GRID TOOLKIT
ACKNOWLEDGMENTS

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INTRODUCTION

WHY DID WE MAKE THIS TOOLKIT?

There are many ways of working with communities. In this toolkit we borrow from design to offer equity-centered and creative approaches for authentic engagement in public health research. This can help uncover health priorities that really matter to everyday people and patients.

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When prioritizing health research topics that are important to patients and other stakeholders.
WHO IS THIS TOOLKIT FOR?

Health researchers
Patient partners
Community members
Stakeholders in improving health for all
Ask These Questions

Before Beginning to Work

Think about what you are working on, who you are working with, what this work is about.

*Designer Kelly Ann McKercher asks these questions:*

- Is the work you want to do needed and will it add value to people’s lives?
- What is the context and history of this health issue?
- Will the work increase or reduce people’s power and dignity?
- Who am I to the people I want to work with?
- Are there power differences and am I trustworthy to them?
- Am I the right person to lead this work together with them?
Positionality is a way of understanding and telling how your personal characteristics may be related to how you see the world and other people.

The Positionality Wheel may be a helpful tool in initial conversations with people you plan to work with in order to understand Equity.

*When we say equity here, we mean sharing power while working together for the benefit of all*
The Positionality Wheel

Who am I?

- Languages I speak & why
- Race & Ethnicity
- Age
- Gender & Sexuality
- Ability / Disability
- Marital Status
- Parental Status
- Where I grew up
- Class or status as a child
- Class or status today
- Level of education
- What do I do for a living?

Dr. Lesley-Ann Noel, 2019
Setting the stage for Equity

BUILDING RELATIONSHIPS

Building a relationship that is founded on trust will mean investing in time and energy to get to know your partners.

Start with communication guidelines and agreements for ways of working (what’s acceptable and unacceptable in speaking and interacting together, and what to do when harm is done).

Invite personal storytelling at the start to promote equity and cultural sharing.

Decision making must be shared from the start, including when and how meetings are held, how the project work is conducted, how data is analyzed, what dissemination will look like.
The way that we use language and words is very important for successful collaboration. Always use people first language (e.g. people with diabetes instead of diabetics). Use ordinary language not jargon. Even if you think people know terms, try to use plain language in your words and materials.

*For example*: instead of using the phrase ‘social determinants of health’ describe what you mean like “the conditions in the places where people live, learn, work, and play that impact their health and quality of life”.
Make sure to engage everyone during conversations.

Who isn’t speaking?
Seek out those who aren’t speaking as much for one on one conversations or meetings.

Is someone talking over other people or talking too much?
Make sure to create space for quiet people to share their perspectives.
Feedback is a gift, encourage partners to feel comfortable sharing critical views from the start.

Make sure that patient partners and community stakeholders know that everyone can be honest and it's ok to disagree.
What technology are people comfortable with? What do they have? Use a technology survey to start, for understanding the team’s access.

How is Accessibility addressed in your project?

Can you provide American Sign Language or other ways to help people who have differences in hearing, mobility, sight, or other abilities?

Can resources such as headphones, wifi, or credit for phone participation be provided?
Setting the stage for Equity

POSITIONALITY & POWER DYNAMICS

Understand positionality in the collaborative team and use the Positionality Wheel.

Pay attention to historically included identities and historically excluded identities as targeted by oppression, and how are those intersectional.

Who is holding positions of power or privilege? Help those with power understand how they appear to those without it. Make people more aware of that power imbalance so they are careful.

Gather feedback along the way from participants in multiple ways such as interviews, group discussion, emails or texts, and offer that participants do not have to complete any activities suggested—create space for participants to opt out.
If you are a person in a perceived position of power, or with a dominant identity, how are you making space for people with historically oppressed identities feel more comfortable throughout the process?

Shift power to participants and team members with less dominant-culture identities by ensuring their knowledge and expertise are recognized. Intentionally create moments where you just listen, reflect, and notice.
If you are a person who thinks you have less power, you may have more power than you think. Your power comes from:

a. your deep knowledge of the topic of interest,

b. your connection with people in the community,

c. the fact that the research can’t happen without you.

