

2023



**NAPCRG**

51<sup>st</sup> Annual Meeting

# Changing the landscape: Building capacity for patient & community involvement: Experiences from the US & Ireland

a CASFM-PHR workshop



# Outline of Workshop

- Our Team (Anne)
- Equality, Diversity and Inclusion (EDI) statement & icebreaker (Denia)
- What is Public & Patient Involvement? (Jon)
- Workshop Activity - Barriers & Facilitators to Institutional PPI (Anna & Lorna)
- Irish Case Study: Building institutional capacity for meaningful PPI (Miriam & Lorna)
- US Case Study: Planning for CEnR and Equity capacity building in the CTSI (Michelle)
- Workshop Activity - Planning your enablers (Denia)
- Closing Activity (Anna)

# Our Team



- Michele Allen Prof Family Medicine, University of Minnesota (US)
- Alphonse Basogomba PPI Ignite @ UL Community Partner (Ireland)
- Dénia Claudino PPI Projects Officer, UL School of Medicine (Ireland)
- Meghan Gilfoyle McMaster University (Canada)
- Zoe Hughes Policy & Research Officer, Care Alliance Ireland (Ireland)
- Lorna Kerin Manager Participatory Health Research Unit, UL School of Medicine (Ireland)
- Anne MacFarlane Prof Primary Health Care Research, UL School of Medicine & Health Research Institute (Ireland)
- Miriam McCarthy Manager, Health Sciences Academy, UL & University Hospital Limerick (Ireland)
- Anna Papyan PPI Ignite Research Assistant, UL School of Medicine, & PPI Ignite @ UL Community Partner (Ireland)
- Jon Salsberg Associate Prof Primary Health Care Research - PPI, UL School of Medicine & Health Research Institute (Ireland)

# Equality Diversity Inclusion Statement

Peer Icebreaker: What motivated you to be at this session?  
(1 minute each!)



# PPI: Public & Patient Involvement in Health Research

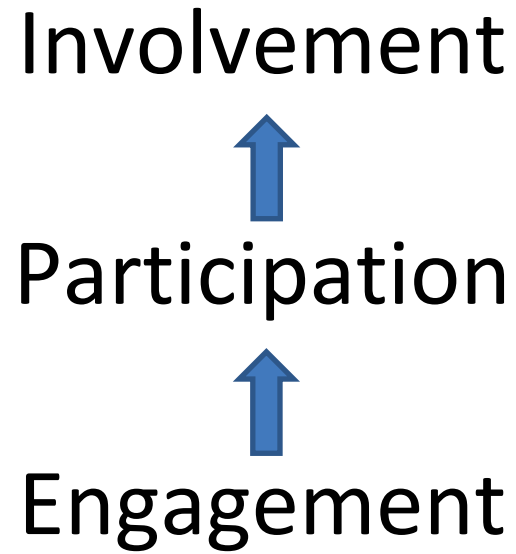
Patient or public involvement in research =

Research being carried out **with** or **by** members of the public

- rather than **on**, **about** or **for** them

UK NHS INVOLVE | <http://www.invo.org.uk/>

# PPI: Public & Patient Involvement in Health Research



# PPI: Public & Patient Involvement in Health Research

## Engagement

Where information and knowledge about research is provided and disseminated.

## Examples of engagement:

- science festivals open to the public with debates and discussions on research
- open day at a research centre where members of the public are invited to find out about research
- raising awareness of research through media such as television programmes, newspapers and social media
- dissemination to research participants, colleagues or members of the public on the findings of a study.



# PPI: Public & Patient Involvement in Health Research

## Participation

Where people take part in a research study.

Examples of participation are:

- people being recruited to a clinical trial or other research study to take part in the research
- completing a questionnaire or participating in a focus group as part of a research study.

UK NHS INVOLVE | <http://www.invo.org.uk/>

# PPI: Public & Patient Involvement in Health Research

Involvement *Meaningful!*

Where members of the public are actively involved in research projects and in research organisations.

Examples of public involvement:

- as joint grant holders or co-applicants on a research project
- identifying research priorities
- as members of a project advisory or steering group
- commenting and developing patient information leaflets or other research materials
- undertaking interviews with research participants
- user and/or carer researchers carrying out the research.

UK NHS INVOLVE | <http://www.invo.org.uk/>

# This is PPI



# PPI: Public & Patient Involvement in Health Research

For PPI Ignite @ UL...

