



# NEWSLETTER

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## THE PORTUGUESE YOUNG PEOPLE'S ADVISORY The ethics of trust: Reflections, debate, and advice on Longitudinal Studies

The Portuguese Young People's Advisory Board (YAB) is formed by a group of six young people, ages between 17 and 20 years old, all of them students and volunteering in NGOs mostly related with Human Rights activism.

Following its first session in February, YAB met again last July with the participation of only three members. The agenda set by the team included gathering the YAB's reflections and opinions about issues such as longitudinal studies, data protection, data linkage and the ethical questions surrounding these matters.



YAB members considered that longitudinal studies are of great interest since their findings can potentially help people in the future. Nevertheless, they find these types of studies very demanding and complex in keeping the participants engaged throughout the years. Specially in the case of children and young people because of the rapid changes occurring in their lives and related uncertainty.

In terms of engagement strategies, YAB members advised researchers to build a relationship with the participants based on transparent and understandable information about the project that can allow for trust to surface (não percebí). This relationship should be maintained between rounds: it's important to promote the feeling of **belonging to a (research) community**.

These strategies become particularly important in case of participants who engage in processes of migration (economic, forced (refugees or asylum seekers), or other). YAB members consider that the best way for researchers to know the participants' whereabouts is to maintain the research relationship. If the relationship works, participants will reach out to update contact information and together they can figure out ways to keep remotely participating, if the physical co-presence is not possible.

In terms of consent and renewing consent in each wave of the study, YAB members express unanimously that consent is a participant's right that must be confirmed during the time of the project to guarantee that people want to continue participating. Although being a right that they strongly recognize, they are sensitive to the hurdles that withdrawing consent brings to research. YAB members advise that the research team and the participants should nurture a relationship where information and trust flows to prevent participants from quitting. **Transparency and trust act as an antidote for withdrawing consent.**

YAB members hesitate between the **right to be forgotten and the right to be remembered**, between privacy and visibility. Again, they point out to the research relationship as the best place to sort this out. They believe that where there is trust, people feel confident to share difficult aspects of their lives and they continue to feel

engaged with the study, its purpose, its importance.

When addressing data protection and data linkage issues, YAB members have a wide definition for personal data, and they feel that participants should always have the right not to answer to some particular question or set of questions. They advise that researchers should always reinforce that the **answers given are anonymous and confidential and that they won't spill over to third parties.**

YAB members feel **uncomfortable and suspicious about data linkage** because they fear that there could be abusive access to personal data beyond the project's purposes. The only way they would feel more confident is by being talked through by researchers with whom they (should) have a trustful relationship.

Despite the specifics of the addressed issues, YAB members are strongly convinced that a transparent and trustful research relationship and a shared sense of purpose of the research are the **keys for success in longitudinal studies.**

