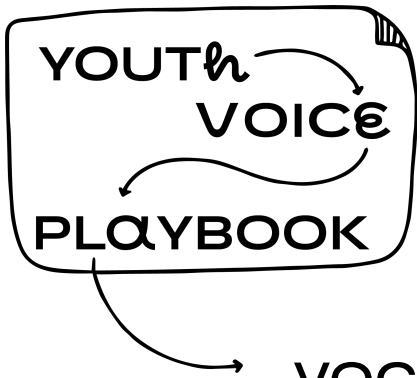

VOCAB YOU SHOULD KNOW

A glossary to ground you in research, ethics, and IRBs.

RESEARCH

Well, this got really existential really fast! What even *is* research?! There are a lot of great arguments about this out there in the world, but for the purposes of this playbook, we'll stick with this definition: research is intentional investigation designed to acquire new, generalizable knowledge.

The word "generalizable" really matters here. For example, imagine you have developed a survey, and you want young people to read your questions and make sure they are understandable. At this stage, you're not really trying to produce generalizable knowledge (though once you actually collect responses to the survey, you will be!). At this stage, you're getting input and feedback, not actually doing research yet.

This definition of research is broad enough to apply to lots of different fields and applications: academic research, applied research, research & development, user research, and probably more. Each of those fields has its own norms, and this chapter will explore implications for all of them.

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HUMAN SUBJECTS RESEARCH

Human subjects research is any research (see above...) done with living human individuals where you obtain information through an intervention or interaction, and then use or analyze that information (U.S. Department of Health and Human Services). Pretty sweeping, right? Human subjects research is highly regulated by the federal government in order to minimize the risk of harm to participants. (This hasn't always been the case, with pretty troubling and tragic consequences.) The institutions who actually *do* the oversight on behalf of the federal government are generally called IRBs; we'll learn more about them below.

This definition of human subjects research is huge, but there are three big important caveats. First is that word "research," as discussed above. The second is that there are some types of human subjects research that are considered "exempt," which means they don't require ongoing IRB oversight. For human subjects research to be exempt, it must be minimal risk (more on that below too!) *and* meet one of eight criteria defined by the federal government (Office for Human Research Protections). Please note that as a person doing a research project, you don't get to decide if your own research is "exempt." You still submit it to the IRB, and they make that call. We'll explain this more below.

MINIMAL RISK

Minimal risk means that the risks of harm anticipated in the proposed research are not greater, considering probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine physical and psychological examinations or tests. In practice, this means that one of the things that you'll need to consider when designing your research activities is how likely it is that the activities will cause harm, including psychological harm.

It's important to note that the standard here is about what harm is caused by the research itself, not by the life situations of the research participants, though those are also real (Fisher et al., 2002; Fisher, 2010; DuBois et al., 2012). The IRB will be the actual decision-maker on whether or not your research meets the criteria for being minimal risk, but you should be thinking about this as you design your study (and as you write about it for the IRB to review).

INSTITUTIONAL REVIEW BOARD (IRB)

As you've probably picked up by now, an IRB is an independent body that reviews and approves human subjects research before it's actually conducted. IRBs are registered with the Office for Human Research Protections under the U.S. Department of Health and Human Services, and must enforce all federal regulations that govern this research. Most IRBs are part of universities and oversee all academic research that happens through that university. However, there are also independent IRBs that can review research in other settings, such as research facilitated by non-profits.

Variations of an IRB in different settings include Ethics Review Boards (ERB), Research Ethics Boards (REB), and Independent Ethics Committees (IEC).

There are three main types of IRB review: exempt, expedited, and full board review. Each of those is explained below. When you are submitting your research proposal to the IRB for review, you will typically tell them which type of review you think is most suitable and why; however, they might disagree with you, and their word goes.

EXEMPT REVIEW

As mentioned above, some human subjects research actually does not require ongoing IRB oversight. It still gets reviewed, but once it's reviewed and deemed exempt, you can go on your merry way and facilitate the project. To be considered exempt, research must meet two criteria: 1) it must be minimal risk, and 2) it must fall into one of 8 categories for exemption (you can find an overview of the 8 categories here). If you're working with minors, there are even fewer categories for exemption, so this is not a super typical outcome.

EXPEDITED REVIEW

This is probably the most typical category of review. This is for research that is minimal risk but doesn't qualify for an exemption to IRB oversight. Usually just 1 or 2 people from the IRB review the project in expedited review, so the process moves relatively quickly, especially if you've done a good job anticipating and answering their questions.

FULL BOARD REVIEW

Studies that involve more than minimal risk require review from a full board, and require approval from a majority of those members. These studies tend to be risky for participants, or involve deception, or involve vulnerable populations as participants. This type of review is the most time-intensive, as the IRB will need to convene a big ol' group of experts to review your study proposal, and there may be lots of back-and-forth to answer questions or make changes they require.

INFORMED CONSENT

Informed consent is the process of telling potential research participants about the key elements of the research and what getting involved will mean for them. Basically, you want your participants to make a thoughtful decision about whether or not they want to join you; the informed consent process is how you ensure that. Usually there are requirements for what information you have to include when telling participants about your project, and how you collect proof that they've agreed. *Note: if a participant is under 18, you actually use the word 'assent' instead of 'consent' but it's the same principle. If they're under 18, their parent/guardian may* also *need to give informed consent, or simply give it on their behalf.*