What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a ‘one-stop shop’ for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally

ACCORDS Upcoming Events

March 11, 2024 AHSB 2200/2201, Zoom	**Statistical Methods for Pragmatic Research** Pragmatic Statistical Learning: From Data to Interpretable Insights *Presented by:* Ryan Peterson, PhD & Kathryn Colborn, PhD
April 3, 2024 AHSB 2002, Zoom	**Ethics, Challenges, & Messy Decisions in Shared Decision Making** Training Clinicians in Shared Decision Making: Lessons from SHARE *Presented by:* Chris Knoepke, PhD, MSW; Laura Scherer, PhD
April 15, 2024 AHSB 2200/2201, Zoom	**Statistical Methods for Pragmatic Research** *Presented by:* Michael Matheny, MD, MS, MPH
April 26, 2024 AHSB 2200/2201, Zoom 11am-1pm MT	**ACCORDS/CCTSI Community Engagement Showcase**
May 20, 2024 AHSB 2200/2201, Zoom	**Statistical Methods for Pragmatic Research** Planning a Pragmatic Effectiveness Trial with a Factorial Design by Targeting the Posterior Distribution Variance *Presented by:* Keith Goldfeld, DrPH, MS, MPA/MURP

*all times 12-1pm MT unless otherwise noted

COPRH Con

Colorado Pragmatic
Research in Health
Conference

Innovations in Pragmatic Research Methods

From Data to Equity, Policy, and Sustainability

June 5 - 6, 2024 | 10am-3:30pm MT

Registration is open now at **www.COPRHCon.com**

Early Bird Registration Ends 3/31

Registration Fees waived for students, staff, and faculty of CU SOM or CHCO

ACCORDS
ADULT AND CHILD CENTER FOR OUTCOMES
RESEARCH AND DELIVERY SCIENCE

UNIVERSITY OF COLORADO
CHILDREN'S HOSPITAL COLORADO

Ethics, Challenges, and Messy Decisions in Shared Decision-Making

2023-2024 Seminar Series

Channing Tate, PhD

Demetria Bolden, PhD

Miria Kano, MD

Lucinda Kohn, MD

Critical Conversations:

Health Equity Considerations for Working With and In Diverse Community

Shared Decision Making In Addressing Racial Disparities in Cardiovascular Disease

