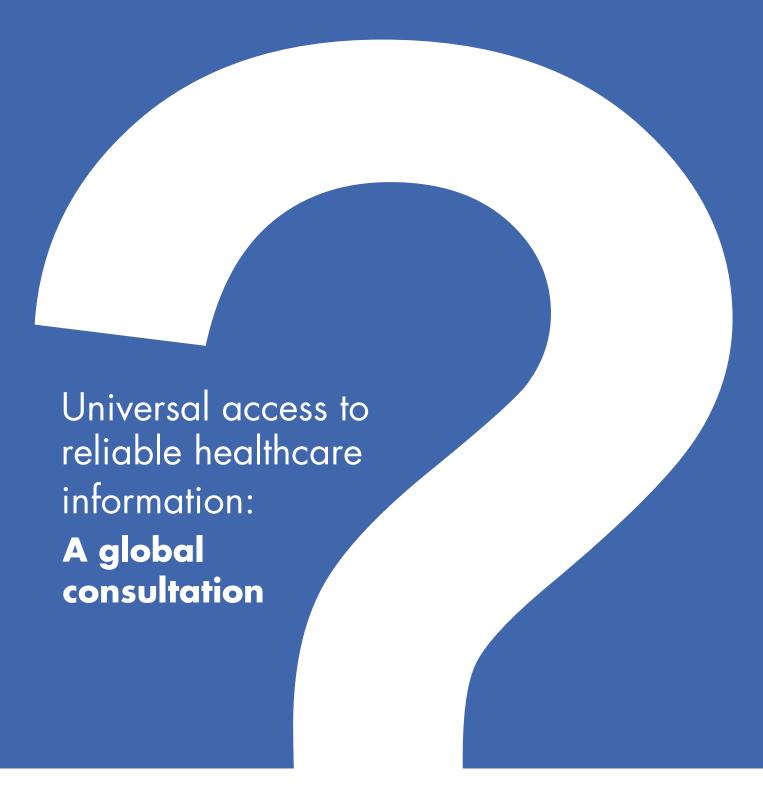




Universal access to reliable healthcare information:

A global consultation









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Methods

The consultation was coordinated by a HIFA-WHO Collaboration Group [12], comprising HIFA Steering Group members, WHO staff and others, and reporting to the main HIFA Steering Group [13]. 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 HIFA and WHO 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 these 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, Spanish, Portuguese) 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.

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".

	Reponses 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	14 <1%	4 <1%	26 1.3%	81 4.1%	1840 94%	98%	1965
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

98% 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.





"I was surprised to see that this is not already in the Declaration of Human Rights"

Communications professional, UK

"Without reliable healthcare information, we cannot make informed decisions about our health and wellbeing."

Library and information professional, UK

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

Health researcher, Brazil

"There is no way to involve the patient if they don't have access to knowledge" (Translated from Portuguese)

Health professional, Brazil



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 is essential for quality care and positive health outcomes, both for health workers and the public. Several stressed the importance of "use" as well as availability of information. Others stressed that information needs to be understandable and relevant to the end-user. Many pointed out that the availability of reliable information is vital but that many other factors are needed for positive health outcomes.



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

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