

## Exercise 2: Connecting Research to Community Priorities

# Discussion Prompts

Use the prompts below to guide your group's conversation.

You can focus on a real research project or make one up for this exercise.

- **If you are an oversight committee member**, consider how you might use or adapt these questions in your review process—for example, by including them in application materials for researchers.
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### Looking at the Evidence You Have

- 1. What evidence can you point to that supports the statement that your research is a priority of the community(ies) whose data you are using?**

For example:

- List academic paper(s) that identify your research question as a priority of the community(ies) you are studying.
    - Did the authors consult directly with patients or community members?
  - List gray literature (such as op-eds, advocacy group reports, or newspaper articles) that identify it as a priority
    - What evidence is there that communities were involved in this reporting?
- 2. Do you know of any evidence suggesting that this line of research is NOT a priority for the community(ies) whose data you are using?**

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For example,

- Native Hawaiian scholars say that studies about human origins are not a priority for their communities. Native Hawaiians would rather their biospecimens be used for research on health issues that impact them.<sup>1</sup>
- Research into the origins of same-sex attraction (often called “gay gene” research) is highly controversial among queer people.<sup>2</sup> These studies often lack scientific rigor, reveal homophobic bias in the researchers, and worsen stigmatization.<sup>3,4</sup>

**3. If your research is NOT a priority for all or some of the community(ies) you are studying:**

- a. What reasons are given?
- b. Does the affected community(ies) recommend any ways to carry out this research ethically? (For example, by working closely with community members?) OR is the community firmly against this line of research?
- c. Can you pivot your study to a topic that *is* a priority?

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## Outlining a Plan to Gather Evidence

If you do not have evidence about whether your research IS or IS NOT a priority for the community(ies) in your dataset, outline a plan for where and how you will look for it.

- 4. Are you aware of any formal priority-setting efforts in your field?** Do they include patient or community voices?
- 5. If you feel community priorities for your research question are not documented,** why do you think that is?
  - a. What steps could you take to begin documenting or surfacing them?

6. **Beyond academic papers, where else could you look** — advocacy groups, media, or patient-led spaces?
    - a. What cautions or considerations would you need to keep in mind when using those sources?
  7. **How can you begin or deepen relationships with communities so that priority-setting becomes a shared, ongoing process** — rather than just a literature search?
  8. **How will you capture and document what you find so it informs your research?**
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## Sources

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3. Ventresca C, Martschenko DO, Wedow R, et al. The methodological and ethical concerns of genetic studies of same-sex sexual behavior. *Am J Hum Genet*. 2024;111(10):2107–2116. doi:10.1016/j.ajhg.2024.08.007
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