a global health issue and to further engage stakeholders in HIFA's mission.

"HIFA should support stakeholders to develop a strategy for universal access to reliable healthcare information"

Q17 Illustrative quote:

"You need a publicly funded solid marketing campaign for this, that reaches people and communicates the process step by step. This could help the public understand what HIFA's mission is and how the process towards tackling misinformation is achieved step by step."

I apply evidence, Switzerland

Q18: The HIFA-WHO collaboration plan has five action areas. Which areas are most important?

Respondents were offered five options and invited to select the two options they thought were most important. There was an additional input for 'Other,' with a text box to provide details.

173 chose to select just one option. The ranking is shown below.

Table 9: Ranking of the five action areas in the HIFA-WHO Collaboration Plan (among those who chose a single option)

Option	Ranking	Number of respondents
1. Promote WHO advocacy to achieve universal access to reliable healthcare information	**1**	53
2. Provide WHO with access to experience and expertise on information needs and how to meet them	**2**	35
3. Support WHO's role in meeting information needs in languages other than English	**3**	30
4. Support the dissemination and uptake of WHO publications	**4**	29
5. Support WHO's role as a leading provider of reliable healthcare information	**5**	26

2,048 respondents followed the instruction and selected two options. There are 10 possible combinations of two options chosen from the five options available. All ten were represented as shown below.

Table 10: Ranking of the five action areas in the HIFA-WHO Collaboration Plan (among those who chose two options).
Only the most popular pairing (1+2) is shown in full. See Table 9 for explanation of options 3-5.

Option pairs	Ranking	Number of selections
1+2: Promote WHO advocacy to achieve universal access to reliable healthcare information + 2. Provide WHO with access to experience and expertise on information needs and how to meet them	**1**	303
2+4	**2**	255
2+3	**3**	218
1+4	**4**	216
1+5	**5**	210
1+3	**6**	209
3+4	**7=**	175
4+5	**7=**	175
2+5	**9**	144
3+5	**10**	143

124 respondents chose 3, 4 or 5 options. Among these respondents, selections were evenly split across the five options.

60 (2.5%) of respondents selected 'Other' in response to the above question. Most of these comments supported one or more of the five areas above.

Q21: Finally, we invite you to say something about your professional and/or personal experience or any other comments

960 respondents provided comments. Most of the comments briefly described the person's professional interests and reiterated the importance of reliable healthcare information. Several requested, on behalf of their organisations, to discuss possibilities for collaboration.

Q14 Illustrative quotes:

"Having access to accurate and reliable health information is critical for our society at large."
I find evidence, Canada

"I think WHO using the phrase "Universal health coverage cannot be achieved without universal access to reliable healthcare information" will go a long way to true universal access."
I generate evidence, Japan

"Congratulations to HIFA and WHO for promoting this relevant initiative for health for all."
(Translated from Spanish)
I generate evidence, Honduras

"Health Care Information is very low in developing countries like ours. A lot need to be done to promote health information in developing countries."
I package evidence, Nigeria

Subgroup analysis

Subgroup analyses were done to assess differences in responses among (a) the six different WHO regions, (b) six stakeholder groups in the global evidence ecosystem, and (c) English-speakers versus other-language-speakers. The results of these analyses are available on request. Few, if any, of the observed differences are large enough to seem of any practical importance, although other-language speakers were slightly more strongly supportive than English speakers of the seven WMA recommendations (Qs 9 –15).

Discussion

Key findings

This consultation has demonstrated remarkably strong support across all stakeholder groups in the global evidence ecosystem for all four statements relating to the importance of access to reliable healthcare information *and* for all seven WMA recommendations on what should be done to improve the availability and use of reliable healthcare information. In particular, there is strong consensus for WHO and HIFA to 'Support stakeholders to develop a strategy for universal access to reliable healthcare information'.

Respondents

Interpretation: The survey attracted 2410 responses from 135 countries, indicating a high level of interest in the theme of universal access to reliable healthcare information. The very wide geographical spread across all six regions indicates that this issue is seen as a priority worldwide. There was particularly strong representation from sub-Saharan Africa (599), the Americas (814), and Europe (594). In the PAHO region, representation from Latin America was especially high with 510 respondents versus 304 in North America. SEARO (124 respondents) and WPRO (138) were relatively less represented, considering their large populations (2.1 and 1.9 billion, respectively). There was an unexpectedly high number of respondents from two countries: Ethiopia (121 respondents) and Greece (125 respondents). This might have been due to differences in publicity between countries. For example, the WMA informed its national medical associations about the survey, but it is possible that only a few countries cascaded this to their members. China (13) and Russia (2) were underrepresented; these countries are also underrepresented in the HIFA membership.

