Equity, Diversity, Inclusion and Decolonization in Knowledge Mobilization

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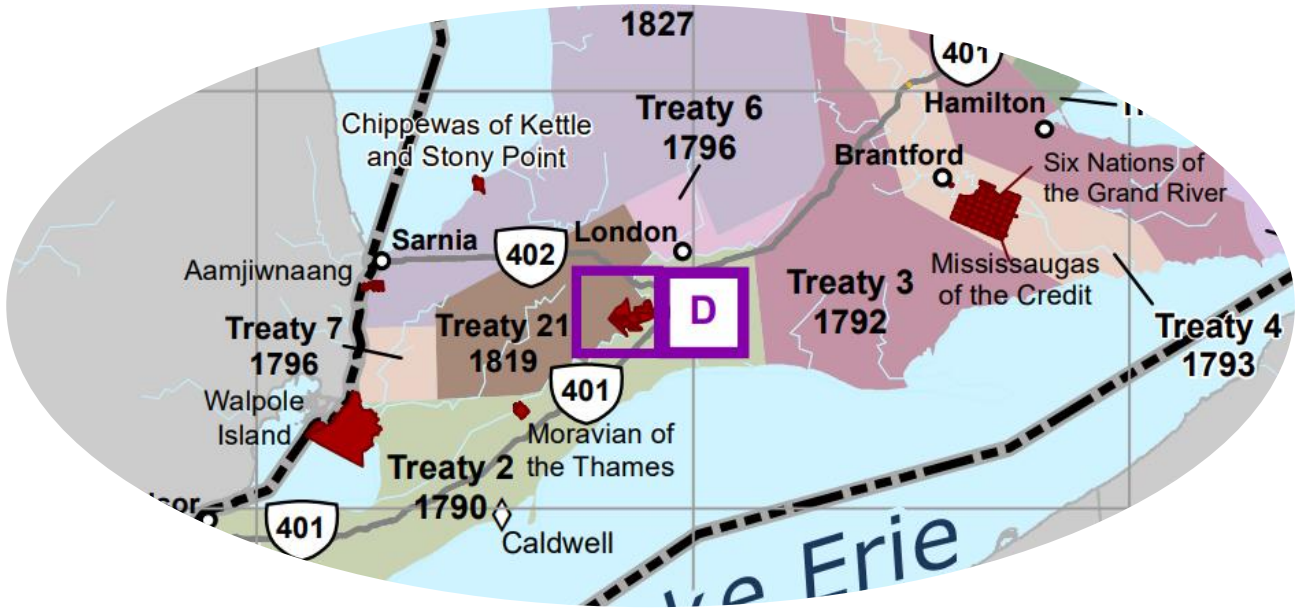

Truth and Reconciliation Commission's 94 Calls to Action

Truth and Reconciliation
Commission of Canada

#19 To establish **measurable goals to close health gaps** between Indigenous and non-Indigenous peoples

#23 Increase **Indigenous healthcare representation** and create culturally safe learning environments

#24 Mandatory education on Indigenous health, history, Treaties, and rights for all students

#65 Establish **national research programs to advance reconciliation** & support Indigenous knowledge

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Positionality

- **Identity:** White, settler, cis, gay, queer, Franco, ADHD
- **Lived experience:**
  - Chronic lumbopelvic pain
  - Both parents with inflammatory arthritis
- **Research & clinical background**
  - Arthritis, pain, pelvic health, LGBTQIA+ health
  - Patient and community engagement
  - Physiotherapist

How does my positionality impact
- **the questions I ask?**
- **what knowledge I value?**
- **how I communicate findings?**

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Why EDID Matters in Knowledge Mobilization

Imagine you've just finished an incredible study...

Consider…

- Who will read it? Who won’t?
- Who will understand it?
- Who trusts the information? Who won’t?
- Who was it designed for?
- Who benefits? Who is left out?
- How do you know?

Has knowledge actually been mobilized?

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Learning Objectives

By the end of this session, you will be able to:

- Describe how **equity**, **diversity**, **inclusion**, and **decolonization** principles influence the **quality, relevance** and **impact** of knowledge mobilization
- Identify where **inequities** can arise across the **knowledge-to-action pathway**
- **Apply EDID principles** to the **design**, **implementation** and **evaluation of knowledge mobilization**
- Reflect on how **positionality influences knowledge production and mobilization**

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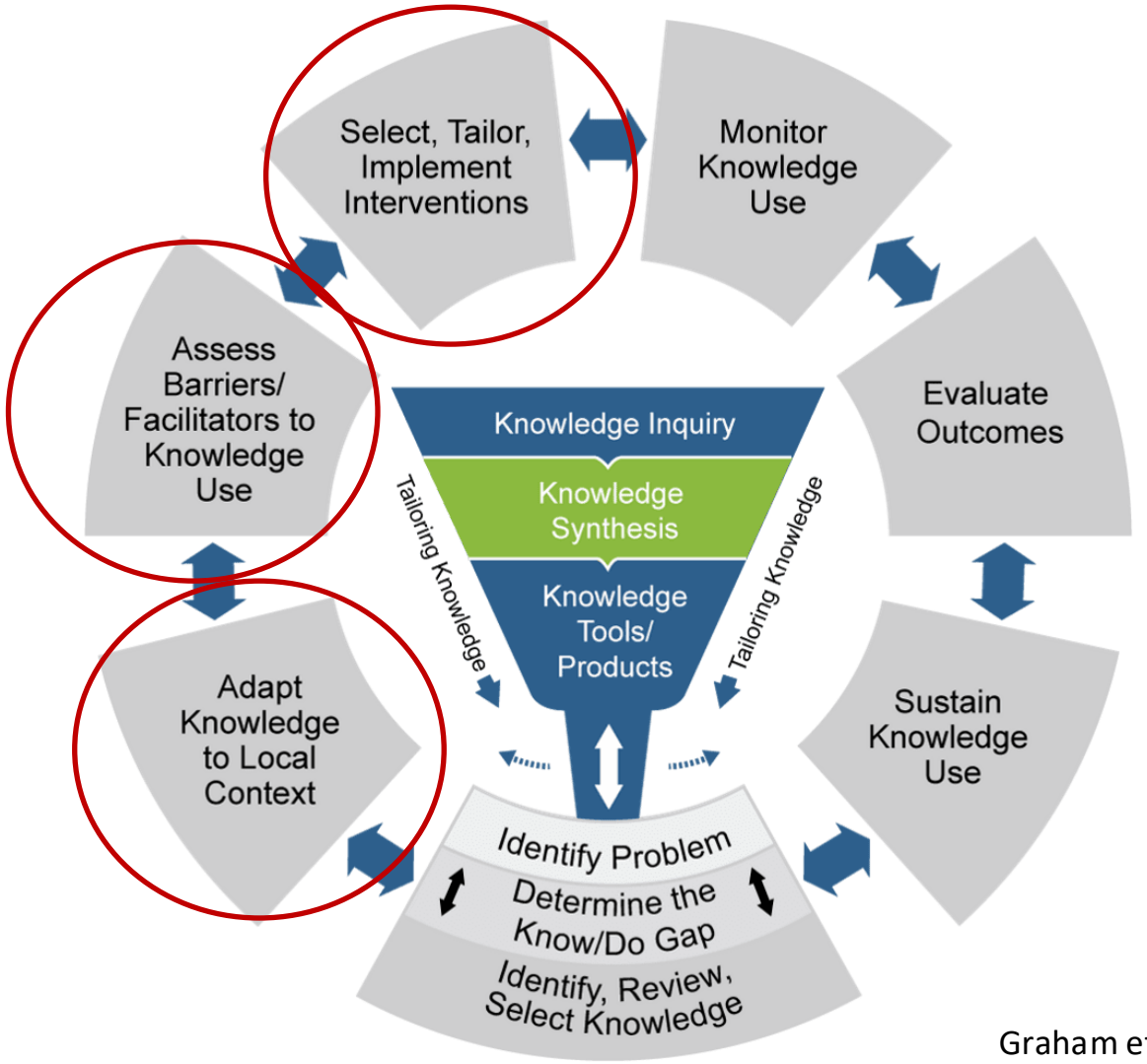
Knowledge-to-Action (KTA) Cycle

