

# Sustaining Community Engagement

*Transcending the community-academic divide & nurturing relationships*

**UW Medicine**  
SCHOOL OF MEDICINE



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University of Washington / Seattle Children's  
Korean Community Service Center of Seattle

July 17, 2024

# Disclosures

- Co-Investigator of the SeqFirst Study
- Associate Editor, *Human Genetics and Genomics Advances*
- **Current consultant for Sage Bionetworks; past scientific advisor**
- Past consultant for Variant Bio
- Previously funded at UW by NIH and GeneDx
- **Currently funded at KCSC from City of Seattle; King County; Snohomish County; WA Depts of Commerce, Labor and Industry; Inatai Foundation; Community Foundation of Snohomish County; The Asian American Fund (TAAF)**
- Board Chair, Asian Pacific Partners for Empowerment, Advocacy, and Leadership (APPEAL)

# Outline

- Reflections on “sustaining community engagement”
- CHIRON: Community Health Interests for Researchers & Oversight Networks
- My experience as an organizer-researcher at UW and KCSC
- Considerations for sustaining community engagement in genomics, precision medicine and precision health



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SPECIAL THEME ARTICLE

## Confronting “Culture” in Medicine’s “Culture of No Culture”

*Janelle S. Taylor, PhD*

ABSTRACT
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“Physicians’ medical knowledge is no less cultural for being real, just as patients’ lived experiences and perspectives are no less real for being cultural.”

“it is no longer possible to imagine [medical competence] as not also being ”cultural.”

# Dictionary

Definitions from [Oxford Languages](#) · [Learn more](#)



## sus·tain

/sə'stān/

*verb*

1. strengthen or support physically or mentally.  
"this thought had sustained him throughout the years"

Similar:

comfort

help

assist

encourage

succor

support



2. undergo or suffer (something unpleasant, especially an injury).  
"he died after sustaining severe head injuries"

Similar:

