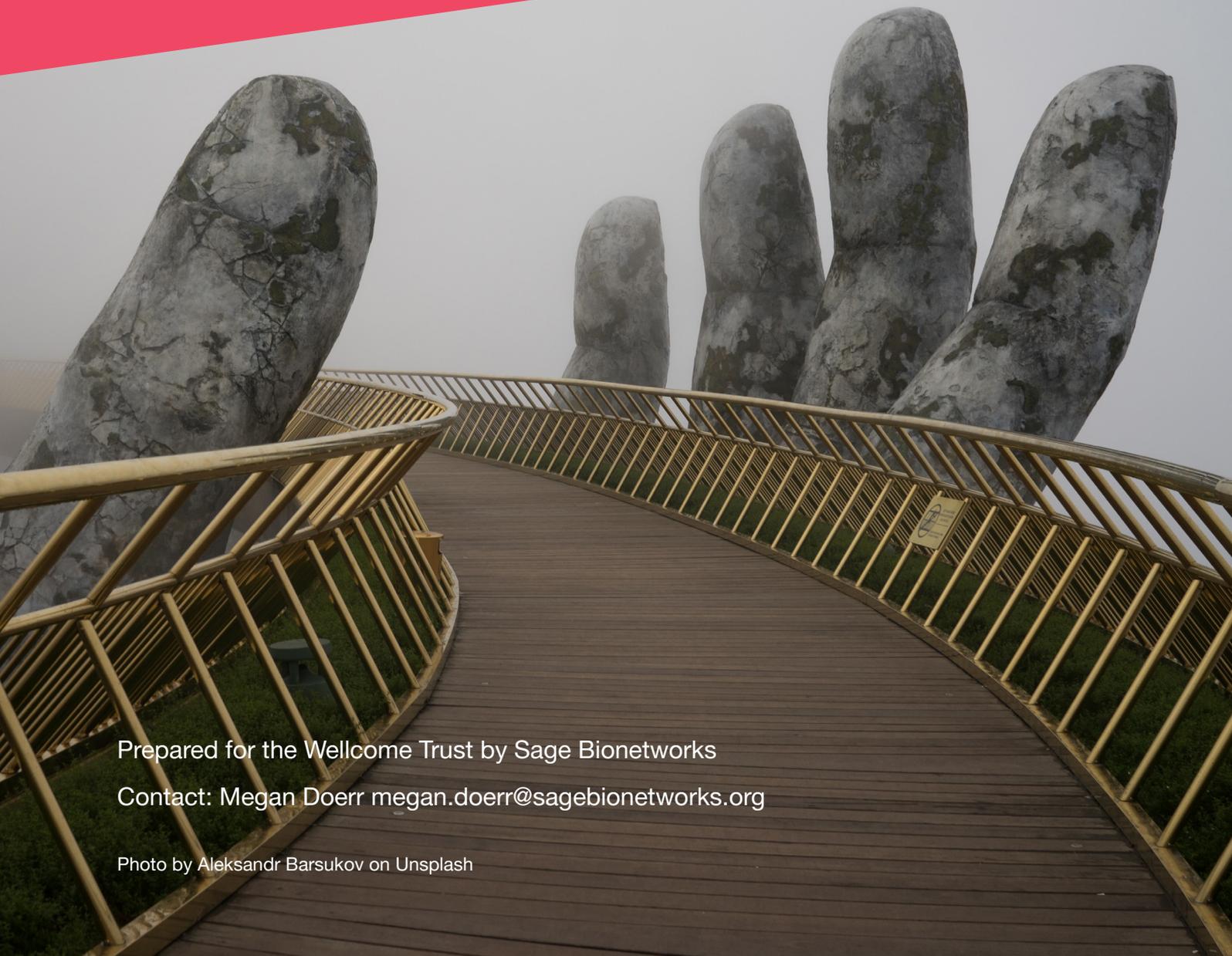


# W

wellcome

# Bridging the gap

2022



Prepared for the Wellcome Trust by Sage Bionetworks

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Photo by Aleksandr Barsukov on Unsplash

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# How to navigate this report

For a short summary of the whole project, see the [Overview](#)

To be reminded of the research question we are answering, see the [Problem Statement](#)

For an overview of each of the project phases, see [Bridging the Gap Project Phases](#)

For a short list of the meta-findings and questions we are still thinking about, see [Learnings](#)

For some detail about...

...our starting point, see the [final normative models](#)

...the why behind this project, see the [literature review](#)

...what we did, see the sections on [Phase 1](#), [2](#), and [3](#) activities

...what youth and researchers told us they wanted, see [Design Values](#) and [Subthemes and Design Requirements](#)

...what tools/features to build, skip right to [Research Platform Hygiene Specifications](#) and [Participatory Research at Scale Specifications](#)

...what youth and researchers' reaction was, see the [Phase 3 findings](#)

## Overview

In early 2021, Sage Bionetworks proposed a supplemental project to the MindKind Study that would leverage the project's existing infrastructure to investigate digital tools and features that might connect researchers and participants in large-scale remote/distributed research projects. The resulting formative investigation, Bridging the Gap, explored the digital infrastructure (i.e., technical, design, and governance tools/features) needed to scale participatory methods while supporting transparent, reproducible, and inclusive science. Building from a set of normative models proposed by Sage Bionetworks and refined through collaborative outreach (Phase 0), youth and researcher advisory groups convened for the MindKind study in co-design sessions to 1) identify the values to drive digital infrastructure design and connect these values to design requirements for digital tools/features (Phase 1), 2) envision how these tools/features would be used through a set of specifications and user journeys (Phase 2), and 3) respond to and refine the tools/features (Phase 3). In addition to articulating good practice tools/features for research platform design ("research platform hygiene"), the Bridging the Gap co-design sessions describe digital tools and features that extend existing/recommended research platform infrastructure and as well as identifying novel tools/features to support the meaningful interaction of researchers and participants throughout the research lifecycle, including for secondary use.

## Problem Statement

What infrastructure can we build to support meaningful connections between youth participants and researchers that enriches and hones the data (and resulting analyses) in a global mental health databank?

## Bridging the Gap Project Phases

This project was organized into three distinct phases:

- [Phase 0](#) established the conceptual grounding for the investigation and was divided into a [literature review](#) and expansion of the initial normative models for the project. The resulting final normative models are [here](#).
- [Phase 1](#) gathered the requirements for features/tools to connect youth and researchers within a global mental health databank. We engaged the MindKind youth panels and researcher advisors for value sensitive design exercises, ideation, and storyboarding [activities](#). We integrated capacity building activities within our youth engagement. Our [findings](#) include the [design values](#) of youth and researchers as well as the [top 10 sub-themes](#) from youth and researchers, and resulting design requirements.
- [Phase 2](#) built from youth and researcher values, sub-themes, and resulting requirements identified in Phase 1 to a set of specifications for features/tools to connect youth and researchers within a global mental health databank. These specifications are organized into baseline [research platform hygiene specifications](#) and the more radical [participatory research at scale specifications](#), those which will most fully “bridge the gap” between researchers and participants in large, remote, secondary use-focused research.
- [Phase 3](#) returned the resulting tool/feature specifications to the youth panels and research advisors for discussion and refinement.

*Original project proposal*

- [Youth-Researcher Dynamic Collaboration Platforms Proposal Final.pdf](#)

*Link to Bridging the Gap project plan*

- [ConnectiveTissueProjectPlan](#)

# Phase 0: Conceptual Grounding

The focus of Phase 0 was to establish the conceptual grounding for the Bridging the Gap project. This work was divided into two phases. In Phase 0a, we conducted a literature review. In Phase 0b, we expanded the initial normative models for the project through two rounds of feedback and codified final normative models for the project.

## Phase 0a: Literature review

Prior to beginning our formative work to identify what infrastructure could support meaningful connections between youth participants and researchers that enriches and hones the data (and resulting analyses) in a global mental health databank, we conducted a short review of the literature. We focused our review on: 1) if and how participatory methods have been used in investigations of youth mental health to date 2) in what ways technology has been used to manage youth mental health 3) methodological approaches to integrating participant voice into design 4) in what stages of the research lifecycle youth have participated in mental health research to date.

*Standalone copy of the completed literature review*

- [Bridging the Gap\\_Phase0a\\_FNL.pdf](#)

## Complete literature review

Most mental illnesses begin between ages 12 and 24 (Patel et al., 2007). Yet this age range of incidence—especially for participants under 18—poses challenges to researchers legally, ethically, and logistically. It is unsurprising, then, that parents, pediatric clinicians, community groups, and other surrogates are often used in research as a proxy for the pediatric population of study. Indeed, a review by Jacquez, Vaughn, and Wagner (2013), found that only 15% of putative community-based participatory research (CBPR) papers focusing on young people partnered with young people at any stage of the research process. The accuracy and relevance of surrogates' assessments is up for debate: "studies have consistently found statistically significant differences between pediatric patients and parents' assessments of the patient's physical and psychological symptoms and behavior" (Hong, Lakshmi, & Wilcox, 2017). This poses major threats to youth mental health research in communities where mental illness is stigmatized and discussing mental health with prospective surrogates may be uncomfortable or taboo.

Researchers that seek to engage with young people directly demonstrate more than just token involvement. In the aforementioned review, the minority of CBPR studies that did bring youth partners into the research process engaged youth informants in multiple phases (Jacquez, Vaughn, & Wagner, 2013). Considerations of *who* is engaged and *at what time* they are engaged call to mind Arnstein's seminal ladder of citizen participation—and its companion ladder of children's participation—which posits that community engagement occurs in differing degrees with differing amounts of power allocated to community members (1969; Hart, 1992). The idea that the population of informants and phase of community engagement are relevant to the depth and impact of their involvement is explored in this paper. The (perceived) digital aptitude of youth people and ubiquity of smart phones in many regions also presents an emerging space in which researchers seek to diversify, scale, and

broaden participatory research with young people. This section will review frameworks and approaches to technology-mediated mental health research involving youth.

Use cases of technological tools for managing mental health in young people span commercial, NGO, and research-oriented spaces. Commercial tools providing mental health counseling include BetterHelp, Talkspace, and 7 Cups (Nguyen et al., 2021). The governance of these tools is often opaque and not primarily driven by research insights (Nguyen et al., 2021). Commercial tools may also lack the security standards that are typically constituent to academic endeavors and medical devices. Indeed, in a recent investigation of 32 commercially available mental health and prayer apps, Mozilla researchers found that 25 apps lacked minimum security standards like requiring strong passwords, including a mood tracking app that accepted the password “1” (Mozilla, 2022). Other mental health tools are run by non-profits, NGOs, and community groups, which include crisis hotlines and text lines (O’Leary, 2018). This space too raises concerns about opaque governance, notably in relation to Crisis Text Line, a mental health chat service that uses artificial intelligence to triage incoming chats. While Crisis Text Line is a non-profit, users and employees expressed doubts about a data sharing agreement with a for-profit entity to train customer service tools on the anonymized data of users in crisis (Levine, 2022). Privacy experts also called into question the re-identification risk posed by this data sharing partnership (Levine, 2022). Events like this remind us of the lifecycle of data beyond its initial collection, highlighting the importance of including community stakeholders in discussion about secondary use of research data, a topic investigated in this paper. Finally, the class of mental health tools created by the research community less frequently reach an end user and are often reported in a prototyped state (Bhattacharya et al., 2019). Researchers developing these tools use a diverse range of methods for soliciting youth feedback.

Mobile health research that features iterative and dialogic engagement between researchers and community members is captured in the SMART framework (Katapally, 2019). The framework balances the health surveillance of big data and desire for dynamic data collection from researchers with the desire to contribute to research processes from citizen informants (Katapally, 2019). It empowers citizens to co-own data and participate in data analysis (Katapally, 2019). SMART is also being tested with Indigenous Canadian youth with the goal “to improve mental health outcomes among youth by embedding a land-based, culturally appropriate active living intervention into the school curricula” (Katapally, 2019). Taken in total, SMART offers both a framework and a use case of mHealth research that directly and deeply engages with the population of interest.

Researchers also engage participants in more intimate design environments to seek scalable insights. Miller, Pollack, and Pratt, 2017, engaged clinicians, caregivers, and pediatric patients with chronic illness about what tech-mediated tools would improve their experiences in clinical spaces. Their proposals included “OneDocAway” (modeled after the public transportation app OneBusAway) that informs patients and caregivers when their doctor is rounding to their room next (Miller, Pollack, & Pratt, 2017). Other use cases focus on emotional self-management and peer support. Bhattacharya and colleagues, 2019, collaborated with teenagers to storyboard the app “Teens Advice” where, in the vision of one participant, “There could be categories too like: ‘Dating & Romance’, ‘Hygiene & health’, ‘Family’, ‘LGBTQ’, ‘School’, ‘Social Life’, ‘Mental Disorders’ etc.” Informants also grappled with the benefits and limits of parental participation in emotional management and proposed app-mediated tools like a “stress toolkit,” wherein the teenage child writes a list of stress management tools (e.g. “walking the dog”) that a parent could remind the child of when the

child is “freaking out about exams” (Bhattacharya et al., 2019). O’Leary and colleagues, 2018, also tested the boundaries of unguided tool use versus guided use in peer chats. Anonymous participants were paired in asynchronous online chats unguided by prompts, which participants reported enabled “smooth” conversation (O’Leary et al., 2018). Other pairs were placed in chats where they were asked to respond to prompts based on evidence-based psychotherapy research, which enabled “deep” conversation (O’Leary et al., 2018). In a still more structured endeavor, Singer and colleagues, 2020, leveraged preexisting WhatsApp use in Malawi to lead remote focus group discussions (FGDs) on adolescent sexual and reproductive health. Not only do they report their findings as eliciting similar quality data as in-person FGDs, suggesting major implications for the scalability of WhatsApp-mediated research, but they add that “[a]dolescents indicated feeling comfort using WhatsApp to share their perspectives on sensitive topics” (Singer et al., 2020). Perhaps owing to comfort with the user interface and sense of privacy as compared to in-person research, the anonymity of WhatsApp is—as is said—a feature, not a bug (Singer et al., 2020).