The vast majority of respondents (94%) self-identified with one of the six components of the global evidence ecosystem, suggesting this novel approach is acceptable and could be used in future research. All six components were represented. Almost half (46%) identified as 'apply' evidence, most of whom were frontline health workers (on the basis of responses to Q21). A considerable number identified with 'generate' evidence (health researchers) and 'find' evidence (library and information professionals).

There were fewer people who self-identified as 'publish', 'synthesise', or 'package' evidence. However, this is to be expected as these stakeholder groups are relatively small compared to other groups.

Most of the respondents (72%) completed the survey in English, but a substantial number completed in Spanish (14%), Portuguese (9%) and French (3%), perhaps encouraged by publicity on the HIFA-Spanish, -Portuguese, and -French forums. Given that the default language of the survey was English, and almost all publicity was done in English, a return of 28% in other languages is notable.

How important is access to reliable healthcare information?

Q4: Access to reliable healthcare information is (or should be) a human right

Interpretation: 96% of respondents agreed or strongly agreed with this statement. This indicates that nearly everyone sees access to reliable healthcare information as a human rights issue. It is likely that most respondents were unaware of the current legal status of access to reliable healthcare information, namely that it is not recognised as a right in itself but it is recognised as a *determinant* of the right to health [18]. Conversely it is possible that a few respondents were aware of this nuance (although none specified it) and disagreed with the statement on the basis that it is more pragmatic to promote universal access around its current legal status as a determinant of the right to health, rather than argue for recognition of access as a right in itself. Given that many of our respondents have a deep professional expertise in one or more aspects of the global evidence ecosystem and represent those who would be most aware of the status of healthcare information in human rights law, it is very likely that Member States are unaware that access to reliable healthcare information is a determinant of the right to health.

Implications: These results suggest that access to reliable healthcare information should continue to be presented as a human rights issue. WHO's Constitution states: 'The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.' HIFA has always grounded its work in human rights and collaborated with the New York Law School to publish a white paper on Access to Health Information Under International Human Rights Law. [19] The paper concludes that States party to treaties such as the International Covenant on Civil and Political Rights have a legal obligation (not only a moral one) under International Human Rights Law to progressively meet the healthcare information needs of their populations.

The pragmatic position of promoting access to healthcare information as a determinant of the right to health is supported by the relevant documentation, which describes determinants of the right to health as including health education and information and as being *equally binding* on governments as compared with the right to health itself. [18]

The above findings present an opportunity for WHO, HIFA and partners to actively promote the goal of universal access to reliable healthcare information as a human rights issue, based on current international human rights law. A logical next step would be to convene stakeholders on what can be done to raise awareness of this issue among governments and support them to recognise and pursue their obligations in national legislation and policy (as suggested by several survey respondents).

Q5: Improving the availability and use of reliable healthcare information would lead to substantial improvements in quality of care and health outcomes

Interpretation: 95% of respondents agreed or strongly agreed that improving the availability and use of reliable information would lead to substantial improvements in quality of care and health outcomes. Review of the comments suggested equal emphasis on health workers and the general public. Several respondents recognised that, although access to reliable healthcare information is essential, it is not the only factor in quality of care.

Implications: Whereas a great deal is known about medical causes of mortality and morbidity, healthcare-related causes are less understood and quantified. The previously mentioned study by Kruk *et al* estimated that 8.6 million deaths a year are due to poor quality care [5]. This is likely to be a major underestimate as it looked only at deaths due to poor quality care in health facilities, excluding deaths relating to poor quality care in the home and community (personal communication, NPW). The study did not attempt to quantify the factors that contribute to poor quality care, such as the availability and use of reliable healthcare information.

The current survey suggests that more research is needed to understand and quantify the role of reliable healthcare information as compared with other factors that affect quality and safety of care.

Q6: Universal health coverage cannot be achieved without universal access to reliable healthcare information

Interpretation: 87% of respondents agreed or strongly agreed with the statement. The level of consensus is slightly less than many other questions. One explanation may be that some people misunderstand 'universal health coverage' as being primarily 'access to health care without financial hardship' rather than 'access to *quality* health care without financial hardship'. Improving access to reliable healthcare information would support the latter but not necessarily the former. Another factor may be the absoluteness of the wording 'universal… universal'. For example, had the original wording been 'Universal health coverage cannot be achieved without improving the availability of reliable healthcare information', the level of agreement may have been higher. It is also possible that some people interpreted the word 'universal' literally (in one or both uses of the term), and therefore see the statement as aspirational rather than a concrete goal.

