

Ethics of health research priority setting

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Women's pelvic floor disorders, Gondar, Ethiopia JLA (James Lind Alliance) Priority Setting Partnership

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Brief description of case study context

Pelvic floor disorder is a major public health problem in Ethiopia as one can imagine in a country where the predisposing factors for the disorders are prevalent¹⁻⁴. Pelvic floor disorders result in emotional, physical, social, and economic suffering of women and their families⁵⁻⁹. However, much has not been done in making the health care services available and accessible. To give patient centered solution, generating robust evidence is paramount¹⁰⁻¹². To date research has been done for treatment uncertainties generated by researchers, pharmaceutical and technology industries. Despite that, evidence has shown there is mismatch between the uncertainties researched and the questions wanted to be answered by patients and health care providers. For these reasons involving patients, carers, and health care providers to identify uncertainties is found to be crucial¹³⁻¹⁴.

Though there is no one best way of setting priorities by involving patients, carers and health providers, research questions identified by using priority setting partnership methodology developed by James Lind Alliance (JLA) has shown high chance of getting funded by research funders. JLA is a non-profit initiative, established in 2004 and partner organization of the National Institute for Health Research (NIHR). The method developed by JLA brings patients, carers, and clinicians together in priority setting partnerships (PSPs) for identifying and agreeing through a consensus process the top 10 priorities for health research. Though this method has been exercised in developed countries and found effective in developing useful research questions, it has never been practiced in Ethiopia¹⁵⁻¹⁹.

The aim of our study is to identify unanswered questions related with pelvic floor disorders cause, diagnosis, treatment, and impact by bringing together patient, carer and clinician perspectives and then prioritize what they agree are the most important in Gondar, Northwest Ethiopia. We have been using the method set by the JLA to adapt the methodology to the context. We completed the first phase prioritization survey in which 392 participants were involved of which 251 were patients, 69 were carer and 72 were health professional. The second phase of interim prioritization, ranking uncertainties left after evidence check, was completed with 124 participants of which 72 were patients, 15 were carers and 37 were health professionals. The next step will be to hold a workshop to identify the top ten priorities by bringing together about 30 patients, carers, clinician, and other related stakeholders. This has been postponed until the security situation in the study setting allows.

Ethical issues

We have uncovered ethical issues whilst implementing the JLA priority setting partnership.

1. Maintaining the following integral principles of JLA PSPs

1.1. Equal involvement

Equal involvement of all stake holders (patients, carers, and clinicians) is one of the integral principles of JLA PSPs. To meet this all participants were given equal opportunities and rights. A steering

committee was organized using equal representation of patients, carers, and clinicians. Each step was under the steering committee's guidance. The initial phase of the priority setting survey was piloted and the process's result was discussed by the steering committee. It was found that many patients and carers had difficulty to directly put forward their priorities because of difficulty in comprehending the essence of the survey which might be as the result of illiteracy. For this reason, the steering committee decided the participants should be asked to speak out what they have in their mind for the open survey questions and their suggestions to be audio recorded. Three sample recordings of the participants were later transcribed, translated, and summarized independently by three project coordinators and checked for consistency and reliability by the steering committee. Then the steering committee agreed that the transcription and translation of the rest of the recordings could be done by the project coordinators. This raises the ethical dilemma of being heard, given that the process is using external rather than internal synthesis.

1.2. Transparency

Transparency is also one of the pillars in JLA PSPs. The principle is expressed in terms of having clear insight into the process and how it operates. However, discussing the principle, which is about the process of defining what needs to be researched to have better healthcare in the future, while each participant is still in difficulty comprehending and checking the process makes it unrealistic to conclude about transparency. To resolve the ethical dilemma associated with transparency, the participant representatives who served on the steering committee closely followed and guided each step of the process. Audio recorders were also used not to miss the contextual meanings.

2. Going back to the same women to ask them to prioritize

We have uncovered ethical issues whilst doing the field work such as ethical dilemma of going back to the same women who we first consulted about their most prominent issues and questions. We went back to the same women, to ask them to prioritize the questions that have been asked by them all, while knowing the women are still waiting for treatment, but then we do not help them. Should we offer priority treatment to them? Is this fair to other women, who have not been involved in the interviews? This is a problem for the fieldworkers, how to approach these women. The reality is that it is not possible to offer special treatment. The field workers approached some new women, which would give more new participants, and means we do not burden the same women to help the project all the time. We have also managed to facilitate the treatment of few women who have been found severely ill and required urgent treatment.

Conclusions and recommendations

Research Priority Setting Partnership using tools proven in the global north is not without consequences of ethical dilemma to use without making context dependent modification. Therefore, producing methodologically proven ways of Research Priority Setting Partnership for global south is required while maintaining the basic principles of PSPs.

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