Some researchers take a step back from testing tools with participants and ask questions about the design of tools in the first place. The field of value sensitive design offers “a theoretically grounded approach to the design of technology that accounts for human values in a principled and systematic manner throughout the design process” (Friedman et al., 2017). One tool for accounting for human values is Envisioning Cards, which design researchers use to elicit informants’ perspectives on four criteria: (1) stakeholders, (2) time, (3) values, and (4) pervasiveness (Friedman & Hendry, 2012). These criteria enable informants to consider who a technology affects, what long-term implications a technology may present, what influence a technology has on human values, and how our environment may change as a result of a technology (Friedman & Hendry, 2012).

Another design strategy to ensure that participant perspective is incorporated into design decisions is participatory design. Participatory design mirrors CBPR in the design space, aiming to democratize the design process and encourage the contribution of marginalized people to design endeavors (Harrington et al., 2019). While participatory design seeks to create collaborative partnerships between designers and community members, Harrington and colleagues, 2019, also describe how this strategy may be isolating to participants with less education, and so-called “blue sky” approaches may reproduce frustration among participants when recommendations are infeasible. As such, Harrington et al., 2019, recommends leveraging existing expertise within communities and reconsidering the hierarchies that separate researchers from participants, ideally as part of a sustained relationship between researchers and communities.

Indeed, deeply embedded research often engages young people not only in high depth but also in many phases. Russ et al., 2019, offers eight stages in which data science can be utilized to advance mental health, including etiology, prevention, treatment evaluation, and disease management. Jacquez et al., 2013, recognizes five stages: 1) input into the research, 2) research question ideation, 3) designing and conducting research, 4) analysis, and 5) dissemination. This investigation will explore four phases: 1) research exploration, 2) research in progress, 3) reactions to research, 4) secondary use of research data. Regardless of the number of divisions, involving youth informants at multiple stages elicits rich data. In a study engaging youth at three phases (as per Jacquez et al., 2013), Yonas et al., 2009, used painting, writing, and discussion to elicit African American young people’s perspectives on safety—and lack thereof—in their communities. As part of a long-term partnership, “[a]ll project-related decisions...were achieved through a consensus

guided format that included expertise from both academic and community partners,” and youth participants specifically “were involved with guiding the direction and implementing each phase of the creative participatory data collection sessions once the project began” (Yonas et al., 2009). In a research endeavor involving youth informants in all five phases, Rosen-Reynoso et al., 2010, engaged young people as co-researchers in a randomized controlled study on disabled students’ support needs as they transition to high school. The study team worked with youth advisory boards at every step of the process, ultimately deeming this project “youth-based participatory research” to highlight the importance of centering youth themselves over surrogates (Rosen-Reynoso et al., 2010).

A stage of the research process that is not always captured in even multi-phasic community engagement endeavors is secondary use. A 2020 review of young people’s involvement in health research identified nearly identical research stages to the 2013 review by Jacquez et al., stages that Wilson and colleagues called 1) agenda setting, 2) research design, 3) data collection, 4) data analysis, and 5) dissemination. Indeed, both reviews conclude the research cycle following dissemination of findings from primary research. But as the aforementioned Crisis Text Line controversy reveals, in the current data sharing economy, datasets seldom complete their lifecycle at initial use. Secondary use of research data is an underexplored area of consideration in CBPR. While many scholars have detailed the harms of unauthorized secondary use, especially those perpetrated by researchers working with Indigenous communities, engagement with the public to envision ethical secondary use remains under-considered (Nowrouzi et al., 2017). Initial guidelines that, at a minimum, mitigate harm have taken root in some contexts. Since 2014, research involving Indigenous peoples in Canada has been governed by the Tri-Council Policy Statement, which limits the use of broad consent by requiring re-consent of participants prior to secondary use of biobank samples (Nowrouzi et al., 2017). As Nowrouzi and colleagues, 2017, detail, this governing framework provides a baseline; it does not capture what would be desirable or germane to Indigenous participants, which is obtainable through “[c]ollaborative research [that] not only recognizes [the] Aboriginal population’s right of self-determination, but could have the potential to improve health measures, health tracking, health evaluations and overall health outcomes in Aboriginal communities.” One such endeavor was conducted by Sahota, 2014, whose informant group of Native American tribal members suggested that consent forms include a checklist regarding secondary use, allowing participants to pick and choose the domains of secondary use that are acceptable to them. The participant group also highlighted how such a checklist may serve a dialogic function between researchers and research participants, allowing the former to raise inquiries beyond the binary of specific consent versus broad consent (Sahota, 2014). Another group seeking community engagement on secondary use is Akinyemi and colleagues, 2020, who published a protocol for a CBPR study that will examine, among other things, acceptable use of biobank materials with stroke survivors and clinicians in Ghana and Nigeria.

Theoretical frameworks are also available to guide further CBPR studies in this area. The American Medical Informatics Association (AMIA) released a 2007 white paper resulting from an expert panel’s considerations of issues relevant to secondary use (Safran). A guiding framework for researchers and stakeholders regarding secondary use would involve, by their account: transparent policies and practices for the secondary use of health data; focus on data control, rather than data ownership per se; consensus on privacy, policy, and security; public awareness; comprehensive scope, beginning with a taxonomy; and national leadership (Safran, 2007).

Researchers continue to seek creative, innovative, and scalable methods to engage with young people about their mental health. Endeavors to this end are part of the rapidly expanding landscape of CBPR, which seeks to involve community members, generate research ideas, and—hopefully—improve public health.

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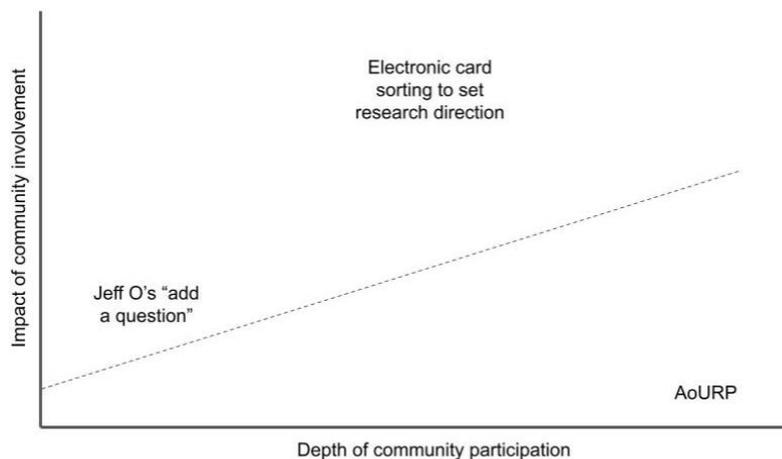
## Phase 0b: Expansion of normative models

We further developed the original normative models for the project, the unfortunately named *Gestalt Tools and Scientific Outcomes* and *Gestalt Tools and Capacity Building*. We conducted this work in two rounds: in round 1 we brainstormed internally and solicited targeted feedback from external thought leaders. In round 2, we consulted with MindKind researcher advisors and youth panels. We then finalized our normative models for the project.

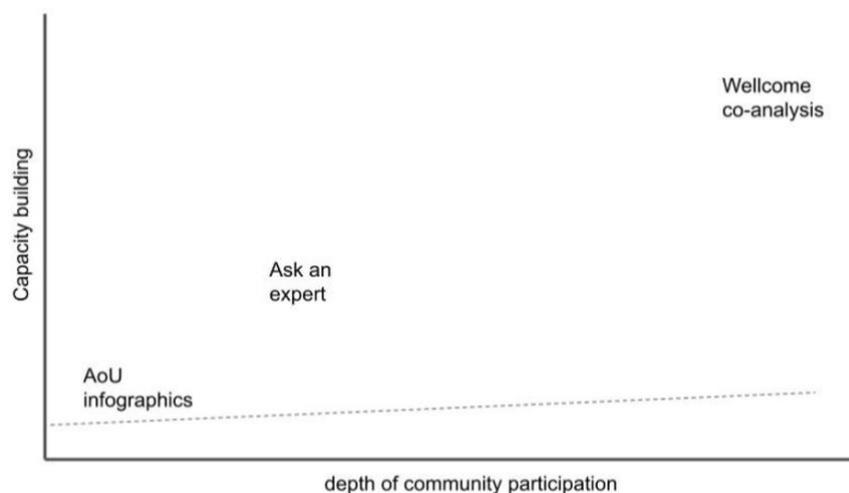
### 0b.i. Original normative models

The original version of *Gestalt Tools and Scientific Outcomes* describes the scientific impact of three example tools/features by depth of community engagement and the impact of community involvement. The original version of *Gestalt Tools and Capacity Building* describes the capacity building impact of three example tools/features by those same metrics.

#### Original version of *Gestalt Tools and Scientific Outcomes*



#### Original version of *Gestalt Tools and Capacity Building*



## 0b.ii. Round 1 expansion of normative models

Through internal brainstorming and targeted outreach to external thought leaders, we refined and expanded the original normative models, adding additional examples of tools to flesh out the space described. We then iterated on each of the two models, designing three versions of each figure, as we tried to refine the models' presentation.

*Link to comments from external researchers/thought leaders*

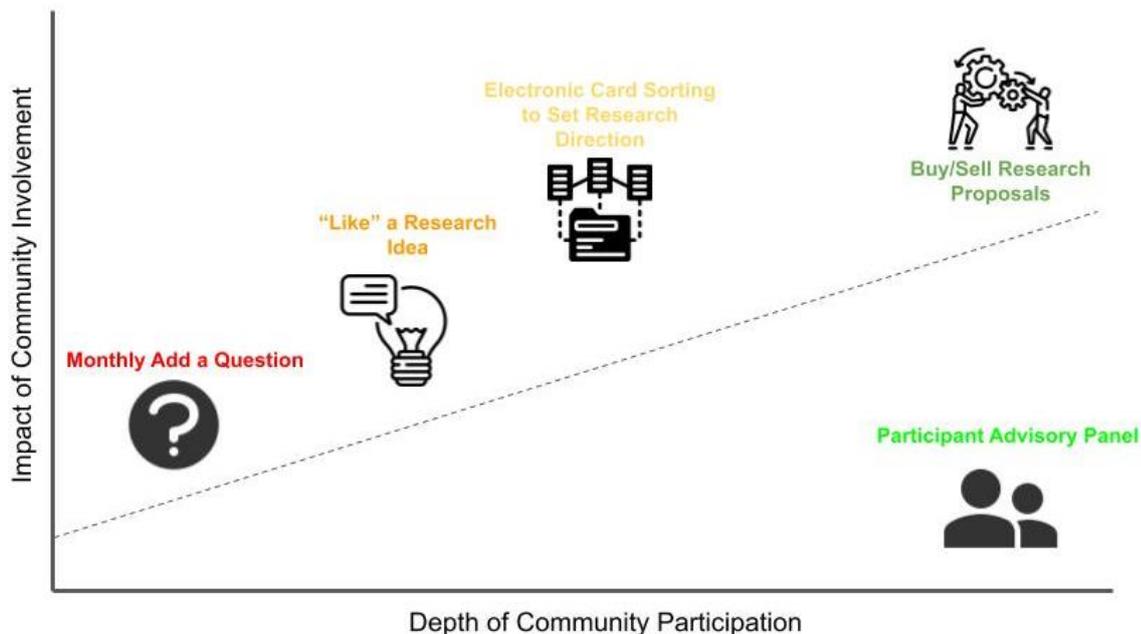
- [CommentsOnFigures](#)