**PPI**



*Participatory Health Research*

# Participatory Health Research (PHR)

*Systematic enquiry, with the collaboration of those affected by the issue being studied, for the purpose of education and taking action or effecting change*

Definition used by **CDC** and **Institute of Medicine**, USA, following the The Royal Society of Canada Study of Participatory Research in Health Promotion - Green, et al. 1995

# What should be negotiated among PHR research partners?

- Terms of partnership agreement
- Research goals and objectives
- Methods and duration of projects
- Strategy and content of evaluation
- Data collection
- Interpretation of data
- Joint dissemination of results
  - in lay language and scientific terms to communities, clinicians, administrators, scientists, and funding agencies

*Based on: Macaulay AC, Gibson N., Freeman W, et al. Participatory Research Maximizes Community and Lay Involvement. BMJ 1999;319:774 -778*

# What should be negotiated among PHR research partners?

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*Based on: Macaulay AC, Gibson N., Freeman W, et al. Participatory Research Maximizes Community and Lay Involvement. BMJ 1999;319:774 -778*

Most importantly...

Those for whom the benefit is intended  
are at the **heart** of the research decision making



# Participant Activity

What might be some of the facilitators and barriers to Institutional embedding of Public Patient Involvement in Research?



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**Example from Ireland**

**Eightercua Stone Row**

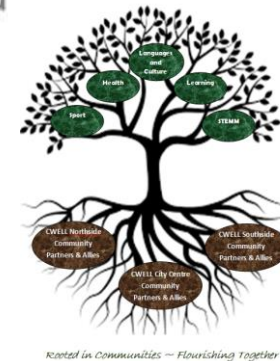


# *PPI Ignite @ UL*

Building capacity for meaningful engagement through *training, networking* and *policy*



# PPI Ignite @ UL Partners



# Objective 1-*Training and Development*

- Training and development
  - Academic
  - Community-based
- Building and maintaining physical and social spaces that are conducive to PPI



# Objective 1-*Training and Development*

Training title	Date	Trainer	Learning objectives
Introduction to PPI and PHR	TBD Spring 2024	Jon Salsberg +	<ul style="list-style-type: none"> <li>Define PPI and how it is supported by the principles and practice of participatory health research</li> <li>Identify minimal requirements for meaningful public or patient involvement in health research</li> <li>Distinguish between patients or members of the public as 'co-researchers' vs. 'research participants' (i.e., 'subjects' or data-sources)</li> </ul>
Finding research partners	TBD Spring 2024	Jon Salsberg Alison Johnson	<ul style="list-style-type: none"> <li>Identify different possible domains of stakeholder partners</li> <li>Determine which stakeholder partners are an appropriate fit for your specific project</li> <li>Identify, contact and engage with specific partners</li> </ul>
Ethics, Governance & Partner agreements	TBD Spring 2024	Virginia Minogue Jon Salsberg	<ul style="list-style-type: none"> <li>Identify additional ethical considerations inherent in PPI research</li> <li>Distinguish between individual and collective rights in protecting community interests</li> <li>Identify the rights and responsibilities of both researchers and PPI partners</li> <li>Negotiate issues of joint data ownership with partners</li> <li>Understand dual ethical review (university/hospital and community/organisation)</li> </ul>
Collaborative research design	TBD Autumn 2023	Anne MacFarlane Alphonse Basogomba	<ul style="list-style-type: none"> <li>Distinguish between the development of research proposals with and without meaningful PPI</li> <li>Describe Arnstein's Ladder of Participation</li> <li>Describe an example of how a research proposal about ethnicity and health changed because of a PPI approach</li> </ul>
Collaborative data analysis & interpretation	TBD Autumn 2023	Anne MacFarlane Ailish Hannigan	<ul style="list-style-type: none"> <li>Understand the relevance of PPI in quantitative and qualitative data analysis</li> <li>Provide examples of PPI in quantitative and qualitative data analysis</li> <li>Reflect on opportunities and challenges for PPI in data analysis and interpretation</li> </ul>
Collaborative Dissemination Planning	TBD Autumn 2023	Jon Salsberg Meghan Gilfoyle	<ul style="list-style-type: none"> <li>Reflect on dissemination goals that include both increasing knowledge and action</li> <li>Identify target audiences</li> <li>Understand how to craft the central messages</li> <li>Understand the importance of the messenger</li> </ul>



# Monitoring and Evaluation

- Knowledge and capacity
- Number of trained PPI trainers
- Cohort of PPI researchers in UL
- Number of PPI-trained public and patients members
- PHR principles - understanding and practice
- Skilled in use of participatory methods
- Securing agency research funding requiring PPI partnerships



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PPI Ignite Participant Code: \_\_\_\_\_

### PPI Training Evaluation Sheet

Please help us to ensure that we deliver the highest quality training possible by taking a few minutes to complete this evaluation sheet.