- **Bridges** the gap between **research** and **practice**
- **Guides** how evidence is **adapted**, **implemented**, and **sustained**
- **Recognizes** that **one approach does not fit every context** or **community**



Graham et al., 2006

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5 Questions Every Knowledge Mobilizer Should Ask

1. **Who are we trying to reach?**
2. **What assumptions are we making?**
3. **What barriers exist?**
4. **How should our strategy change?**
5. **How will we know it worked?**

Producing Knowledge Worth Mobilizing

Why Representation Strengthens Science

- Health research often includes a **homogeneous sample – lack of diversity**
  - **Knowledge gaps** in epidemiology, disease experiences, treatment response

- Findings appear **universal**, but are **less directly applicable** to many seen in practice

- **Inclusive data** improves **validity, generalizability** and **clinical relevance**

When people's realities are missing from our data, our science loses accuracy

Thomas et al., 2024; Wiens et al., 2024; Yip et al., 2021

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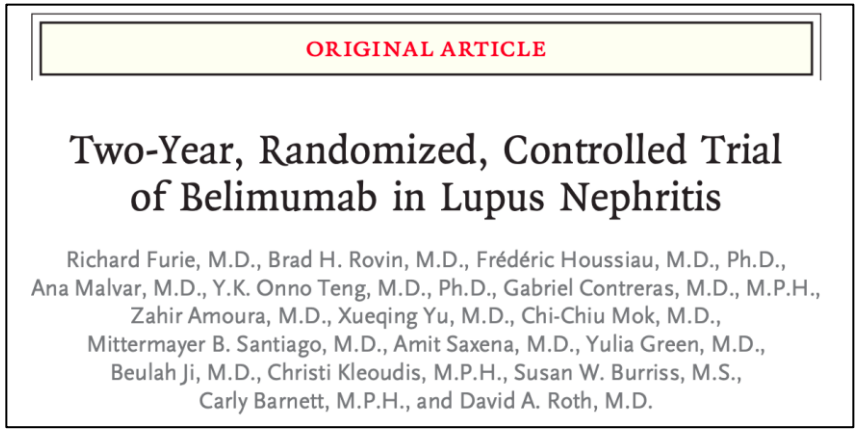
Example: Belimumab for Lupus

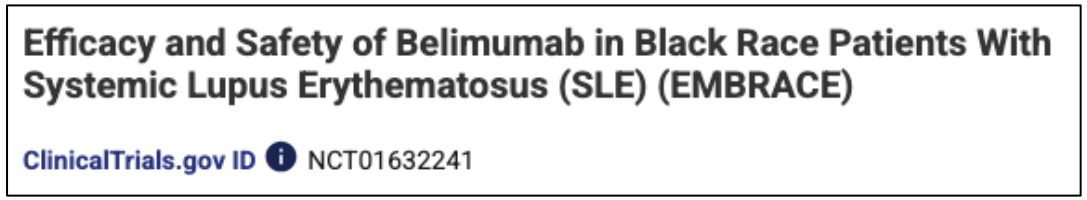
- Early trials included **few Black participants → results uncertainty**
- Regulators advised **caution in prescribing** to **Black patients** due to limited evidence
- A **dedicated trial (EMBRACE)** was launched to assess safety and effectiveness
- EMBRACE results confirmed **similar benefits for Black patients**
  - Removal of the cautionary statement
- Shows how **underrepresentation** creates **data gaps** that affect **care and equity**



ORIGINAL ARTICLE

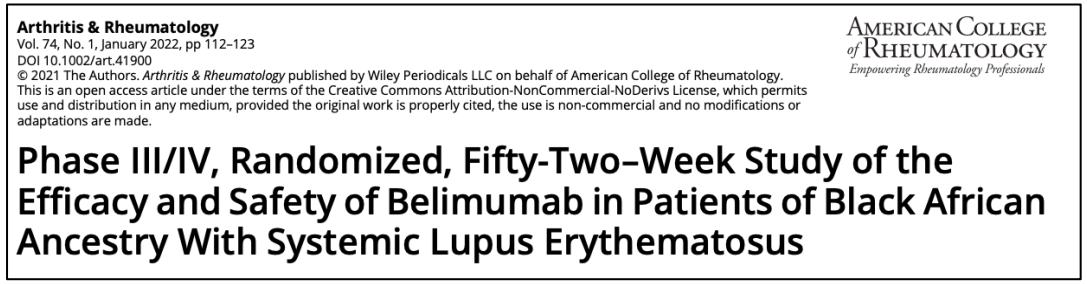
Two-Year, Randomized, Controlled Trial of Belimumab in Lupus Nephritis

Richard Furie, M.D., Brad H. Rovin, M.D., Frédéric Houssiau, M.D., Ph.D., Ana Malvar, M.D., Y.K. Onno Teng, M.D., Ph.D., Gabriel Contreras, M.D., M.P.H., Zahir Amoura, M.D., Xueqing Yu, M.D., Chi-Chiu Mok, M.D., Mittermayer B. Santiago, M.D., Amit Saxena, M.D., Yulia Green, M.D., Beulah Ji, M.D., Christi Kleoudis, M.P.H., Susan W. Burriss, M.S., Carly Barnett, M.P.H., and David A. Roth, M.D.



Efficacy and Safety of Belimumab in Black Race Patients With Systemic Lupus Erythematosus (SLE) (EMBRACE)

ClinicalTrials.gov ID NCT01632241



Arthritis & Rheumatology
Vol. 74, No. 1, January 2022, pp 112–123
DOI 10.1002/art.41900

American College of Rheumatology
Empowering Rheumatology Professionals

Phase III/IV, Randomized, Fifty-Two–Week Study of the Efficacy and Safety of Belimumab in Patients of Black African Ancestry With Systemic Lupus Erythematosus