*Link to Round 1 versions 1-3*

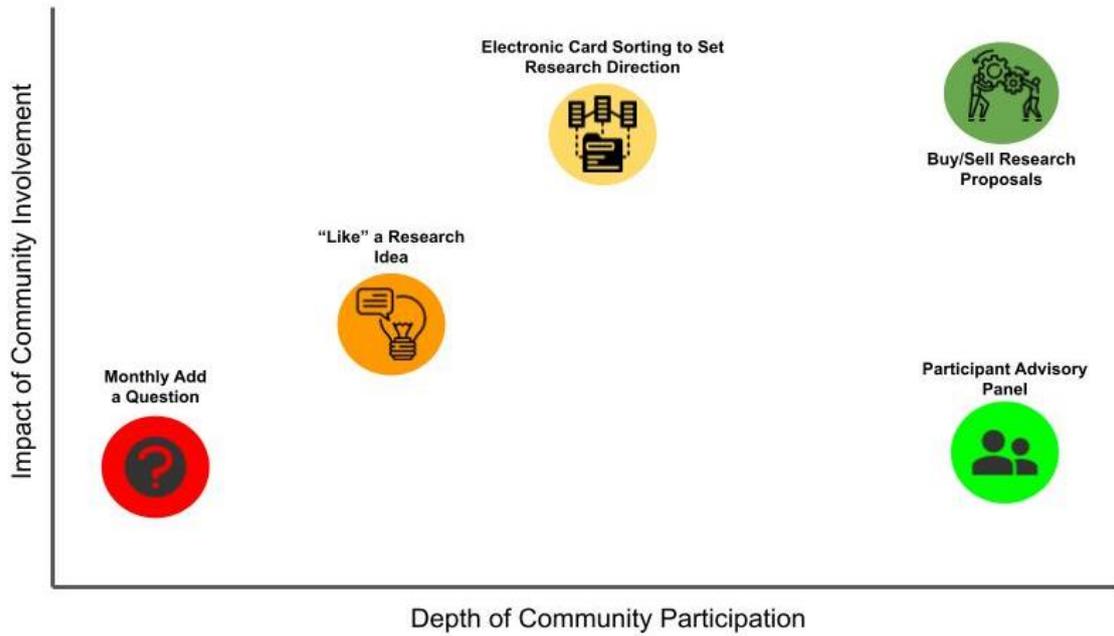
- [Figures OriginalCopies Op-Ed IterativeVersions](#)

### Example: three versions of *Gestalt Tools and Scientific Outcomes* from Round 1

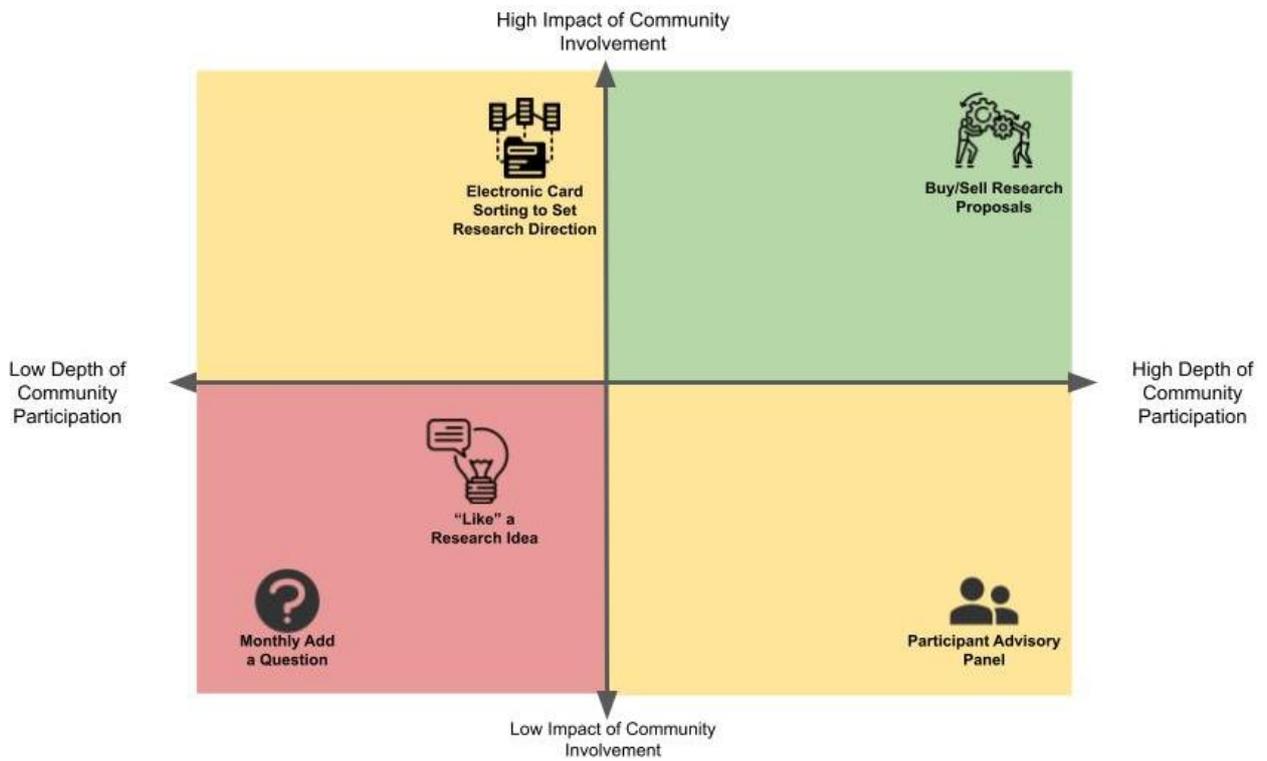
Version 1 of *Gestalt Tools and Scientific Outcomes*



Version 2 of *Gestalt Tools and Scientific Outcomes*



Version 3 of *Gestalt Tools and Scientific Outcomes*



### 0b.iii. Round 2 expansion of normative models

We shared the expanded normative models with the MindKind research advisors and youth panels, iterating on the examples to develop final versions of the models and identify which version of the figures was the preferred visual presentation of the models. Research advisors were presented versions of *Gestalt Tools and Scientific Outcomes*. Youth panelists were presented the versions of *Gestalt Tools and Capacity Building*.

#### *Summary of feedback*

- [Phase0b\\_OverallSummaryDoc](#)

#### Researcher feedback

MindKind research advisors provided feedback via survey on the round 1 expanded versions of *Gestalt Tools and Scientific Outcomes*; however, a limited number of responses were received. Research advisors generally preferred version 2. They generally understood the normative model and provided refining guidance on the placement of tools/features. Researchers suggested that there would be a role for both qualitative and quantitative tools/features that connect researchers and participants. They detailed barriers to tool/feature use such as trust from the community about how the information shared will be used and institutional ethics approvals and guidelines.

#### *Qualtrics Survey*

- [BTG\\_DUG\\_ModelSurvey.pdf](#)

#### Youth feedback

MindKind youth panel members were engaged on the round 1 expanded versions of *Gestalt Tools and Capacity Building Conceptual Model*. Each of the three in-country panels (UK, India, SA) were provided written pre-session education, participated in virtual discussion sessions, and were sent a short post-panel survey. Sessions were video recorded with members' permission and findings were extracted separately by two members of the research team. Highlights include a broad preference for version 2, varying understanding of the examples provided to illustrate the figure. Youth also suggested different modes of presentation to further support understanding of the concepts presented.

#### *Pre-session educational materials*

- [Phase0\\_GlossaryandInfoSheet](#)

#### *Example session facilitation slide deck*

- [Phase0\\_UK\\_YouthPanel\\_Slides](#)

#### *Link to post-session survey*

- [Post-Session Survey](#)

## 0b.iv. Final normative models

The original normative models were updated following the feedback provided by research advisor and youth panel consultations. Of note, both figures were retitled: *Gestalt Tools and Scientific Outcomes* became Bridging the Gap Tools for Big Data and Scientific Outcomes (figure 1), and *Gestalt Tools and Capacity Building Conceptual Model* became Bridging the Gap Tools for Big Data and Capacity Building (figure 2).

*Final normative models description document*

- [Normative Models - Examples and Final Version](#)

Figure 1: Bridging the Gap Tools for Big Data and Scientific Outcomes

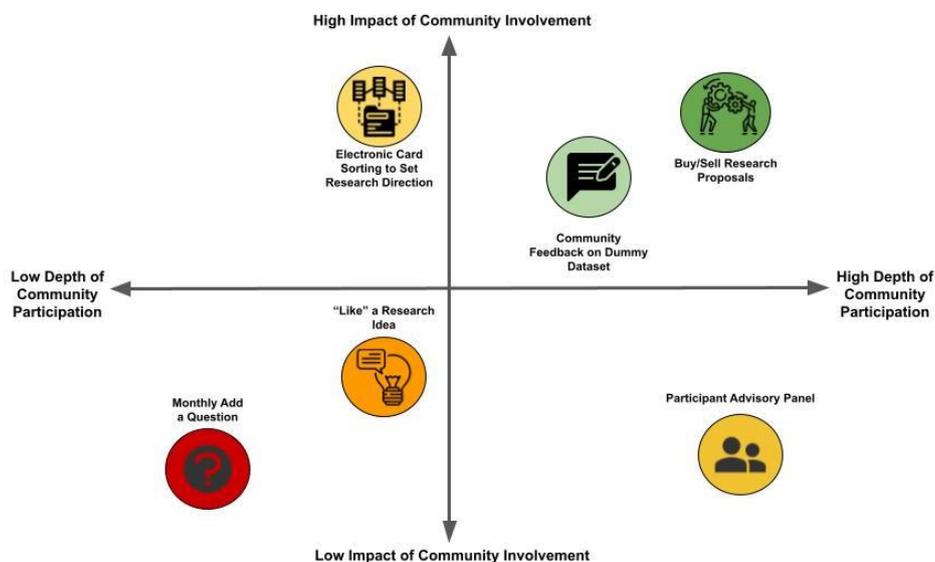
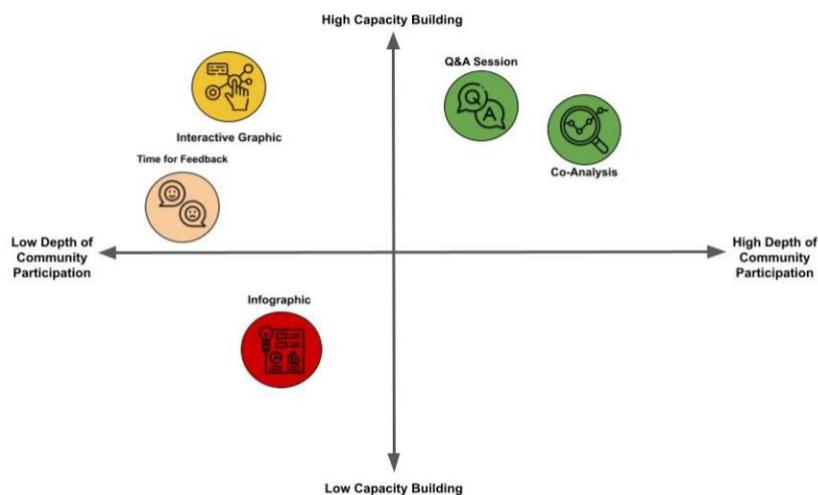


Figure 2: Bridging the Gap Tools for Big Data and Capacity Building



# Phase 1

In Phase 1 we focused on gathering the requirements to guide the development of tools/features that could connect youth and researchers in global mental health databank. Again, we engaged both the MindKind youth panels and research advisors to inform our work.

## 1a. Activities

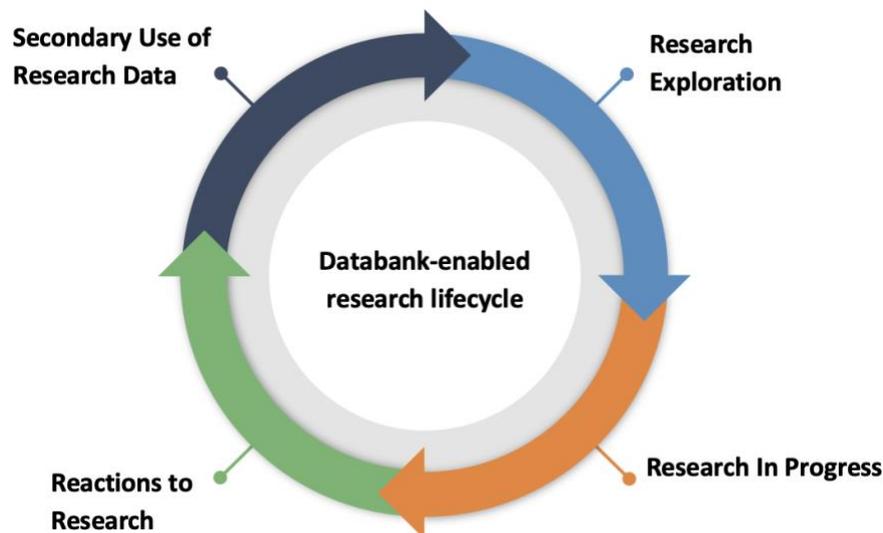
### Youth activities

We spent a total of approximately three hours with each of the YPAG over a series of two sessions. In **Part 1**, we led capacity building and facilitated two value sensitive design activities. In **Part 2**, we led additional capacity building and engaged panelists in ideation and storyboarding activities.

#### Part 1: Capacity building & value sensitive design

Following a brief refresher on the focus of the Bridging the Gap project, we led capacity building discussions the stages of a databank-enabled research lifecycle (figure 3), highlighting four potential points of implementation tools/features in the future databank: research exploration, research in progress, reactions to research, and secondary use of research data.

Figure 3: Databank-enabled research lifecycle



Additionally, we facilitated two [value sensitive design](#) activities to lead youth to discover and define the values that should drive the development of tools/features connecting them with researchers within the databank. The first activity used Value Sensitive Design [Envisioning Cards](#), and youth panelists worked in small groups using adapted prompts. After a brief

capacity building description, youth then pivoted to conducting one-on-one semi-structured interviews of one another using a guide we provided to further elicit design values.

