

The fifth principle: renegotiable ethical frameworks! A commentary to Goodyear-Smith and colleagues' article on 'Co-design and implementation research: challenges and solutions for ethics committees published in BMC Medical Ethics (request for waiver of publication fee denied).

After receiving a negative response to my request for a waiver at BMC Medical Ethics that could have allowed me to publish my letter to the editor and engage in the debate, I decided to make it freely available through Lirias, hereby supporting the #christmasisover campaign from the League of European Research Universities and opening up the debate about new inequalities between academics. No money, no voice!

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<http://www.biomedcentral.com/1472-6939/16/78>

Goodyear-Smith and colleagues rightfully discuss the many challenges encountered by researchers when working collaboratively with the target groups they are interested in, in terms of how to achieve and register informed consent and guarantee a research procedure that minimizes harm and maximizes benefits for people involved. They propose four important principles to try and bridge those challenges including 1. ensuring acknowledgement and recognition for a diversity of research in institutional review board members, where necessary through educational initiatives; 2. the establishment of ground rules for participatory research applications on a more national level; 3. acknowledgement of the benefits of power-sharing in the co-design process and giving credit to measures that support this goal when researchers succeed in making those explicit in their applications; 4. stimulate and engage in learning processes related to the emergent area of ethical concerns in co-creative or participatory research. While we see value in each of these recommendation, the target group itself remains largely absent in many of the suggestions made. To a large extent it is assumed that when we optimize processes and develop a learning curve in the ethical board members and who knows, the researchers as well, then the major ethical obstacles that we encounter in the field will be removed. We often tend to forget that we, researchers, are being trained to understand the impact of research, to incorporate what it means to be analyzing and interpreting data and how this then further influences the way we communicate about our research. In a fast digitalizing society the concept 'data' has shifted from numbers and narratives that could easily be anonymized to protect the privacy of participants to visual data in which participants may or may not be portrayed. Our co-creators are no longer the people that work with us behind the screen but become part of the tangible set of instruments we use to convey our message and disseminate online: still and moving images, sounds, oral history etc. This makes me wonder whether none of the drop-out or Roma youngsters, girls suffering from anorexia or teenagers addicted to drugs or any of the other vulnerable populations we worked with in the past would change their mind, wanting to pull back their informed consent. The authors claim that much of the work in collaborative research is emergent and difficult to be protocolled, that we need to allow ethical board members a learning curve concerning ethical issues in such research. As a fifth principle, should we not allow our participants to renegotiate their informed consent for how research findings are used and disseminated within and beyond the projects' deadlines and develop a strategy that allows them to do so?