

STAKEHOLDER ENGAGEMENT IN RESEARCH

TUNG NGUYEN, MD

There is an “I” and an “us” in
“genius.”

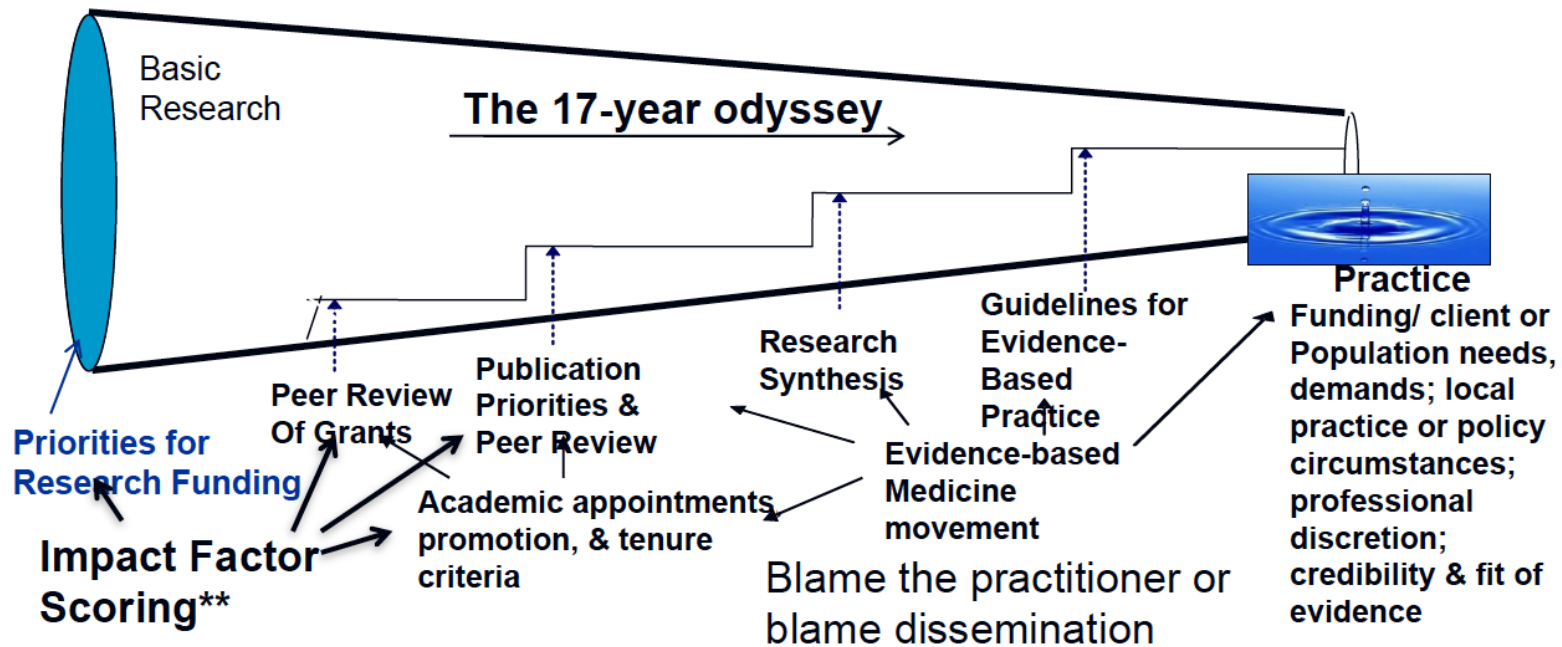
ASSIGNMENT

You are a researcher with all the grants, publications, and academic advancement you need.

- What is the change in health behavior or outcome that you want to have achieved to consider your research career a success?
- How long are you willing to wait for this change?
- Who are the people who need to know, understand, and/or care about your work to make this change possible?