**1. Overall Rating:**

	Excellent	Very Good	Satisfactory	Fair	Poor
Overall rating of programme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Programme material	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**2. Relevance:**

	High		Medium		Low
Relevance to present job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expected relevance to your future job requirement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**3. Contents:**

	Too advanced		About right		Too simple
Level of content	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depth of content	Over detailed	<input type="radio"/>	About right	<input type="radio"/>	Over general
Usefulness of contents	Very academic	<input type="radio"/>	Academic yet practical	<input type="radio"/>	Very practical
Pace of programme	Too fast	<input type="radio"/>	About Right	<input type="radio"/>	Too slow

**4. Specific questions:**

A. Before receiving this training what was the level of your knowledge about PPI in research?

Very high	High	Intermediate	Basic	No Knowledge
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

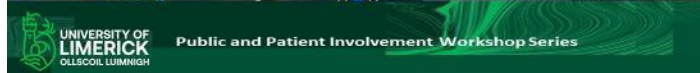
B. After receiving this training what is the level of your knowledge about PPI in research?

Very high	High	Intermediate	Basic	No Knowledge
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Evaluation Sheet Page 1 of 2 Document number TP002.3



# Objective 2-Designing Network Events



Looking for help or advice with **Public and Patient Involvement** in health research?

- identifying patients or public partners for your project?
- searching PPI in your IRB grants?
- how to create a public/patient co-researchers of the public in your research?
- any other PPI questions

Welcome to

**PPI Club**



UHL GRAND ROUNDS RESEARCH FAIR

**PPI Ignite@UL@**

FIND AND MEET NEW RESEARCH PARTNERS

Unique networking opportunity for UL and UHL clinicians, researchers, students, and patient & community groups

MAY 10TH, 2019 | 12-2 PM

CERC BUILDING UHL



# Objective 2-*Designing Network Events*

Through a range of channels:

- Health Research Institute
  - Lunchtime sessions
  - PPI Tasters
- University Hospital Limerick
  - Grand Rounds
  - Find and Meet New Research Partners



# Monitoring and Evaluation

- Number and reach of PPI researchers across the Health Research Institute research themes
- PPI activities across these research themes
- PPI involvement in clinician research



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### HRI Networking Evaluation form

1. Do you have experience of involving public or patient partners as collaborators in your research?  
Yes No n/a

If yes  
a. Are you likely to continue?  
Yes No n/a

If no  
b. Are you likely to start?  
Yes No n/a

As a result of the PPI Testers, and other PPI presentations at the HRI Members' Update Lunches,

2. Have you increased your understanding of what Public & Patient Involvement in Health Research (PPI) means?  
Yes No n/a

3. Have you changed your perception of the value of PPI for your own research?  
Yes No n/a

4. Are you more likely to seek out further PPI skills or training?  
Very likely Likely Somewhat likely Unlikely Very unlikely

5. What would you like to see in future PPI Masters?

Topic	Definitely 5	4	3	2	Not so much 1
How to approach partners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to collaborate/identify design projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Examples of existing PPI research projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PPI Implications on your academic career (progression and promotion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="text"/>				

# Objective 3-Expand PPI in UL's policies, procedures and practices

- Systematic inclusion of PPI provisions throughout UL policies, procedures and operating practices
  - within UL administrative and management structures
  - develop/amend policies and procedures

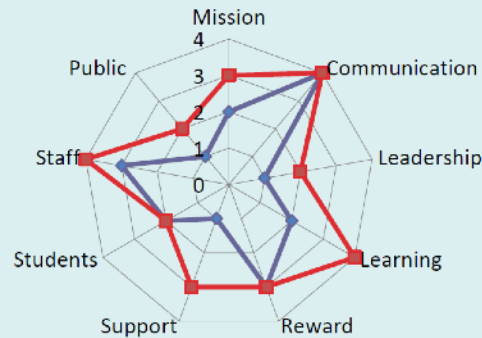
IPPOSI



Care Alliance Ireland



Health Research Charities Ireland



— How embedded is PE in your organisation?  
— Where does your organisation want to be?

EHS  
Education & Health Sciences



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IRISH WORLD ACADEMY  
OF MUSIC AND DANCE  
DÁMH CHRUINNE ÉIREANN  
RINCE agus ceol

KEMMY BUSINESS SCHOOL  
University of Limerick



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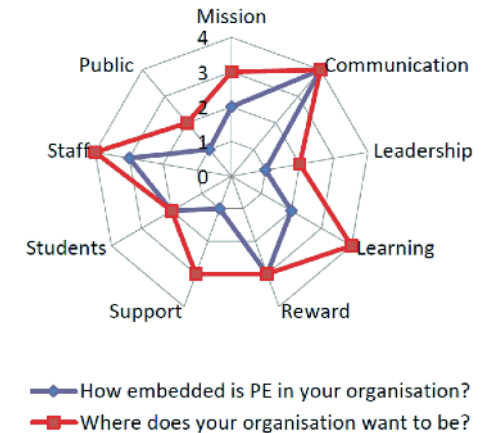
PPI  
ignite  
UL@