undergo

experience

go through

suffer

endure

Strengthening

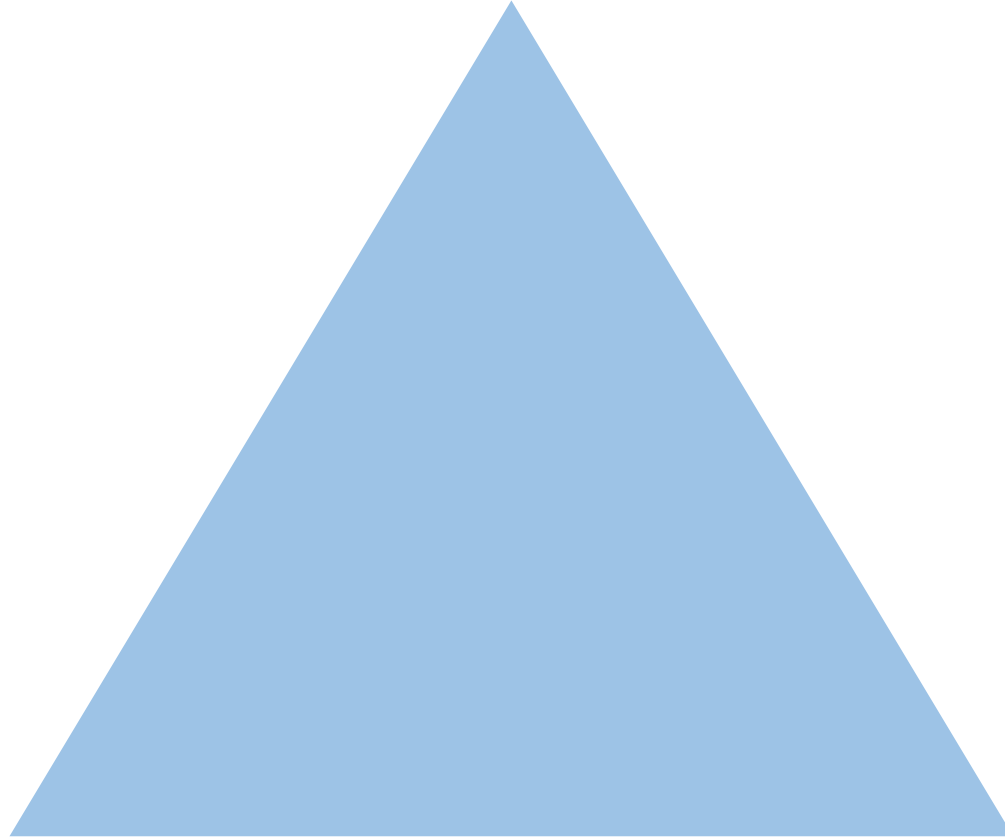
Maintaining or keeping up

Suffering

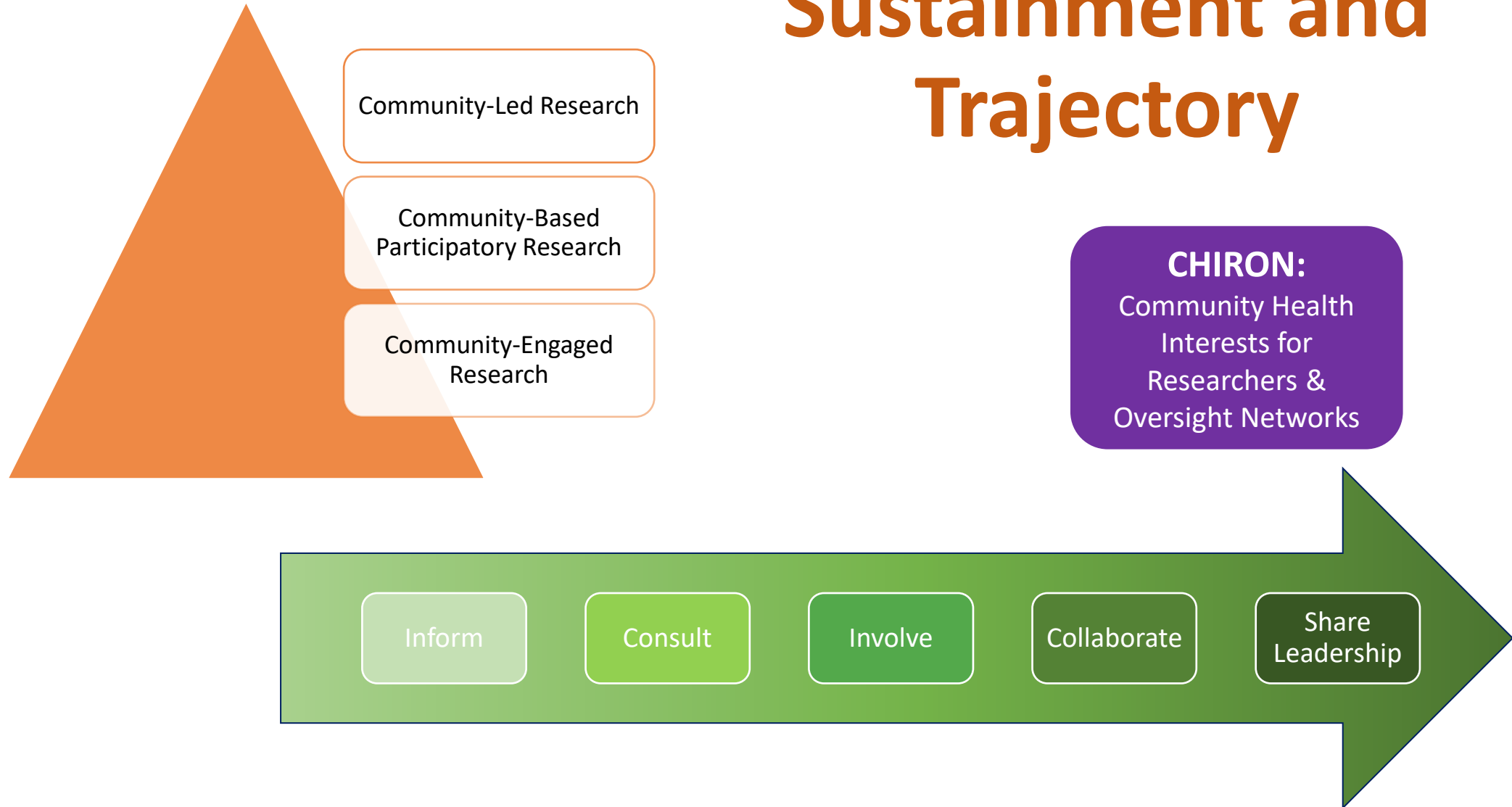
Product

People

Process



# Sustainment and Trajectory





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# Rationale

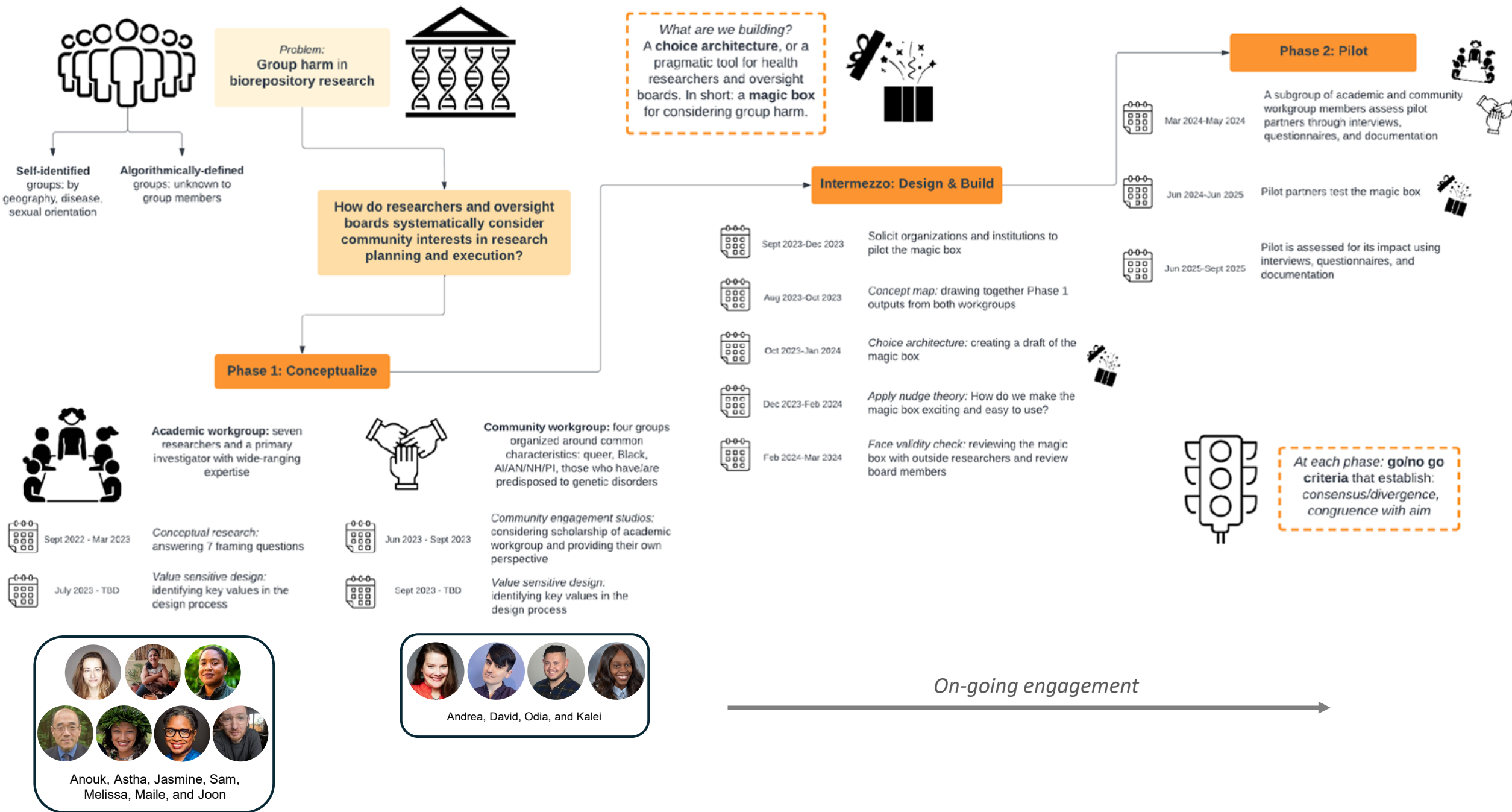
- Data reuse is good
- Research is better when communities are involved
- When aggregated for reuse, data are further separated from the communities from which they are derived
- We need tools to support bringing community context back into biorepository-driven research