Demetria M. (McNeal) Bolden, PhD, MBA, CPLP

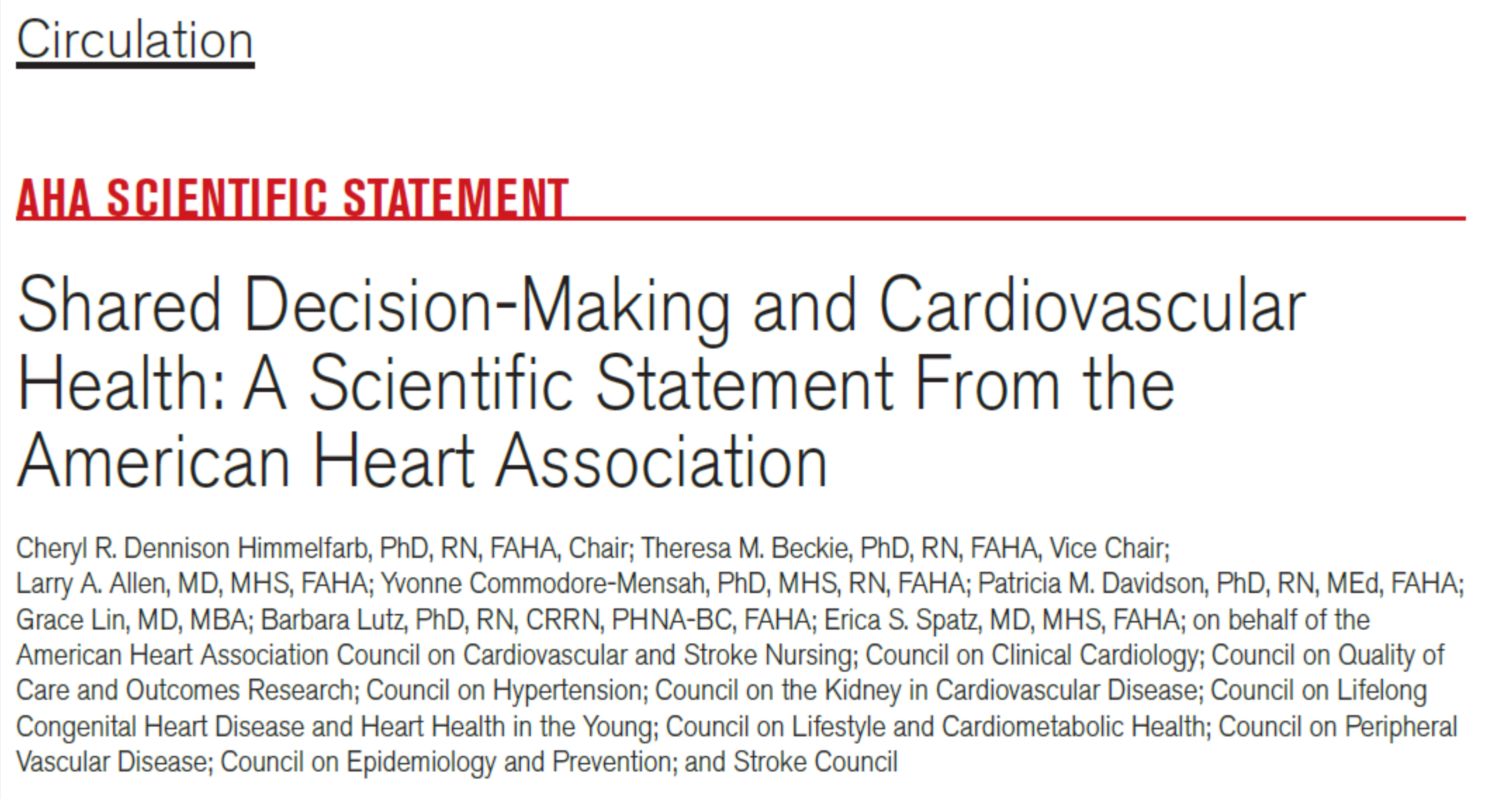
Assistant Professor, Division of General Internal Medicine

Department of Medicine, University of Colorado Anschutz Medical Campus

Overview

- Shared Decision Making in Cardiovascular Disease
- Gaps in Care for Peripheral Artery Disease
- Lessons Learned (and still learning) about Shared Decision Making and Community-based Research

Path to Shared Decision Making



Circulation

AHA SCIENTIFIC STATEMENT

Shared Decision-Making and Cardiovascular Health: A Scientific Statement From the American Heart Association

Cheryl R. Dennison Himmelfarb, PhD, RN, FAHA, Chair; Theresa M. Beckie, PhD, RN, FAHA, Vice Chair; Larry A. Allen, MD, MHS, FAHA; Yvonne Commodore-Mensah, PhD, MHS, RN, FAHA; Patricia M. Davidson, PhD, RN, MEd, FAHA; Grace Lin, MD, MBA; Barbara Lutz, PhD, RN, CRRN, PHNA-BC, FAHA; Erica S. Spatz, MD, MHS, FAHA; on behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Clinical Cardiology; Council on Quality of Care and Outcomes Research; Council on Hypertension; Council on the Kidney in Cardiovascular Disease; Council on Lifelong Congenital Heart Disease and Heart Health in the Young; Council on Lifestyle and Cardiometabolic Health; Council on Peripheral Vascular Disease; Council on Epidemiology and Prevention; and Stroke Council

SDM is a communication process by which patients and clinicians collaborate to choose tests, treatments, and care plans that most align with an individual patient’s preferences and values.

Lowest (worst) decision process scores are for breast and prostate cancer screening, hypertension and cholesterol-lowering medications, and screening for colon cancer, and cataract surgery.

There is still considerable paternalism in medical decision making

Dennison Himmelfarb CR, Beckie TM, Allen LA, Commodore-Mensah Y, Davidson PM, Lin G, et al. Shared Decision-Making and Cardiovascular Health: A Scientific Statement From the American Heart Association. Circulation. 2023;148(11):912-931; Fowler FJ, Gerstein BS, Barry MJ. How patient centered are medical decisions?: Results of a national survey. JAMA internal medicine. 2013;173(13):1215-1221.