*Example slide deck from Part 1:*

- [SouthAfrica Phase1 Part1](#)

*Design values focused interview guide*

- [YouthPanels Finalized InterviewQuestions](#)

Part 2: Ideation and storyboarding

Following a brief refresher on the four potential points of implementation, we led capacity building on ideation and storyboarding, two techniques used frequently by designers. Youth then completed an ideation activity and a storyboarding activity.

*Example slide deck from Part 2:*

- [SA YouthPanel Phase1 Part2](#)

## Researcher activities

We sought to identify researchers' values and design ideas to guide the development of tools/features that could connect youth and researchers in global mental health databank across the research lifecycle. We conducted semi-structured one-on-one interviews with a subset of four researchers to identify values; the subset interviewed were nominated by the team facilitating the group based on perceived interest. Interviews ranged in length from 30 to more than 60 minutes.

*Guide for researcher interviews:*

- [InterviewLayout Questions](#)

## 1b. Findings

We conducted a thematic analysis of the Phase 1 youth and researcher panel sessions. We identified key values that youth and researchers felt should guide the design of tools/features for connecting youth and researchers in a global mental health databank (table 1). For example, both groups highlighted global inclusivity, capacity building, relationship building, iterative interaction, amplifying participants' voices, and ensuring mutual benefit.

Quotes within each of these values were further categorized into sub-themes. Sub-theme tagged quotes were then used in an affinity diagramming exercise to identify design requirements. We present the ten most frequently coded sub-themes and related design requirements for youth and for researchers in tables 2 and 3, respectively, below. There is significant overlap between youth and researcher design values.

## Design values

We present youth and researcher values side-by-side (table 1) to facilitate seeing both overlap and difference between the two groups. Of note, there is one row containing two youth values and two researcher values that collectively overlap with one another.

Table 1: Youth and Researcher Design Values for Bridging the Gap Tools/Features

Youth Values	Researcher Values
<b>Trust:</b> trust as a guiding principle in designing tools/features to connect youth and researchers; need for tools/features to reinforce respect between participants and researchers.	<b>Building Trust:</b> potential mechanisms for building trust using these tools/features, e.g., feedback loops/acting on feedback; transparency.
<b>Building Rapport:</b> necessity of connecting tools/features building rapport, e.g., account for time needed for community building; support level setting; information exchange.	<b>Relationship Building and Community Involvement:</b> role of these tools/features to build relationships with participants, identify and nurture research partners within communities.
<b>Transparency:</b> need for transparency within the proposed tool/feature set, e.g., how participant contributions are used by researchers; transparency in data protection and use.	<b>Youth Empowerment:</b> creating an environment where youth are comfortable sharing their voices; platform for partnership; supporting youth ownership of their data/stories.
<b>Conflicts and Concerns:</b> youth's conflicted feelings/concerns with regards to the use of these tools/features, including worry over safeguards for youth participation and unequal power dynamics between researchers and participants.	<b>Concerns of Working with Youth:</b> concerns about collaboration with vulnerable populations, safeguarding, youth tokenism. <b>Researcher Concerns:</b> that tools/features sustainably support continuity of research; barriers to implementation; compliance.
<b>Impact:</b> anticipated impact of databank with these tools/features for participants directly, e.g., capacity building; broadly, e.g., impact the lives of people with mental health conditions globally. <b>Researcher Values:</b> perspectives on what youth imagine researchers want from the tool/feature set, e.g., that the tool/feature set provide tangible benefit to researchers, is a source of active engagement between youth and researchers.	<b>Participant/Researcher Benefits:</b> ensuring there is participant benefit e.g., capacity building and mutual benefit to participants and researchers and the broader community. <b>Youth/Participant Involvement:</b> integration of youth into the research process, tools/features serving as a vehicle for participant guided research and recognition of youth as experts/lived experience as a form of expertise.
<b>Inclusive of a global audience:</b> ensuring that the tools/features are inclusive and culturally appropriate for a global audience.	<b>Inclusive of a global audience:</b> ensuring that the tools/features are inclusive and culturally appropriate for a global audience
<b>UI Values:</b> key user interface needs identified by youth participants for the tool/feature set including that the UI should be simple, adapted for different levels of technology proficiency, and have interactive elements.	<b>UI Values:</b> key user interface needs identified by researchers for the tool/feature set including allowing for synchronous and asynchronous engagement, accessibility, and simplicity.

## Sub-themes and design requirements

While there was high concordance in the design values expressed by youth (table 2) and researchers (table 3), as we categorized quotes within each of these values into sub-themes, we observed greater variation between youth and researcher input.

We used affinity diagramming to identify design requirements based on each of the top ten sub-themes for youth and researchers. Requirements that are a close/exact match between youth and researchers are marked with an asterisk.

Table 2: Youth's top ten sub-themes and resulting design requirements.

Value	Sub-themes	Tools/features should...
Trust	Mutual respect	...support respectful rapport between participants and researchers
	General trust	...enhance the level of trust between youth and researchers
Impact	Capacity building	...build participants' knowledge and skills over time*
Building rapport	Time for communication	...account for the time needed for respectful and trust-building communication
	Building community	...contribute to the process of building community among participants and between participants and researchers*
Conflicts and concerns	Safety	...create safe spaces for researcher and participant interaction*
	Privacy/Security	...ensure participant/participant data privacy and security
	Cause for concern	...ensure high data quality and amplify participant voice
Transparency	Feedback	...have mechanisms for closing the loop between participants and researchers so youth know how their feedback has been used*
	Clear communication	...support bi-directional communication between researchers and participants

Table 3: Researcher's top ten sub-themes and resulting design requirements.

Value	Sub-themes	Tools/features should...
Building Trust	Transparency	...support transparency between participants and researchers
	Iteration/Feedback loop	...have mechanisms for iterative interaction between participants and researchers so youth know if/how their feedback has been used*
Youth/Participant Involvement	Participants as research partners	...support participants as co-equal partners in all stages of the research process
Relationship Building and Community Involvement	Trust building	...actively build trust between participants and researchers*
	Research partners within the community	...support identifying and nurturing research partners not only with youth participants but within the broader community
Researcher/Participant Benefits	Training/capacity building	...build participants' knowledge and skills over time*
	Participant benefit	...ensure benefit flows to participants for their engagement
	Mutual benefit	...provide a platform for both researchers and participants to benefit one another
Youth Empowerment	Comfortable sharing their voices	...support youth sharing their lived experience and insights in a safe and respectful space
Concerns of Working with Youth	Vulnerable populations	...have appropriate safeguarding to support collaborating with vulnerable populations*

# Go/no go assessment

At the end of Phase 1 we completed a go/no go assessment to determine if we should proceed to Phases 2 and 3 as written, rescope Phases 2 and 3, or to close the project (not complete Phases 2 or 3). Participants in the go/no go decision included the Sage research team for the project, the MindKind Professional Youth Advisors, and representatives from Wellcome Trust.

*Go/No Go presentation for discussion*

- [Go/NoGoSlides](#)

*Go/no go criteria*

- Is there a defined set of requirements from youth and researchers? → YES
- Is there reasonable potential overlap between the youth/researcher requirements (literal overlap not required) such that solutions could be imagined to address elements of both? → YES
- Is there a reasonable probability that solutions meeting the requirements would not be outside of applicable regulations? → YES
- Do the requirements allow for developing multiple solutions ( $n > 3$ ) that address both youth and researcher needs across the space described in the original version of *Gestalt Tools and Scientific Outcomes* and the original version of *Gestalt Tools and Capacity Building*? → YES
- Is there a reasonable expectation that one or more solutions could be implemented to the benefit of the eventual Global Mental Health Databank? → YES

## Phase 2

Using youth and researcher values, sub-themes, resulting design requirements, and design ideas developed by youth panel and research advisors in Phase 1, we moved to developing a menu of tools/features and journey maps for these tools/features that could connect youth and researchers in the global mental health databank across the research lifecycle.

### 2a. Activities

Through a series of virtual and in person workshop sessions and one-on-one meetings with Sage's design team, we mapped the values, sub-themes, requirements, and design ideas generated in Phase 1 to the four stages of the databank research lifecycle, iteratively building to a set of tool/feature concepts, leveraging affinity diagramming and related design methods.

*Slide deck for kick off of design team collaboration*

- [DesignTeamMeeting\\_BridgingtheGap](#)

*Outcomes of design team collaboration*

- [Design Team Meet Up Ideas.pdf](#)

### 2b. Findings

Our work identified two key categories of tools/features to connect youth and researchers in a future databank. First, one category included a set of baseline specifications for tools/features we describe as *research platform hygiene* ("RH"). Second, another category included specifications for tools/features that scale participatory research, like those used in community-based participatory research (CBPR) and related approaches, to the context of a global, secondary data use-enabling databank. These *participatory research at scale* ("PR") specifications add to and extend baseline research platform hygiene features, providing opportunities for co-equal engagement of researchers and participants in research activities.

N.B.: **Research platform** refers to the **devices** (i.e., apps and other technology) used in data collection, the **research study portal** accessible to participants and researchers, and the **technical infrastructure** accessed by researchers for their investigations.

#### Research platform hygiene specifications

Research platform hygiene describes the set of technical, design, and governance infrastructure tools/features of a research platform that enable and encourage transparent, reproducible, inclusive science. These baseline specifications are designed to support both researchers and participants in a mental health databank, and address the values and design considerations of the youth panels and research advisors who participated in Phase 1 consultations.

Below, we list the hygiene design tool/feature specifications and tool/feature ideas focusing on requirements that were common to both youth and researchers, with some specifications

addressing more than one design requirement. Please note that this list is not exhaustive of the potential specifications that could arise from the requirement sets described in Phase 1.

*Research Hygiene tool/feature specification workspace:*

- [BGP\\_ResearchHygiene.pdf](#)

### RH specification 1: Safeguarding, Flagging, Aggregation, and Information Sharing

*Requirement:* Safe space for participants to share their lived experience

*Research hygiene specification:*

- The research platform is a safe space for participants to share their lived experience
  - Has **safeguarding** features that account for use by youth
  - Implements systems that allow for users to **flag** inappropriate content
  - Ensures any information presented in publicly accessible areas is **aggregated**
  - **Shares information** about data security processes and safeguard systems with participants and researchers

### RH specification 2: Devices & Models, Reliable Infrastructure

*Requirement:* Inclusive of a global audience

*Research hygiene specification:*

- The devices (i.e., apps and other technology) used in data collection and the research study portal are inclusive of a global audience
  - Adapted to different types of **devices** (smartphones, tablets, computers, etc.) as well as older **models** of these devices
    - Text and images should be supported on a variety of devices especially small screens, with ability to zoom in and change text size
    - Lean toward making materials image-rich (rather than text-rich) given blocks of text can be overwhelming on small screens
  - Adapted to different levels of **reliable infrastructure** (electricity and internet access)
    - Provide versions that work on low-speed connections
    - Lean toward asynchronous (rather than synchronous) engagement/use options to allow for unpredictable internet access/electricity

### RH specification 3: Education About Research, Ease of Navigation

*Requirements:* Inclusive of a global audience *and* build youth skills and knowledge

*Research hygiene specification:*

- The technical infrastructure is inclusive of a global audience and build youth skills and knowledge
  - The system should support **education about research** (research in a broader context)
    - Dedicated space that describes the stages of scientific research, who usually comprises a research team, the role of participants in different types of research
  - UIs should be **easy to navigate** for people of different experience levels with technology
    - Designed for simplicity and accessibility
    - *Consider:* providing a “connect me” button for someone who’s trying to access/use data and doesn’t fully understand it to be put in contact with the uploader of the data set/sharer of the idea to ask questions

## RH specification 4: Definitions, Support Resources, and Research Stages

*Requirement:* Support transparency and builds trust *and* is inclusive of a global audience

*Research hygiene specifications:*

- The research study portal supports transparency and builds trust and is inclusive of a global audience
  - Acknowledges different parts of the world may have different **definitions** or understanding of key concepts associated with research (e.g., *mental health*)
    - Provides clear, easily understood definitions of key terms associated with the research in a place accessible to participants and researchers
    - *Consider:* Tying articles/resources to each definition in the glossary
  - Hosts a dedicated space for **support resources**, accessible to participants and researchers
    - List mental health resources by country (as included in MindKind feasibility study)
      - *Consider:* Allowing participants/community members to submit resources (resource pages, information about resource centers, pamphlets, etc.) that, once reviewed and approved by study staff, are shared via the portal in country/region specific folders/spaces
  - Creating an infographic describing the **stages of research** (infographic) that is a landing page/central to the user experience
  - *Consider:*
    - Searchable abstracts of publication manifests that include data/participants/information from the databank/research platform
    - Include specific mental health related terms mentioned in the articles and/or a list of key search terms associated with glossary definitions

## RH specification 5: Global Tracker & Progress Updates

*Requirement:* Support transparency and builds trust *and* is inclusive of a global audience