Implications: The finding suggests there is a need to consider issues around access to reliable healthcare information in the context of current thinking on universal health coverage. Improving the availability and use of reliable information is widely seen as an important driver of universal health coverage. Recognition of this dependency would increase the political and financial support needed for universal access to reliable healthcare information.

HIFA has started to explore this perspective in recent years. In 2020, HIFA steering group members published a paper that 'highlights the growing evidence of the impact of wider access to practical and actionable information on health for the public, carers and frontline health workers… and a call to action to key stakeholders to explicitly recognise the foundational role of universal access to essential health information for achieving UHC and… to include it in the relevant SDG target and associated monitoring indicators, and to incorporate actions in their own policies and programmes to promote and enable access' [8]. In 2023 the then-Deputy Director-General of WHO and coauthors published 'Universal health information is essential for universal health coverage', which suggests WHO senior management already supports, at least in principle, the goal of universal access to reliable healthcare information as a pathway to UHC [9]. HIFA members have long argued that if WHO were to explicitly support universal access to reliable healthcare information, and lead efforts to accelerate progress, this would be a game-changer.

Q7: More support is needed for health literacy

Interpretation: 97% agreed or strongly agreed with with this statement. This question was different from the preceding three questions in that it invited agreement about 'what should be done to improve access' rather than 'how important is access'. Two key areas are individual health literacy, especially for those who are disadvantaged in any way, and the responsibility of those who provide healthcare information to ensure that it is accessible and understandable for all end users.

Implications: The finding supports a continued focus on building individual health literacy, especially for those who currently face challenges. Education and training are important. On the other hand, as mentioned by a few of the respondents, people who are highly educated are often unable to differentiate between reliable information and misinformation. Respondents noted that reliable information is often presented in ways that are not engaging or even understandable or in the right language. This suggests that more could and should be done to ensure that reliable information is more accessible and visible; that it meets the needs and expectations of end users; and that reliable information can be more easily differentiated from misinformation.

Q8–15: What should be done to improve access to reliable healthcare information?

Q8: Ranking of the seven WMA Recommendations

The most popular option (1289 selections) was 'Support initiatives to improve access to reliable healthcare information', reflecting wide concern that such initiatives are seriously underfunded (see interpretation/implications below). This is indeed a concern for HIFA itself as well as many of its supporting organisations. The second most popular option was 'Ensure health workers have access to reliable healthcare information'.

Q9–15: Individual WMA recommendations

Interpretation: There was overwhelming support for all seven of the WMA recommendations, with 81–95% of respondents agreeing or strongly agreeing with each statement. None of the statements drew substantive criticism.

Implications: The seven WMA recommendations (2019) represent a way forward with which people can identify. It is notable that the WMA, representing about 10 million doctors worldwide, is the only stakeholder group in the global evidence ecosystem to have a policy statement on universal access to reliable healthcare information. HIFA urges other global stakeholder groups across the global evidence ecosystem to make similar collective statements, setting out their own recommendations from their perspectives.

Q9: There should be more support for initiatives that improve access to reliable healthcare information

Interpretation: 94% agreed or strongly agreed that there should be more support for initiatives that improve access to reliable healthcare information. This echoes the views of HIFA members over many years, who have repeatedly noted a lack of political and financial support for healthcare information initiatives.

Implications: The lack of political and financial support has been recognised since at least 2004, when *The Lancet* published the paper 'Can we achieve health information for all by 2015?' [11]. The authors called on WHO to champion healthcare information for all, but high-level political commitment to this goal remains elusive. There is also a lack of financial commitment. In 2006 (when HIFA was launched) global health leaders wrote: 'The Gates Foundation identified fourteen challenges but a fifteenth challenge stares us plainly in the face: The 15th challenge is to ensure that everyone in the world can have access to clean, clear, knowledge — a basic human right, and a public health need as important as access to clean, clear, water, and much more easily achievable.' [20] Their call was unheard and to this day no funding agency explicitly supports universal access. This would change if WHO were itself to explicitly support universal access to reliable healthcare information as a means to deliver universal health coverage, improve quality of care, and achieve optimum health outcomes.