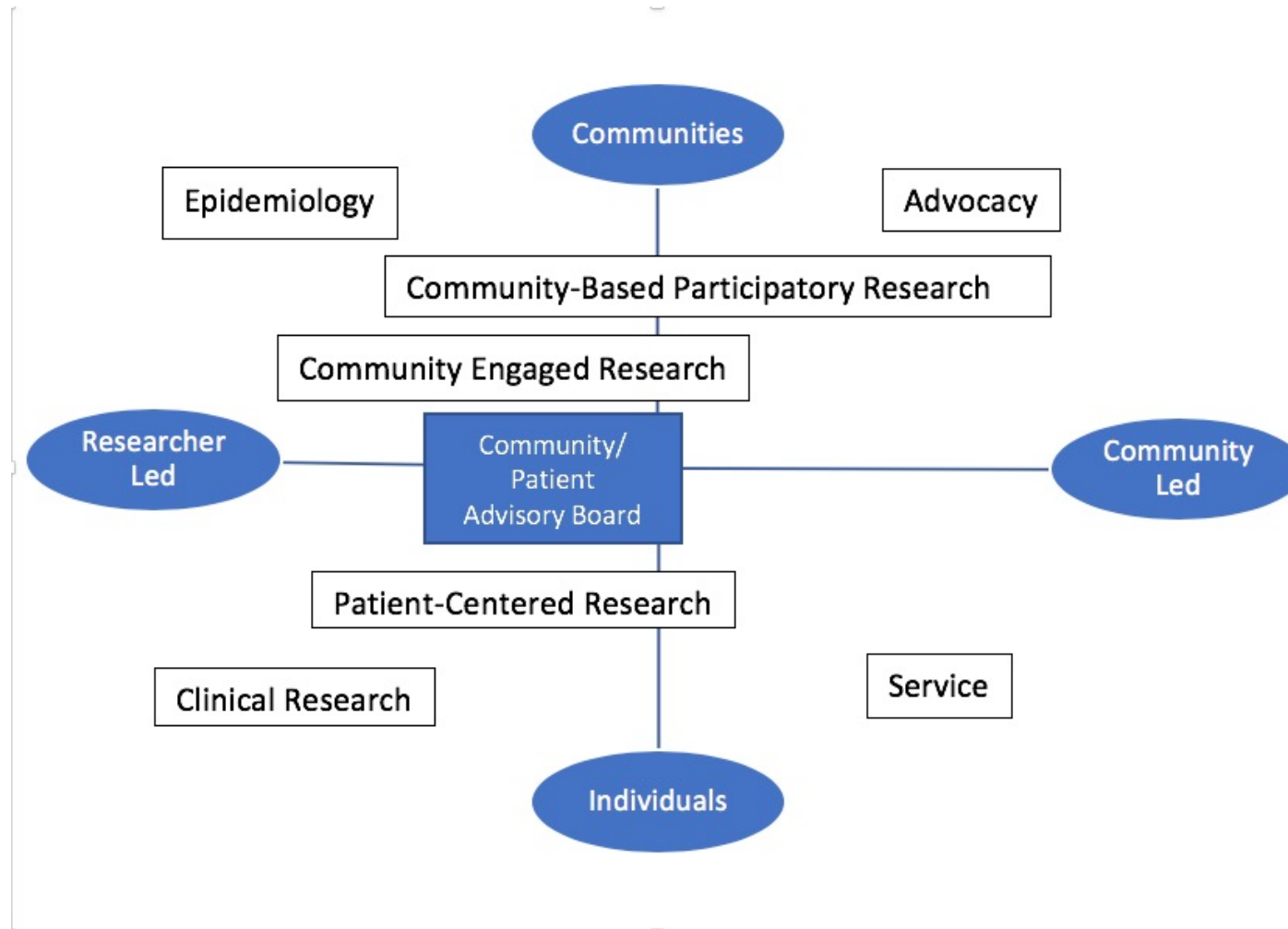
WHY STAKEHOLDER ENGAGEMENT IS NECESSARY

The Pipeline Fallacy of Producing & Vetting Research to Get Evidence-Based Practice*



*Green LW (2008). If it's an evidence-based practice, where's the practice-based evidence? *J Family Med* 25 (suppl 1): 20-24; ***J Partic Med* 2009;1(1).<http://iopm.org/index.php/ipm/article/view/16/31>.

A PRELIMINARY TAXONOMY OF TYPES OF HUMAN RESEARCH AND OTHER ACTIONS FOR CHANGE



WHO ARE STAKEHOLDERS?

“individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavor”

