Health Equity Research: Challenging the Research Paradigm

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What is Health Equity?

- The absence of *unfair* and *avoidable* differences in health among population groups defined socially, economically, demographically or geographically

- "Pursuing health equity means striving for the highest possible standard of health for all people and giving *special attention* to the needs of those at greatest risk of poor health, based on social conditions"

- "Action requires not only equitable access to healthcare but also means working *outside the healthcare system* to address broader social well-being and development."
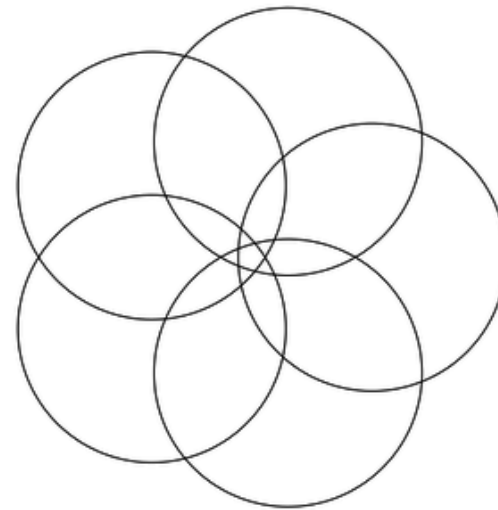

World Health Organization. https://www.who.int/health-topics/social-determinants-of-health#tab=tab_3

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Some(!) People who Commonly Experience Inequities

-Racialized communities

-Immigrant/refugee/internally displaced communities

-Women

-LGBTQ2S+ populations

-Indigenous peoples

-People who have housing insecurity

-People with food insecurity

-People living with low income

-People from some religious/faith communities

-People without OHIP

-People with low internet literacy

-People without internet access

-People without phone access

-People who cannot readily communicate in English

-People with intellectual and developmental disabilities

-Single parents

-Older adults

-People with disabilities (e.g. physical/mobility, deaf, visual, intellectual/developmental, learning, mental illness, additions/substance use, etc.)

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What is Health Equity Research?

- Understanding and addressing disparities in health outcomes among different populations

- Identifying determinants of health

- Community engagement and partnerships

- Recognizing the intersections of multiple social identities and how they shape individuals' healthcare experiences

- Assessing the impact of policies and interventions on health equity

- Addressing the systemic factors that contribute to disparities

- Developing and implementing interventions that prioritize the needs of structurally marginalized populations
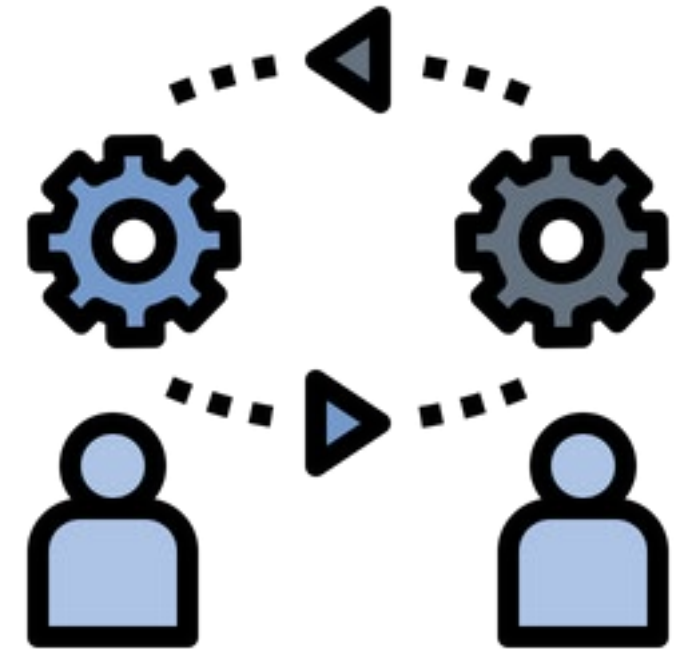
Current Research Paradigm

- Short time frame for applications (e.g. letters of support)

- Restrictive definitions of co-investigators

- Privileging individual-level interventions

- Fully designed interventions when applying for funding

- Individual-level results expected in a relatively short time frame from funders

- Certain populations are "hard to reach"

- Tokenistic approach to patient voices at the table

- Publish or perish

Paradigm Shift

- Patient partnership

- Who is an investigator?