Considerable Gaps in Recommended Care for Peripheral Artery Disease

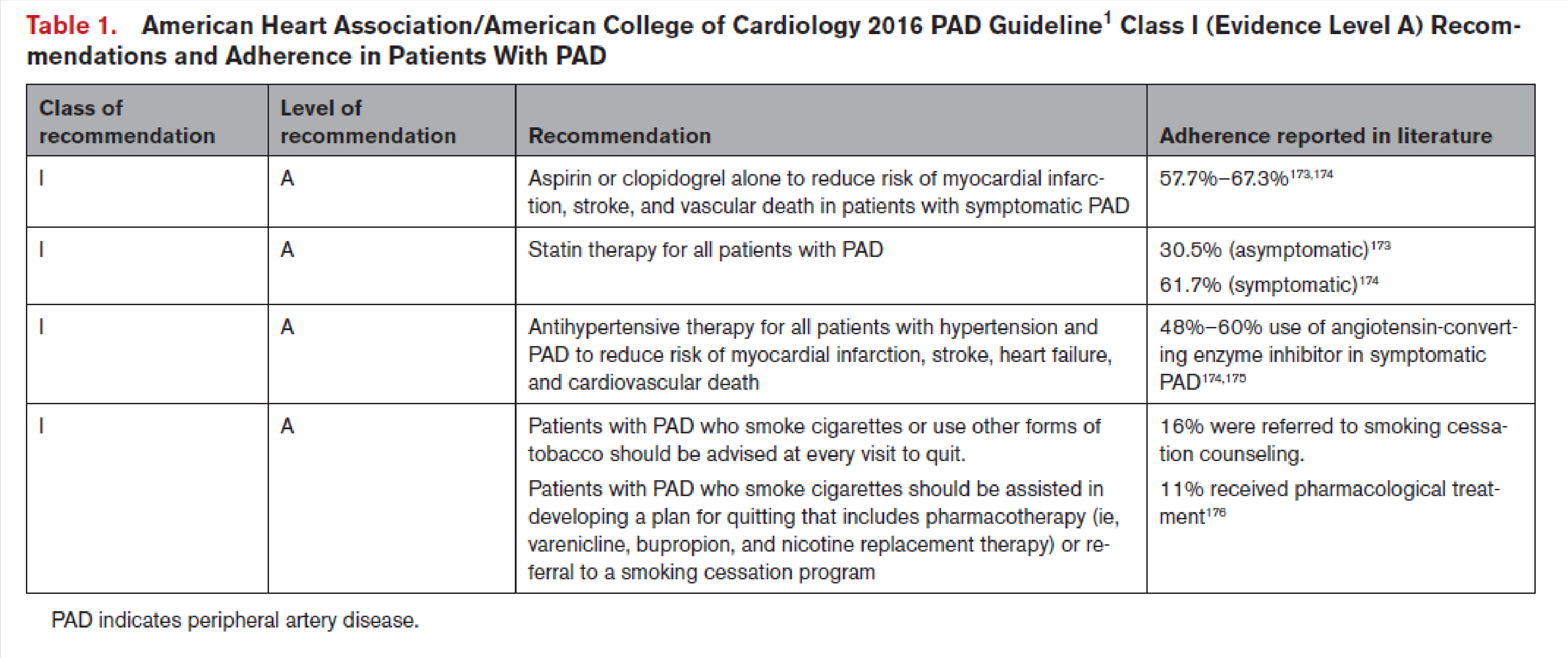


Table 1. **American Heart Association/American College of Cardiology 2016 PAD Guideline[1] Class I (Evidence Level A) Recommendations and Adherence in Patients With PAD**

Class of recommendation	Level of recommendation	Recommendation	Adherence reported in literature
I	A	Aspirin or clopidogrel alone to reduce risk of myocardial infarction, stroke, and vascular death in patients with symptomatic PAD	57.7%–67.3%[173,174]
I	A	Statin therapy for all patients with PAD	30.5% (asymptomatic)[173] 61.7% (symptomatic)[174]
I	A	Antihypertensive therapy for all patients with hypertension and PAD to reduce risk of myocardial infarction, stroke, heart failure, and cardiovascular death	48%–60% use of angiotensin-converting enzyme inhibitor in symptomatic PAD[174,175]
I	A	Patients with PAD who smoke cigarettes or use other forms of tobacco should be advised at every visit to quit. Patients with PAD who smoke cigarettes should be assisted in developing a plan for quitting that includes pharmacotherapy (ie, varenicline, bupropion, and nicotine replacement therapy) or referral to a smoking cessation program	16% were referred to smoking cessation counseling. 11% received pharmacological treatment[176]

PAD indicates peripheral artery disease.