NAPCRG

# Monitoring and Evaluation

- Expanded reach of PPI in all UL policy areas
- Impact of policy change on UL indicators
- Uptake of policy guidelines in PPI Ignite partner organisations
- Impact of policy guidelines in PPI Ignite partner organisations on PPI capacity
- EDGE evaluation tool from the UK National Co-ordinating Centre for Public Engagement.
- Social network analysis



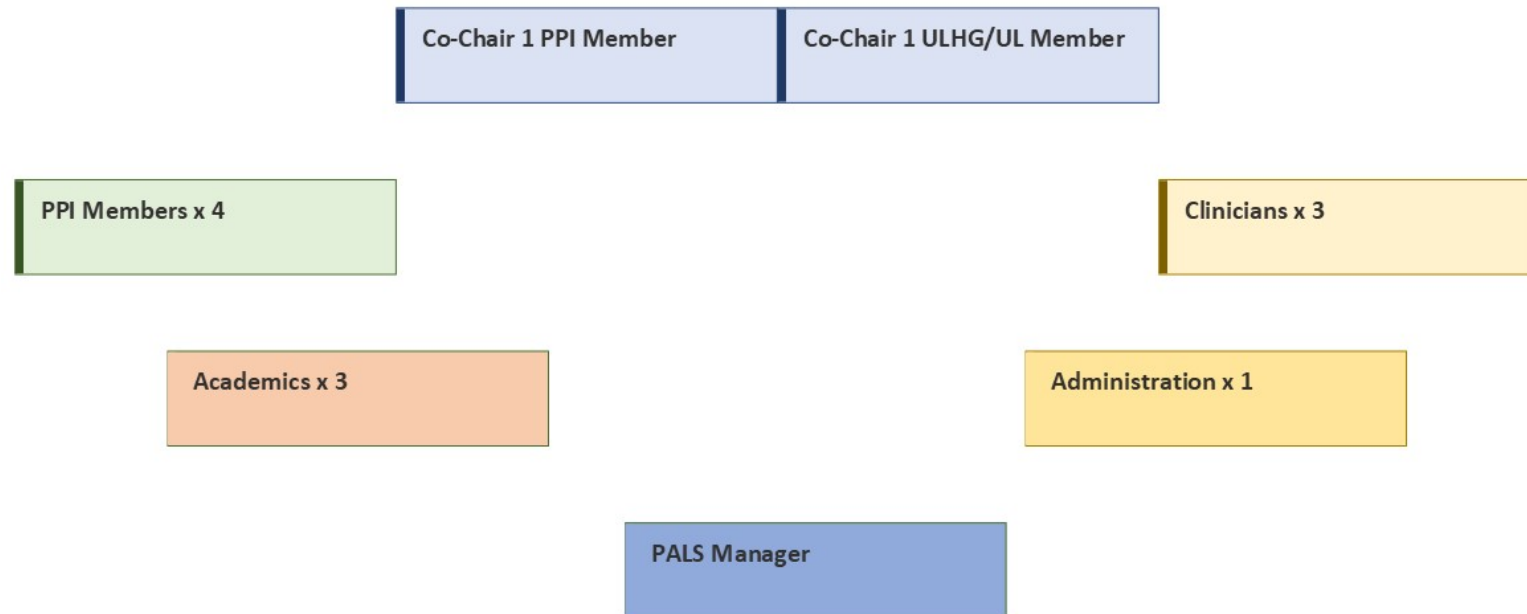
# PPI Cancer Collaborative Panel



# PPI Cancer Collaborative Panel

## Purpose:

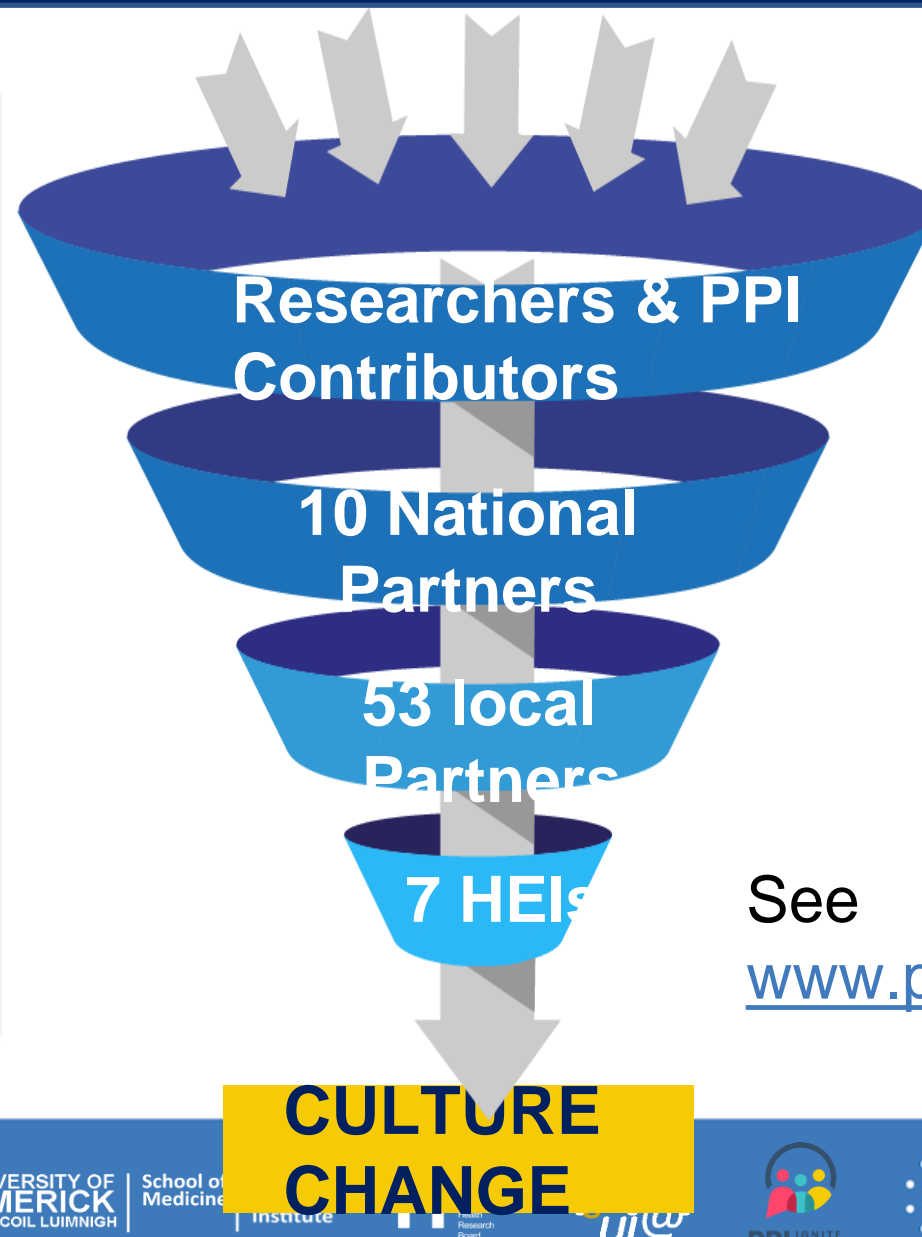
- Get relevant people involved in research at all stages
- Centralised engagement group for the management of PPI in cancer research in UL Hospitals Group and University of Limerick



# University of Limerick now lead site on HRB National PPI Ignite Network

2021-2025

- Build national PPI capacity/train PPI contributors
- Embed PPI in postgraduate & undergraduate education
- Embed PPI across academic institutions and other agencies involved in health research.
- Promote PPI excellence
- Build a strong national network to improve public health outcomes



See  
[www.ppinetwork.ie](http://www.ppinetwork.ie)

# Special Considerations for Institutional Embedding of PPI



## Enablers from PPI Ignite Network (Ireland)

- ✓ Showcase PPI & report up to Management
- ✓ Include PPI in strategy documents
- ✓ Develop reimbursement guidance & procedures