Q10: There should be higher standards of practice and ethics among information providers

Interpretation: 89% agreed or strongly agreed. The wording of the question is perhaps ambiguous as it does not define key terms such as 'information providers', which might be interpreted as professional publishers or more widely as any individual or organisation 'providing' information. The comments were similarly varied but there was a shared view that 'there is too much false information and poor quality information that is easily published and accessed online', particularly with social media.

Implications: There is a wide range of issues here, each of which calls for specific action, including quality control in scholarly and secondary publishing, predatory journals, paper mills, social media misinformation, political and financial incentives.

Q11: There should be more support for research on the availability and use of reliable healthcare information

Interpretation: 88% agreed or strongly agreed. This indicates the level of importance that respondents place not only on the reliability of healthcare information, but also on the need for a scientific and systematic approach to understanding information needs and how to meet them.

Implications: As with 'initiatives that improve access to reliable healthcare information', HIFA members have noted a lack of support for information research, including ways to measure the impact of (lack of) information, and systems-thinking approaches to strengthen the global evidence ecosystem as a whole. A key finding of the current survey is that WHO (and HIFA) should convene stakeholders to develop a global strategy to accelerate progress towards universal access to reliable healthcare information. Such action could provide the enabling environment for reviewing and generating research questions and attracting financial support to commission research (primary and secondary) to help answer those questions.

Q12: More should be done to ensure that health workers have access to reliable healthcare information

Interpretation: A very high number (95%) agreed or strongly agreed with this statement, emphasising that health workers clearly have unmet information needs. Respondents commented that such information is not only vital for quality of care, but also for empowering health workers to advise patients and the public. They also pointed out that many health workers lack skills to differentiate reliable information for misinformation.

Implications: The unmet information needs of health workers were highlighted in a paper by HIFA steering group members in 2009 [21]. Throughout HIFA's history, health workers of different cadres have demonstrated unmet needs at every level, from CHWs to specialist hospital workers, especially in LMICs. There appears to be a need not only to improve access, but to facilitate health workers to access content that is accurate, readily understandable and applicable in their context.

Q13: More should be done to protect people from misinformation

Interpretation: 92% agreed or strongly agreed with this statement. The comments highlighted the role of social media, but also the mass media and political influences. Many expressed concern that the situation is escalating and dangerous, with increasing lack of trust in authority. Several people pointed to the importance of helping people to differentiate reliable information from misinformation.

Implications: A common theme was how misinformation mutually reinforces a breakdown in trust in governments, health organisations (including WHO) and science. A few respondents noted that if we can facilitate access to reliable healthcare information, this would help address misinformation. Future efforts to accelerate progress towards universal access to reliable healthcare information could be presented as a key component of wider efforts to rebuild trust and address misinformation.

Q14: Governments should recognise their obligation to improve the availability and use of reliable healthcare information

Interpretation: 93% agreed or strongly agreed. At one level, it is clear that governments should provide reliable healthcare information in ways that meet people's information needs, and they should avoid dissemination of misinformation. A few respondents commented that policymakers who deliberately spread misinformation (particularly at the height of the COVID-19 pandemic) in ways that undermine or endanger public (or individual) health should be held accountable. At another level, governments have a broader legal obligation under international human rights law to ensure universal access to reliable healthcare information. In this sense, governments' responsibility goes far beyond their role as an information provider.

Implications: Governments not only have a shared responsibility as information providers. They are also uniquely responsible to provide the enabling environment and legal frameworks whereby all stakeholders in the evidence ecosystem can play their part to ensure universal access to reliable healthcare information. This suggests it could be helpful to develop guidance for Member States, based on a survey of current policies and examples of good practice.

Q15: Governments should provide more support for WHO to 'extend to all peoples the benefits of medical, psychological and related knowledge' as described in the WHO Constitution

Interpretation: 81% agreed or strongly agreed with this statement, indicating that they support WHO's constitutional role to 'extend to all peoples the benefits of medical, psychological and related knowledge'.

Implications: WHO is a leading provider of healthcare information in its own right, but HIFA members have argued that WHO's mission 'to extend to all peoples the benefits of medical, psychological and related knowledge' cannot be achieved by WHO's provision of information alone. WHO is uniquely positioned to address the wider systemic challenge and convene stakeholders to develop a global strategy.

Q16: What more can WHO do to accelerate progress towards universal access to reliable healthcare information?

Interpretation: There was strong support for three options, in order of priority:

1. Support stakeholders to develop a strategy for universal access to reliable healthcare information
2. Promote access to reliable healthcare information in languages other than English
3. Make a public commitment to accelerate progress towards universal access to reliable healthcare information

By contrast, there was relatively little support for WHO to increase investment in its publications programme.