Ginzler et al., 2022

Furie et al., 2020

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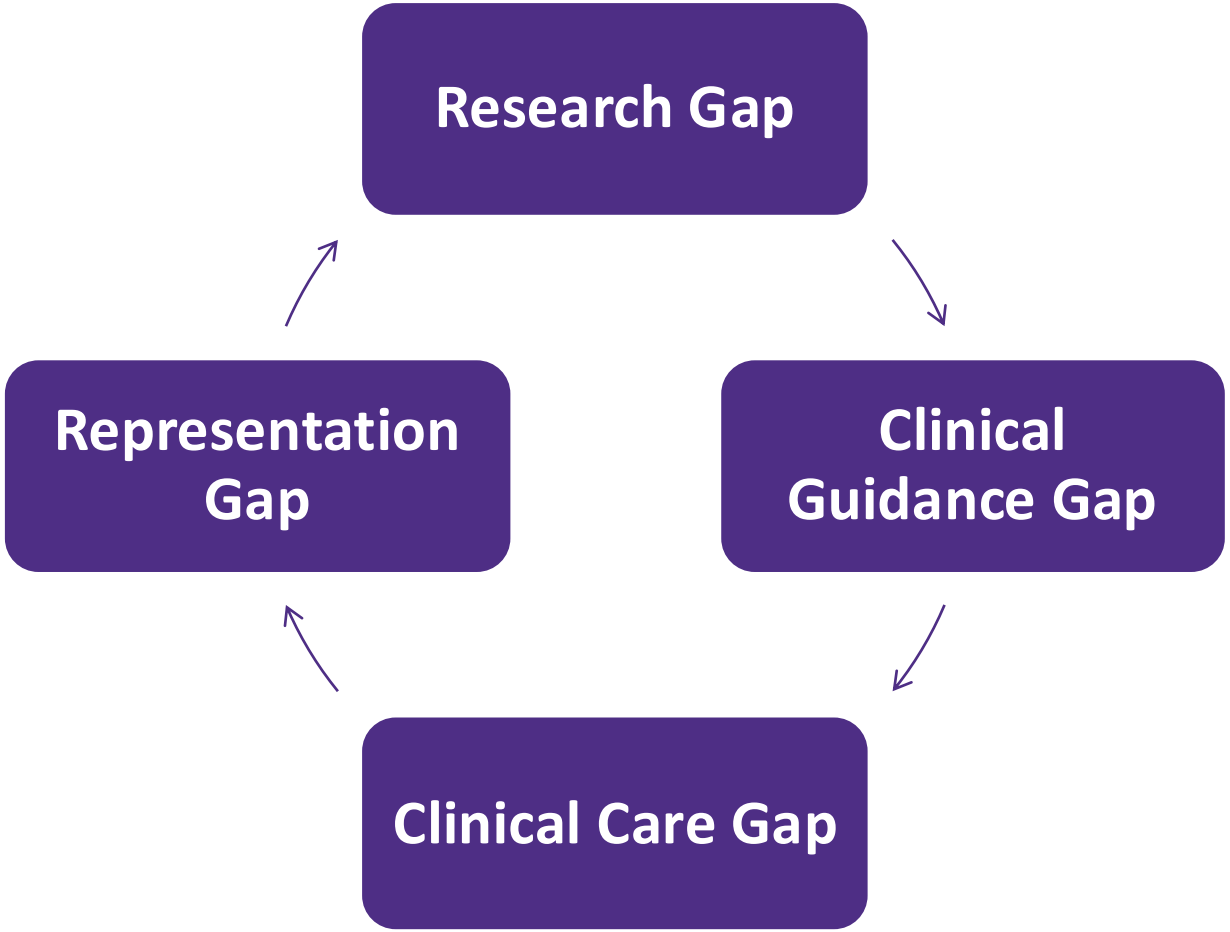
From Representation to Impact



Representation in research closes the loop between evidence and care

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Who Benefits From Knowledge?

- Individuals with which identities or life circumstances become **invisible** when eligibility criteria function as filters?
- Which assumptions about **participation**, **language**, **risk**, or **ability to consent** show up here?
- How does this impact **generalizability**?

Who is missing from the evidence we hope to mobilize?

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When Populations Are Missing

Missing populations → missing guidance

- How does this show impact effective and accurate KMb?
  - Many **MSK and orthopedic trials** still **exclude cognitive impairment**, **multimorbidity** or **polypharmacy** despite being common in practice
  - Limited rehabilitation research with **neurodivergent adults**
  - Sparse data on **pain communication** across **cultures**, **languages** and **health beliefs**
  - Minimal examination of how **racism**, **discrimination** and **stigma** influence **care seeking** and **participation**

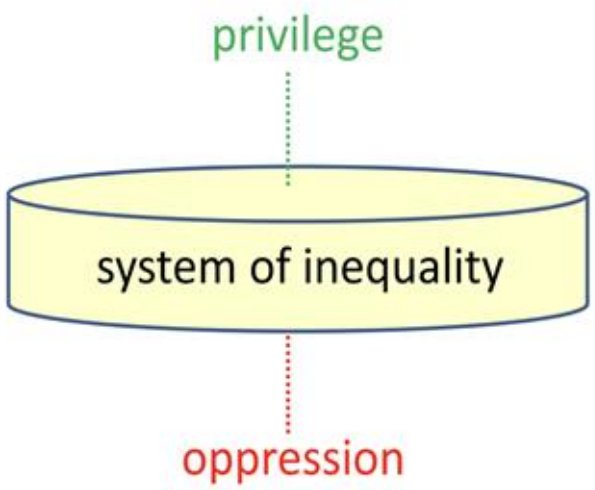
Mathias et al., 2023

Systems Shape Who Benefits From Knowledge

The coin model of privilege and critical allyship: implications for health

Stephanie A. Nixon[1,2]

Power & Privilege

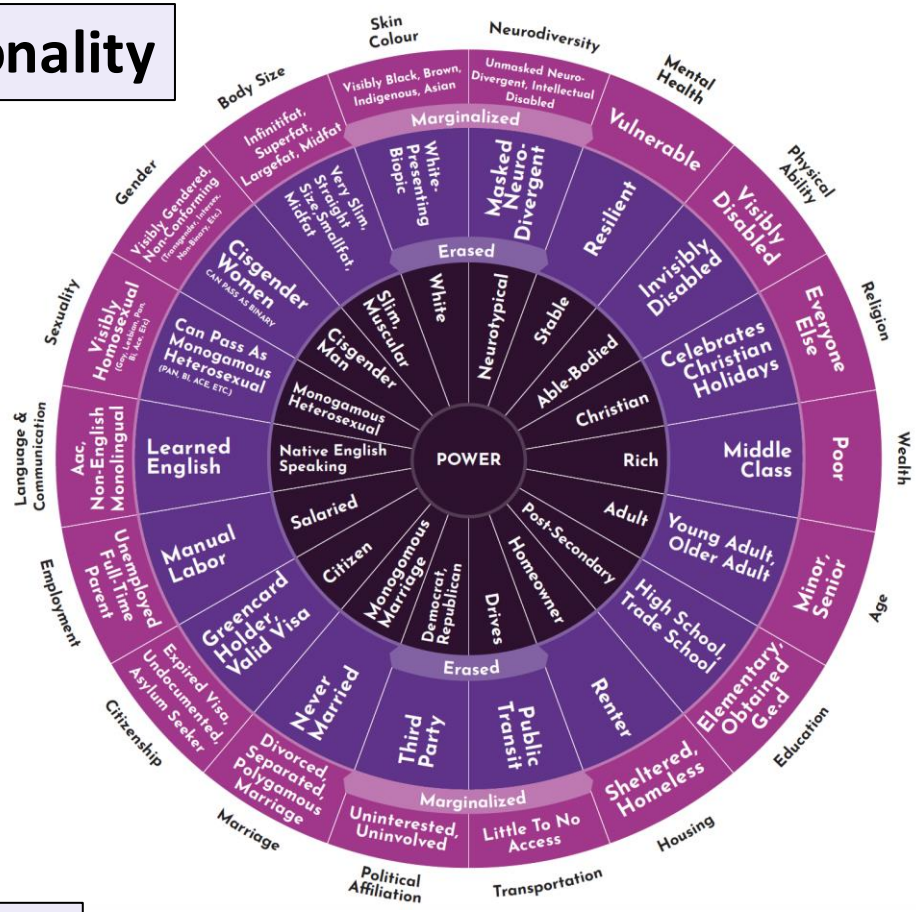


Top of the coin
- You have advantage others do not
- You did not earn it
- You have it because of who you happen to be