- ✓ Evidence grant income & publication metrics from PPI
- ✓ Ensure good accessibility & design
- ✓ Reward, promote, incentivise, award PPI
- ✓ Train RECs & include PPI diversity
- ✓ Co-design PPI Comms & relationship building

Dorris, E.; Kerin, L et al. (2023). Embedding public and patient involvement in research at an institutional level: A landscape report. figshare. Preprint. <https://doi.org/10.6084/m9.figshare.21995156.v2>





@PPI\_Ignite\_UL

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Participatory Health Research Unit, School of Medicine, UL  
<https://www.ul.ie/ehs/medicine/research/research-groups/public-and-patient-involvement-ppi>



National PPI Ignite Network  
[www.ppinetwork.ie](http://www.ppinetwork.ie) or [Lorna.Kerin@ul.ie](mailto:Lorna.Kerin@ul.ie)

Come join us at our PPI Summer School in Ireland! June 2023  
[PPI-ignite@ul.ie](mailto:PPI-ignite@ul.ie) or [Denia.Claudino@ul.ie](mailto:Denia.Claudino@ul.ie)

Consider our postgraduate diploma in Participatory Health Research  
[PPI-ignite@ul.ie](mailto:PPI-ignite@ul.ie) or [Jon.Salsberg@ul.ie](mailto:Jon.Salsberg@ul.ie)

A scenic view of a river in Yosemite National Park. The foreground shows a rocky riverbank with a large fallen log. The river is clear and reflects the surrounding greenery and blue sky. In the background, there are large, rugged granite cliffs and dense evergreen forests under a clear blue sky.

