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Development of an international sexual and reproductive health survey instrument: results from a pilot WHO/HRP consultative Delphi process

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ABSTRACT

Population health surveys are rarely comprehensive in addressing sexual health, and population-representative surveys often lack standardised measures for collecting comparable data across countries. We present a sexual health survey instrument and implementation considerations for population-level sexual health research. The brief, comprehensive sexual health survey and consensus statement was developed via a multi-step process (an open call, a hackathon, and a modified Delphi process). The survey items, domains, entire instruments, and implementation considerations to develop a sexual health survey were solicited via a global crowdsourcing open call. The open call received 175 contributions from 49 countries. Following review of submissions from the open call, 18 finalists and eight facilitators with expertise in sexual health research, especially in low- and middle-income countries (LMICs), were invited to a 3-day hackathon to harmonise a survey instrument. Consensus was achieved through an iterative, modified Delphi process that included three rounds of online surveys. The entire process resulted in a 19-item consensus statement and a brief sexual health survey instrument. This is the first global consensus on a sexual and reproductive health survey instrument that can be used to generate cross-national comparative data in both high-income and LMICs. The inclusive process identified priority domains for improvement and can inform the design of sexual and reproductive health programs and contextually relevant data for comparable research across countries.

BACKGROUND

Sexual health is an integral part of overall health and well-being.[1 2] Understanding sexual practices and behaviours are necessary to design appropriate services for populations and to monitor the impact of interventions. Comparable, cross-national, population-representative data can help to address social determinants of health,[3–5] better understand social norms related to gender and sexuality,[6] and improve sexual health systems. However, such data on sexual health are limited.

Many national population-representative surveys assessing sexual practices, behaviours and health-related outcomes focus on high-income countries (HICs).[7–14] These surveys often use different sexual health measures, making cross-national comparison difficult. In low- and middle-income countries (LMICs), some key indicators are captured in standardised national surveys, such as the Demographic and Health Surveys (DHS) and Multiple Indicator Cluster Surveys.[15 16] However, these instruments go beyond sexual behaviours and collect few indicators on sexuality.[17] Additionally, most existing survey instruments were created by experts from HICs with limited feedback from LMIC researchers or communities. Certain subgroups are particularly under-represented, such as women, sexual minorities and people with disabilities.[18–22] Also, social acceptance and cultural beliefs towards sexual health and practices vary by geographical regions and social groups. Thus, priorities of key domains for a sexual health survey differ greatly across countries. Furthermore, access to means of data collection varies, making administration of long instruments especially difficult in some LMIC settings. These issues indicate a need for global expert consultation to seek a consensus on what measures should be included in a global sexual health instrument and guidance on its implementation.

METHODS

Three key methods were employed including a crowdsourcing open call for ideas, a hackathon and an iterative modified Delphi exercise (figure 1). Crowdsourcing open calls invite individual participants or groups with a wide range of backgrounds to offer a solution, identify solutions and share with the wider community.[23 24] The purpose of the crowdsourcing open call was to solicit survey

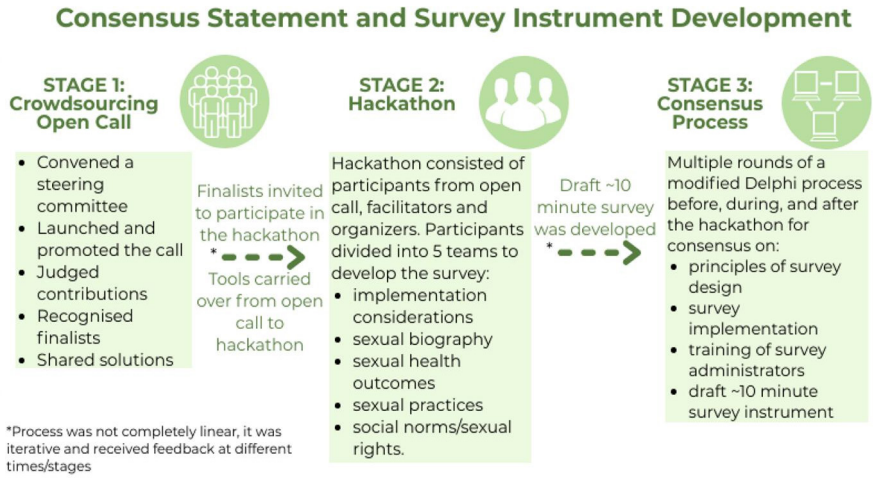

Figure 1 Key components of the consensus process.

