Tailor informed-consent processes

The first step in studying mental-health interventions across cultures is to adjust procedures to participants' needs, says **Mónica Ruiz-Casares**.

The enduring mental-health consequences of armed conflict, natural disasters and forced migration are increasingly recognized. But clinicians and the people they help often come from different backgrounds, each unfamiliar to the other¹. This can result in tensions, inappropriate health services and misleading research.

It is hard to assess how well existing scientific evidence for effective mental-health care applies to any group under-represented in mental-health research. That evidence is based mainly on adult, Western populations. Refugees, migrants and young people from other cultures are much less studied; conducting the necessary research can raise thorny ethical issues. Investigators and their institutional review boards must be flexible and patient so that this work can progress.

Informed, reasoned and voluntary consent is core to the ethical conduct of research, but the norms vary across cultures². Even the standard practice of explaining a research protocol to study participants and then obtaining signed consent can raise complex issues. Some communities value verbal agreements more than written contracts, which they might view with suspicion. The very act of requesting signatures could create mistrust and the misperception that participants are entering into binding agreements that they will not be able to withdraw from. In places with repressive political regimes or for undocumented immigrants, signed consent could put participants in danger. Women who make decisions about their own or their children's participation in research without their partner's consent could face serious family conflict or even violence.

Alternative procedures tailor information and consent to participants' needs. The basis of robust informed consent is respect — for dignity, intercultural dialogue, equality and solidarity. Researchers must find more ways to present information clearly, particularly to non-literate participants. Some investigators use colourful visual aids or multimedia. We are developing visual informed-consent forms with children in Canada³ and Cameroon in which potential research subjects take photographs to represent ethical issues. Children have, for example, photographed a lock or someone's mouth with a finger

Community gatherings can be part of an informed-consent process.

crossing it to represent confidentiality.

Researchers must also think about potential consequences that a research project might have on participants and their community. This requires time to build trusting relationships and to engage communities and local co-investigators. Focused discussion groups, local advisory committees and participants themselves can share oversight of the appropriateness of study design and implementation. Schedules must allow for presentations to multiple stakeholders and allocate time for participants to reflect on the study and discuss it with others before deciding to participate.

Local beliefs about who has decision-making authority must be considered. In 'collectivistic' cultures, which emphasize the needs of groups over individuals, informed consent operates through relationships. Other community members act as consultants or permission granters⁴. Physicians, elders, senior males or mothers-in-law might be assumed to know best. In western Kenya,

community assemblies known as *mabaraza* were consulted in a long-term study of children separated from their parents or orphaned, and they recommended community decision-making in the consent process for biomedical and behavioural research⁵.

Informed consent at the community level can conflict with Western standards for voluntary individual decisions. In a child-protection study that I led in Laos, we first obtained explicit permission from provincial, district and village authorities, deemed necessary and sufficient by local standards. But our own principles and those of our institution also made it essential to gain individual informed consent from parents and assent from children. We learned to respect individuals' silences and left unstructured time so that people could depart before group discussions. In this way, people could decline participation without being singled out by the community in socially damaging ways.

Assessing voluntary involvement is essential to produce valid research. Orphan children participating in group discussions as part of another child-protection study in Liberia all signed consent forms, yet we later realized that the children had been pressured to participate and told what to say by the administrators of the orphanages.

The study of mental health across cultures requires creativity, tenacity and time. But these investments must be made. There is a dearth of cross-cultural mental-health research to inform practice. Ultimately, collaborative partnerships make for better research and boost the utility of findings. To relieve suffering, we must learn what works best in each setting, and we must ethically build the capacity to do so. ■

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