- Funding support for relationship-building

- Co-design

- Centering on the margins

- Guiding framework

Patient Partnership

Sayani A, Maybee A, Manthorne J, Nicholson E, Bloch G, Parsons JA, Hwang SW, Lofters A. Building Equitable Patient Partnerships during the COVID-19 Pandemic: Challenges and Key Considerations for Research and Policy. Healthc Policy. 2021 Aug;17(1):17-24. doi: 10.12927/hcpol.2021.26582. PMID: 34543172; PMCID: PMC8437252.

1. Use an equity-oriented approach to patient engagement – who is **most** likely to experience oppression or inequity in the context of the research? Prioritize them in partnership

2. Co-build sustainable safe spaces – partner beyond the life cycle of a single study; listen and learn; be **humble**; create space where patient partners feel comfortable speaking up

3. Consider issues of accessibility – working hours, childcare responsibilities, virtual vs in person, tech support, arranging internet access

4. Build capacity one relationship at a time – clear communication on research processes, time commitment, expected deliverables, financial compensation

5. Do no harm – including use of language that can convey judgment and power

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Patient Partnership

The Power Wheel

POWER WHEEL

INFORM · CONSULT · COLLABORATE · DECIDE
CLOSED · INVITED · CREATED
MACRO · MICRO · MESO

PLACE
SPACE
INFLUENCE

DIMENSION	LEVEL
PLACE: A socially constructed area that has acquired meaning through human activities and interactions and where social, political and economic power is held. Place directs the levels on which agents can exert influence and each level is interrelated to the others.	**MICRO:** Individual projects (clinical practice, research) or localised policy issues.
	MESO: Intermediate-level projects that lead to changes in institutions, organizations, or specific communities.
	MACRO: Large-scale social, economic or political issues that have a wide-ranging impact on society as a whole.
SPACE: An abstract or physical setting where social interactions and relationships occur between agents and actors. Space is typically confined within the ideological possibilities of the actors who create the space.	**CLOSED:** Healthcare spaces where decision-making occurs without patient engagement.
	INVITED: Healthcare spaces where patient partner perspectives on a predetermined topic or area of study are solicited.
	CREATED: Informal or formal spaces where patient partners collect and gather around a common need, creating their own boundaries around priorities, policies and programs.
INFLUENCE: Also understood as social power, in which a social relation between two individuals is able to impact an outcome such as a decision.	**INFORM:** Patient partners are provided information about what is being done and what it means for them. Patient partners have no influence on the outcome.
	CONSULT: Patient partners are involved in providing feedback and input on a specific project. Patient partner input is taken into consideration when decisions are made.
	COLLABORATE: Patient partners work together with decision-makers to develop alternatives. Decisions are made together with patient partners.
	DECIDE: Patient partners prioritise and decide what is relevant and important. Decisions are made by patient partners and implemented by institutions and project teams.

Sayani A, Cordeaux E, Wu K, Awil F, Garcia V, Hinds R, Jeji T, Khan O, Soh BL, Mensah D, Monteith L, Musawi M, Rathbone M, Robinson J, Sterling S, Wardak D, Amsdr I, Khawari M, Niwe S, Hussain A, Forster V, Maybee A. Using the Power Wheel as a transformative tool to promote equity through spaces and places of patient engagement. BMJ Open. 2024 Mar 21;14(3):e074277. doi: 10.1136/bmjopen-2023-074277. PMID: 38514144; PMCID: PMC10961587.

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Who is a Co-Investigator?

So, You Say You Want Patients as Partners in Research, Eh? longwoods.com. Insights March 2023. Mohammad Shabani, Razia Rashed, Mary A. Hill, Kelly M. Smith and Sara Shearkhani

"The concept of engaging patients as partners in research is a great idea that can start with developing a proposal and then applying for grants. In our case, we planned to apply for a Canadian Institutes in Health Research (CIHR) grant. The steps to submit a CIHR grant with patient co-applicants are as follows: open an account on ResearchNet, acquire a personal identification number (PIN) and create and submit a curriculum vitae (CV) for each patient partner. It seemed simple enough – *or so we thought*.

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We found that the procedures were **not patient-friendly and posed challenges** for all the team members. While one patient partner was facing obstacles getting his PIN, the other patient partner did not have an existing ResearchNet account and needed additional support from scientists on the team to navigate the process, which took longer than expected. Questions about patient partners' "affiliations" caused further confusion. No resources are available that can assist patients in these procedures, to the best of our knowledge. It is the responsibility of the scientists and patient partners to navigate these complexities on their own. This was considered a significant barrier."

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"The process of developing a CV for each patient partner was considered **another barrier** by the team. The scientists on our team had experience crafting CVs describing their previous work experience relevant to the grant proposal, but this process was new to our patient partners and required **additional time and resources** for planning and coaching on behalf of the research team.