*Research hygiene specifications:*

- The research platform supports transparency and builds trust and is inclusive of a global audience
  - Showing the progress of data gathering and use around the world (**global tracker**)
    - By region/country, age, similar large-scale variables
      - *Consider:* Providing context by creating composite profiles of participants in the different studies/data sets to help researchers get to know participants and for participants to see themselves in the databank
      - *Consider:* Presenting a global distribution (map) showing where researchers and youth participants are from and/or showing where people are benefiting from the research/data
    - Providing **progress updates** on the entirety of the research lifecycle (from research exploration to secondary use of research) to promote clarity on what is happening during specific stages of the research process
      - Create a notifications system to alert subscribers to research progress
      - Create interactive clickable graphics process to:
        - Explain what researchers did or doing and why at each stage of the research
        - Include a feature whereby a participant could, for each point of the research cycle, click to get more involved
      - *Consider:* Combined progress of global tracker and progress updates
        - Have an accessible written wiki available to both researchers and participants for each data set added to the databank that describes the context of the collection of these data
        - Publish a newsletter about what is going on in the databank that researchers/youth could opt-in to when they sign up for the community
          - Include who is using what data and what they are using it for, global stats on study intervention use, list of all people (research area, organization, location) using the data
          - *Consider:* include capacity building concepts for youth, list of upcoming studies they can join as a participant or co-researcher, highlight new data added to the databank for researchers

## RH specification 6: Community Guidelines, User Profiles, Feedback

*Requirements:* Amplifies participants' voices *and* supports transparency and builds trust

*Research hygiene specifications:*

- The research platform amplifies participants' voices and supports transparency and builds trust
  - Having **community guidelines** to establish behavioral/usage norms
  - Having features that encourage relationship building and trust between its two main user groups, for example:
    - **User profile** feature for researchers and youth interested in being a part of the community component of the databank:
      - Profile could offer choice to be anonymous or not
      - Profile could offer to choose own username or require auto generated usernames
      - Choose profile image from pre-selected images
      - Selection of role (researcher/youth) to determine what “about me” questions they are asked
        - Researcher “about me” questions could include: what type of research they do, what is the motivation behind doing their research, option to include links to current work, if they are looking to recruit participants for certain projects
          - *Consider:* Allowing researcher to record a video of themselves talking about the motivation for their research
        - Youth “about me” questions could include: what type of research they are interested in being a part of or learning more about; also include a list of research topics they can select from that they are interested in learning more about (to guide capacity building efforts)
- The research platform amplifies participants' voices and supports transparency and builds trust
  - Enables knowledge exchange between the participants and researchers
    - Tool/space for participants to give **feedback** while they are participating in a study

## Participatory research at scale specifications

The purpose of participatory research at scale tools/features is to identify scale participatory research methods for large-scale, remote/distributed, or secondary use-focused research projects that will enhance our ability to do truly transparent, reproducible, and inclusive science. These technical, design, and governance tools/feature specifications either build off of research platform hygiene tools/feature specifications or are novel, independent tools/feature specifications. These specifications arise from the Phase 1 activities of this project, with many building off of research platform hygiene specifications above, addressing the values and design considerations of the youth panels and research advisors.

For just over half of the specification concepts we provide journey maps, highlighting the personas, activities, and expected outcomes for a given participatory research at scale specification, as well as a short assessment of the concept's intrigue, feasibility, and similarity to known tools.

### *Participatory Research at Scale Tool Ideas*

- [BGP\\_PRatScale.pdf](#)

### *Bridging the Gap Learnings Report Presentation PDF*

- [BTG\\_Slides\\_LearningsReportMeeting.pdf](#)

### *Bridging the Gap Phase 2 Wellcome Report*

- [BTG\\_Phase2\\_WellcomeReportExtended](#)

## PR specification 1: Co-Creating and Implementing Community Safeguards, Security Tracking, and Data Security Explainer

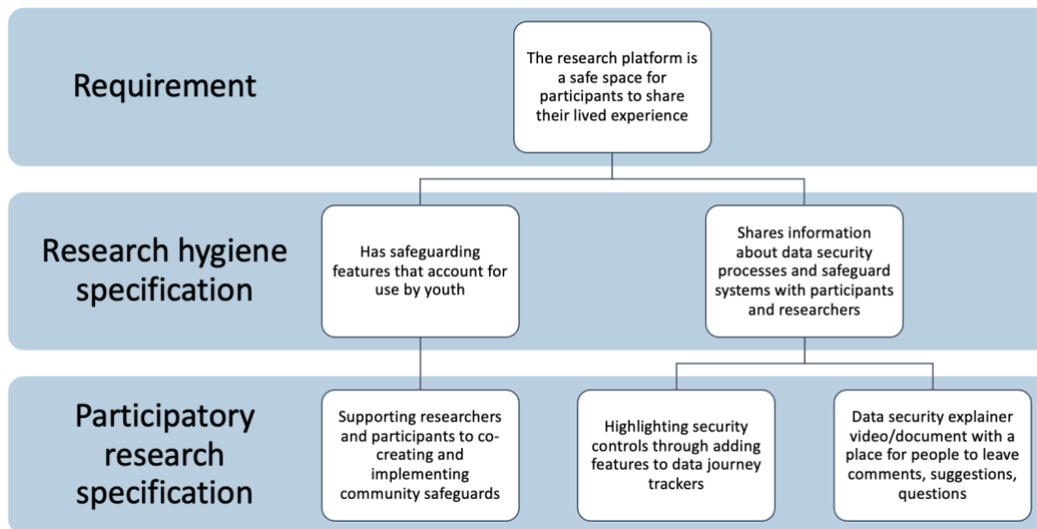
*Requirement:* Safe space for participants to share their lived experience

*Research hygiene specification:*

- The research platform is a safe space for participants to share their lived experience
  - Has safeguarding features that account for use by youth
  - Implements systems that allow for users to flag inappropriate content
  - Shares information about data security processes and safeguard systems with participants and researchers

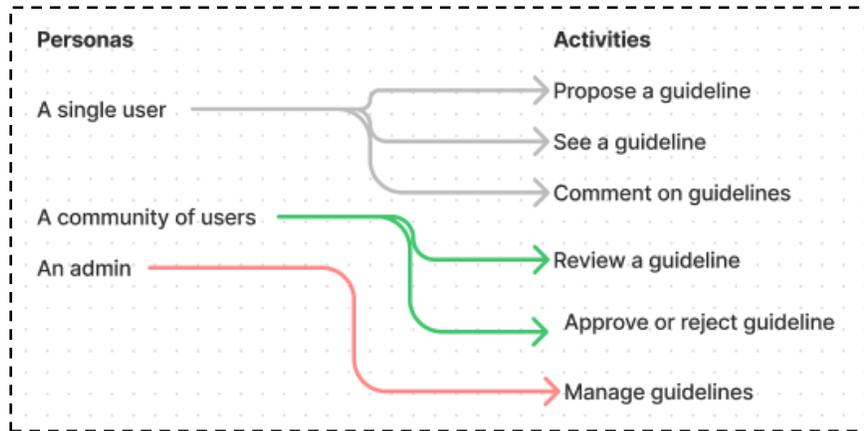
*Participatory research at scale specifications:*

- Encourages youth and researcher involvement in selection and tracking of privacy and security controls by:
  - Supporting researchers and participants to **co-creating and implementing community safeguards\***
  - Add features to data tracking systems highlighting security controls (**security tracker**)
  - **Data security explainer** video/document with a place for people to leave comments, suggestions, questions



*\*See additional detail on **co-creating and implementing community safeguards** specification on the next page.*

*Journey map for co-creating and implementing community safeguards* specification:



*Assessment of co-creating and implementing community safeguards* specification:

- How intriguing (interesting, creative, compelling)? Medium to highly intriguing
- How feasible (our rough guess on the feasibility of building and implementing this tool/intervention as compared with other tools/interventions)? Moderately feasible
- Is there similar work already out there? Probably similar work in commercial, non-profit, and smaller research settings. However, not with research and online and not at scale.

## PR specification 2: Pizza Tracker and Status Bar

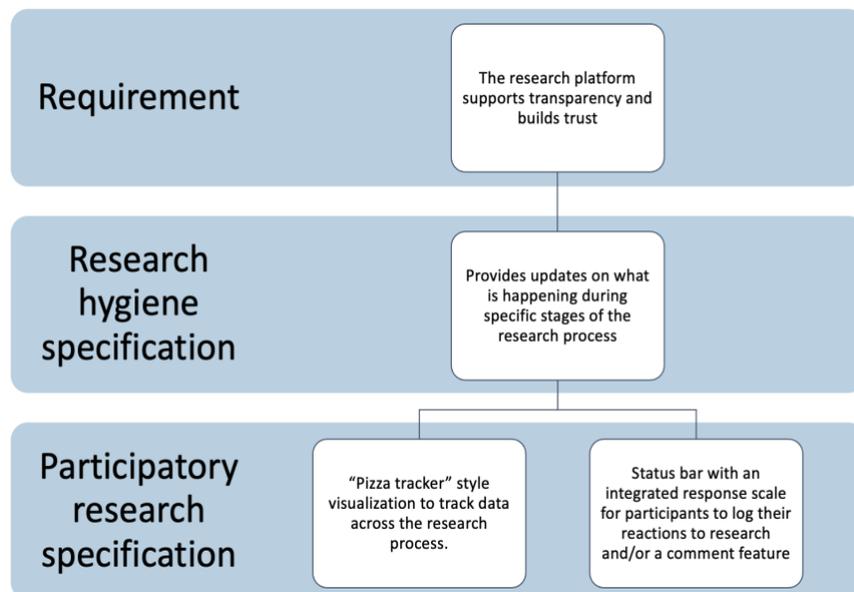
*Requirement:* Supports transparency and builds trust

*Research hygiene specification:*

- The research platform supports transparency and builds trust:
  - Providing informational updates on the entirety of the research lifecycle (from research exploration to secondary use of research) to promote clarity on what is happening during specific stages of the research process

*Participatory research at scale specifications:*

- A “**pizza tracker**” style visualization to track data across the research process. This could be distilled down in each phase of the research process (for example, a sneak peak of a report).
- A **status bar** for the study with an integrated Likert or similar response scale for participants to log their reactions to research and/or a comment box with threads



### PR specification 3: Expert Advice, Dedicated Area for Feedback, and Extensions: Public Draft of Analysis, Field Notes

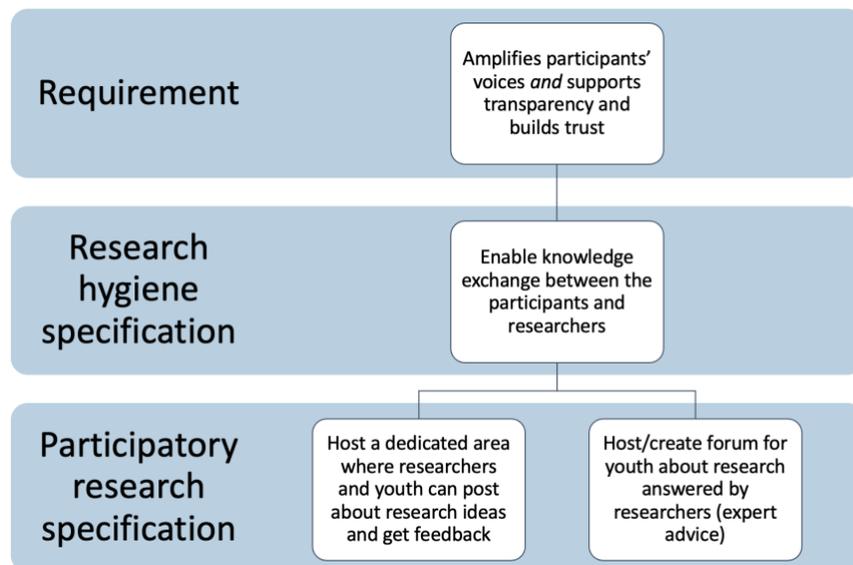
*Requirement:* Supports transparency and builds trust *and* amplifies participants' voices

*Research hygiene specification:*

- The research platform supports transparency and builds trust *and* amplifies participants' voices
  - Enables knowledge exchange between the participants and researchers

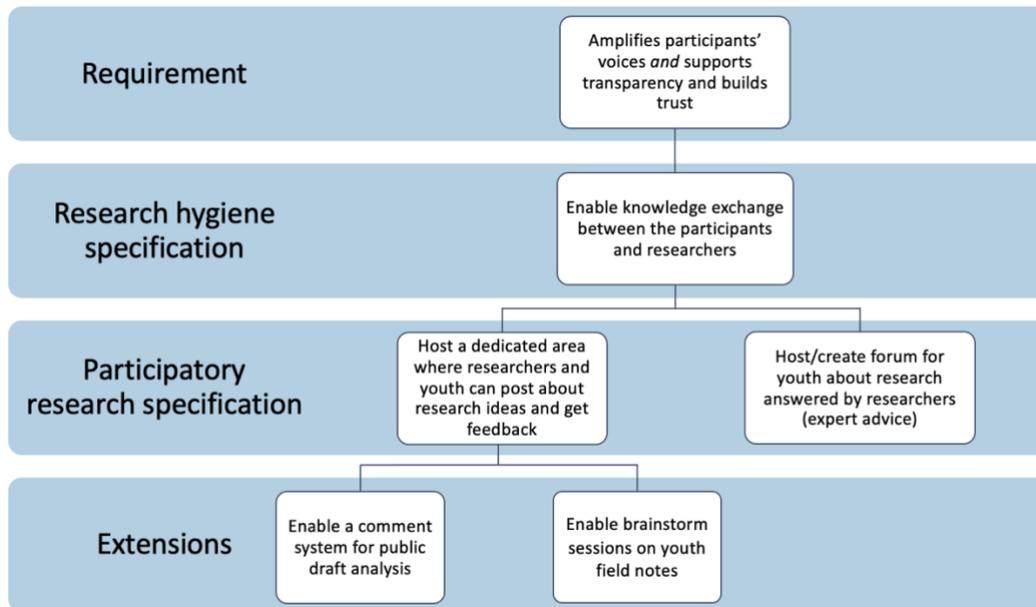
*Participatory research at scale specifications:*

