

Appendix 3

Study design and aims

The main goal of this study is to evaluate how individuals who identify as Lesbian, Gay, Bisexual, Trans, Queer or Intersex (LGBTQI) perceive research that directly concerns them. Scientific studies are typically designed and implemented by trained scientists, who do not necessarily represent the views and needs of their research participants. In this study we chose to focus on research concerning LGBTQI individuals, as this group is often the focus of social science, psychology or neuroscience studies, but is traditionally underrepresented in academia. Our main goal is to quantify the degree to which members of LGBTQI communities view research that directly concerns them as ethical, useful and respectful.

Through a first set of questions we will evaluate which types of studies that concern LGBTQI individuals our participants are familiar with, and also by which means they are typically informed. Then, participants will be asked to rate the last study they heard of. To this aim, we have identified unique metrics, that represent specific elements of the study that we would like to rate. These metrics include its perceived utility, relevance, respectfulness etc.

In a second set of questions, participants will be asked to rate which aspects of a study design and delivery are important to them, through the a 10-point scale, known as the net promoter score approach.

In a third set of questions, we will evaluate participants' experience with participating in research that concerns LGBTQI individuals, if they have any. We will use similar metrics as for the first set of questions, in order to be able to contrast the perceived utility of research while it is conducted, and upon completion and communication to participants.

In the last part of the survey we will collect socio-demographic information, such as participants' age range, country of residence, gender identity and sexual orientation. We expect to use these variables to evaluate whether participants' socio-economic status and sexual orientation influences the way they perceive or experience research.