components (items, domains and instruments) and to identify interdisciplinary sexual and reproductive health experts to join a hackathon. A hackathon or designathon is a sprint-like event that brings together individuals with diverse backgrounds to solve a problem.[25] A hackathon can tap into participants' experiences and expertise to generate high-quality outputs in a transparent and systematic way.[26] The purpose of this sexual health hackathon was to harmonise entries received during the open call and deliberate on key items to be included in the survey, aiming to assemble a draft brief sexual health survey at the end of the hackathon. Participants were told that the module needed to be designed for integration with existing research infrastructure. National surveys with existing focus on sexual practices could incorporate this module as a part of a more extensive survey instrument. The module could also complement other population-based surveys. The goal average completion time was 10 min. The intended participant is a member of the population aged 15 years or older. The process favoured single items that had been used before in population surveys.

The Delphi method is an iterative multistage process used to achieve expert consensus on a subject.[27] The purpose of this method was to develop consensus statements on the design, training and implementation of a sexual health survey and to finalise items to be included in the sexual health survey instrument. Each of these methods provided an opportunity for participant engagement to enhance collaboration. The instrument included sections on sociodemographic characteristics and health, sexual health outcomes, sexual biography, sexual practices, social perceptions/beliefs, identity and sexual rights. This articles documents this process and presents the resulting draft survey instrument and consensus statement.

RESULTS

Crowdsourcing open call

For this call, the community of interest was the diverse community of researchers, leaders, programme implementers and care providers who work in sexual and reproductive health (including family planning and STI prevention communities), as well as HIV prevention, control and care. The call for ideas (online supplemental file 1) was launched on 4 September 2019 and remained open until 1 November 2019. It was hosted on the WHO/Human Reproduction Programme official website and was promoted by partner organisations, including at a special symposium at the 24th Congress of the World Association for Sexual Health in October 2019. The call was translated into Spanish and not other languages. At the same time, we accepted contributions in all six official languages of the WHO (Arabic, Chinese, English, French, Russian and Spanish).

At the end of the call, all contributions were screened for eligibility and judged using prespecified criteria (online supplemental file 2). The HRP open call received 175 total submissions from 49 countries, of which 59 submissions were received from LMICs. Participants came from all six WHO regions, including the Americas (85), Europe (38), Africa (25), Eastern Mediterranean (10), Southeast Asia (10) and Western Pacific (8). We received six entries in Spanish and two entries in French, all of which were translated into English for screening and judging. After initial screening, 139 unique entries were eligible for judging. Twelve independent judges (sexual health researchers, leaders and officers at WHO/HRP) reviewed submissions. Of 12 judges, 11 had experience with LMIC sexual health research and 8 were women. Judges had expertise in epidemiology, demography, sociology, anthropology, clinical medicine, health behaviour and management. Each submission was reviewed by at least four judges and numerically scored on a 1–10 scale, 10 being the best. Scores for each contribution were averaged, and those with an SD greater than 2.5 were reviewed by two additional judges. After collating judge scores, 47 entries achieved a mean score of 7 or greater, emerging as semifinalists. These were further reviewed by the steering committee, which ultimately selected 18 finalists based on the mean score achieved coupled with the desire to balance participant demographics and experience working in HIC and LMIC settings. Among finalists, 83% (15/18) had LMIC sexual health research experience. This group included principal investigators on LMIC sexual and reproductive health studies, data analysis experts, sociologists, demographers, epidemiologists, reproductive health leaders and others with experience in developing national surveys and analysing multicountry data. Finalists were then invited to attend the following hackathon in January 2020.