- Host/create forum for youth about research answered by researchers (**expert advice**)
  - Consider opportunities for one-on-one chat feature alongside group chat/forum with attention to safety/privacy
- Host a **dedicated area for feedback\*** where researchers and youth can post about research ideas
  - Ability to flag (bad) or double heart (good) (or similar using a specified set of emojis to allow for greater nuance) research ideas that they think are particularly relevant to youth
  - Enable up voting/down voting ideas or ranking research ideas
  - Ensure system actively prompts youth and researchers for their feedback
  - Enable discussion through comments/threads on the research ideas



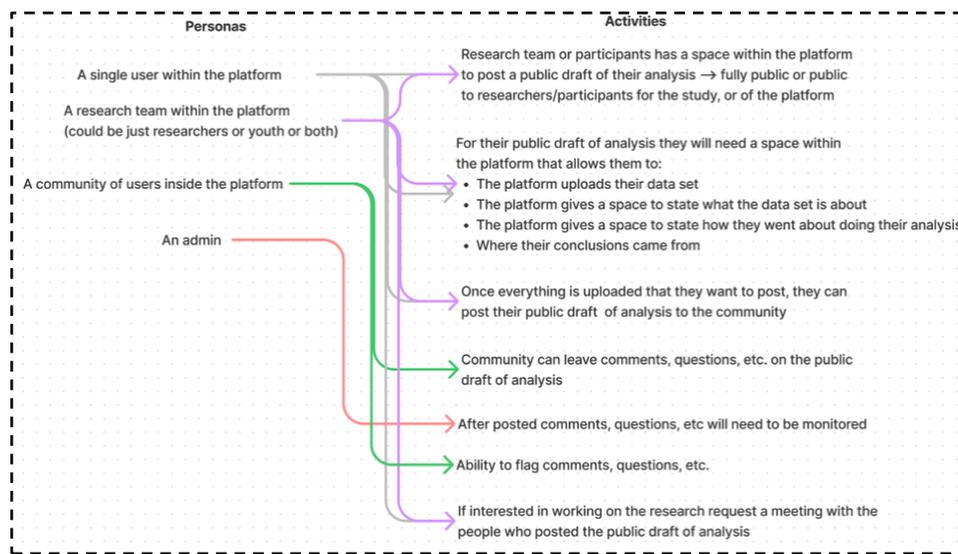
*\*See additional detail on two extensions of the dedicated area for feedback specification: the **public draft of analysis** specification and the **field notes** specification on the next two pages.*

### Extensions: Public Draft of Analysis and Field Notes



**Public draft of analysis** specification: Enable researchers (and youth researchers) posting a public draft of their analysis where stakeholder can leave comments/feedback about the analysis. Stakeholders may include: participants from the specific substudy being described, the databank community (youth participants and/or other researchers), or it is fully public. Introduces a foothold for participants in the analysis/reporting process.

*Journey map* for the **public draft of analysis** specification:

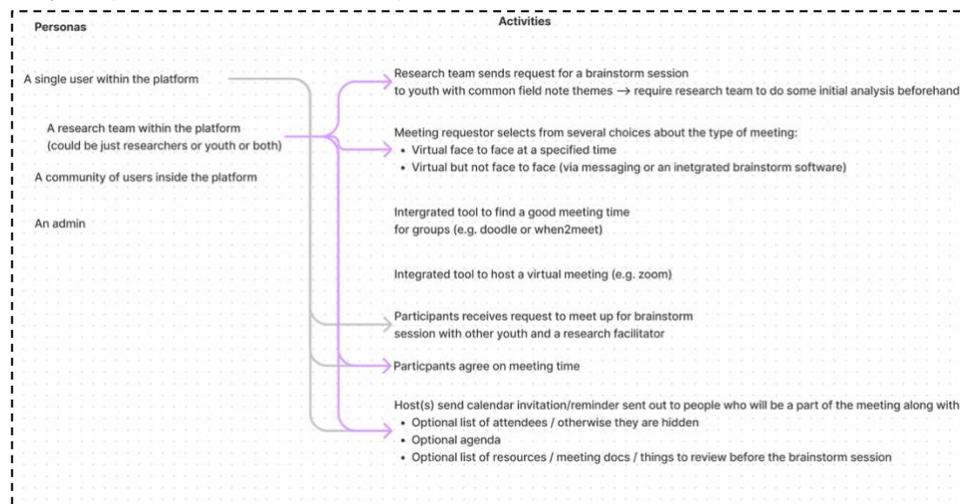


**Assessment of public draft of analysis specification:**

- How intriguing (interesting, creative, compelling)? Highly intriguing
- How feasible (our rough guess on the feasibility of building and implementing this tool/intervention as compared with other tools/interventions)? Moderately feasible to more challenging (less feasible)
- Is there similar work already out there? <https://www.biorxiv.org/> → Pre-print service (pre-publication), read, and comment. Have not seen examples of participant/broader community engaged versions of this service, though.

**Field Notes** specification: enable researchers bringing together youth participants who have similar themes within their fieldnotes, so that youth participants have the chance to discuss their field notes and experiences with one another and researchers who are a part of that specific research project.

**Journey map for the field notes specification:**



**Assessment of field notes specification:**

- How intriguing (interesting, creative, compelling)? Highly intriguing
- How feasible (our rough guess on the feasibility of building and implementing this tool/intervention as compared with other tools/interventions)? More challenging (less feasible)
- Is there similar work already out there? Nothing known at scale

## PR specification 4: Co-Creating Definitions and Co-Creating Definition Videos Extension

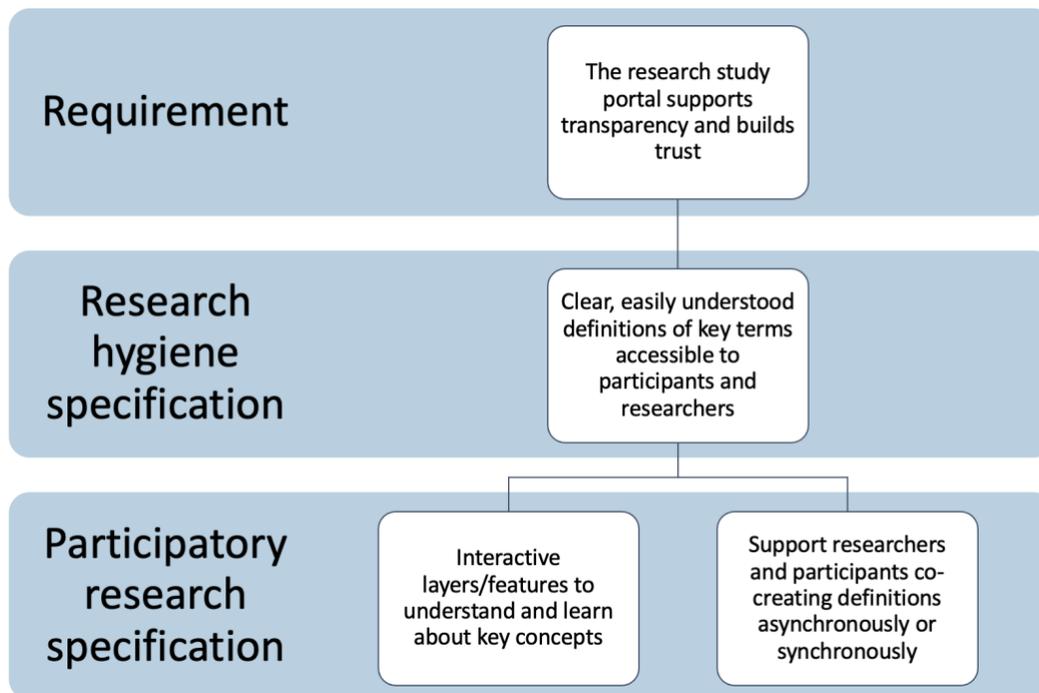
*Requirement:* Supports transparency and builds trust

*Research hygiene specification:*

- The research study portal supports transparency and builds trust by
  - Recognizing different parts of the world may have different definitions or understanding of key concepts associated with research (e.g., *mental health*)
  - Providing clear, easily understood definitions of key terms associated with the research in a place accessible to participants and researchers

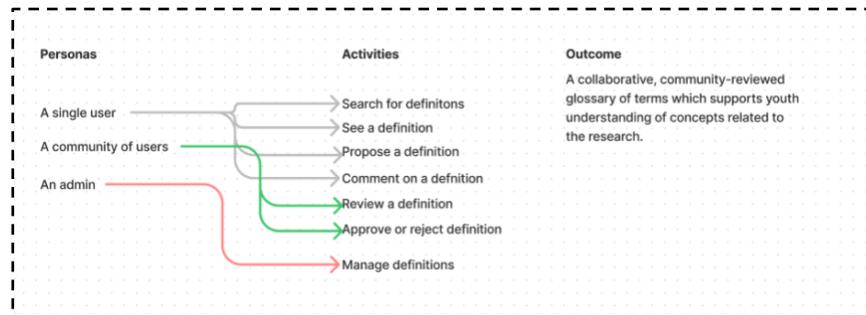
*Participatory research at scale specifications:*

- Support interactive layers/features to understand and learn about key concepts, such as a system for youth to share short videos explaining terms in their own words
- Support researchers and participants **co-creating definitions\*** for terms through iterative interaction (e.g., asynchronously through comments or a “suggesting” feature; synchronously through a live chat or hosted discussion)



*\*See additional detail on **co-creating definitions** specification and its extension, **co-creating definition videos**, on the next two pages.*

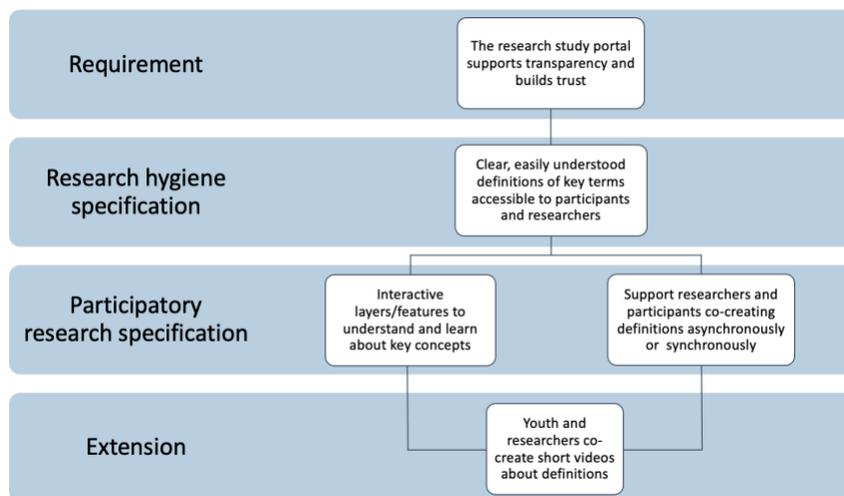
*Journey map for co-creating definitions specification:*



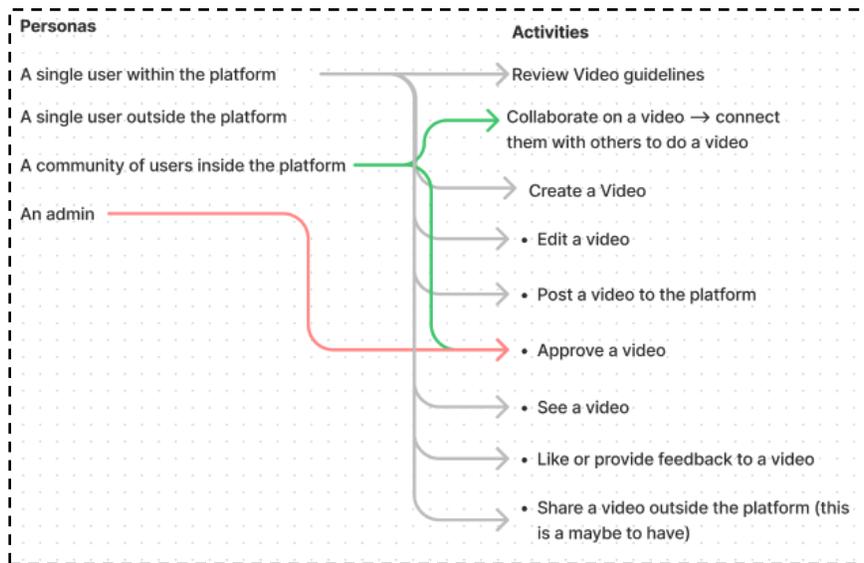
*Assessment of co-creating definitions specification:*

- How intriguing (interesting, creative, compelling)? Moderately intriguing
- How feasible (our rough guess on the feasibility of building and implementing this tool/intervention as compared with other tools/interventions)? More feasible
- Is there similar work already out there? Yes, we believe there is similar glossary work done both in “small research” settings and in non-research, collaborative online spaces (e.g., Wikimedia), but not in research at scale like this.