The coin
- The social structure that produces and maintains inequality
  e.g., sexism, racism, ableism

Bottom of the coin
- You have disadvantage others do not
- You did not earn it
- You have it because of who you happen to be

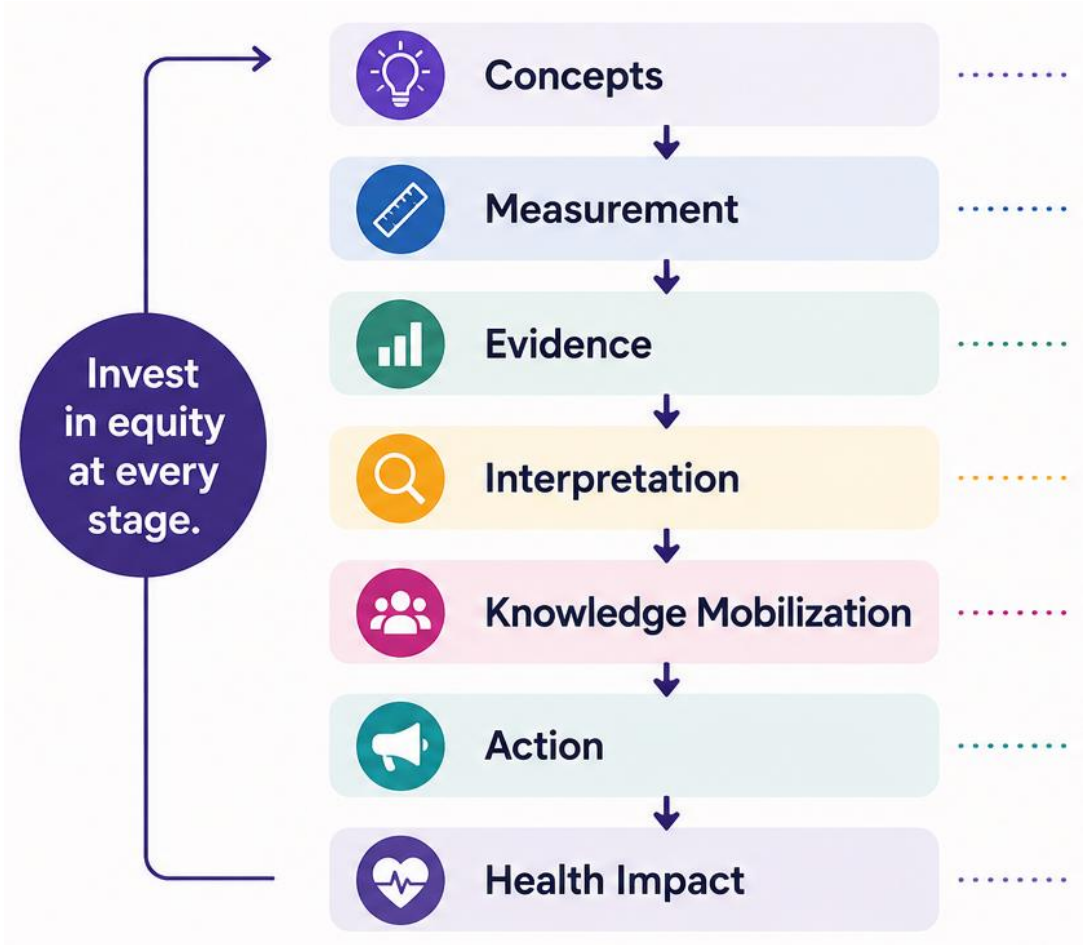
Intersectionality



Bias

Nixon, 2019
Hankivsky, 2014

When Populations Are Missing



What questions are we asking and why?

What and who are we measuring?

What data are we generating and whose is missing?

How do we make sense of the data?

How do we share knowledge equitably and accessibly?

What will partners, clinicians, communities do with it?

Who benefits and how do we close the gaps?

Every upstream decision shapes the knowledge that is ultimately being mobilized

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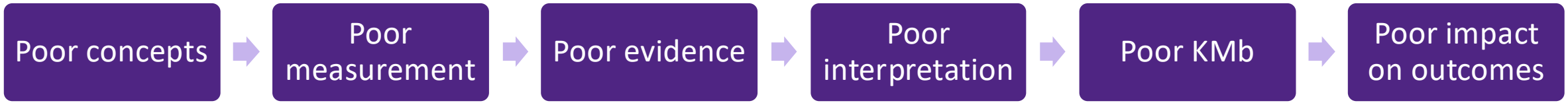
Producing Knowledge We Can Trust

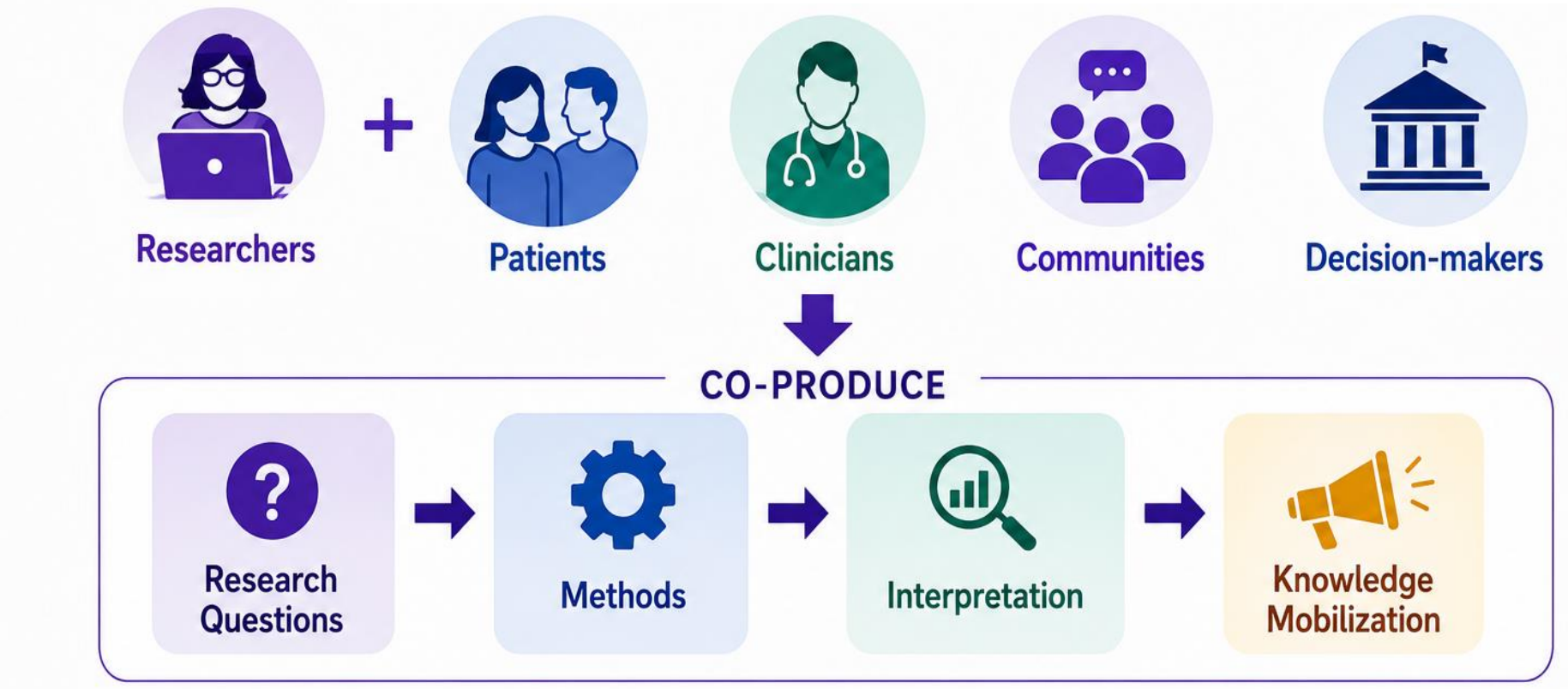
Trustworthy Knowledge Requires Trustworthy Partnerships