Hackathon

This hackathon was jointly organised by the team members at the London School of Hygiene and Tropical Medicine (LSHTM), WHO/HRP and hosted by the African Population and Health Research Center (APHRC) in Nairobi, Kenya. Other hackathon participants were organisers from WHO/HRP, LSHTM, French National Institute for Health and Medical Research

Table 1 Characteristics of the hackathon participants

Characteristics	Number (n=35)
Participant's sex	
Male	7
Female	28
Role in sexual health research	
Survey leadership	19
Survey design	26
Survey piloting	23
Data analysis	28
Administration	29
Years of sexual health experience	
1–5	5
6–10	7
11–20	10
>20	13
Field research experience	
LMICs	14
HICs	13
LMICs and HICs	8

HIC, high-income country; LMICs, low-income and middle-income countries.

and the host APHRC. In total, 35 individuals participated in the hackathon (table 1). Participants included 7 organisers from the partner organisations, 10 facilitators and 18 finalists from the open call. Facilitators were more senior sexual health researchers and experts with extensive research in developing and implementing large population-representative surveys such as DHS,[15] the British National Survey of Sexual Attitudes and Lifestyles,[10 11] the French CSF[13] and Finnish FINSEX.[12] Participants were provided with documents to review prior to the hackathon, including themes analysed from contributions to the open call, other relevant sexual health surveys and a hackathon guide (online supplemental file 3). The hackathon event ran for 3 days (14–16 January 2020), with detailed agenda and expected outcomes presented in the hackathon guide. Participants were divided into five small groups of five or six members. Group topics included survey implementation considerations, sexual biography, sexual health outcomes, sexual practices and social norms/sexual rights. Each group had one facilitator, one organiser, and three or four finalists from the open call. Two additional lead facilitators rotated across all five groups and helped to provide guidance and resolve conflicts arising during group discussions. Groups were asked to prioritise items for a brief survey and to propose measures already used and standardised in previous surveys. Groups presented their sections at the end of each day for feedback and discussion.

Modified Delphi

A multiround modified Delphi was also completed, with each round informing the next (online supplemental file 4). A 5-point Likert scale from strongly agree to strongly disagree was used to record responses. The definition of consensus was set at ≥80% achieved for agree and/or strongly agree. The first round of consensus building focused on establishing statements on the principles for survey design, survey implementation and training of survey administrators. These were identified and extrapolated from open call submissions. These statements were intended to guide and inform sexual health researchers and implementers towards standardised procedures when conducting sexual health surveys. The first round was conducted just before the hackathon event and included all participants of the hackathon and volunteers identified through the open call. The results from the first round of the consensus statement survey were provided to participants at the hackathon. Statements were revised based on feedback from the first round of the survey. The second round of the consensus statement survey was undertaken during the hackathon event and included both statement items and potential sexual health survey items. This second round was completed by hackathon participants only. The third and final round of the consensus statement and sexual health items survey was conducted after the hackathon via email correspondence and included the revised consensus statements and the draft items selected for the sexual health survey during the hackathon. Participants invited to provide feedback in this round included all participants and facilitators in the hackathon, members of the steering committee and participants on the open call with a mean score of ≥5. For the consensus statement, participants graded each of the statements. Items that achieved 100% agreement were graded as 'U' (unanimous); 90%–99% agreement were 'A'; and 80%–89% agreement were 'B', and items with less than 80% agreement were not included. The steering committee reviewed all grading and made final decisions.

Sixty people were invited to take part in the first-round online survey focused on consensus statements and 47 (78%) responded. This survey included 12 statements on principles of sexual health survey design (7), training (2) and implementation (3). Participants who responded indicated expertise in survey design, piloting, data management, data analysis and field work. Two statements on the design stage did not reach 80% agreement and were revised for the second round. The second round of the survey, focusing on consensus statements and draft sexual health items, was conducted at the start of the hackathon and included 31 participants, with a 100% response rate. Of the 31 participants, 22 (71%) had LMIC sexual health research experience. Seven statements were removed or substantially revised.

The final round of the survey included 19 consensus statements (table 2) alongside the draft sexual health survey instrument. A total of 35 people were contacted and 23 responded with a 66% response rate. All items on the consensus statements achieved ≥80% agreement, and 66/71 items on the survey instrument achieved 80% agreement. Items with lower agreement levels were presented and discussed with the steering committee to either remove or revise. Finally, the resulting survey instrument was distributed through an open call by HRP for further feedback. The open call ran for 10 weeks between October and December 2020 on HRP's website and was disseminated through its social media channels. Respondents were requested to provide feedback on the consensus statement and the survey as a whole. They were also specifically asked for any feedback on modules E (social perceptions/beliefs) and F (identity and sexual rights). Respondents had the option to provide written feedback, as well as to upload any accompanying attachments. The open call received a total of 19 eligible submissions and included feedback from all six WHO geographical regions. Feedback was consolidated; the resulting sexual health survey instrument is included as online supplemental file 5 and the consensus statements are provided in table 2.