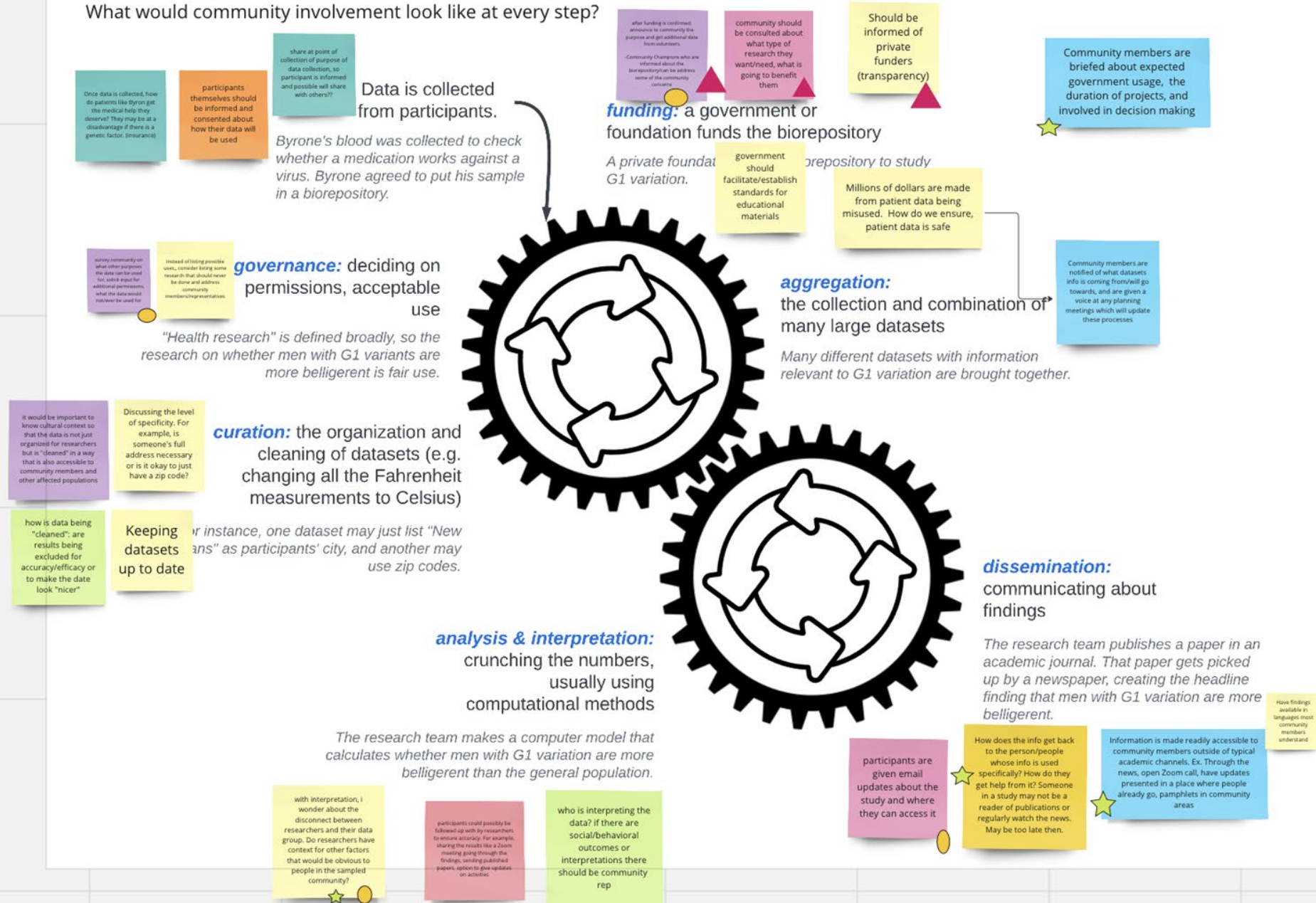
Photo by Kaja Reichardt on Unsplash

# Goal

Develop and pilot a toolkit that helps researchers, ethics boards, and data access committees reconnect with community context as they conduct and oversee big health data research



What would community involvement look like at every step?





We are seeking additional pilot partners - researchers, IRB, and/or data access committee members

#### Resources:

1. Doerr M, Yu JH. Translational Research and Communities. *Ethics Hum Res.* 2023 Sep-Oct;45(5):34-38
2. CHIRON bi-weekly blog series which began April 4<sup>th</sup>
3. Contact: [megan.doerr@sagebionetworks.org](mailto:megan.doerr@sagebionetworks.org)