If we conceptualize or measure the **wrong construct**, we produce **knowledge that is less trustworthy** and **less useful**



Integrated Knowledge Translation (iKT)

Researchers and **knowledge users work together** throughout the research



Partnership builds more trustworthy and useful knowledge

Gagliardi et al., 2016; Kothari et al., 2017

Knowledge Mobilization Depends on Relationships

Trust

Build and maintain trust over time

Reciprocity

Exchange value and benefit equitably

Shared Decision-Making

Involve partners in priorities and decisions

Long-term Relationships

Invest in relationships that last beyond a single project

Strong relationships lead to trusted knowledge and meaningful impact.

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Evaluate Trust & Representation

Questions to ask when designing or appraising research:

- Who was **invited** and who **participated**?
- Did the study **engage with communities** or simply **extract data**?
- Were **language, imagery and materials** accessible and culturally relevant?
- Was participation **compensated** and **recognized** appropriately
- Were **community priorities** reflected in study aims or outcomes?
- Did the research build **ongoing relationships** or rely on one-time interactions?

Consider, would recruitment have been **accessible**, **safe**, **affirming**, **logistically feasible**, and **trust-building** for the populations we want represented in the evidence?

Ashley, 2020; Cwinn et al., 2021; McCormack, 2014; Owen-Smith, 2016

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Audience Mapping

Who have we forgotten?

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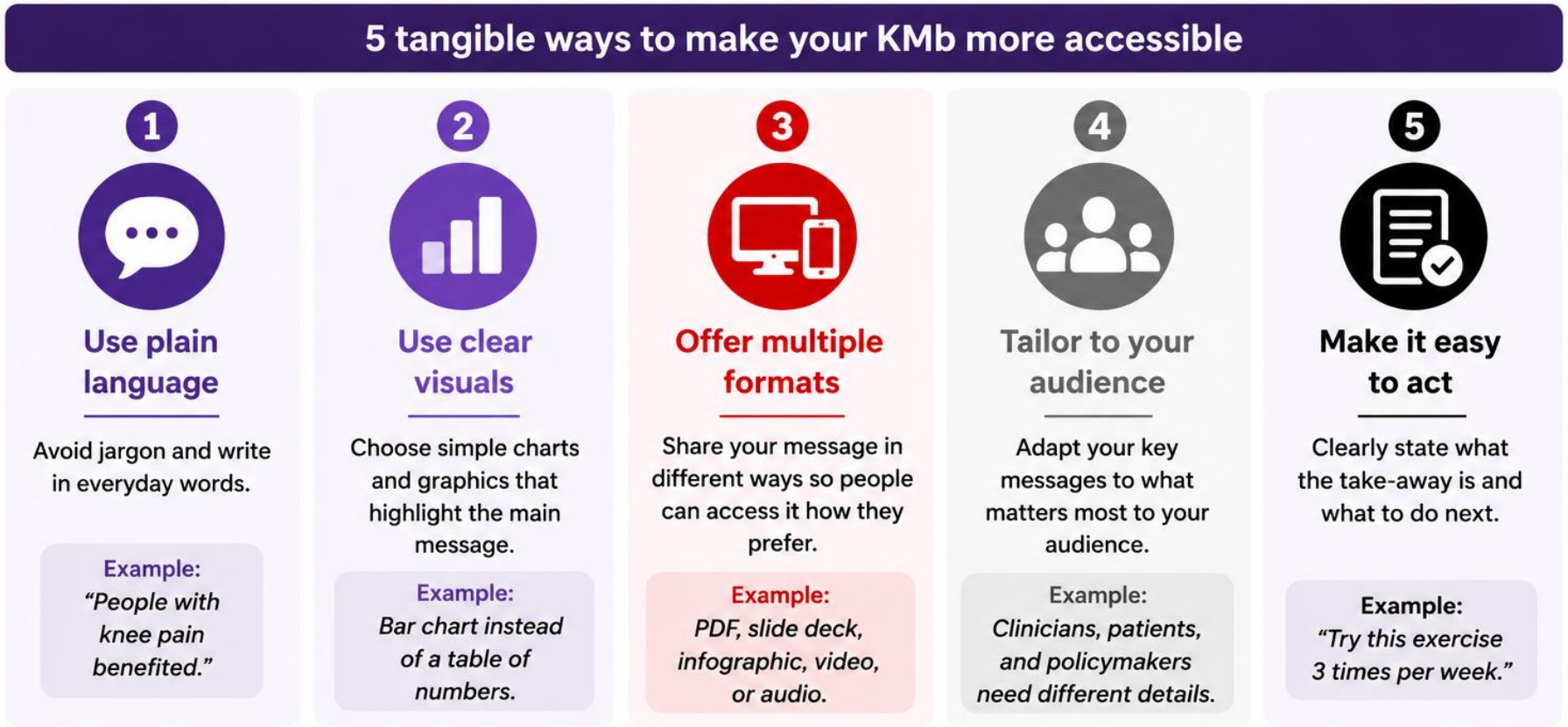
Hidden Assumptions

We often assume people…

- Speak English
- Have internet
- Trust researchers
- Have transportation
- Can read
- Can attend daytime events

Accessibility is good KMb

When we make knowledge **accessible**, more people **understand it**, **use it**, and **act on it**



Accessibility includes literacy, language, disability, technology, culture & format

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PROGRESS-Plus Framework

PROGRESS-Plus can help identify factors we should be thinking about that influence who is **represented in KMb products**, and who has **access to information through KMb**

PROGRESS-Plus	Potential constructs captured
Place of residence	Rural, remote, or local access differences
Race and ethnicity	Self identified categories and relevance to condition
Occupation	Work demands, employment status, return to work factors
Gender and sex	How measured, which variables used, and why
Religion	Cultural or care participation considerations when relevant
Education	Literacy, self management, and rehab engagement
Socioeconomic status	Income, insurance, or financial barriers
Social capital	Social support, caregiving roles, community networks
Plus	Disability, language, comorbidity, age, newcomer status