Implications: If WHO were to make a public commitment to accelerate progress towards universal access to reliable healthcare information, this would be strongly supported across the global evidence ecosystem. Furthermore, stakeholders would strongly welcome WHO to take the next step and support stakeholders to develop a strategy for universal access to reliable healthcare information. WHO is widely seen as uniquely positioned to convene stakeholders for this purpose.

A second key finding is the high level of support for WHO's role in promoting access to reliable healthcare information in languages other than English. This emphasises that multilingualism should be a key element of a global strategy.

As with other questions, many of the comments on this question related to meeting the information needs of people living with disabilities and those who are disadvantaged or marginalised. This speaks to the central promise of the 2030 Agenda for Sustainable Development and the Sustainable Development Goals: Leave No One Behind.

The relatively low level of support for 'Increase investment in WHO publications' might reflect a common perception, among HIFA members and others, that more and more publications (whether by WHO or anyone else) will not meet information needs. Meeting information needs requires all components of the global evidence ecosystem – not just publishers – to be working together.

Q17: What more can HIFA do to accelerate progress towards universal access to reliable healthcare information?

Interpretation: As with the preceding question on what more WHO can do, the most popular option was: 'Support stakeholders to develop a strategy for universal access to reliable healthcare information'.

Implications: The finding suggests that HIFA would have a role in supporting stakeholders to develop a strategy. With only 1 professional staff and a part-time administrator, HIFA does not have the capacity to lead on such a strategy. By contrast, WHO is uniquely positioned to lead, and HIFA is uniquely placed to provide a supportive role.

HIFA's capacity is currently limited but it has strong potential for growth and it is encouraging that a separate question in the survey (Q20: 'Are you willing for HIFA to contact you to explore whether and how you can support our work?') elicited 1210 respondents who are willing to be contacted for this purpose.

Q18: HIFA-WHO Collaboration Plan

Interpretation: Among the five action areas in the plan, respondents identified 'Promote WHO advocacy to achieve universal access to reliable healthcare information' as the top priority. In second place was 'Provide WHO with access to experience and expertise on information needs and how to meet them'

Implications: The text of the Collaboration Plan was agreed between HIFA and WHO and the purpose of the current survey is described in terms of 'pursuing universal access to reliable healthcare information'. WHO has an opportunity to make explicit its commitment to universal access (which is already implicit in its Constitution), support an outline plan for next steps, and consider options for engagement of stakeholders to discuss the potential for a global strategy, as recommended by survey respondents. HIFA would provide a supportive role, continuing to promote communication, understanding and advocacy across the global evidence ecosystem.

Limitations

Survey participants are more likely to have an interest in the subject matter of the survey than the general population and would be expected to attach greater importance to the issue, as well as greater understanding and support for the seven WMA recommendations. The survey was available in ten languages, but there is likely to have been bias towards English-speakers, partly because the majority of HIFA members use the HIFA-English forum and partly because publicity was primarily in English.

The original wording for this activity as agreed with WHO was: 'To identify best practices, opportunities and challenges from relevant health related stakeholders, towards pursuing universal access to reliable healthcare information.' Our interpretation of this brief, in consultation with WHO, was to identify stakeholders' views on the importance of access to reliable healthcare information, ways forward (as proposed by the WMA statement recommendations), and what WHO and HIFA can do to accelerate progress. This was done for pragmatic reasons given our capacity and level of resources. A full investigation of 'best practices, opportunities and challenges' would require a thorough systematic approach led by WHO.

Conclusion

Improving the availability and use of reliable healthcare information is a neglected global health issue, and the vision of universal access to reliable healthcare information is currently absent from international and national policy, despite advances in information and technology across multidisciplinary sectors globally. This survey has demonstrated an overwhelming need for high-level support for universal access to reliable healthcare information and for the seven WMA recommendations to improve availability and use. Respondents agreed that WHO can do more to accelerate progress, *by explicitly championing the goal of universal access and convening stakeholders to develop a global strategy.* This strategy would serve to strengthen the global evidence ecosystem as a whole, thereby complementing existing initiatives that focus on individual parts of the system. WHO and HIFA are uniquely placed to take a leadership and supportive role, respectively.