Aspirin

↓ Statin

Anti-hypertensive

Referrals

↓

pharmacotherapy

Criqui MH, Matsushita K, Aboyans V, Hess CN, Hicks CW, Kwan TW, et al. Lower Extremity Peripheral Artery Disease: Contemporary Epidemiology, Management Gaps, and Future Directions: A Scientific Statement From the American Heart Association. Circulation. 2021;144(9):e171-e191.

Lessons Learned

Recruitment populations are different

Promotional strategy matters (is it replicable?)

Ongoing engagement is desired

Identify what is modifiable and/or actionable from study findings

Lessons That I Am Learning

- Patients want to learn more about their disease
- Patients want to understand their healthcare team
- Patients want to improve their health
- Patients want to be seen and heard as people, not their condition

Patient Voice is the Impetus for...

- Change
- Interventional design
- Implementation planning
- Dissemination strategy
- Community connection
- Sustainment assessment

Patient Voice Sounds Like…

“…not knowing what causes it [PAD], not sure on that either. I know that a lot of what I’ve been told over the years is that the root cause of everything going on in my body is high blood pressure and diabetes…”

“I don't even know how you get this artery disease. How do you get it? Is it something genetic, or something I've done to myself?”

“To know why that disease came to me; why I have that disease. Nothing like that had ever happened to me. I don’t know why that happened to me.”

What To ‘Do’ with Patient Voice

INTEGRATE IT INTO HOW WE DELIVER CARE

CONNECT WITH THE COMMUNITY

CHANGE LAWS

EXPAND FROM IT

INNOVATE FROM IT

Potential of Shared Decision-Making as a Driver of Health Equity

---

"**Multilevel solutions** must align to address challenges in policies and reimbursement, system-level leadership and infrastructure, clinician training, access to decision aids, and **patient engagement** to fully support patients and clinicians to engage in the shared decision-making process and to drive equity and improvement in cardiovascular outcomes."

Dennison Himmelfarb CR, Beckie TM, Allen LA, Commodore-Mensah Y, Davidson PM, Lin G, et al. Shared Decision-Making and Cardiovascular Health: A Scientific Statement From the American Heart Association. Circulation. 2023;148(11):912-931

Thank you

Stay in touch

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Engaging Diverse Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ)+ People in Cancer Healthcare and Research

Panel for the *Ethics, Challenges, and Messy Decisions in Shared Decision-Making Seminar Series*

Miria Kano, PhD
Associate Professor of Community & Behavioral Health
University of Colorado, Colorado School of Public Health
University of Colorado Cancer Center