**Example from the US**

**Yosemite National Park**

# Planning for CEnR and Equity capacity building in the CTSI

CEARCH – Community Engagement to Advance Research and Community Health



CLINICAL AND TRANSLATIONAL  
SCIENCE INSTITUTE

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UNIVERSITY OF MINNESOTA

**Driven to Discover®**

# CEARCH Mission, Vision, & Values

## Mission



CEARCH advances **solutions to health issues** important to all Minnesota communities.

## Vision



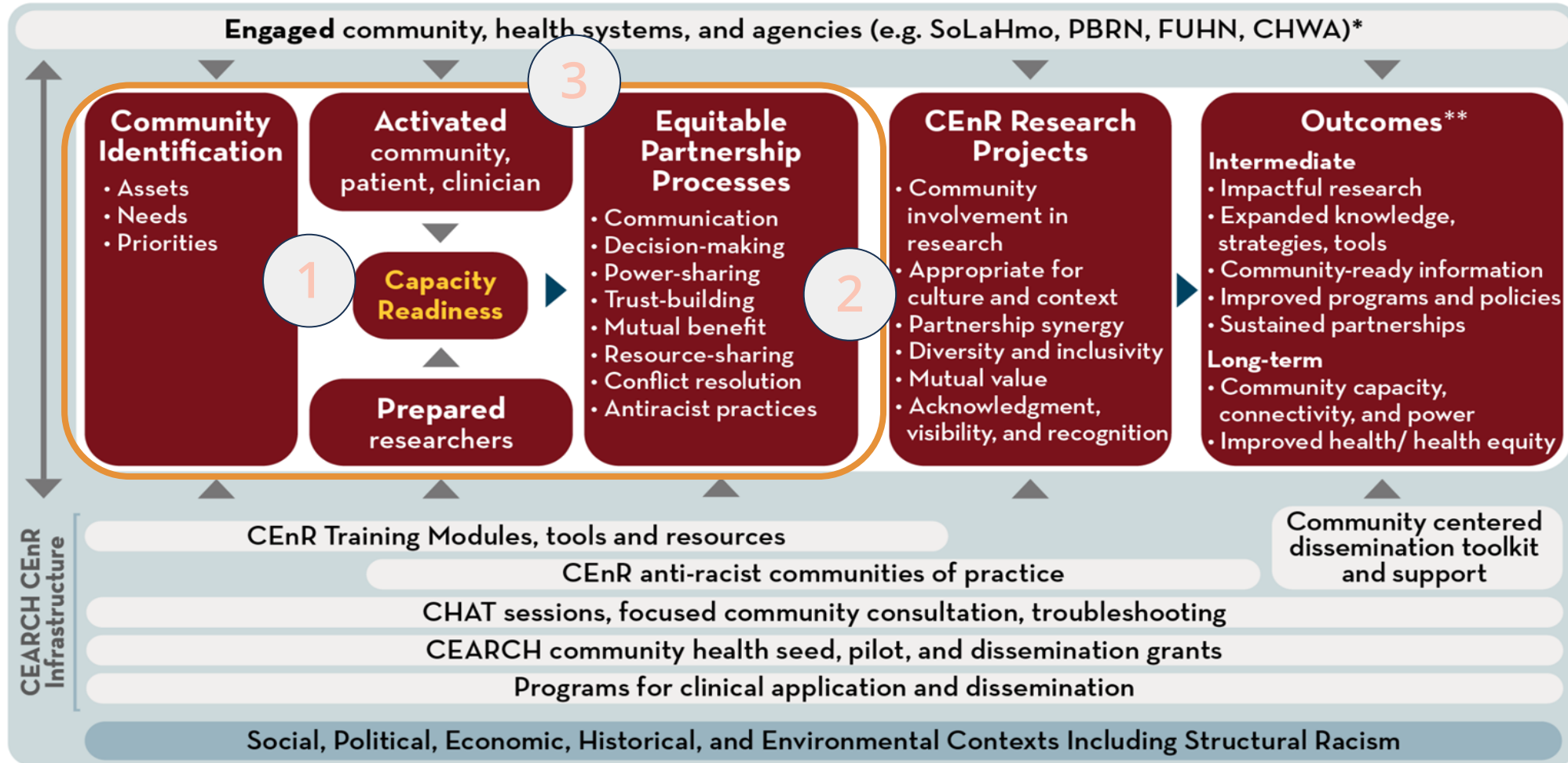
Community and University of Minnesota researchers **work together** to create a healthier and equitable Minnesota.