*Extension:* Build tools/features into the research platform that support youth and researchers **co-creating definition videos** about the different glossary definitions



*Journey map for co-creating definition videos specification:*



*Assessment of co-creating definition videos specification:*

- How intriguing (interesting, creative, compelling)? Highly intriguing
- How feasible (our rough guess on the feasibility of building and implementing this tool/intervention as compared with other tools/interventions)? Moderately feasible
- Is there similar work already out there? Unsure

## PR specification 5: My First Research Profile

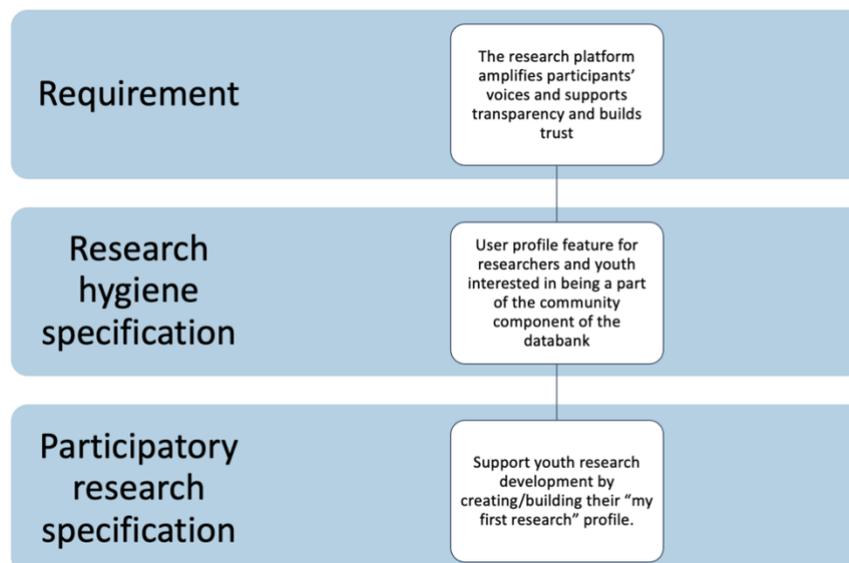
*Requirement:* Amplifies participants' voices *and* supports transparency and builds trust

### *Research hygiene specifications:*

- The research platform amplifies participants' voices and supports transparency and builds trust
  - User profile feature for researchers and youth interested in being a part of the community component of the databank

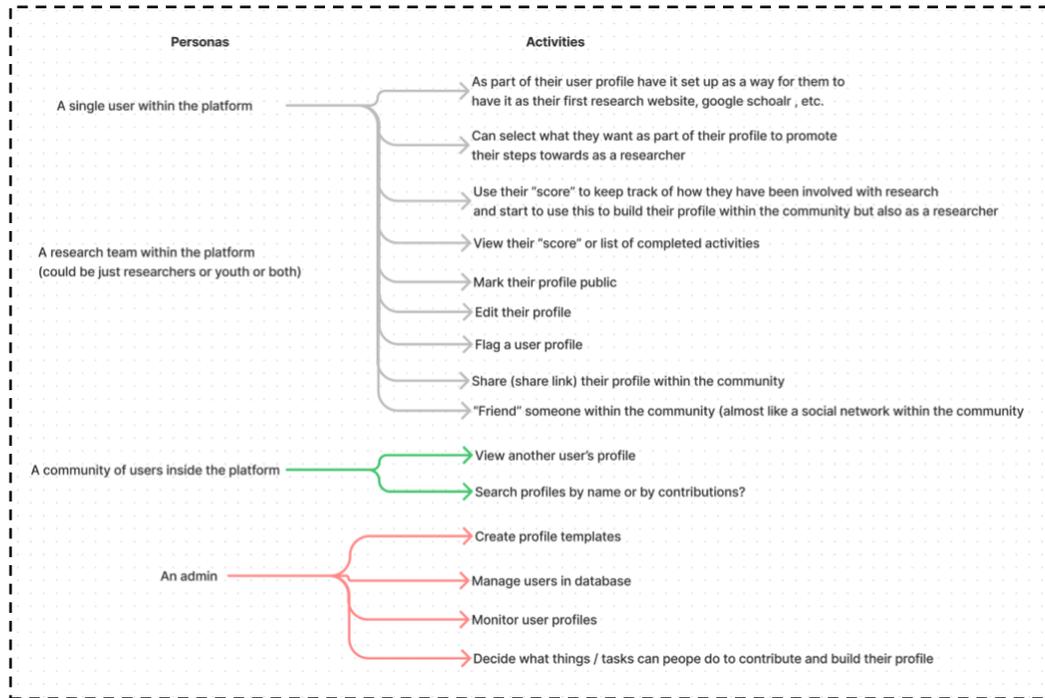
### *Participatory research at scale specification:*

- Build tools/features to support youth research development by creating/building their "my first researcher" profile. The "**my first research profile**" will serve as a rough documentation of the value of youth participant's contributions to the databank. The profile will support youth leveraging their engagement in the databank to demonstrate ways they have been involved with community organizations, to document volunteer hours, for use in university admissions and scholarships, etc.
  - Potential activities youth researchers can do to build their profile:
    - Be interviewed as participants
    - Commenting on research
    - Co-analysis with dummy data
    - Attend workshop
    - Research support/tasks
    - Gain/demonstrate a relevant skill



*Continues next page*

**Journey map for my first research profile specification:**



**Assessment of my first research profile specification:**

- How intriguing (interesting, creative, compelling)? Highly intriguing
- How feasible (our rough guess on the feasibility of building and implementing this tool/intervention as compared with other tools/interventions)? Moderately feasible
- Is there similar work already out there? Technology examples to potentially reference (Google Scholar or ORCID) as well as smaller scale research projects that may do something similar but are focused on mental health design work.

## PR specification 6: Request a Brainstorm

*N.B.: This specification includes a persona not included in other specifications: community organizations.*

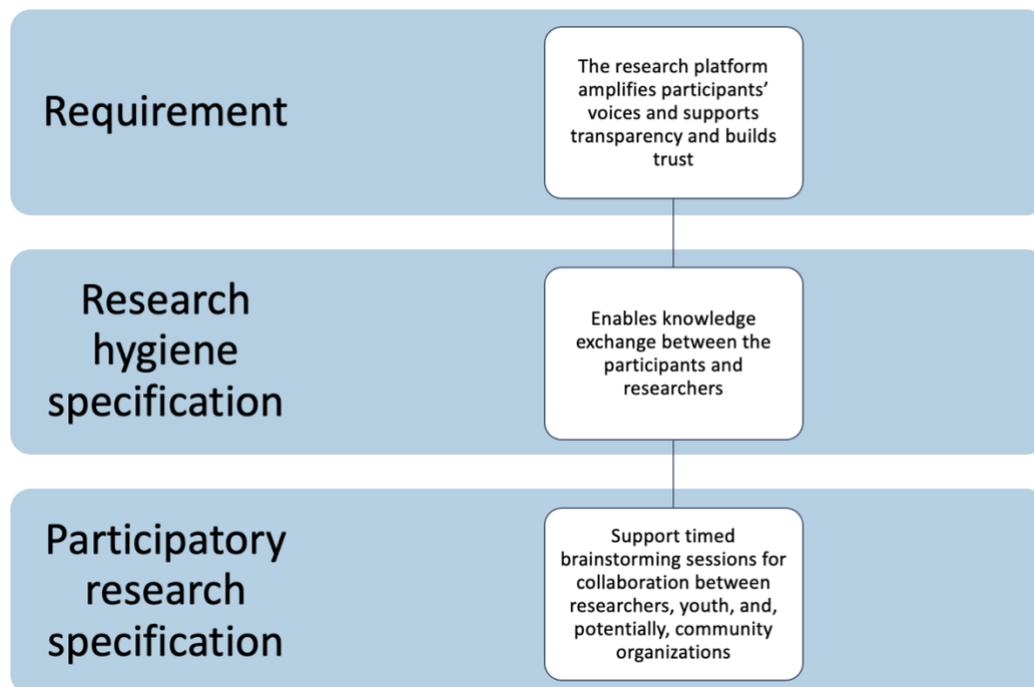
*Requirement: Amplifies participants' voices and supports transparency and builds trust*

*Research hygiene specifications:*

- The research platform amplifies participants' voices and supports transparency and builds trust
  - Enables knowledge exchange between the participants and researchers

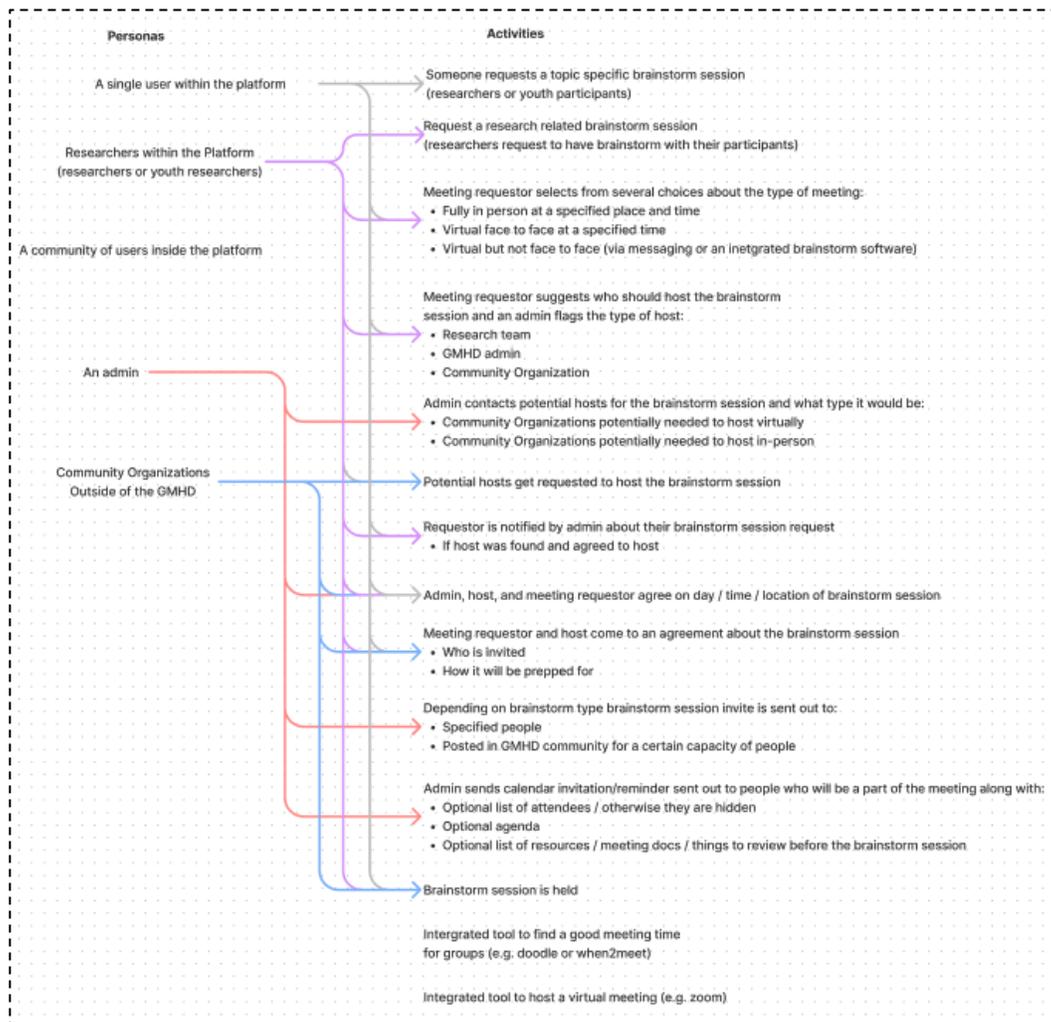
*Participatory research at scale specification:*

- Build tools/features to support collaboration between researchers and youth participants through timed brainstorming sessions (**request a brainstorm**). A collaborative way for youth participants, researchers, and potentially community organizations to come together and engage throughout several parts of the research process (e.g., during ideation or analysis) as partners



*Continues next page*

## Journey map for request a brainstorm session specification:



## Assessment of request a brainstorm specification:

- How intriguing (interesting, creative, compelling)? Highly intriguing
- How feasible (our rough guess on the feasibility of building and implementing this tool/intervention as compared with other tools/interventions)? Feasibility is more challenging / difficult
- Is there similar work already out there? Similar work (brainstorm sessions) in smaller scale research settings and industry organizations

# Phase 3

We re-engaged our youth and researcher panels in Phase 3, gathering feedback, suggestions for refinement, and assessing face validity of the menu of tools/features we developed from their input that could connect youth and researchers in global mental health databank across the research lifecycle.

## 3a. Activities

We engaged two of the in-country youth panels and two cohorts of researchers for feedback sessions. We structured these feedback sessions to be discussion based, so that we could focus on the panel members' initial reactions to some of the tools that came out of Phase 2. The sessions started with a refresher on the Bridging the Gap project as a whole, including reviewing the different project phases and their outcomes, followed by a targeted discussion of four participatory research at scale specifications:

- [Co-Creating Definitions and Co-Creating Definition Videos Extension](#)
- [Co-Creating and Implementing Community Safeguards, Security Tracking, and Data Security Explainer](#)
- [My First Research Profile](#)
- [Public Draft of Analysis Extension](#)

We hosted the international youth panel for a similarly structured feedback session, sharing four additional examples of participatory research at scale tool/feature specifications given the overlap in membership with the in-country youth panels. The tools/features discussed included [Request a Brainstorm](#) and [Field Notes](#).