Any global strategy should be informed by the best available evidence. There is a case for a WHO global guideline for Member States on improving the availability and use of reliable healthcare information, produced in ways consistent with internationally accepted best practices. This guideline would be based on systematic reviews to support its recommendations for consideration and adaptation by Member States, and would provide Member States with examples of good practice. The guideline would draw on the perspectives of the full range of stakeholders.

In terms of immediate next steps, WHO and HIFA could explore the findings of the survey with stakeholders, including public webinars and further discussion on the HIFA forums (English, French, Portuguese, Spanish). The survey findings and deliberations could be synthesised and submitted for publication in a peer-reviewed journal.

The survey's central message is for WHO to explicitly champion the goal of universal access to reliable healthcare information and to convene stakeholders to develop a global strategy. HIFA stands ready to collaborate with WHO for a world where every person, every health worker and every policymaker will have access to the information they need to make evidence-informed decisions and thereby protect their own health and the health of others.

Acknowledgements

Technical support

This consultation was only possible thanks to the pro bono support of several organisations and individuals:

- The HIFA-WHO Collaboration Group; HIFA Steering Group; HIFA Forum moderators (English, French, Portuguese, Spanish); HIFA Social Media Working Group; HIFA Fundraising Working Group; HIFA Country Coordinators; HIFA Supporting Organisations; and HIFA members at large.
- The Evidence for Global and Disaster special interest group of the International Federation of Library Associations, represented by Margaret Sullivan and Emma Farrow, who contributed to the planning and implementation of the consultation, including development, hosting and testing of the online survey; writing of the present report; and presentation of results (special thanks to Florida State University for pro bono hosting the survey).
- JBI (formerly Joanna Briggs Institute) provided invaluable communications support and assistance with fundraising.
- The Evidence Based Health Care Day 2023 committee, including JBI, Cochrane and others provided ad hoc input and help with publicity.
- Digital Medic, an initiative of the Stanford Center for Health Education at Stanford University, provided help with data analysis.
- Costello Medical provided support for stakeholder engagement.
- *The Lancet, The BMJ* and the World Medical Association assisted with publicity.

We are grateful to Isabelle Wachsmuth, HIFA's Designated Technical Officer at WHO, for her longstanding support and guidance.

Report authors: Neil Pakenham-Walsh, Geoff Royston, Chris Zielinski, Saran Gill, Margaret Sullivan

Survey development and testing: Neil Pakenham-Walsh, Margaret Sullivan, Ola El Zein, Chris Zielinski, Joseph Ana, Meena Nathan Cherian, Jackeline Alger, Poorvaprabha Patil, Tracy Eastman, Alice Meadows

Data analysis: Jamie Johnston, Geoff Royston, Chris Zielinski, Margaret Sullivan, Neil Pakenham-Walsh

Graphic design: Adrian Lancini, Ben Nicholls

Financial support

The funding for this work (US$15,000) was raised from the following organisations:

Lead sponsors: Oxford Pharmagenesis, Elsevier Foundation, National Institute for Health and Care Research

Also: CABI, ecancer, Enablement, Instituto Antonio Vidal, International League of Dermatological Societies, and International Primary Care Respiratory Group

None of the above organisations influenced the development of the survey or its implementation.

Personal donations were received from HIFA members Vikram Patel and Geoff Royston.

References

[1] Constitution of the World Health Organization.
https://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf

[2] HIFA website
https://www.hifa.org

[3] 3-year Collaboration Plan between Global Healthcare Information Network and WHO.
https://tinyurl.com/3w4eenam

[4] World Medical Association Policy Statement 2019
https://www.wma.net/policies-post/wma-statement-on-healthcare-information-for-all/

[5] Kruk M et al. Mortality due to low-quality health systems in the universal health coverage era: a systematic analysis of amenable deaths in 137 countries. *The Lancet*, 392;10160:2203-2212, 2018
https://pubmed.ncbi.nlm.nih.gov/30195398/

[6] WHO: Quality health services.
https://www.who.int/health-topics/quality-of-care

[7] WHO. Thirteenth General Programme of Work 2019–2023
https://www.who.int/about/general-programme-of-work/thirteenth

[8] Royston G, Pakenham-Walsh N, Zielinski C. Universal access to essential health information: accelerating progress towards universal health coverage and other SDG health targets. *BMJ Global Health* 2020;5:e002475.
https://gh.bmj.com/content/5/5/e002475

[9] Muscat D, Hinton R, Nutbeam D, Kenney E, Kuruvilla S, Jakab Z. Universal health information is essential for universal health coverage. *Family Medicine and Community Health* 2023;11
https://fmch.bmj.com/content/11/2/e002090