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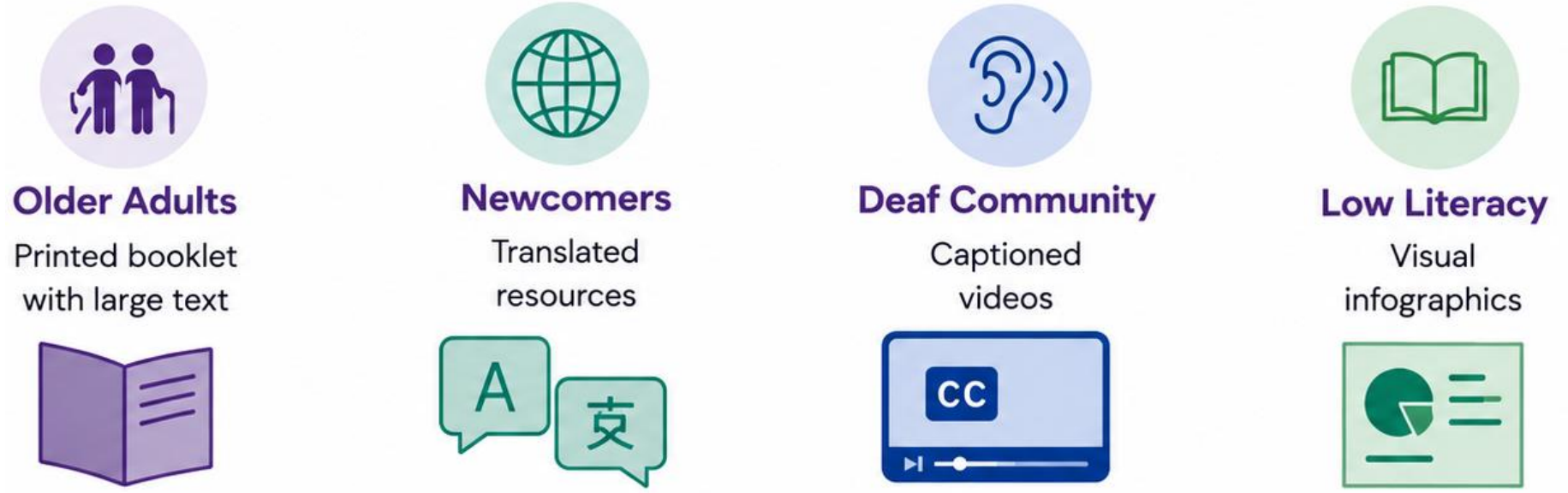
Cochrane Health Equity

Oliver et al., 2008; 2012
O'Neil et al., 2014

PROGRESS-Plus in Action

For example…

You will likely need to tailor your KMb to specific audiences



But also, do not make assumptions reinforced by stereotypes

Oliver et al., 2008; 2012
O'Neil et al., 2014

But Don't Confuse Tailoring with Stereotyping

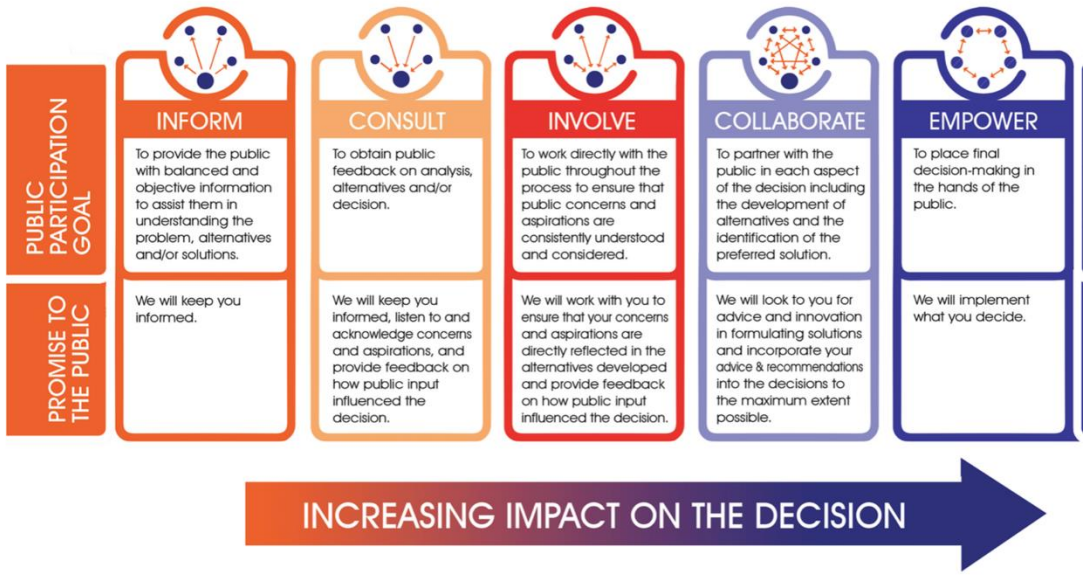
Tailor communication **with** communities, **not based on assumptions** about communities. For example:

- "Older adults don't use technology"
- "Everyone with low literacy wants pictures"
- "All newcomers require translation"

Instead:

- **Ask**
- **Co-Design**
- **Test**

And remember IAP2…



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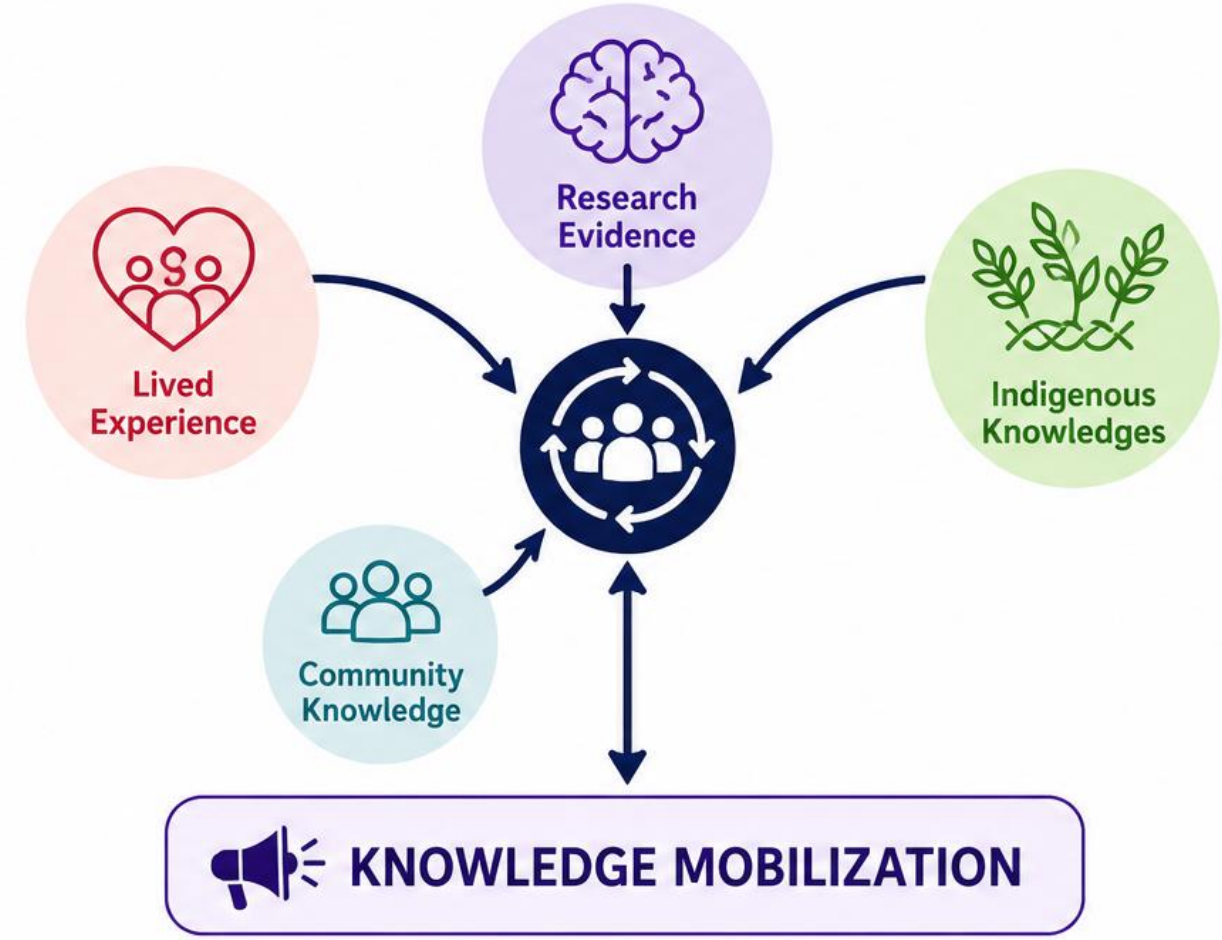
Decolonizing KMb