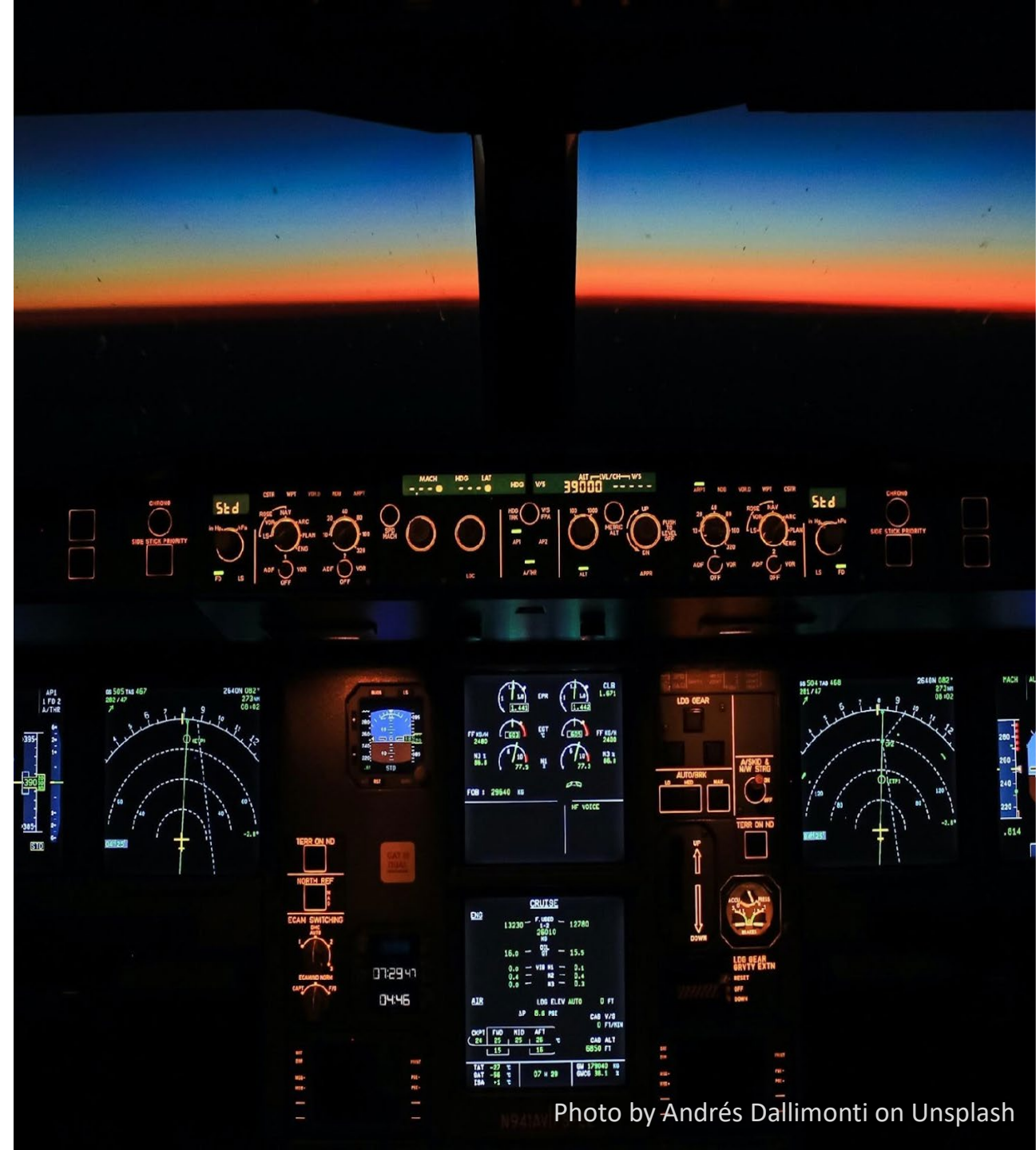


Photo by Andrés Dallimonti on Unsplash



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KCSC  
한인생활상담소

*Preserving the past, serving the present,  
and shaping the future.*







**Mission:** To be a bridge for Korean immigrants and the wider Asian community to fully integrate into society and overcome economic, health, cultural and linguistic barriers so that they become independent and thriving members of the community.

We help Korean newcomers, especially those linguistically and culturally isolated, with limited resources, to **access services and resources**, address the **holistic needs of our families**, and **improve community health**.

# Services and Programs

Pro Bono Legal Aid	
Citizenship & Immigration Service	
Mental Health Counseling	<ul style="list-style-type: none"><li>• Community-based Behavioral Health Program</li></ul>
Senior Services & Case Management	<ul style="list-style-type: none"><li>• Medicare/Medicaid, SSA, SSI Enrollment</li><li>• SNAP(Food Stamp) Enrollment</li><li>• Public Housing Enrollment</li><li>• Culturally Relevant Food Bank for Low-income Seniors</li><li>• Unemployment Insurance Navigation</li></ul>
Family & Youth Program	<ul style="list-style-type: none"><li>• Ottuki Parenting Course &amp; Support Group (0-3 caregivers)</li><li>• Expectant Parents + APPA Hour Fathers' Course &amp; Support Group</li><li>• OASIS Caregiver respite program for neurodiverse adults</li><li>• Parenting Expert Speaker Series to Promote Early Childhood</li><li>• WeKan (middle school-aged) &amp; YouthKAN Council (HS-aged)</li><li>• Becoming a certified Youth &amp; Family Resource Center</li><li>• <b>K-PEDS Community-based UDS</b></li></ul>
Community Safety Program	<ul style="list-style-type: none"><li>• Violent Crime Victims Support</li><li>• Workplace Safety</li><li>• Community Law Enforcement Partnerships</li><li>• Anti-Asian Hate Reporting and Support</li></ul>
COVID-Response	
Culturally relevant Pop-up Food Bank	



# Origins of the Relationship

Asian Pacific Islander  
American Health  
Forum (1997-2002)



Asian Pacific Partners  
for Empowerment,  
Advocacy and  
Leadership  
(2000-present)

Asian Pacific Islander  
Coalition Advocating  
Together for Health  
(1999-present)



Korean Community  
Service Center  
(2017-present)



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Korean Community Service Center

Korean Community  
Service Center  
(2017-present)

- JY consultant on \$27K Korean Youth Health Survey (2018)
- JY grant-writer/collaborator numerous KCSC local & state programs with research and evaluation components (2019-present)
- KCSC member of Health Literacy and Family Communication Workgroup (2017-2020)
- KCSC pilot site for Making Healthcare Decisions (2019-2021)
- JY joined KCSC as paid part-time staff (2021)
- Dual role as UW PI and as KCSC Deputy Director



# Making Healthcare Decisions

*Investing in health literacy and family communication*

A curriculum developed by the Health Literacy and Family Communication Workgroup

Made possible by a grant from the National Human Genome Research Institute, National Institutes of Health, K99R00 HG007076 (PI: Yu)

## Sessions



Session 1: Different visions of health and health literacy



Session 2: Navigating the U.S. Healthcare System



Session 3: Making healthcare decisions together



Session 4: Talking families & standing up for yourself and family



Session 5: Coming to American, what we bring, and self-care while caring for others



Session 6: Hereditary testing and participating in health research?



Session 7: Surveys and celebration!



한인생활상담소

Korean Community Service Center

## Korean Community Service Center (2017-present)



## HHS Public Access

Author manuscript

*Am J Bioeth.* Author manuscript; available in PMC 2023 February 07.

Published in final edited form as:

*Am J Bioeth.* 2021 October ; 21(10): 49–51. doi:10.1080/15265161.2021.1965253.

### Leveraging Academic Institutional Structures to Support Asian American Community Organizations' Engagement in Research: The Korean Community Service Center

Joon-Ho Yu, MPH, PhD<sup>1,2,†</sup>

<sup>1</sup>Division of Genetic Medicine, Division of Bioethics and Palliative Care, Department of Pediatrics; Institute for Public Health Genetics, Department of Biostatistics, University of Washington, Seattle, WA, USA.