Let the research organizers know if you have any concerns about the research. Share your opinions. Make suggestions on how the process would feel better to you.
The following are some examples of great warm-ups
WARM-UPs FOR CREATIVITY

Warm-Up activities help to make participants more comfortable before the research activity begins. The aim is to help break down research hierarchies, create empathy and change the power dynamics between the researchers and research participants. You can draw inspiration for warm-ups from children’s games, party games, therapy exercises etc. As you select your warm-up, think about what the aim could be: to build community, to exercise creative muscles, to connect with each other. Budget about 15 minutes at the start of each meeting for relationship building.
Squiggle bird

Invite participants to create a doodle or squiggle on a piece of paper.

**Step 1:** Give them a few seconds to create the doodle.

**Step 2:** Challenge them to turn the doodle into a bird.

**Step 3:** They then share their birds with a partner or the group.
In this warm-up participants will brainstorm fun and crazy ways to use the object in a different way than it was originally intended, for example using a face mask as a sweatband or as a sleep mask for covering eyes.

This can be competitive where there is a prize for the person with the most or the wackiest ideas, and is a great way to get creativity flowing.

*In this project we used a face mask because it is related to the health topic of COVID-19, but you could use any culturally appropriate object related to the health theme, for example a blood pressure cuff (for work on hypertension) or a banana (for nutrition/diet themed work).
Empathy game
(on one hand this & on the other...)

In this warm-up, the first person will state a fact about themselves on one hand, and another fact on another,

*e.g. On one hand I’m a mother, and on the other hand I just went back to school.*

Other players have to connect to either the left or right hand by saying a matching fact

*e.g. “I’m also a parent!” The fact can even only be tangentially connected.*

Players form a circle as they all connect to each other with matching facts. The challenge is always how to close the circle! AND the circle always closes.

This is a great intro activity for conversations about empathy, relationships and equity. It demonstrates that there is always something in common, even when people think there is nothing.
VIRTUAL ETHNOGRAPHY
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Ethnography is a way to learn about people, culture or society. Sharing photographs is one way to do this at a distance and learn about people by communicating with pictures. Images can often convey experiences, desires, and needs in a more direct way than asking questions. Both researchers and patients/stakeholders should share photos related to the health issue at hand for this exercise. This activity puts everyone on an equal footing, and allows the group to learn together about one another.

NOTE:

This activity should be done only after building equitable partnership and rapport.
VIRTUAL ETHNOGRAPHY ACTIVITY
STEP 1

Choose a topic relevant to the health issue that your group is working on for participants to consider visually.
STEP 2

Ask participants to take photos using their phone *(or if needed provide disposable cameras).*
STEP 3

Have participants return the digital photos to you by text or email.
STEP 4

At a group meeting post these photos where all participants can look at them, without knowing who the owner of the photo is.

This could be on a PowerPoint, Google slide, an online white board, etc.
STEP 5

Have participants write down and share their observations of the photo.
Discuss and prioritize any patterns or 'themes' that you notice together.

*This can be done either on an online whiteboard, a collaborative Google doc/slide, or on a piece of paper/sticky note*
CULTURAL INQUIRY

Also known as Culture Sharing, this exercise uses creative exploration to uncover insights about health and individuals. Materials are offered to participants to complete and return to the research team. Designers often explore people's feelings and environment to understand how these drive behavior. Sharing information through worksheets (without having to say things out loud in person) can help people feel comfortable to express themselves freely and inform health priorities. Ideally researchers will share too.

NOTE:

This activity should be done only after building equitable partnership and rapport.
CULTURAL INQUIRY ACTIVITY
Identify the health issue that you are interested in working on and consider what the bigger picture is for community members, for example what factors are part of this health problem in social circles, environment, or behavior? The factors should be something that reflects the person’s culture, for example, the experiences and stories of family and friends.

*e.g. health issue: vaccine hesitancy*
STEP 2

Select tools and materials that would best capture what you are trying to study.

For example:
worksheets, journals, cameras, & maps.

Example Worksheet:
Design Libs (A COVID story)
A COVID Story

__________________________

name is a _______ year old __________________.

age job

The biggest issues they have faced related to the coronavirus have been

__________________________

and ________________________

__________________________.

Their family’s thoughts and feelings about the coronavirus are

__________________________

__________________________

__________________________.
and their friends thoughts and feelings about the coronavirus are

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________ .