Decolonizing Knowledge Mobilization

Decolonization asks us to reconsider **not only how knowledge is shared**, but **whose knowledge is prioritized**, **who has authority**, and **who benefits**

Good KMb values <u>multiple ways of knowing</u>, not just published evidence



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How CARE Shapes Indigenous Health Research

Collective Benefit

Who benefits?

Does this knowledge create value for Indigenous communities?

Authority to Control

Who decides?

Who controls interpretation and sharing?

Responsibility

Who is involved?

Are Indigenous communities partners throughout?

Ethics

How is knowledge shared?

Does mobilization respect Indigenous priorities and protocols?

CARE helps ask if KMb is <u>accountable to Indigenous communities</u>, not just about them

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Carroll et al., 2020; 2022

Example to Apply the CARE Lens

A provincial health study compared chronic disease rates between Indigenous and non-Indigenous populations using administrative data

The study:

- Reported **disparities**
- Used **rigorous methods**
- Interpreted findings without **Indigenous governance** or **voice**
- Did not **return findings** to Indigenous communities
- Offered **no collective benefit** to Indigenous communities
- Reinforced **deficit narratives**

While this study is methodologically rigorous, discuss what makes it inequitable from a CARE perspective?

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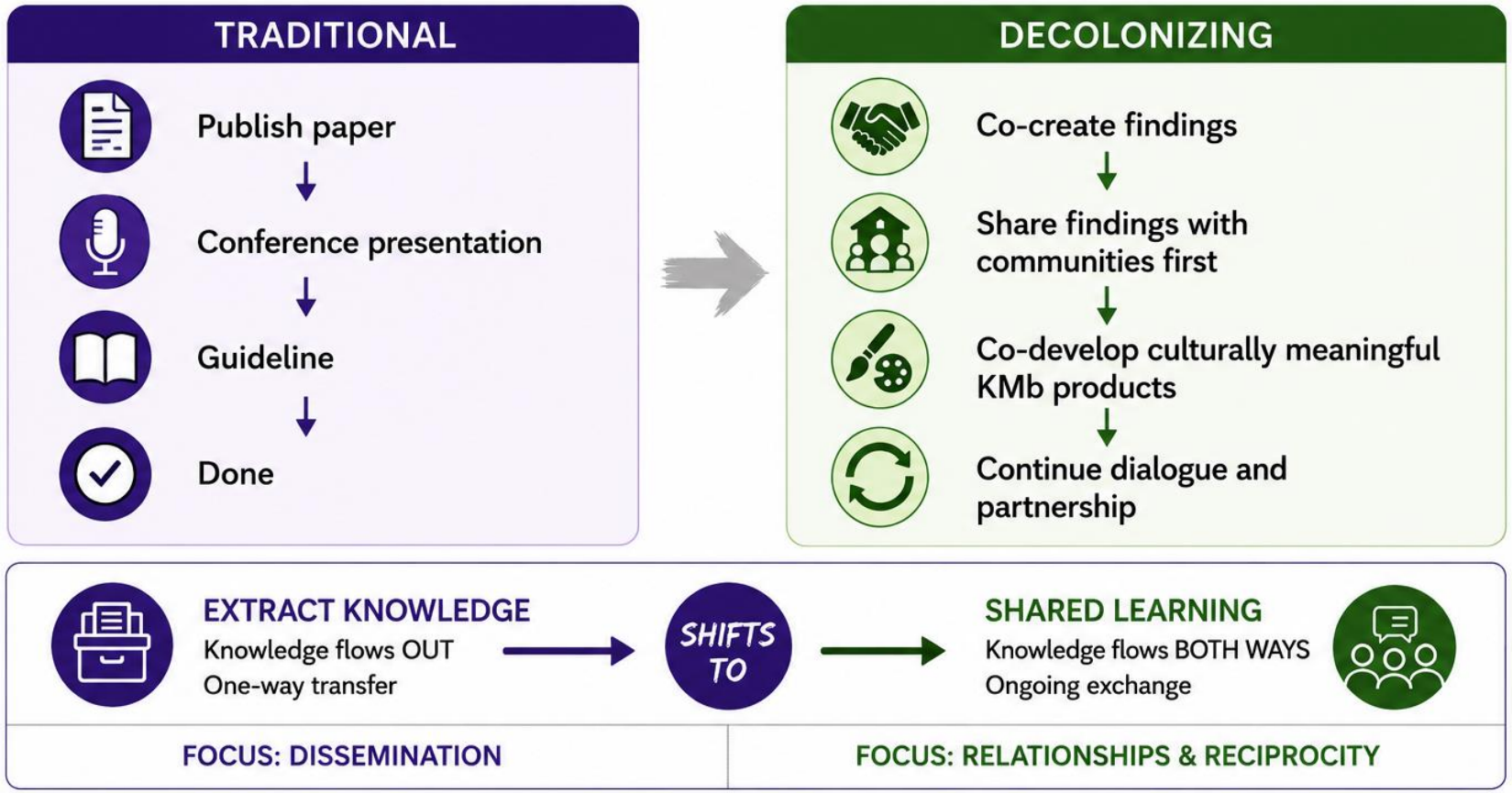
What does Decolonizing KMb Look Like?

From **dissemination** to **reciprocity**



Decolonizing KMb is not simply sharing knowledge differently. It changes who shapes knowledge, who interprets it, and who benefits from it

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What This Means for Graduate Researchers

When planning KMb involving Indigenous Peoples ask:

- **Who has authority** over interpretation?
- **Who benefits** from this knowledge?
- **Are findings returned** in meaningful ways?
- Are **Indigenous priorities reflected**?
- Are **Indigenous partners shaping KMb** products?

