

The PATIENTS Program at



UNIVERSITY of MARYLAND
SCHOOL OF PHARMACY



State of the evidence: relationship of engagement, culture and disparities

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From community-based participatory research to community-based participatory healing

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What you should know about partnering with the community to do research

- Any community consists of persons joined by some commonality (e.g., political, racial, educational, occupational, etc.); no community is monolithic
 - Be authentic and intentional in understanding what defines “community” for your place/people of research, but also be authentic and intentional about its differences
 - Bottom line: do not approach community members as all the same, but rather as individuals who make up the whole
- Co-create a bidirectional and mutually beneficial research structure



What you should know about partnering with the community to do research

- Many Native Americans, African Americans, Latinos, and other minorities are very distrustful of researchers because of “research history”
- Before trying to engage a community in your research, seek to understand the community
- What are its SWOT? Who are its leaders? What are its assets? What are its needs? Who are its stakeholders?



What you should know about partnering with the community to do research

- Seek the advice of “recognized” community leaders or persons of influence
- Be intentional about leaving a community better; research that is more self-serving than community healing is harmful to future research
- Never approach your research from a Messianic perspective

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Creating a Learning Health Care *Community*

Institute of Medicine (IOM) defined a learning healthcare system

- Generates and applies the best evidence for the collaborative healthcare choices of each patient and provider;
 - Drives the process of discovery as a natural outgrowth of patient care; and
 - Ensures innovation, quality, safety, and value in healthcare
-
- BUT seems to require that patients enter the system in order to start learning



Creating a Learning Health Care *Community*

The successful implementation of a Learning Health Care Community

- Requires significant shifts from the current healthcare model
- Most vulnerable patients/stakeholders often are left out
 - Even when the catchment area extends into community neighborhoods
 - Geographic proximity does not equate to access or engagement
- Is aligned with the NIH's *All of Us* Initiative
 - "Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in environment, lifestyle and genes *for each person*"



Creating a Learning Health Care *Community*

Requires active participation by community members and leaders

- Learning: answering patients' (not researchers') questions
- Health Care: improving health and well being of patients & community
- Community: applying principles of community-based participatory research



Creating a Learning Health Care *Community*

Facilitated by community organizations and leaders

- Community clinics
- Faith-based organizations
- Neighborhood stores, barber shops, and beauty salons
- Where people live and work