

## Q&A

- **Usha Vatsia:** John, how are these ethical concepts different from what applies to adult involvement in research? Are the standards you are discussing universal for all countries?

The ethical principles are the same but the application is different, particularly in thinking about respect for persons. The same is true in comparing research with adults and research with children – the principles are the same but the application is different. Respect for persons with adults means respecting the autonomy of the individual; from this follows the notion of informed consent and voluntary consent. With children, respect for persons often means special protections, realizing that young children are not fully capable of protecting themselves. With adolescents, respect for persons may have elements of both; adolescents are often capable of autonomous decision-making based on cognitive development (see Hein reference in Brief #3.). The UNICEF brief suggests that we use the concept of evolving capacity in the Convention on the Rights of the Child in thinking about adolescent capacity to provide informed consent.

Regarding universality among countries: Most ethicists believe that these principles are universal but that their interpretation should be sensitive to cultural context and cultural beliefs.

- **Alisa Michelle Phillips 2:** This is Alisa Phillips from World Vision. My question is about 10 year olds as very young adolescents. Where do they fall in the continuum of being able to make decisions about their well-being and help and understand certain information?

Developmental research suggests that 10 year olds display considerable capacity to make decisions about research situations but their cognitive capacity and judgment are not as developed as adults. Of course, there is great diversity in the abilities of 10 year olds; diversity is common among people at any age! Beyond cognitive capacity, the youngest adolescents may be more prone to coercion or poor judgment in emotionally charged states. In practice, we often obtain adolescent assent for research but supplement that assent with the informed permission of parents and guardians. Where parental permission is problematic, surrogate informed permission may be needed and/or researcher can conduct an individual assessment of the adolescent's capacity for informed consent. Individual assessment becomes more important when the research presents considerable risk to the adolescent.

- **Alex Coombs:** Hi John, we are working on an intervention for pregnant adolescents/new mother aged 10-19 in Kenya. Would they be considered emancipated and therefore able to give consent without parental permission? It's a household-based intervention, so parents will also be involved but I'm unclear on how much they can or should restrict girls' enrollment in the intervention.

The legal status of pregnant adolescents varies among countries, so it is important to become familiar with local laws and local practices. In general, 18 and 19 year olds are considered adults for all purposes and they can make their own decisions about medical care and research involvement. Those under 18 years may be emancipated in certain countries. The Government of Kenya, Guidelines for Conducting Adolescent HIV Sexual and Reproductive Health Research in Kenya, 2015 suggestion adolescents under the age of 18, researchers may waive parental permission for research involving care related to treatment of pregnancy.

Adolescents before and after age 18 commonly live in households with extended families and researchers should respect the family in these cases. An adolescent who is legally an adult may want to consult elders or desire privacy from parents; both of these preferences should be respected.

- ***Maria Fernanda Salazar Rodríguez:*** Can you discuss briefly the particular challenges of doing research with youth and adolescents who are particularly at risk, or particularly vulnerable, for example victims of violence. How do you ensure participation and inclusion while still guaranteeing protection and ensuring they are not being re-victimized.

Researchers should be sensitive to the specific situations and history of disadvantaged, vulnerable and marginalized adolescents including those who are victims of violence. Such adolescents may have been victimized by adults and therefore suspicious about adult plans for research. Building trust with such adolescents is essential; working through trusted service programs may be helpful. See UNICEF brief on Research with Disadvantaged, Vulnerable, and/or Marginalized Adolescents by Colette L. Auerswald, Amber Akemi Piatt, Ali Mirzazadeh.

- ***Fabiana Maglio:*** Ethical research with adolescents should also include a commitment to going back to young participants to inform them on what was done with the information they provided (e.g. share key findings with them and solicit their feedback). Do you have any recommendation in this respect?

I agree and this should be the case across research populations, not just adolescents (provided that knowing the findings is of benefit to them). Publications which outline the guiding principles of participatory research are a good starting point for recommendations on how to take research findings back to young people. For an example, see [this brief](#) by Emily Ozer and Amber Akemi Piatt (Phase 4 and ethical issues) and also resources in the [YPAR Hub](#). In true participatory research, young people are involved in interpreting the findings and communicating them to key stakeholders. They can actively use the findings to advocate for change and this can be done online (petitions, discussion forums, social media, etc.), in youth clubs, meetings with decision-makers, etc. In research which is not participatory, results can be communicated back to young people via similar avenues. However, like with the research process itself, it is important to account for the potential risks to adolescents that stem from being engaged in the communication of findings, and even from receiving them passively. When speaking out on certain topics, adolescents may be at risk of a backlash from authority figures or some type of previously confidential aspect of their life may become known more widely. This and many other potential risks must be considered in the development of a participatory research communication strategy. Even where adolescents are not engaged in the communication of results and are only the recipients, issues of confidentiality and the potential of de-identification must be at the forefront of deciding how to communicate results back to them. For example, disseminating results on line creates a permanent digital footprint and it is important to ensure that individuals will not be identified as having participated in a particular study without their consent. Another issue is to communicate the findings in a way that is appropriate to the age, culture, gender, etc. of the target group. For a comprehensive resource on Ethical Research involving Children, see [this website](#).