*Phase 3 in-country youth panel slide deck*

- [Copy of YPAG India SlideDeck](#)

*Facilitator guide for in-country youth panel sessions*

- [YPAG Feedback Activity Instructions](#)

*Phase 3 DUG slide deck*

- [DUG SlideDeck](#)

*Facilitator guide for researcher panel sessions:*

- [DUG ZoomRoomActivities](#)

*Participatory Research at Scale example specifications for use in in-country youth panel and researcher panel sessions*

- [PRatScaleSamples\\_YPAGs.pdf](#)

*Phase 3 international youth panel slide deck*

- [IYP Phase3 SlideDeck](#)

*Facilitator guide for 3 international youth panel session*

- [IYP Feedback Activity Instructions](#)

*Participatory Research at Scale example specifications for use in international youth panel session*

- [IYP PRatScaleSamples.pdf](#)

## 3b. Findings

We documented feedback and suggestions for refinement for the participatory research at scale tool/feature specifications. We assess face validity through review of the panel discussions for indications that the specifications address the design values and requirements of our respective informant groups and for agreement that a given specification could connect youth and researchers in global mental health databank across the research lifecycle.

### Youth findings

Youth were largely enthusiastic about the tools/features presented, with a few expressing skepticism. Enthusiasm centered on excitement to learn, build capacity, and be co-engaged. Areas for skepticism included if the tools/features were truly feasible and if youth and/or researchers would truly engage. Much of the discussion time was spent expanding and refining tools and features. Based on the response from youth, the tools/features presented appear to have face validity.

#### Phase 3 YPAG quotes/analysis document

- [BTG\\_Phase3\\_YPAGQuotes \(1\).pdf](#)

#### Enthusiasm

*"I feel like the idea of the [definitions] tool would be really helpful and would most definitely help understand a lot of the research jargon!"*

*"It could even be used almost as an online summer school to help young people get into research"*

*"...So it's basic like model... it is to make research as I can see it, like research a firsthand thing to, you know, youth participants or something like that. So, and research as a feasible thing to understand for a youth participant. So I think it's really intriguing and it would lead a youth participant to understand more and more things related to research. And at the same time, maybe it will boost up his confidence in the field of research or something like that. So I think in terms of that, it's quite impressive."*

*"...[the field note tools/features] seems to be very much interesting in terms of like, you know, ...helping in the observation from the both side of the researcher and the youth participant, but I think this, this will also [prove] a means to crosscheck the observation from the researcher side and then the, or from the side of youth as well... how the researcher has understood the things about the youth participant and then how the participant itself sees those things. So I think that combo will be quite very much interesting."*

*"I think [the field note tools/features] is umm really great for sort of capacity building with regards to qualitative research, which is, I mean, I guess an obvious thing to note, but like this, this whole thing of exchanging field notes is something that's very interesting to me because I mean, like I have taken few notes, I have done a little bit of qualitative research,*

*but exchanging field notes with the lead researcher, with fellow participants. Hasn't been something that I have come across and I'm very excited about that."*

*"I, I really don't see a lot on research and I think that a lot of what I see online on mental health is very, is very singularly produced in that it's not, it's very rarely community produced. So if, if this is a very research based and collaborative way to produce it, it's not, it's almost like a peer reviewed ...but [in a] non-academic ...which I really liked because [real people are] not an academic, ...not in an elite space ...but at the same time you have kind of the good principles that you would find in academic spaces and, you know, generally in colleges, stuff that you're taught. So I liked the, this kind of has the best of both worlds for me. So yeah, I'm for, for me, like, I, the more I think about it, like the more I see that this is quite a cool, cool concept, actually, because initially, initially I was like, why doesn't this already exist? Like, I see so much stuff online, but this, this sounds quite different actually from, from all of the stuff that exists online."*

*"...when it comes to upvoting and downvoting and comments and whatnot [the feedback tool/feature specifications], like a sort of social media... that's a way better idea. And the whole upvote/ downvote [and] possible comment thing is definitely well valuable, quite creative, actually and very unique."*

*"I think obviously synchronous [tools/features] are more effective because you have a discussion with people at the same time and it, and it flows and it carries on and you go over certain points, but maybe engagement is an issue with those sorts of tools and features. So if you have asynchronous and synchronous features in the same place, maybe that increases engagement on that front."*

*"[thinking about the video definitions specification] I learn a lot of things on [YouTube] watching short concise videos on particular topics which just has someone talking with related footage/animation"*

#### Skepticism

*"...one drawback, I mean, I think you would require a lot of human capital because [the comment tool] ...would require someone to be vetting all of this information very thoroughly and some reminders... [and] at least like post-op kind of checking to see that all the information is right and stuff like that. And... since we are talking about mental health, a lot of this stuff will be required to be dealt with very sensitively and because this is global also, then you will run into all of the issues about having to be culturally sensitive. So I can, I mean, you know, immediately, like I can, I can see that you will have to, a lot of training is involved in that doesn't come very easily or quickly."*

*"I would avoid the [my first researcher profile] scoring system as I think it adds too much bias to participating and also may not convert into real life capital so easily."*

*“Honestly, I think most people wouldn’t take the time to read it and engage in such guidelines unless it was absolutely compulsory.”*

*“...there are already tools to do all of those things. And I think when it comes to sort of changing habits, it gets a bit hard to do, especially if you already used zoom or if you used to like an LMS forum or something like that, then getting a feature into the databank that sort of is a forum or is a, you know, video call sort of seems a bit redundant to me.”*

Suggestions for additional refinement of tool/feature specifications:

*“...[the user should] have all the tools in one sort of space, like all the tools that they already use.”*

*“...Synchronous [tools/features] limits you to only people who can be there at that time and can miss out on a whole lot of feedback”*

*“I think it is important but I wonder how co-constructed it can be in the wake of admin work...would it be continually negotiated, I wonder?...I imagine there would be moderators as middle-men”*

*“I like this idea too, but I guess if feedback was given, what scope would there be for that feedback to be taken on board [by researchers]?”*

*“People on Instagram often post those info compilations on important topics, they can be really useful for easy info retention...almost like mini presentations [to enhance definitions tools/features specifications]”*

*“I was thinking regarding the mental health glossary, and even though I really like that idea of categorizing from A to Z...Perhaps we could even make a categorize it, like some commonly used terms and some complex terms and under the complex category, we can have more of the clinical jargon. So, you're able to create that as a sort of differentiation for the participants.”*

*“...could be like some kind of questionnaire that someone fills in when they join in ... that can be used to allocate projects and it's less so about the [my first research profile specification], but more so about refining skills and kind of getting what you want from it as well as it's kind of mutually beneficial in that sense.”*

*““I imagine the interface having different tabs such as workshops, calls for participants, calls for feedback, etc. You navigate the interface using your profile, which is also visible. From your profile, you have your curated research interests, previous volunteer work, previous projects, etc. Each contribution made through the website will need to be validated by a moderator before it is added to your profile. Maybe contributions can be confirmed by the research lead?”*

*“The other idea is to, and I don't know how much of this is actually glossary related, but I think it would be interesting to have certain misconceptions addressed. For example, if there are, there are, there are some very obvious lines we've heard about mental health, which we might have the opportunity to actually break down and talk about. So maybe the segment could be called just a thought it would be called, “But What About?”, and we have actually, you know, lines that we've heard from people around us and maybe then there is a carousel explaining or breaking down that concept for them.”*

*Back and forth on the topic of definition tools/features*

*Participant 1: “I agree, well produced animated videos would be ideal as it's less distracting? focus on the info not the ppl...allows you to frame the information better in the video without worrying about people in it too...infographics”*

*Participant 2: “I would envision it with a button labeled definitions/help sheet which would bring up a new tab with all of the definitions. Ideally, it would be something that doesn't always need to open/close to access the other parts of the website for ease of access when reading/ doing tasks etc.”*

*Participant 3: “...building off of what you said X, if jargoned words could be linked the glossary so that clicking it opens to that in another tab or a hover over explanation”*

*Participant 5: “How I envision it: After clicking the glossary link, you are taken to a page with a search engine (it is blank until you type one letter, but you can also click 'see all'), and you can either click on the existing definitions and add to them, or there is an option to 'add new term'. You are then taken to a page that is similar to those 'get revising' or 'my tutor lesson spaces', which is essentially an artillery of different tools for creating infographics/presentations/mindmaps/video recording tools. From there, you can add to the database.”*

## Researcher findings

Researchers were also enthusiastic about the tools and features presented. Skeptical responses focused on the ethical/oversight barriers to implementation, researcher capacity to authentically engage, and concerns about the mechanisms for using youth input. Based on the response from researchers, the tools/features presented appear to have face validity.

*Phase 3 researcher quotes/analysis document*

- [BTG\\_Phase3\\_DUGQuotes.pdf](#)

*Enthusiasm*

*“the co-creation [tools/features] would be essential...”*

*“I really liked the [tools/features supporting] a network, particularly internationally.”*

*“...I'm very, very keen that [the tools/features are] not just about smart technology things about using the Android or the smartphone to get this data in from all those distant places too. But it's, it's also about how we build networks of assistance.”*

*“...I do think [these tools/features] are ways we could acknowledge that [youth] might have just a distinct expertise, meaning that maybe their contribution to that could be something like accounting for the lived experience around a glossary term, for instance. So maybe they submit things like videos or provide some more narrative account of what it's like to live with that experience [using these tools/features]. And I know that would also need to have some sort of supervision and structure for contributions...but I think the narratives could be an interesting addition in a way that we could acknowledge the expertise they might have in sort of defining the lived experience around those glossary terms.”*

*“And I guess one way to [implement these tools/features] ...is really based on like patient reported outcomes. And, and sometimes when you're doing, you know, a big data...data studies, sometimes we just think of the same old outcomes, not necessarily the ones that people are interested in. And if you did it on something like that, where, where people are feeding in on what the outcomes might be, or when they get measured, then, then the research is also getting something out of that process and they would enter into a dialogue about it and it would actually influence what the research is. So it becomes much more focused.”*

*“So one more quick, I guess opportunity [when considering of youth and researcher profile specifications] ...there are definitely examples out there ... where people participate in things that they have to register for, but not as themselves as that they registered themselves, but they can present an avatar that represents the true feelings or the true person. And, you know, the flip side of this is where we to enable something like that, as long as there is accountability in the background for who that individual really is, it might make some people who were able to put on a different face, more willing to share what it is about them that belongs in this kind of a project.”*

### Skepticism

*“Okay, I'm going to be a slightly, a bit more negative about this [pre-print comment forum specification] and the only reason is, is I just think the burden on researchers even before they get started... the idea of having another thing. So as well as officially publishing your analysis there's another thing as much as I liked the idea of it. I think if you do it and you need to find a way that it doesn't become just another burden on the ever-growing checklist that people need to do to do research.”*

*“...when you're doing that sort of this participatory, co-design stuff, but then when you come across things [through interaction with you] like, you know, [indicators of potential self-harm]... those things become really difficult and you can, you could end up making young people feel like, well, you're just pretending really to co-produce this with me.”*

*“[Tools/features will need] concrete avenues that have been thought through around how these [youth input streams] are going to be fed back into policy or service delivery or understanding or whatever, it’s all very well to say, come and analyze those with us.”*

Suggestions for additional refinement of tool/feature specifications:

*“...are these videos going to be made open access through some other platform that doesn’t necessarily require people to use their own data?”*

*“I think it’s, it’s really important [to]... put [key research terms] in a format or, or terminology that can be easily understood, and... you know, there is no one such thing as the lay public and people will read what we provide or view what we provide through their own lens.”*

*“... there are probably some best practices from the open publishing world that we could extract to be incorporated into something like [the pre-print comment forum specification]...”*

# Learnings

These learnings are meta-findings from the Bridging the Gap project as a whole.

1. Reuse of the existing MindKind project infrastructure (youth panels, research advisors) enabled this project's (low) budget and rapid pace
2. Our participatory approach yielded rich detail that allowed for the development of more than a dozen participatory research at scale tool/feature specifications
3. Our participatory approach amplified the voices and values of youth to be co-equal with researchers
4. Throughout the Bridging the Gap project itself we were able to do a significant amount of capacity building with youth that they responded to with enthusiasm
5. Research initiatives may not necessarily be able to jump from non-participatory research at scale directly to participatory research at scale—research platform hygiene is a critical intermediary stepping stone that lays the groundwork for participatory engagement
6. To be truly participatory, research platforms must enable engagement in every stage in the research lifecycle, especially secondary data use
7. Open questions:
  - a. What are the micro-level incentives needed for youth and researchers to co-engage?
  - b. What is the technical effort needed to enable one or more of these tools/features?
  - c. What might the regulatory hurdles be to implementation of any of these tools/features?
  - d. Are these tools/features facilitators of youth agency?
  - e. Do these tools/features build trust such that science/scientific outcomes are more accepted by youth? Yield better health outcomes?
  - f. Do these tools/features make research more equitable? More reliable? More tailored, specific, and/or precise?

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