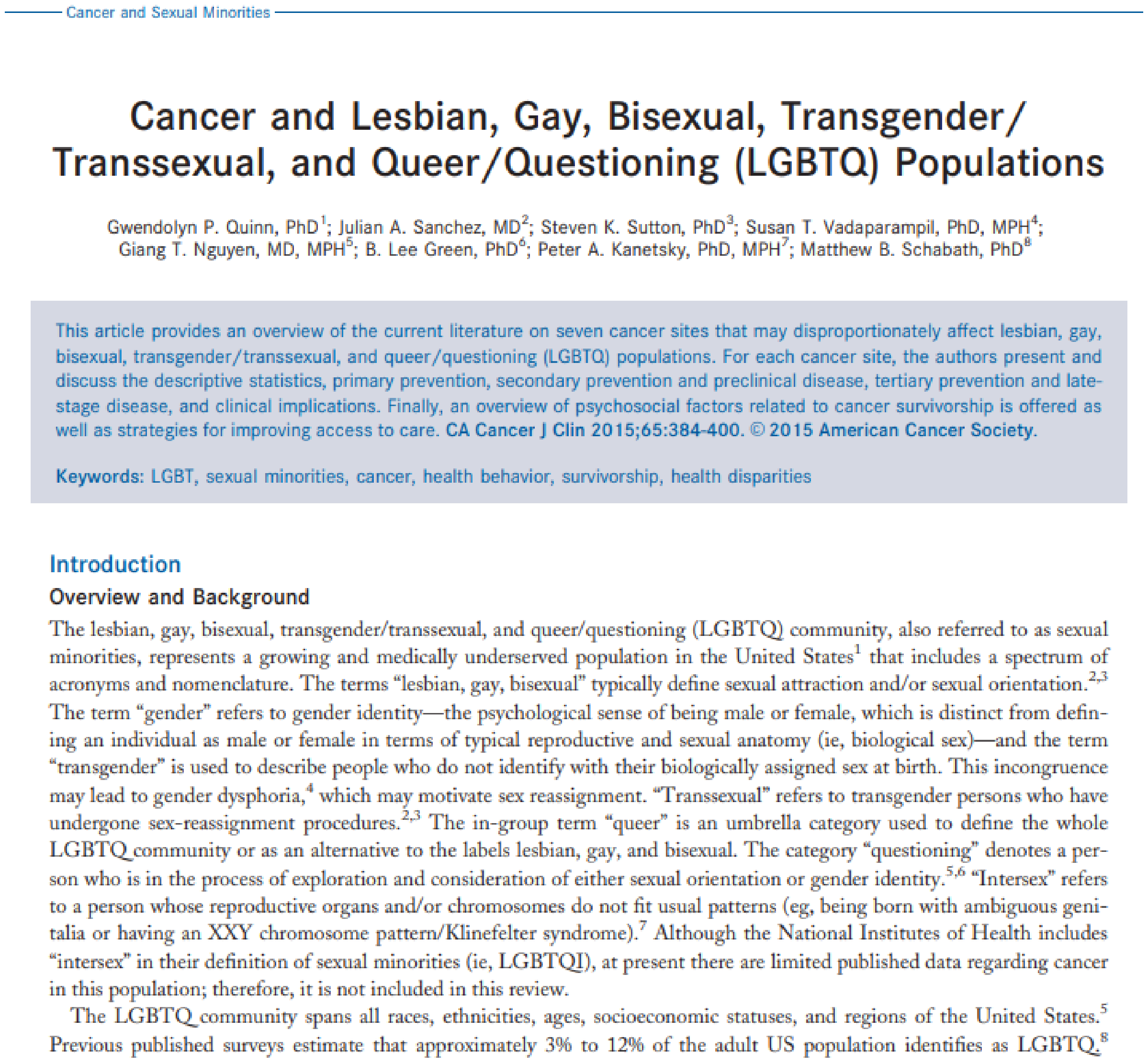
Disparities in LGBTQ Cancer Care

National level cancer organizations such as the Institute of Medicine and American Society of Clinical Oncology have highlighted the following disparities:

- Lack of LGBTQ+ cancer research
- Lower rates of cancer screening
- Lower satisfaction with cancer treatment
- Higher rates of psychological distress in survivorship when compared to their heterosexual, cisgender counterparts
- Gaps in patient-provider communication
- Body image issues and eating disorders
- Health problems for LGBTQ people who have experienced violence

Elevated Rates of Certain Cancers

- Anal cancer
- Breast cancer
- Cervical cancer
- Colon and rectal cancer
- Endometrial cancer
- Lung cancer
- Prostate cancer, and
- Cancer-related issues affecting transgender/transsexual men and women



Cancer and Lesbian, Gay, Bisexual, Transgender/Transsexual, and Queer/Questioning (LGBTQ) Populations

Gwendolyn P. Quinn, PhD[1]; Julian A. Sanchez, MD[2]; Steven K. Sutton, PhD[3]; Susan T. Vadaparampil, PhD, MPH[4]; Giang T. Nguyen, MD, MPH[5]; B. Lee Green, PhD[6]; Peter A. Kanetsky, PhD, MPH[7]; Matthew B. Schabath, PhD[8]

This article provides an overview of the current literature on seven cancer sites that may disproportionately affect lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. For each cancer site, the authors present and discuss the descriptive statistics, primary prevention, secondary prevention and preclinical disease, tertiary prevention and late-stage disease, and clinical implications. Finally, an overview of psychosocial factors related to cancer survivorship is offered as well as strategies for improving access to care. **CA Cancer J Clin 2015;65:384-400. © 2015 American Cancer Society.**

Keywords: LGBT, sexual minorities, cancer, health behavior, survivorship, health disparities

