Priority Setting

A guide to using priority setting methods to do impactful work

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We know that research has greater impact when researchers listen to the people it affects.[1] In biorepository-enabled research, this can mean the people who donated samples *and* broader groups of people represented in the data.

The field of *Priority-setting* can help repository researchers center communities in their work. Priority-setting is a process for identifying research questions. It brings together interest-holders to build consensus on research priorities.[2]

Common Approaches to Priority-Setting

There are a variety of both qualitative and quantitative priority-setting methods. Here is an overview of three common approaches.

The following table is adapted from a table provided by Leitch et al. in "International research priority setting exercises in stroke: A systematic review.":[3]

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Method	Patient and public involvement	Example
Child Health and Nutrition Research Initiative (CHNRI)	The research team creates a list of research ideas and potential evaluation criteria, such as affordability or novelty. Interest-holders contribute by deciding which criteria are most important. Researchers combine this input with experts' input to develop a final score for each idea.[4]	In a study to set research priorities for engaging men and boys in sexual and reproductive health rights (SRHR), researchers adapted CHNRI by holding focus groups with SRHR interest-holders to develop research ideas. Next, a larger group of SRHR interest-holders ranked these ideas in a survey based on two criteria: answerability and impact.[5]
Delphi Method	Interest-holders complete several rounds of questionnaires and share questionnaire findings to reach a group decision. This method has been adapted to use in priority-setting research.[3]	In a study to determine training priorities for nurses in care homes, researchers used a modified Delphi method with a panel of 352 nurses and related professionals. The panel reached a consensus through two iterative survey rounds. Researchers used the results from the first round to shape the questions in the second.[6]
James Lind Alliance (JLA)	Patients and carers interact with healthcare professionals through a combination of surveys and workshops to identify and agree on a "top ten" list of research questions.[3]	In the Dementia Priority Setting Partnership, researchers applied the James Lind Alliance approach to gather 1,563 survey responses from patients, carers, and professionals regarding their unanswered questions about dementia care. A representative group collaborated in a final workshop to reach consensus on a Top 10 list of priorities.[7]
Dialogue Model	Patients contribute as partners who first define their own priorities. They then collaborate directly with researchers in dialogue meetings to negotiate and jointly decide on a final shared research agenda.[8]	In the BhURN project, burn survivors and professionals identified their research needs separately through focus groups and questionnaires. They then collaborated in a dialogue meeting to merge these lists into a shared agenda. This led the foundation to fund previously overlooked patient concerns, such as research on itching and edema on scars.[8]

Here are a few more examples of priority–setting studies that involved patient communities:

➔ Studies using the *James Lind Alliance* method:[3]

- "What Are the Top 10 Research Questions in the Treatment of **Inflammatory Bowel Disease**?…" (Hart et al., 2017)[9]

- "Identifying research priorities for **digital technology in mental health care**…" (Hollis et al., 2018)[10]

- "Top ten research priorities for **type 2 diabetes**…" (Finer et al., 2017)[11]

- "Research agenda setting with **children with juvenile idiopathic arthritis**…" (Aussems et al., 2022)[12]

➔ Studies using the *Dialogue Model*:[8]

- "The most important problems and needs of **rasopathy patients with a Noonan syndrome spectrum disorder**" (Tiemens et al., 2023)[13]

- "Research in **haematological cancers**: What do patients in the Netherlands prioritise?" (Schölvinck et al., 2019)[14]

- "Living with **Parkinson's disease**: Priorities for research suggested by patients" (Schipper et al., 2014)[15]

"Hard to Reach" Communities

Researchers should not assume that a given community's priorities are unknowable. The perspectives of some communities may be hard to find, especially within academic literature. Community views may not have yet been published in the scientific literature for many reasons. For example, research in the past often left communities out—intentionally or because they didn't think to engage them. Also, some communities have been harmed

by research. This history can make people hesitant to take part in research today. However, **there are priority-setting strategies that researchers can use in these cases.**

Qualitative Methods

Many studies have used qualitative methods to seek out the perspectives of "hard to reach" groups. Here are a few examples:

- **People with conditions that may feel hard to talk about** – "Research priorities in urinary incontinence: results from citizens' juries" (Herbison et al., 2009)[16]

- **People who are currently in prison or jail** – "Identifying research priorities to improve the health of incarcerated populations…" (Simpson et al., 2021)[17]

- **Members of marginalized groups** – "Members of Minority and Underserved Communities Set Priorities for Health Research" (Goold et al., 2018)[18]

Beyond Academia

Even when a group's views are absent from academic writing, they may be documented in other places. This "grey literature" might include:

- Advocacy-group statements

- Newspaper articles

- Social-media organizing

Specific examples include:

- The **AIDS Coalition to Unleash Power (ACT UP)** continues to issue statements calling for affordable HIV therapies and a cure.[19]

- The **Ehlers-Danlos Society** publishes research-priority lists.[20]

- Patient communities often share priorities through **Reddit, Facebook,** or **Discord groups**.

Caution:

➔ CHIRON community experts caution researchers to be careful when reaching out to advocacy groups. This is especially true for groups that started online. People who are not part of a group may find it hard to understand the relationships and conflicts that go on inside of them.

➔ Groups might feel intruded upon if researchers come in simply to collect information. Sharing openly with communities about the research from start to finish helps build trust. (See *CHIRON Exercise 7 – Communicating Transparently.*)

Final Thoughts

This is not a complete list of priority–setting approaches, but we hope this will inspire readers to explore further. Making sure that research lines up with community needs is both ethical and makes for more effective science.

Sources and Further Reading

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