They are uncertain about whether they want to get a COVID-19 vaccine because

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________ .
They have mostly gotten information about the coronavirus from

________________________________________

and ____________________________________

________________________________________.

Most likely they [ will or will not ] get the vaccine because

________________________________________

________________________________________

________________________________________

________________________________________.

5.7
STEP 3

Write the instructions on how and when to use each tool.

*e.g. please fill in the blank to complete the story*
STEP 4

Package your tools with instructions and distribute to participants, with a method for the completed tools to be returned to researchers. This can be in written form by mail or email, by text, taking photos, creating a map, or even recording and sending an audio file.
STEP 5

After the responses come back, compile and discuss the results with participants.
Optional:

Using the information and insights gained from cultural inquiry tools and discussion, invite participants to do low fidelity 3D prototyping or in other words to make models of their ideas with materials they have on hand e.g. colored paper, markers, aluminum foil, tape, etc. In making and working with their hands, participants will have another way of processing the topics that they are discussing.
FUTURE THINKING

This technique allows people to dream-build future health scenarios that can help understand patient’s emotions, desires, and needs, as well as understanding how the world around them impacts those. This is also known as Rapid Critical Utopian Action Research. Using the future as a reference point can allow health researchers and community members to start from a common place of understanding about how things ‘could be’, and how to get there by working together.

NOTE:

This activity should be done only after building equitable partnership and rapport.
FUTURE THINKING ACTIVITY
Consider in depth the health situation that the patient is experiencing.

*e.g. vulnerability to the COVID19 pandemic*
STEP 2

Choose a time point in the future to imagine a utopian or ‘ideal’ health situation, even if it isn’t yet possible from biomedical science or reality. The health issue of interest is resolved or cured in the future.

e.g. Wakanda 2030 and the SARS-CO-V-2 virus has been eradicated (use culturally relevant examples appropriate to the group you are working with)
STEP 3

Describe in detail the utopian health future:

a. What does the physical world look like, what is the social situation, what do health services, community and government look like?

   Break into pairs or small groups and share these ideas on a whiteboard.

b. Write a news headline from the utopian future, describing what it is like.

   e.g. ‘Wakandan adults have longest life expectancy in the Universe at 132 years!’

   Share these headlines on a whiteboard.
Use different strategies to consider how this knowledge of the utopian future can inform steps needed to change the current situation.

a. If you could go back in time to 2019, just before the pandemic, what would you tell people to change to make sure that it doesn’t happen?

   Patients share these ideas on a whiteboard.

b. Thinking about the situation in the present and the possible utopian future, describe 3 wishes using the Three Wishes Worksheet

   Record these wishes using audio to text* or share on a whiteboard.

   *information that feels private may be more easily shared directly on a worksheet or through messages, rather than shared in a large group whiteboard.
Three Wishes Worksheet

Wish 1. ____________________________________________

____________________________________________________

____________________________________________________

Wish 2. ____________________________________________

____________________________________________________

____________________________________________________

Wish 3. ____________________________________________

____________________________________________________

____________________________________________________
At the end of your project, don’t forget to build in an activities to share the results of the work with participants.

This could be a final meeting with a powerpoint presentation, or an exhibition or even a party.

Who do the partners think the work should be shared with?

Build in a celebratory moment.

Build in a point of reflection on the next steps for both the researchers and the participants.

Create an action plan. Can you co-create the next steps?

Hi-5s all around for getting the work done together!
RESOURCES FOR FURTHER EXPLORATION

Designer’s Critical Alphabet
by Lesley-Ann Noel

Model of Care for Co-Design
by Kelly Ann McKercher

Liberatory Design
by Tania Anaissie, Victor Cary, David Clifford, Tom Malarkey, and Susie Wise

Denizen Designer Zine:
https://ehilab.cdm.depaul.edu/ddzine/

The Power Manual:
How to Master Complex Power Dynamics
by Cyndi Suarez

Health Design Thinking
by Bon Ku and Ellen Lupton

The Relationship is the Project
edited by Jade Lillie