## Values



- **Bi-directional** learning and sharing knowledge for mutual benefit.
- **Authentic and transparent** research partnerships built on trust and accountability.
- **Community knowledge and trust** that communities know how to best solve the health issues that impact them.
- Health, **equity** and **anti-racism**.
- Engaging communities in creating, carrying out, and **sharing research results**.

# CEARCH Equity-promoting CEnR Conceptual Model



\* SoLaHmo = Somali, Latino, Hmong Partnership for Health and Wellness, PBRN = Practice Based Research Network, FUHN = Federal Urban Health Network, CHWA = Community Health Worker Association. \*\* These outcomes are metrics from the National Academy of Medicine, "Assessing Meaningful Community Engagement: A Conceptual Model to Advance Health Equity through Transformed Systems for Health" publication.

# Specific Aims

1

Build and evaluate **capacity and readiness** for CEnR across the translational science spectrum and enhance quality of partnership processes



# Specific Aims

2

Create and evaluate approaches to identify and mitigate **research & partnership practices** contributing to inequities including racism at the structural and interpersonal levels



# Specific Aims

3

Support the development of **engaged & activated** community and clinic-focused research networks

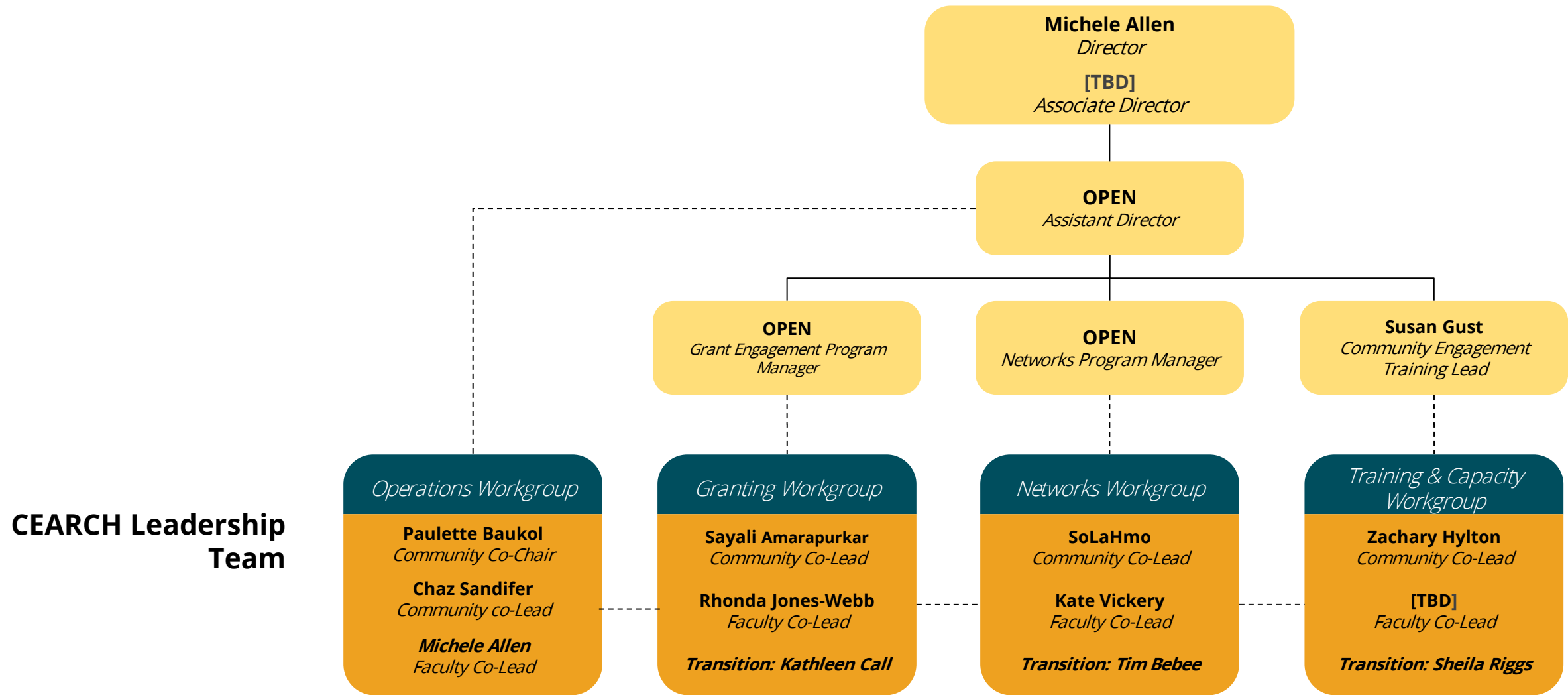




# Planning Principles

- Increase community involvement in decision making at all levels
- Decentralize the work to allow creativity and create accountability and alignment with grant commitments
- Center on equity in all decisions