Introduction

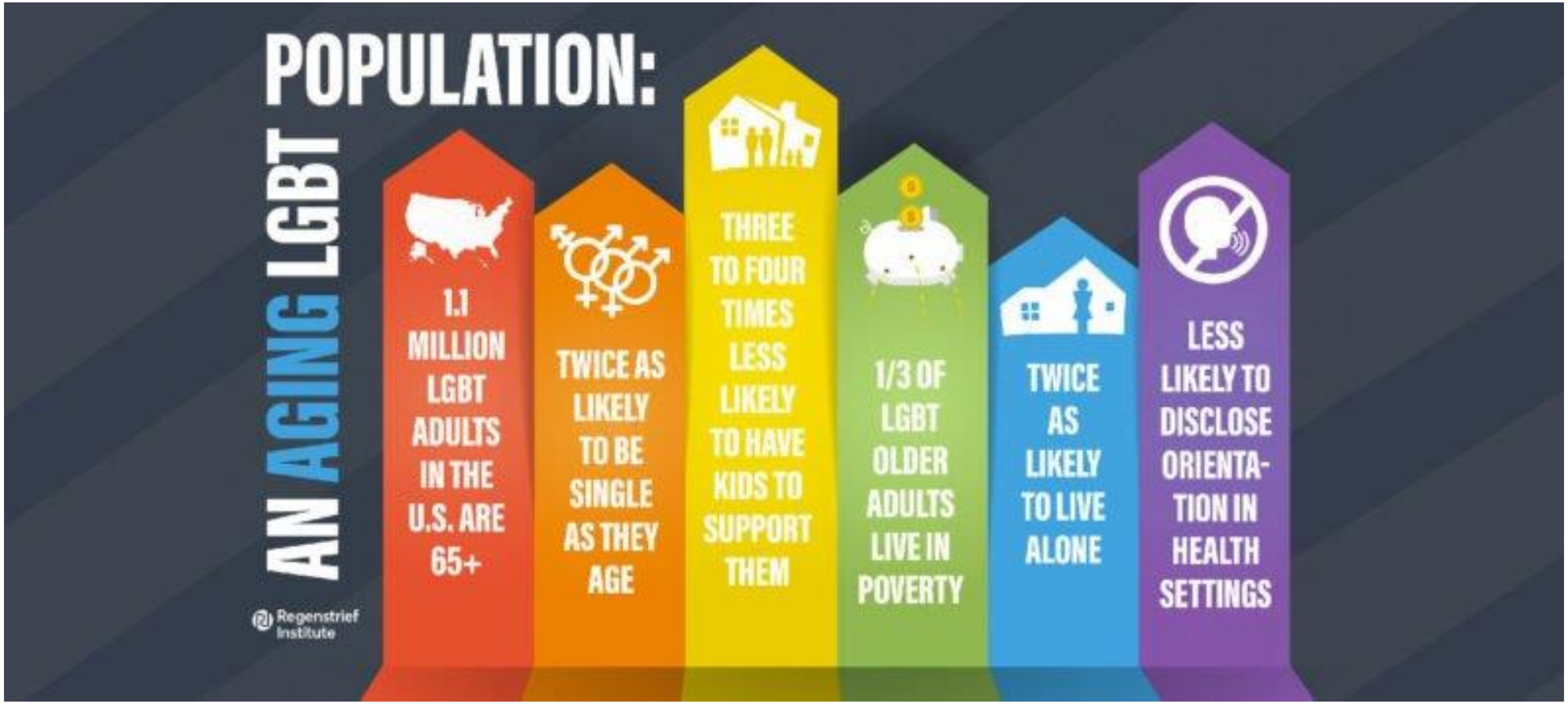
Overview and Background

The lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) community, also referred to as sexual minorities, represents a growing and medically underserved population in the United States[1] that includes a spectrum of acronyms and nomenclature. The terms “lesbian, gay, bisexual” typically define sexual attraction and/or sexual orientation.[2,3] The term “gender” refers to gender identity—the psychological sense of being male or female, which is distinct from defining an individual as male or female in terms of typical reproductive and sexual anatomy (ie, biological sex)—and the term “transgender” is used to describe people who do not identify with their biologically assigned sex at birth. This incongruence may lead to gender dysphoria,[4] which may motivate sex reassignment. “Transsexual” refers to transgender persons who have undergone sex-reassignment procedures.[2,3] The in-group term “queer” is an umbrella category used to define the whole LGBTQ community or as an alternative to the labels lesbian, gay, and bisexual. The category “questioning” denotes a person who is in the process of exploration and consideration of either sexual orientation or gender identity.[5,6] “Intersex” refers to a person whose reproductive organs and/or chromosomes do not fit usual patterns (eg, being born with ambiguous genitalia or having an XXY chromosome pattern/Klinefelter syndrome).[7] Although the National Institutes of Health includes “intersex” in their definition of sexual minorities (ie, LGBTQI), at present there are limited published data regarding cancer in this population; therefore, it is not included in this review.