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After a while, panic creeped in. We had to make a choice: Do we involve our patient partners as co-applicants or collaborators? Including patient partners as collaborators is the easier route as there is no need for a CIHR PIN or a CV. In fact, in conversations with experts, this was the route that was suggested to us. However, including patients as collaborators would mean their names would not appear on the grant application. This was disheartening as the team aimed to meaningfully involve patients as partners in the proposal. *Excluding patient names dismisses all the hard work they have put into the proposal development."*

Funding Support For Relationship-Building

CCS Health Equity Research Grants – Advancing a more accessible and inclusive cancer care system

Authentic Team Building

Recognizing that team building in an authentic, collaborative way takes time, newly formed teams may submit applications that comprise the team building and issue identification process (for up to 1 year of funding), with a subsequent application (in a future competition*) for the (cancer-related health equity) research itself. Applications framed in this way will need to provide a well-justified rationale and detailed plan for the team building activities and requested budgets should reflect the work proposed. Members of the team will need to be identified at the application stage. *Note that teams utilizing this approach will be subject to the same evaluation criteria as other applicants in a future competition

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Funding Support For Relationship-Building

Research teams will be comprised of relevant partners as integral members of the team from the outset:

- A Principal Investigator who meets the eligibility criteria, and who brings with them an authentic, demonstrated commitment to health equity research. Researchers that have not traditionally worked in cancer, but are focused on health equity research (e.g. social scientists, arts-based researchers, community-engaged researchers) are encouraged to apply. For applications involving First Nations, Inuit and Métis Peoples, the Principal Investigator or co-Principal Investigator must self-identify as Indigenous or engage (an) Indigenous Elder(s) or Knowledge Keeper(s) to provide evidence of meaningful and culturally safe engagement with Indigenous communities.

- A team (Principal Investigator, Co-Principal Investigator(s), Co-Applicant(s), People affected by cancer, Implementers and Decision-makers, Additional Authors and Collaborators) whose clear focus is on health equity, and who collectively bring the appropriate experience and expertise to bear towards achieving the research objectives. Health equity training may be required for some members of the research team (e.g. trainees) and should be described where needed.

- People affected by cancer are people both affected by structural marginalization and at risk of cancer, patients, survivors, and/or caregivers. These individuals must be integrally involved in co-creating all aspects of the research plan from the outset, beginning with the identification of a research issue of importance and relevance, through to dissemination of results. The characteristics and intersections of sub-populations should be carefully considered to ensure fair representation. Teams may consult the CIHR Strategy for Patient-Oriented Research – Patient Engagement Framework for guidance on meaningful engagement.

- Implementers and decision-makers include professionals (healthcare, community-based, administrators, policy makers) who may be involved in implementing the proposed approaches to enhance health equity. These individuals must be integrally involved in the project from the outset and must demonstrate their commitment to the proposed work.

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Co-Design

Creating a healthcare solution WITH the people who will experience it

Co-Design

❑ Engage = establish meaningful relationships with partners to best understand and improve health services

❑ Plan = work with partners to come up with ideas about the goals and how to go about doing it

❑ Explore = understand patient experiences of services and identify things that can be improved

❑ Develop = turn the ideas into specific improvements

❑ Decide = choose what improvements to make and how to make them

❑ Change = turn improvement ideas into action

Centering on the Margins

Relationships and Networks
Connections with family, friends, partners, community, and workplaces that:

+ Promote health and support systems health-promot...

− Intensify hea... social netw... health-ha...

Systems of Power
Policies, processes, practices that:

+ Promote health equity through fair access to resources and opportunities that enable healthy lives

− Intensify health inequities by allowing unfair social, economic or environmental advantages for some groups over others

Individual Factors
A person's response to social, economic and environmental conditions that:

+ Promotes health equity through attitudes, skills and behaviors that enable their personal and community's health

− Intensify health inequities through attitudes, skills or behaviors that cause harm to their personal or community's health

Physiological Pathways
Factors that:

+ Promote health equity when a person's physical, cognitive and psychological abilities are maximized

− Intensify health inequities when a person's environment or experiences has impaired their physical, cognitive or psychological functions

- There are structural oppressive power systems that are in place BUT there is also sizeable strength and resilience that lies within communities.

My Lessons Learned

Each community consists of many communities

Relationships are reciprocal

Keep partners updated every step of the way

Listen! (to what's said and not said)

Give community partners a skeleton to work from

Be aware of researcher ego, humility is key

Community-partnered work requires TIME

Practicalities of the CV

What happens when funding is gone?

References

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Questions?