# CEARCH Roles & Leadership Structure



# Buckets of Work

1

## Training and Capacity Building

- Summer Institute\*
- CEnR modules
- CBPR course\*
- Workshops
- CTSI capacity - CTSI Ed
- *Dissemination Toolkit*

2

## Community Networks & Collaboration

- CHAT sessions
- FUHN
- CHW research training and apprenticeship\*

3

## Grant Making

- Administer grants
- Update granting priorities
- Focus on improving relationships & support
- Technology & reporting updates

4

## Operations & Evaluation

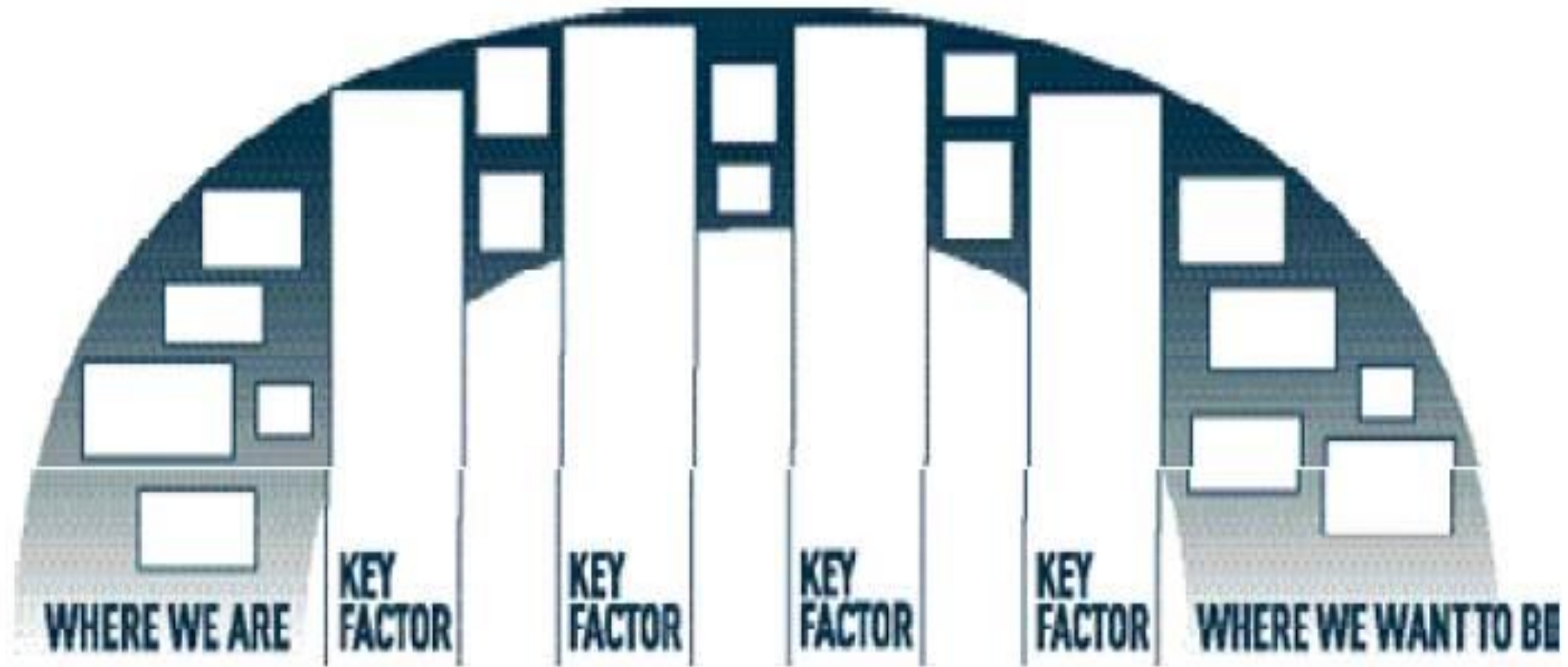
- Operations strategy
- Communication & Dissemination
- Program evaluation and management
- DEI & Antiracist capacity and work\*

\* Significant partnership

# Lessons Learned & Next Steps

- Institutional readiness for CEnR is crucial
- Cannot be successful without equitable and inclusive culture
- Establishing institutional change strategy
- Within each work group establish:
  - The why of the work - purpose statement
  - Goals and activities for year
- Re-launch in Winter 2024!

# Over to you! Bridge Exercise



# Workshop Evaluation Tree Exercise