[10] SDG Target 3.7 Sexual and reproductive health
https://tinyurl.com/3cyxwwf3

[11] Godlee F, Pakenham-Walsh N, Ncayiyana D, Cohen B, Packer A. Can we achieve health information for all by 2015? Public Health, *The Lancet*, 364;9430:295-300, 2004
DOI: https://pubmed.ncbi.nlm.nih.gov/15262109/

[12] Overview of HIFA and definitions.
https://www.hifa.org/about-hifa/overview

[13] HIFA-WHO Collaboration Group
https://www.hifa.org/projects/hifa-who-global-consultation-2023

[14] HIFA Steering Group
https://www.hifa.org/people/steering-group

[15] World Evidence Based Healthcare Day.
https://worldebhcday.org/

[16] Global equity in access to health information: collaborating toward breaking barriers, 88th IFLA World Library and Information Congress, 24 August 2023.
https://iflawlic2023.abstractserver.com/program/#/details/sessions/282

[17] The Lancet 200. Spotlight on Research for Health.
https://www.thelancet.com/lancet-200/research-for-health

[18] CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12) 2000.
https://digitallibrary.un.org/record/425041

[19] Land M & Pakenham-Walsh N. Access to Health Information Under International Human Rights Law. 2012
https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3670747

[20] Pang T, Gray M, Evans T. A 15th grand challenge for global public health. *The Lancet* 367;9507:284-286. 2006
https://pubmed.ncbi.nlm.nih.gov/16443025/

[21] Pakenham-Walsh N & Bukachi F. Information needs of health care workers in developing countries: a literature review with a focus on Africa. *Human Resources for Health* 2009
https://pubmed.ncbi.nlm.nih.gov/19356239/

Appendix: The Survey Questions

Language

English

PLEASE NOTE: The survey is now closed. We thank all 2,410 respondents for completing the survey. To keep informed on future developments, and to discuss the implications and next steps, please join the HIFA forum: www.hifa.org/joinhifa

Help shape the future of health care worldwide

Can you imagine a world where every person and every health worker has timely access to the information they need to protect their own health and the health of others? Where every person is protected from misinformation?

This 5-minute global survey is the first critical step towards universal access to reliable healthcare information. Please take this first step with us and complete the survey. Your voice is important.

The results of this survey will be made publicly available and will inform next steps by the World Health Organization, Healthcare Information For All* (HIFA) and partners on how to accelerate progress in 2024 and beyond.

Thank you for your support!

Any questions? See our website www.hifa.org or contact the HIFA Coordinator (Dr Neil Pakenham-Walsh): neil@hifa.org

*Note: **This survey has 21 questions and we invite you to answer as many as you can.** Many of the questions in this survey are global in nature but there is an opportunity to share your personal and professional experience at the end if you wish. You have the option to complete the survey anonymously. If you choose to provide any personal details, these will be handled responsibly.*

*Healthcare Information For All (HIFA) is a global health initiative administered by Global Healthcare Information Network CIC, a UK-based NGO in official relations with WHO since 2022. www.hifa.org

About you

Q1: Your name (optional)

Q2: Your country of residence

Select one

How would you describe yourself in relation to the global evidence ecosystem?

The availability and use of reliable healthcare information is dependent on a global evidence ecosystem (the term 'evidence' applies here specifically to healthcare evidence). HIFA uses the following graphic to describe this system:

Q3: How would you describe yourself? We invite you to select *one option* that you most identify with (even if you are active in two or more areas)

- ◯ I **generate** healthcare evidence (e.g. researcher)
- ◯ I **publish** healthcare evidence (e.g. journal editor)
- ◯ I **synthesise** healthcare evidence (e.g. systematic reviewer, guideline developer)
- ◯ I **package** healthcare evidence (e.g. publisher of manuals for health workers)
- ◯ I help people to **find** healthcare evidence (e.g. library and information professional)
- ◯ I **apply** healthcare evidence for better health (e.g. patient, health worker, policymaker)
- ◯ Other:

How important is access to reliable healthcare information?

For each of the following statements, please say whether you strongly disagree (1), disagree (2), neither agree nor disagree (3), agree (4), or strongly agree (5).

There are optional comment boxes below each statement.

Q4: Access to reliable healthcare information is (or should be) a human right

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q5: Improving the availability and use of reliable healthcare information would lead to substantial improvements in quality of care and health outcomes

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q6: Universal health coverage cannot be achieved without universal access to reliable healthcare information

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q7: More support is needed for health literacy (helping people find, understand and use healthcare information)

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

What should be done to improve access to reliable healthcare information?