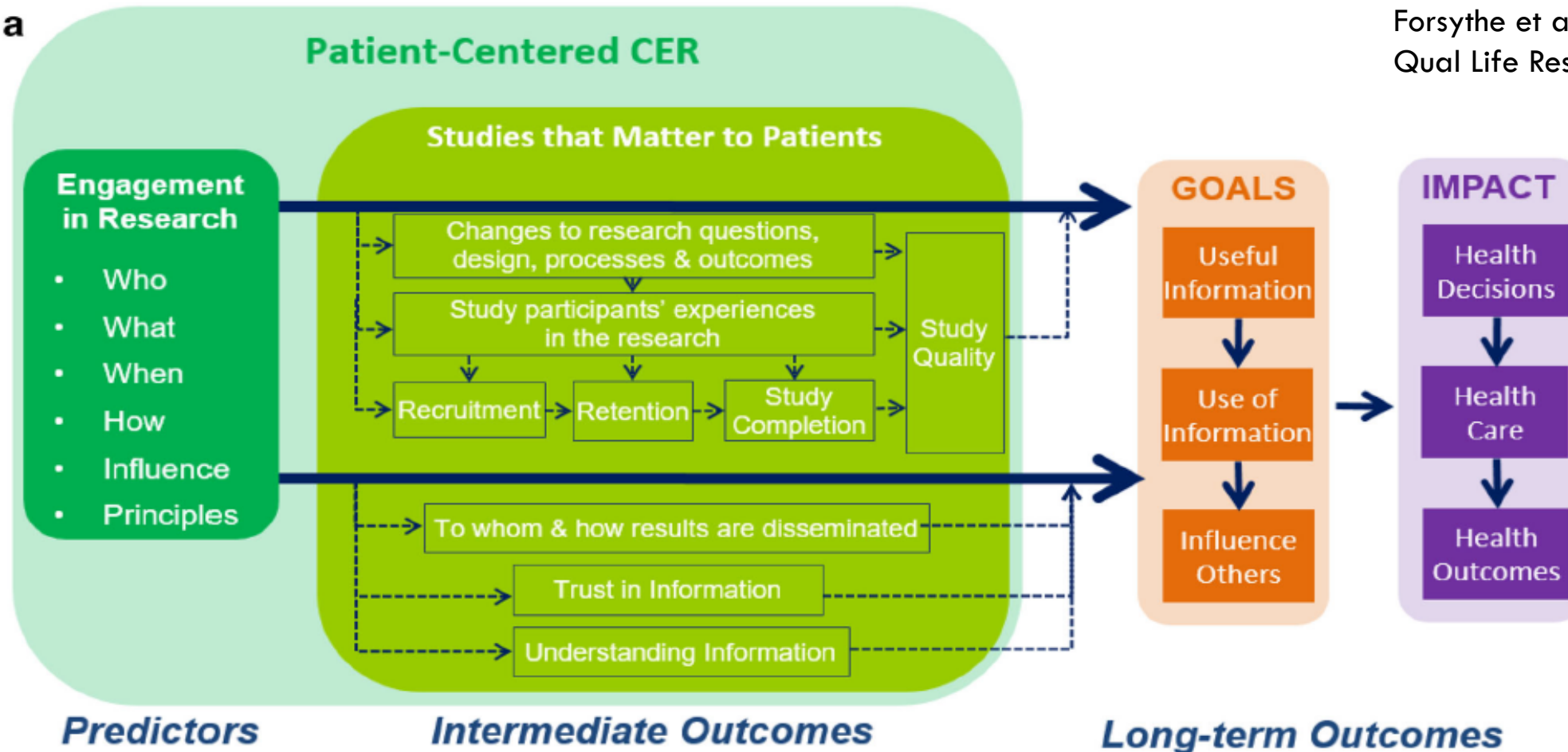
Deverka et al. J Comp Eff Res. 2012;1(2):181–94.

- Patients and the public
- Providers
- Purchasers
- Payers
- Public policy-makers and policy advocates in non-governmental sector
- Product makers
- Principal investigators

Concannon et al. J Gen Intern Med. 2012;27:985–91

HOW DOES STAKEHOLDER ENGAGEMENT INFLUENCE RESEARCH?