DISCUSSION

The global sexual health survey instrument, along with a consensus statement and implementation considerations, is intended for use in diverse global settings to facilitate cross-country comparisons. It provides a set of core sexual health

Table 2 Consensus statements (19 items)

Number	Statement	Grade
General principles that apply to design, implementation (including identifying and training interviewers), and dissemination		
A sexual health survey instrument should do the following:		
1.	Draw on a holistic view of sexual health, as described by the WHO's working definition.	U
2.	Recognise the potentially sensitive nature of certain concepts and be informed about local and national norms and laws related to age of consent, same-sex relationships, abortion, sexual violence, gender issues and related macrolevel factors.	U
3.	Engage local multisectoral key stakeholders across all stages of the survey research project including design, implementation and dissemination. Key stakeholders might include potential research participants, government officials from across the socioeconomic and political spectrums, policy makers, members of civil society and others, depending on the context.	U
4.	Ensure the survey and its data are used in ways that promote, protect,and fulfil human rights, including sexual rights, per the WHO's working definition (here).	U
5.	Be adaptable to the local population's priorities, needs, norms and practices.	U
Design stage		
6.	Capture information on one's sexual and reproductive health, related choices and outcomes.	U
7.	Reflect the lived reality of the participant taking part in the survey in their local context.	A
8.	Acknowledge the broader determinants of sexual and reproductive health outcomes per the WHO's working definition (here).	U
9.	Include young people under the age of 18 years if in line with local regulations, laws and ethical norms. This may benefit from discussions with the local ethical review committee whose approval would be required prior to starting research.	A
10.	Avoid language that is derogatory or discriminatory as informed by the local community; use people-centred language (eg, 'people with disabilities' instead of 'disabled people').	U
Implementation (dentify and train interviewers)		
11.	Select interviewers who understand the local context. Special consideration should be given to including interviewers with knowledge of or experience with subgroups of participants identified as important by the research team (eg, older people, sexual minorities and people with physical or mental disabilities).	U
12.	Core topics of interviewer training include protecting participants, rapport building, the sociolegal environment, ethics training, gender dynamics (eg, women interviewing men or vice versa), age dynamics (eg, younger people interviewing older people), trauma-informed care and quality control.	U
13.	Core competencies of interviewers include obtaining participant consent/assent (for minors), asking sensitive questions, understanding behaviours considered illegal, managing participant responses to sensitive issues, avoiding biassing participant responses and demonstrating a non-judgemental demeanour.	U
14.	Training should focus on building mutual understanding between the participant and the interviewer, using participatory training methods where appropriate (eg, role-playing and/or implicit bias training). There should be regular ongoing supervision and support for interviewers in order to address issues that arise during data collection, particularly when asking about sensitive issues, such as sexual abuse or gender violence.	A
15.	Interviewers must be trained in their legal duties regarding reporting requirements (eg, with regard to sexual violence, consensual sexual activity among adolescents, even parental consent to access sexual and reproductive health referral services) and ethical duties. The research team should be aware that their actions or omissions may carry legal implications. If a conflict arises between a legal obligation and an ethical duty, the research team should obtain advice from their professional association on how best to proceed and, ultimately, to choose to always act in an ethical manner. When relevant issues are identified, the research team must provide information on appropriate services and assist in linking those affected to these services (eg, legal services, local hotlines, shelters, health and social services) and consider the safety of those affected when dealing with mandatory reporting requirements.*	U
16.	Ensure the confidentiality and privacy of participants.	U
Dissemination		
17.	Create a summary of the research findings accessible to participants.	U
18.	Create a summary of research findings to be shared with policy makers, public audiences or others.	U
19.	Work in partnership with local communities to disseminate research findings to key stakeholders as defined previously.	U
U=100%, A=90%–99%		