The World Medical Association Policy Statement on Healthcare Information For All is the highest-level consensus statement to date, representing 10 million doctors worldwide.

Q8: Which of the seven World Medical Association recommendations (listed below) do you think are most important to achieve universal access to reliable healthcare information? *Please select TWO (2) options*

- [ ] Support initiatives to improve access to reliable healthcare information
- [ ] Promote standards of good practice and ethics
- [ ] Support research to identify enabling drivers and barriers
- [ ] Ensure that health workers have access to reliable healthcare information
- [ ] Combat myths and misinformation
- [ ] Urge governments to recognize their moral obligation
- [ ] Urge governments to provide political and financial support to WHO
- [ ] Other:

We now invite you to consider each of the seven recommendations in turn:

Q9: There should be more support for initiatives that improve access to reliable healthcare information

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q10: There should be higher standards of practice and ethics among information providers

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q11: There should be more support for research on the availability and use of reliable healthcare information

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q12: More should be done to ensure that health workers have access to reliable healthcare information

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q13: More should be done to protect people from misinformation

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q14: Governments should recognise their obligation to improve the availability and use of reliable healthcare information

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

Q15: Governments should provide more support for WHO to 'extend to all peoples the benefits of medical, psychological and related knowledge' as described in the WHO Constitution (1948)

Strongly disagree — Strongly agree

1 — 5

Comment (optional):

What should WHO and HIFA do to accelerate progress?

Q16: The World Health Organization is a leading publisher of reliable healthcare information and supports a number of important several healthcare information initiatives. What more can WHO do to accelerate progress towards universal access to reliable healthcare information?

Please select TWO (2) options

- [ ] Make a public commitment to accelerate progress towards universal access to reliable healthcare information
- [ ] Support stakeholders to develop a strategy for universal access to reliable healthcare information
- [ ] Increase investment in WHO publications
- [ ] Promote access to reliable information in languages other than English
- [ ] Other:

Q17: HIFA aims to bring stakeholders together around the shared goal of universal access to reliable healthcare information. What more can HIFA do to accelerate progress?

Please select TWO (2) options

- [ ] Support stakeholders to develop a strategy for universal access to reliable healthcare information
- [ ] Use the HIFA forums to explore key healthcare information issues
- [ ] Harness the collective expertise of stakeholders to accelerate progress towards universal access
- [ ] Promote access to reliable information in languages other than English
- [ ] Other:

Q18: Your response to this question will help prioritise action in 2024 and beyond. The draft HIFA-WHO collaboration plan has five action areas. Which areas are most important?

Please select TWO (2) options

- [ ] To promote WHO advocacy to achieve universal access to reliable healthcare information
- [ ] To provide WHO with access to experience and expertise on information needs and how to meet them
- [ ] To support WHO's role as a leading provider of reliable healthcare information
- [ ] To support the dissemination and uptake WHO's publications, information and public health messages
- [ ] To support WHO's role in meeting information needs in languages other than English
- [ ] Other:

Q19: HIFA seeks financial and technical partners to implement the HIFA-WHO collaboration plan in 2024 and beyond. Are you willing for HIFA to contact you to explore whether and how you can support our work?

- ○ Yes
- ○ No
- ○ Other:

Q20: Are you willing for HIFA to contact you to discuss your answers to this survey?

- ○ Yes
- ○ No
- ○ Other:

If you answered "Yes" to Q19 or Q20, please provide your email address here (optional):

Q21: Finally, we invite you to say something about your professional and/or personal experience or any other comments (optional):

Thank you for completing the survey. Please now click the Submit button!

Submit

The survey's central message is for WHO to explicitly champion the goal of universal access to reliable healthcare information and to convene stakeholders to develop a global strategy. HIFA stands ready to collaborate with WHO for a world where every person, every health worker and every policymaker will have access to the information they need to make evidence-informed decisions and thereby protect their own health and the health of others.

For further information please contact:
Healthcare Information For All
c/o Global Healthcare Information Network CIC
Corner House, Market Street, Charlbury
Chipping Norton OX7 3PN, United Kingdom
Web: https://www.hifa.org
Email: admin@hifa.org

Healthcare Information For All HIFA .org
Child Health and Rights CHIFA .org
Informação em saúde para todos HIFA -pt
Information de santé pour tous HIFA -fr
Información en salud para todos HIFA -es