a

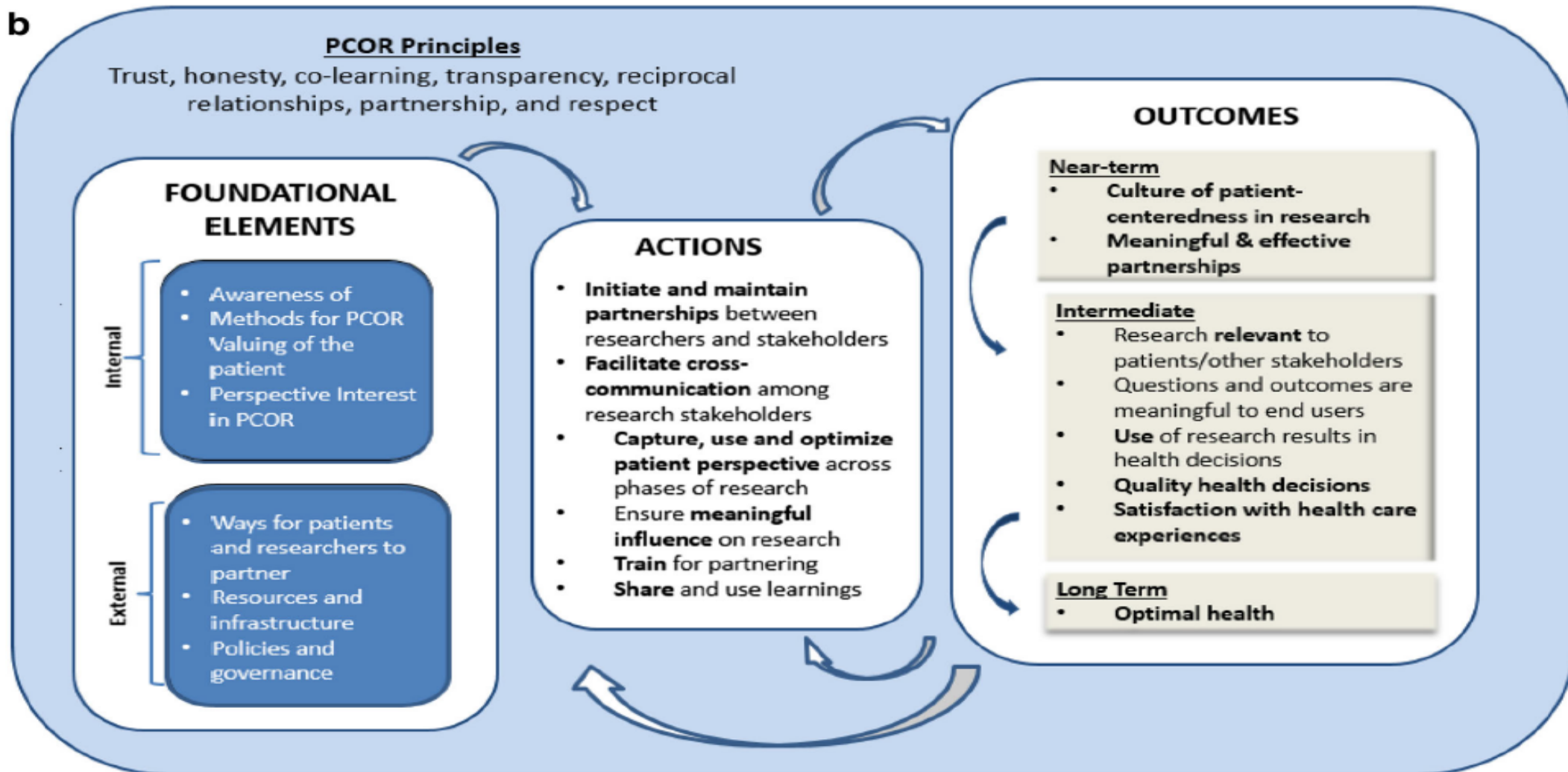


Forsythe et al.

Qual Life Res (2018) 27:17–31

PATIENT-CENTERED OUTCOMES RESEARCH LOGIC MODEL

b



SECONDARY DATA ANALYSIS AND STAKEHOLDERS

- To identify the most relevant questions from the data
- To obtain the data
- To analyze the data
- To interpret the data
- To disseminate the data
- To implement policies as a result of the data
- To help obtain funding for next step or intervention to address data

PRACTICAL ADVICE ABOUT STAKEHOLDER ENGAGEMENT

- If you need a letter of support for this grant, that person should be involved as a stakeholder (and vice-versa).
- If you need a letter of support for the follow-up grant, that person should be involved as a stakeholder.
- Ask mentors, navigators, and community leaders for additional referrals to other stakeholders.
- Pay your stakeholders commensurate to the cost of their time, especially patients and community members/leaders.

PRACTICAL ADVICE ABOUT STAKEHOLDER ENGAGEMENT-PT 2

- Genuine stakeholder engagement takes time—have faith that it will make the research better.
- Try to have some meetings NOT at your research office.
- Share meeting agenda early to get feedback.
 - People are more likely to come to a meeting whose agenda they shaped.
- Provide food.
- Your job at the stakeholder meeting is not to talk or to defend. It is to listen, to acknowledge, and to respond with immediate or future actions.
- Stakeholder engagement work is fun and regenerative.

FOR MORE INFORMATION

- UCSF CTSI Community Engagement and Health Policy Program:
 - Community-Engaged Research Guides and Resource Manuals:
<https://accelerate.ucsf.edu/research/community-manuals>
 - Community-Engaged Research Consultation
<https://accelerate.ucsf.edu/consult/community-engaged-research>
- PCORI Engagement in Health Research Literature Explorer
<https://www.pcori.org/literature/engagement-literature>
- Center for Participatory Research at University of New Mexico: CBPR Engage for Equity
<https://cpr.unm.edu/research-projects/cbpr-project/index.html>