*Researchers may be legally required to report certain types of violence or sexual activity to relevant authorities, even though this reporting may conflict with the ethical obligation to protect participants' confidentiality and respect their autonomy. It is essential that researchers understand and plan appropriately for situations in which mandatory reporting requirements may apply, recognising that different standards apply across countries. They will need to explain the limits of confidentiality to research participants. In addition, it may be ethically appropriate to screen participants for immediate safety concerns and to refer them directly to additional support services for their own and their children's safety and well-being.
A, agreement; U, unanimous.

items resulting in a brief survey instrument and implementation guidance that can be flexibly adapted according to local cultures and contexts. The global consensus was reached by a combination of engagement strategies. These engagement activities empowered and involved sexual health experts from many research fields and backgrounds, especially LMIC experts. We believe this survey would be relevant in various legal and cultural contexts across countries.

We achieved high agreement levels regarding principles for the design process of a national sexual health survey, local capacity building and training of organisers, and implementation principles. Some items related to sensitive issues (eg, types of sexual behaviours, including same sex behaviours, and sexual violence) will need to be field tested in local settings to understand how best to implement.

Our process underlined the need for further research and measures development for social norms related to sex, sexuality and sexual rights. A wide range of aspects related to social norms were discussed, and we narrowed these down to eight subdomains (online supplemental file 5) that were considered important topics shared across different contexts. These subdomains focused on four domains of social norms (sex education, contraception, abortion, sexual needs and same-sex relationships) and four domains on gender norms (consent to sex, premarital sex and sexual pleasure). Reaching consensus on these indicators for measuring social norms and gender norms was particularly challenging compared with other domains. We determined two main barriers. First, many important social norm constructs were measured using scales too lengthy for this brief instrument, including the Sexual Consent Scale,[28] the Gender Equitable Men Scale[29] and the Intimate Partner Violence Attitude Scale.[30] Hence, our brief survey excluded many survey items simply because of length and not because the topic was unimportant. Further research on devising and validating short-version scales to measure these indicators is needed. Second, these subthemes are strongly associated with local beliefs and cultures, and

priority themes are contextually relevant. This highlights the need for cognitive testing and further comparative research. Validated measures related to sexual rights are needed.

Experienced, in-country researchers from around the world will be invited to conduct cognitive testing on the instrument. We recommend researchers to include a local group of participants with diverse sociodemographic backgrounds (eg, gender, age, education and sexual orientation) in cognitive interviews to obtain feedback on survey content and flow, comprehensibility, wording, cultural appropriateness and length. Further community engagement would facilitate country-level implementation.

Our process has some limitations. First, a wider engagement of audiences from some subgroups (eg, low-income countries in Asia) to the open call could have led to more submissions from these nations. However, we had strong representation of people undertaking LMIC research across all regions. Second, the open call and hackathon were organised using the English language. However, we invited submissions from all official WHO languages and had hackathon participants fluent in Spanish and French review the respective survey instruments. Third, our process involved an in-person hackathon event which would be more difficult in the COVID-19 era. At the same time, many hackathons have transitioned to digital formats to organised COVID-19 responses, suggesting an alternate pathway. This suggests that digital hackathons may be able to accomplish the same goals without the risk of in-person activities. Other strengths of our process included the wide and iterative engagement from a range of professional disciplines related to sexual and reproductive health in a range of cultural settings, the involvement and commitment of leading national and international health organisations, and the strong consensus achieved on quality items throughout the phases of development.

This standardised instrument and consensus statement has implications for policy, practice and research. The instrument can help inform local policy makers and SRH researchers about priority domains for improvement in the local context. Then, it can be used to collect data on sexual and reproductive health-related norms and practices at the population level in order to guide stakeholders to design and implement responsive services and programmes to improve SRH. The crowdsourcing approach that we used to develop this survey instrument contrasts conventional guideline development and could lay the foundation for a more participatory consensus statement development process. Research comparing the crowdsourcing approach to conventional approaches is needed.

CONCLUSION

We successfully recruited a wide range of experts to engage in rigorous, tested participatory approaches. We achieved consensus on a brief module for a global sexual health survey instrument and on guiding implementation strategies. Our sexual health survey instrument could provide comparable indicators across settings and has implications for policy, practice and research. Our survey instrument could also allow flexibility for adaptations to better reflect different contexts and understand sexual and reproductive health issues for many around the world.

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