<sup>2</sup>Treuman Katz Center for Pediatric Bioethics, Seattle Children's Hospital and Research Institute, Seattle, WA, USA.

My research partnership with the Korean Community Service Center (KCSC) of Seattle is the deepest research relationship I have had since transitioning from working with a national "minority health" organization, the Asian & Pacific Islander American Health Forum (APIAHF), to academic research. As director of the APIAHF Chronic Disease Programs, I served local community-based organizations like KCSC. My subsequent academic scholarship has focused on community engagement and community-based research but from a perspective primarily situated outside of the community. My relationship with KCSC, an organization founded by locally-defined Korean American stakeholders to serve their Korean American community began in 2018 on a small limited project (the Korean American Youth Survey) and over time has blossomed into my current role as part-time Deputy Director and Director of Assessment, Research and Evaluation. Through this ongoing journey, I have learned much about community-academic collaborations; thus, I offer my reflections on the KCSC "partnership" because of its unique qualities and my deep involvement.

#### Partnership vision and strategies.

The overall vision of research partnership is to develop and promote a model in which the KCSC is a learning community-based organization (CBO) akin to learning healthcare organizations (Greene, Reid, Larson 2012). This approach is a significant shift for an organization founded 37 years ago for mutual aid and service. For example, the parent/caregiver education implementation project sponsored by Best Starts for Kids (BSK) King County-DCHS 2021) has been our most important investment of time and energy because it provided access to key capacity building resources (e.g., staffing and organizational development, data platform development, data visualization trainings, etc.).

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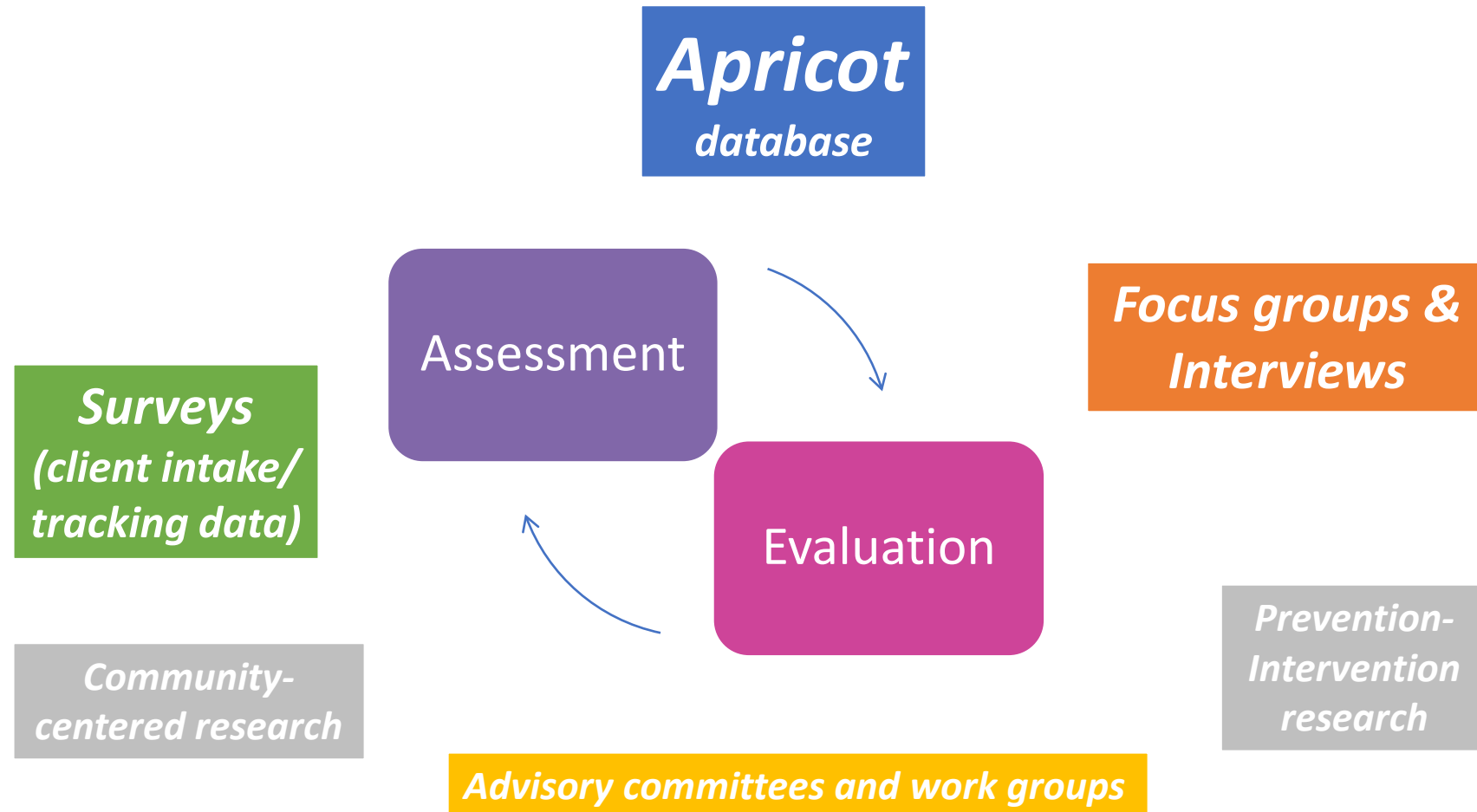
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# KCSC as a Learning Community-based Organization



# Ethical Challenges of Community-Based Organizations Engaged in Community-Led Research: a case study to inform future genomics and big health data research



Joon-Ho Yu, MPH PhD. University of Washington, Department of Pediatrics & Institute for Public Health Genetics; Seattle Children's Hospital and Research Institute, Treuman Katz Center for Pediatric Bioethics and Palliative Care; Korean Community Service Center of Seattle, WA, USA



## BACKGROUND

- Community-based organizations (CBOs) are key to community-centered research in genomics.
- CBOs face ethical issues spanning the decision to partner with academic researchers to the research practices of community research workers.
- Unregulated community-led research (CLR) conducted by CBOs, either in the absence or with limited involvement of academic partners, presents potentially more nuanced ethical challenges.
- In 2018, Korean Community Service Center (KCSC) adopted the goal of becoming a "Learning Community-based Organization (LCO)." PMID: 34554067
- Since then, KCSC has struggled with challenges and decisions while engaging in community-led research.