Practice shift: Move from mobilizing knowledge ***about*** Indigenous communities to mobilizing knowledge ***with*** Indigenous communities

Carroll et al., 2020; 2022

Wrap-Up

5 Questions Every Knowledge Mobilizer Should Ask

1. **Who are we trying to reach?**
2. **What assumptions are we making?**
3. **What barriers exist?**
4. **How should our strategy change?**
5. **How will we know it worked?**

One Message. Different KMb Products

Research Finding = Exercise Helps with Knee Osteoarthritis Symptoms

The audience determines the strategy.

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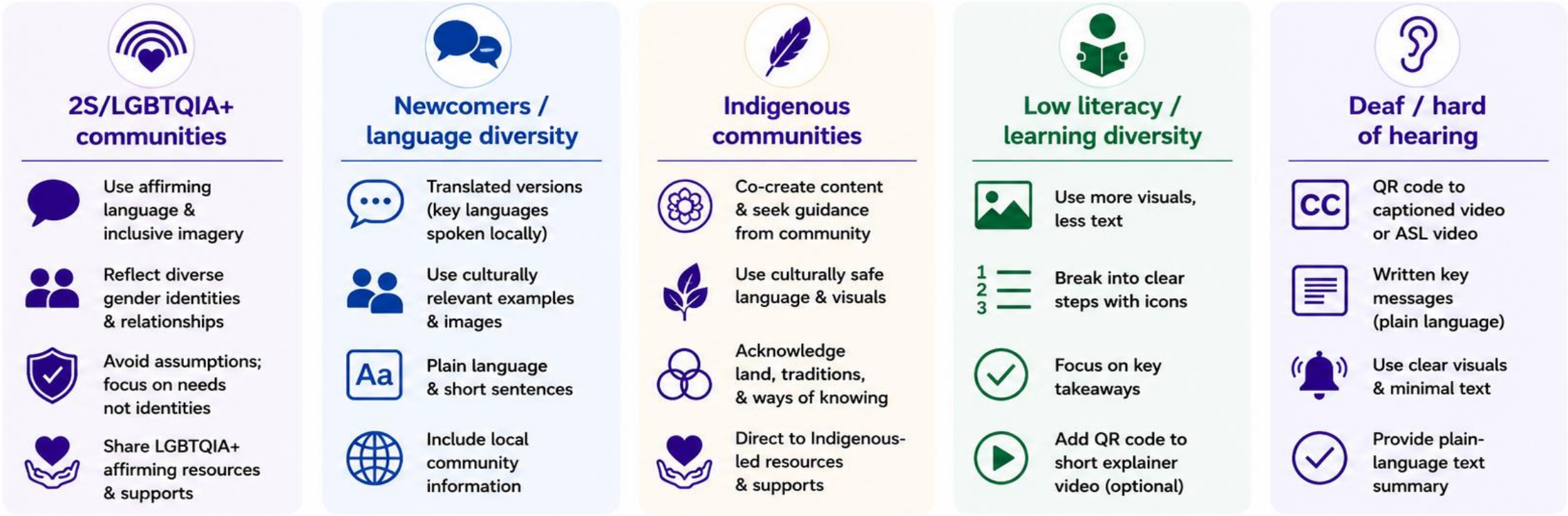
Same Format. People Have Different Needs

E.g., Infographic showing therapeutic exercise helps with knee OA symptoms



Equity happens in the **details.**

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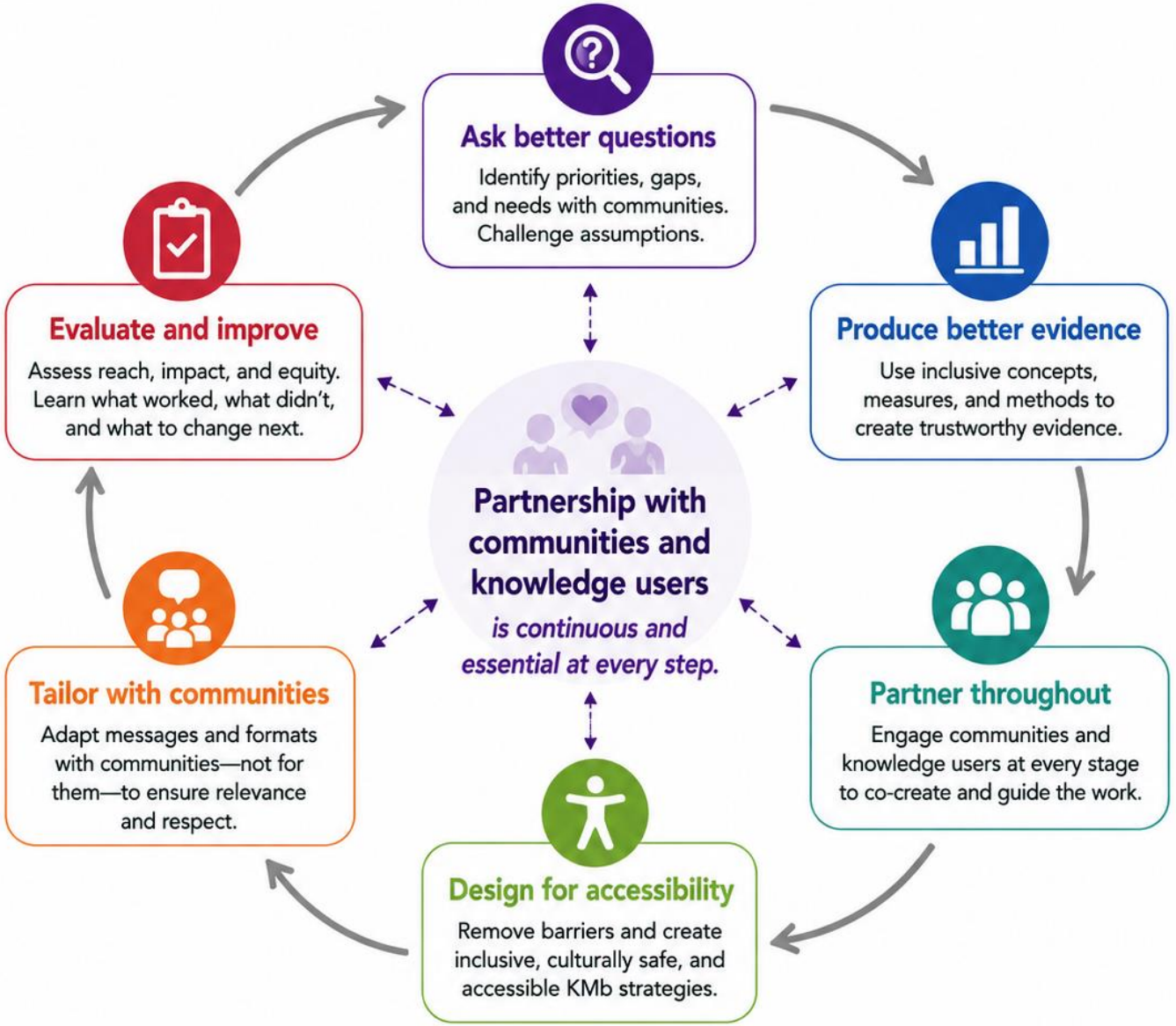
Equitable Knowledge Mobilization Is A Process

Equity is not something we "add" to KMb, it is something we build into every stage of research



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Thank you!

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