## METHODS

- Case series of community-led research efforts at the Korean Community Service Center of Seattle (a Learning Community-based Organization)
- Ethnographic exploration of research-related decisions facing CBOs, and potential contributions of organizational ethics and communitarian praxis
- Relevance and application to genomic, precision medicine, and big data research



## 1: Korean Community Safety Survey

### Values-based commitment to community assessment

**Context:** Korean American (KA) small businesses experience violent crime, substance use, and homelessness. Shootings at businesses and rising anti-Asian hate raised awareness but offers few strategies. KCSC examined the feasibility of mapping businesses to real-time crime data and conducting Korean-specific analysis of existing annual regional safety survey data. These public data sources offered little utility. KCSC and partner organizations (e.g., KA chambers of commerce and business/trade associations) had many ideas for prevention projects, yet KA business owners were skeptical and dissatisfied with proposed strategies.

**Issue:** Should KCSC engage KA business stakeholders or follow suit with approaches offered by gov't and partner agencies? Should KCSC engage in assessment or install a KA rapid response team as a common response?

**Deliberation and action:** After internal deliberation and discussions with partners, KCSC decided to conduct an assessment. The Korean Community Safety Survey is a community-led, mixed methods project that solicits crime incidents, mental health status, and access to tangible supports from KA small business owners. Started in Seattle, the survey has grown to 3 other counties.

**Outcome:** Today, the KCSC Community Safety Program, engages KA small businesses throughout the Puget Sound, conducts safety seminars (e.g., de-escalation trainings) and community events, disperses WA state funds to compensate victims of violent crimes, receives reports from and provides support to victims of anti-Asian hate, and more. The initial local program has been leveraged into state initiatives supporting violent crime victims and encouraging community-law enforcement partnerships. Survey results continue to inform design, stakeholder and community engagement, and led to the development and installation of a new Korean American community-based Behavioral Health Program (KBHP).

## 2: Ottuki Parenting Program Study

### Ending a community-academic research partnership

**Context:** In 2019, KCSC received its first substantial award (>\$250K) from King County's Best Starts for Kids (BSK) to implement a 0-5 parent-caregiver education program. KCSC established a research partnership with an academic, though community-based, researcher to adapt an evidence-based curriculum and agreed to an intervention study of parenting outcomes.

**Issue:** The research partnership revealed a number of challenges. The award was for a community-based program and the investigator brought no additional funding; a very high research burden on KCSC staff and participants; and curriculum access was controlled by the investigator on condition of research partnership. Should we endure the research burden for curriculum access?

**Deliberation and action:** The situation represented a severe power imbalance and caused constant conflict between the researcher and staff for over 2 years. Both parties made concessions but ultimately the research requirements remained untenable.

**Outcome:** KCSC "ended" the research relationship as the program entered into the sustainment period of implementation. Staff were prepared to create a new curriculum. Fortunately, the researcher agreed to allow continued curriculum use to benefit the KA community.

## 3: Strategic Planning

### Embracing emic-etic community-staff positionality

**Context:** For the first time in 40 years, KCSC is engaged in strategic planning. At a recent all-staff retreat, KCSC began the internal process of assessing community needs and mapping KCSC services and programs. Nearly all KCSC staff come from and identify with different segments of the Korean American community (e.g., generation, legal status, language, SES, etc.).

**Issue:** Given the multiplicity of perspectives within "the" KA community and pressures to represent KAs in various contexts, the tendency to rely on staff perspectives as "community" perspectives caused moral distress.

**Deliberation and action:** Discussions unpacked KCSC staff's related discomfort and distress. As such, staff engaged in exercises to explore our own emic-etic (insider-outsider) perspectives, develop tactics to engage in emic-etic informed praxis, and committed to investing greater time and effort to direct outreach and engagement, especially in strategic planning.

**Outcome:** The retreat deepened KCSC's understanding of positionality, complicated and advanced understandings of "community," reinforced the importance of and our responsibilities to engage in continuous community engagement, iterative assessment, and evaluation.

## DISCUSSION

As CBOs increasingly conduct community-led research (CLR), we are confronted with difficult decisions akin to academic research institutions, albeit within circumscribed communities rather than society-at-large. Yet, CLR as an approach to engagement and learning often sits in tension with CBOs bounded roles as advisors, recruiters, and disseminators in engaged research. This case series highlights challenging ethics-laden decisions such as balancing limited resources toward research versus action (the traditional domain of CBOs), recognizing when to "go-it-alone," guarding against potential risks and harms of CLR, and maintaining a self-reflexive, self-questioning stance. These cases evidence moral distress, self-doubt, and sensitive intra-community tensions. Case-based, advanced research ethics scholarship and learning could aid CBOs' CLR efforts by offering narrative handholds for CBOs, our staff, and community members, as we engage in translational genomics, precision medicine, and big data research.



# KCSC K-PEDS Program


- Promoting Early Development and Screening
- Learning opportunities
- 1-on-1 personalized support
- Access and support to Korean Ages and States Questionnaire (ASQ)
- Referrals to early intervention



**KCSC is here to help you!**

KCSC can help you understand how your child is growing and reaching important milestones during their early years. We can help you access development screening tools, and even connect you to resources and providers that can help your child grow. Support and information is available in Korean and English!

## OUR SERVICES



- ★ **1-on-1 Personalized Support**
  - Early development resource navigation in English and Korean
  - Connections to ESIT providers for early education, speech, occupational and physical therapy, feeding and nutrition support.
  - General translation and interpretation
- ★ **Learning Opportunities**

Regular parents and caregivers support programs for:

  - Expectant Parents
  - Parents of children ages 1-5 (Ottuki Parent Training Program and Support Group)
  - Appas/fathers of children 0-5 (Appa Hour)
- ★ **Referrals**

KCSC can introduce you to other services and institutions that may be helpful to your child's growth and development.


## RESOURCES




Centers for Disease Control and Prevention (CDC) Developmental Screening Guidance  
<https://www.cdc.gov/ncbddd/childdevelopment/screening.html>




CDC Child Milestone Checklist (English)  
<https://www.cdc.gov/ncbddd/actearly/milestones/index.html>



CDC Child Milestone Checklist (Korean)  
<https://www.nyc.gov/site/doh/health/health-topics/child-development.page>



Help Me Grow Washington  
<https://helpmegrowwa.org/what-is-help-me-grow>




Check on your child's development today!


## CONTACT US!

425-776-2400  
KPEDS@kcsc-seattle.org  
kcsc-seattle.org


Korean Americans  
Promoting Early  
Development and Screening



## LET'S GROW TOGETHER



Curious about your child's growth journey?  
Explore how you can check on the growth of your baby, toddler or preschooler!



한인생활상담소

# Clinical Genome and Exome Sequencing (CGES) in Community-based Universal Developmental Screening

**Aim 1:** Co-create a provider educational strategy on CGES with academic partners and community-based organizations who are promoting and conducting community-based developmental screening.

**Aim 2:** Conduct a pilot of the provider educational strategy to assess feasibility, accessibility, acceptability, and immediate and mid-term impact.

- Collaborative partnership between UW, CISC, and KCSC
- Engage in co-design development of a community-based universal developmental screening (cUDS) provider educational strategy on CGES (cUDS-CGES)
- Conduct a pilot study of the cUDS provider education strategy (e.g., provider trainings) with KCSC and CISC
- Assess feasibility, acceptability, accessibility of the cUDS-CGES educational strategy



# Community uses & benefits?





# Outline

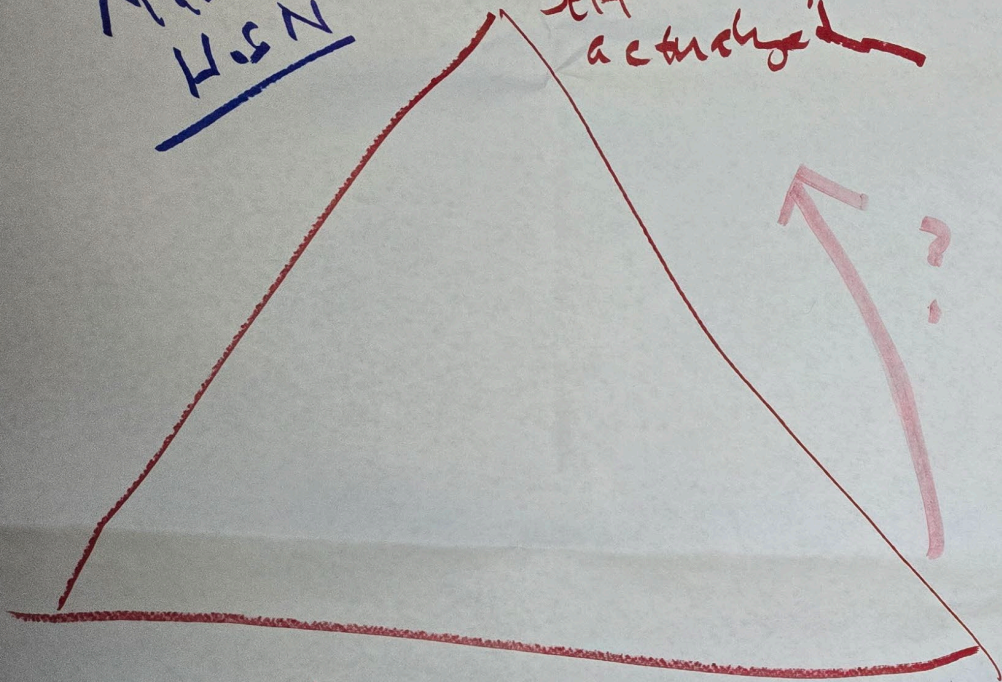
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# Parking Lot

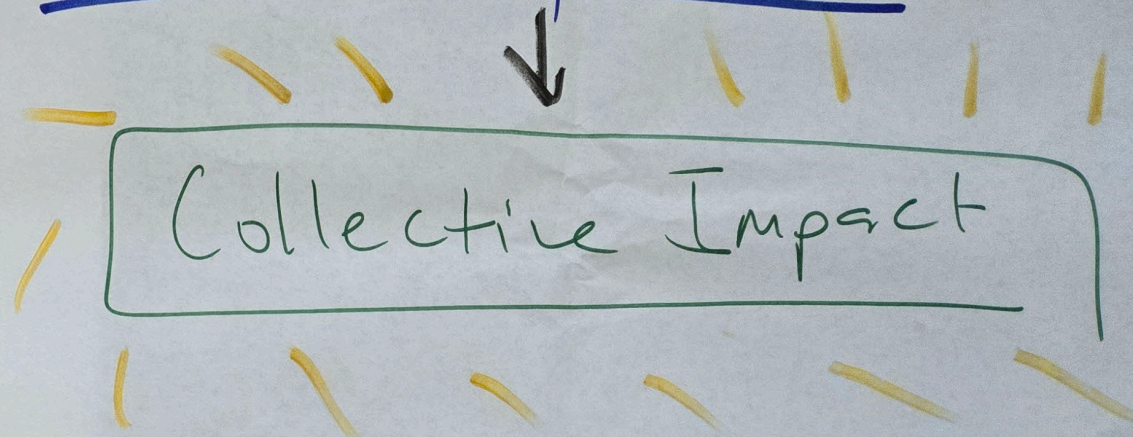
Maslow's  
H&N

Self  
actualization



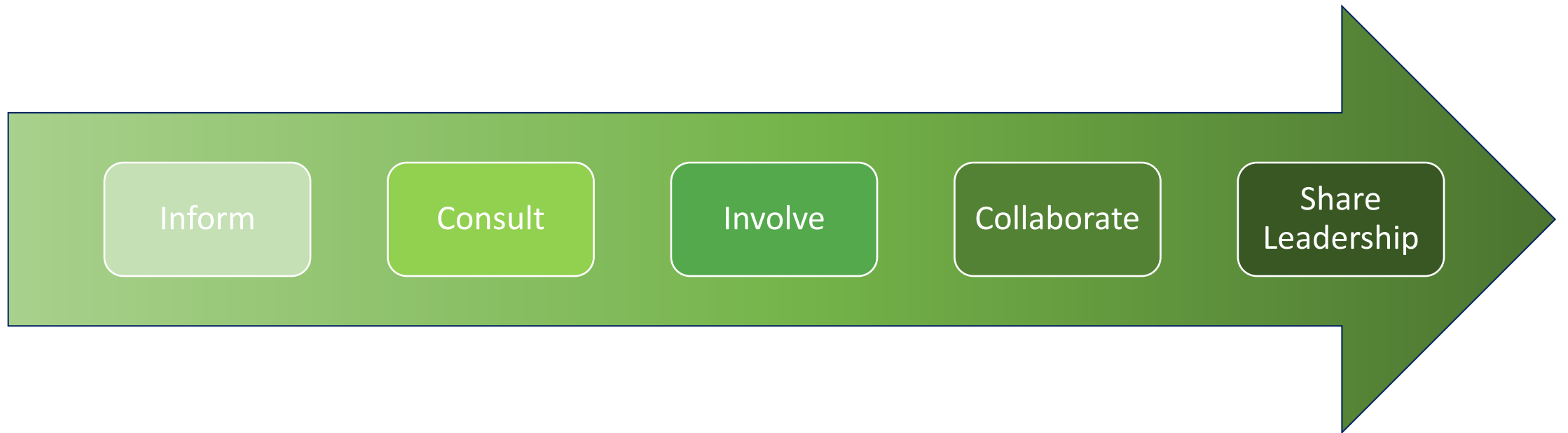
BASIC

# Community Power



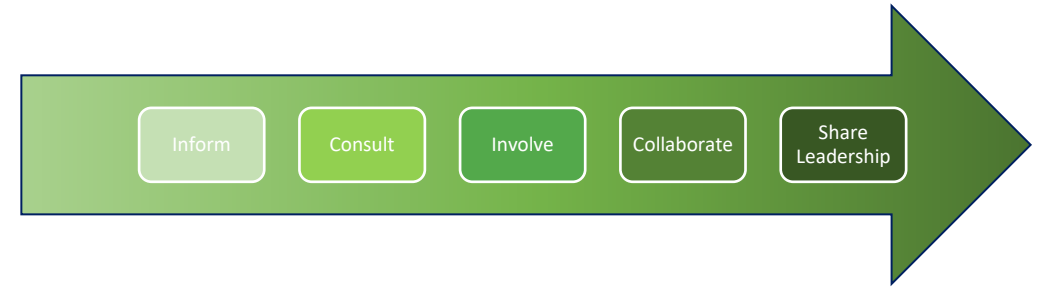


# Sustainment and Trajectory





# Key Considerations



- Being “in-community” recognizes and means \*we\* are in relationship with each other → PEOPLE
- Centering equity seeks “belonging” for individuals, families, communities, etc. in institutions, systems, and society.
  - Foster the ability to hold multiple perspectives
- Centering community power and collective impact requires institutions to reconceive of purpose and mission in fields like genomics.
  - Imagining beyond the pipeline might require “re-piping.”

# Acknowledgments

NASEM Workgroup members

ELSI colleagues and mentors who have encouraged me to share

Staff and leadership of KCSC, and other community-based partners

CHIRON workgroup members and Sage staff, especially Meg Doerr

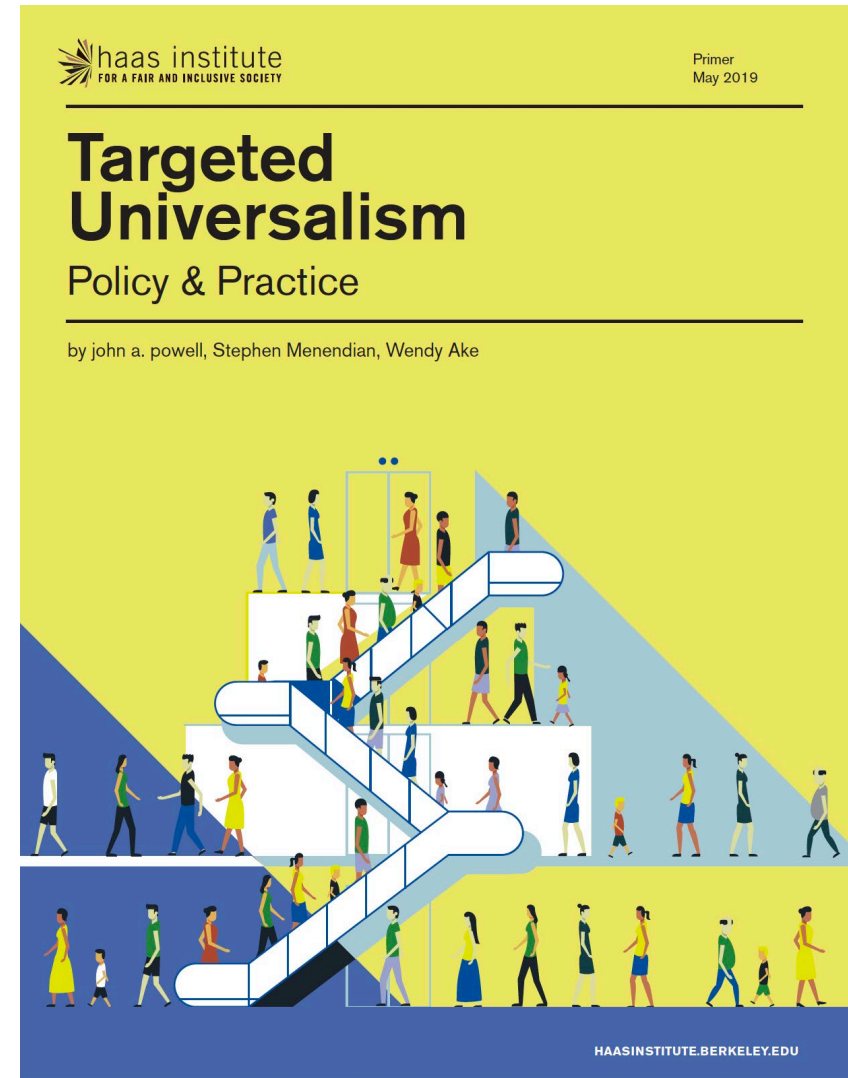
UW Peds Genetic Medicine leadership

UW Peds Bioethics & Palliative Care leadership





**Targeted universalism** is the use of targeted processes to achieve universal goals, deliberately taking policies and practices to dismantle forces of marginalization, othering, and exclusion in the pursuit of equity.



powell, john, Stephen Menendian and Wendy Ake, "Targeted universalism: Policy & Practice." Haas Institute for a Fair and Inclusive Society, University of California, Berkeley, 2019. [haasinstitute.berkeley.edu/targeteduniversalism](https://haasinstitute.berkeley.edu/targeteduniversalism).



Sources: Elmina B. Sewall Foundation and Saskatoon Health Region Advancing Health Equity