The LGBTQ community spans all races, ethnicities, ages, socioeconomic statuses, and regions of the United States.[5] Previous published surveys estimate that approximately 3% to 12% of the adult US population identifies as LGBTQ.[8]

Background and Context

LGBTQ Elders



AN AGING LGBT POPULATION:

1.1 MILLION LGBT ADULTS IN THE U.S. ARE 65+

TWICE AS LIKELY TO BE SINGLE AS THEY AGE

THREE TO FOUR TIMES LESS LIKELY TO HAVE KIDS TO SUPPORT THEM

1/3 OF LGBT OLDER ADULTS LIVE IN POVERTY

TWICE AS LIKELY TO LIVE ALONE

LESS LIKELY TO DISCLOSE ORIENTATION IN HEALTH SETTINGS

Regenstrief Institute

Background and Context

Research for Consideration

- Between 12/2020 and 07/2021 we conducted an American Cancer Society funded multi-methods research project, recruiting 10 patients through UNMCCC, SGM community partners and social media
- Patients identified their informal cancer caregivers
- We conducted qualitative interviews lasting 1-2 hours with first patients and then their caregivers
- Patients and caregivers also filled out Quality of Life Surveys using PROMIS validated measures

Help Improve LGBTQI Cancer Care

Sexual and Gender Minority Cancer Research at UNM

More than a third of the 75,000 Lesbian, Gay, Bisexual, Transgender, Queer and Intersex people in New Mexico are likely develop cancer in their lifetimes.

JOIN TODAY

LGBTQI people are more likely to be diagnosed at later stages and to have higher rates of anal, breast, cervical, colorectal, endometrial, lung, and prostate cancers. Additionally, transgender persons who have undergone sex-reassignment may be at higher risk for hormone-sensitive cancers.

We know little about the needs of LGBTQI cancer patients and how best to support them, their families and their communities during cancer treatment and recovery.

Take part in our study

To join our study, you must:

- be 18 or older
- identify as lesbian, gay, bisexual, transgender, queer or intersex
- be receiving cancer treatment or have completed cancer treatment in the last 5 years

If you join our study, we will ask you and your caregiver to spend 90 minutes with us to answer some questions. We will ask you questions about the challenges you both went through during your treatment. We will talk to you at your home, in our clinic, or in another space that is private and comfortable for you.

For taking part in our study, you and your caregiver will each receive a $75 merchandise card.

If you have questions or would like to join our study, please call or email today:

833-323-0230

Dr. Miria Kano
505-925-1115
mkano@salud.unm.edu

Ellen Burgess
505-272-4595
emburgess@salud.unm.edu

Miria Kano, PhD, is a member of the LGBTQI community and has been working to improve LGBTQI health for the last 15 years. She leads a team of scientists and oncologists who are committed to improving LGBTQI cancer care for patients and their caregivers. Dr. Kano is an Assistant Professor in the Department of Internal Medicine at The University of New Mexico School of Medicine and is a research member of the UNM Comprehensive Cancer Center.

Phase 1 Study number 20-385

COMPREHENSIVE CANCER CENTER

Experiences of anti-SGM stigma and discrimination

SGM patients with cancer and their caregivers reported:

- Verbal assaults
- Loss of jobs
- Bathroom policing
- Loss of child custody
- House purchase issues
- Structural Trauma
  - AIDS Epidemic
  - Politics
  - Marriage exclusions
  - Hiding/Closeted

People told us…

“*I’m 80 years old, so I go way back. Being gay in the 60s and 70s was really scary, especially in the military. If you even had a friend who was gay, you could be discharged. It was very difficult to hide that. Every day, you’re living a lie. Every day, you live in fear*.” – Lesbian Caregiver

“*I’ve always looked over my shoulder. I’ve always monitored what I say and how I behave.”*
– Lesbian Patient

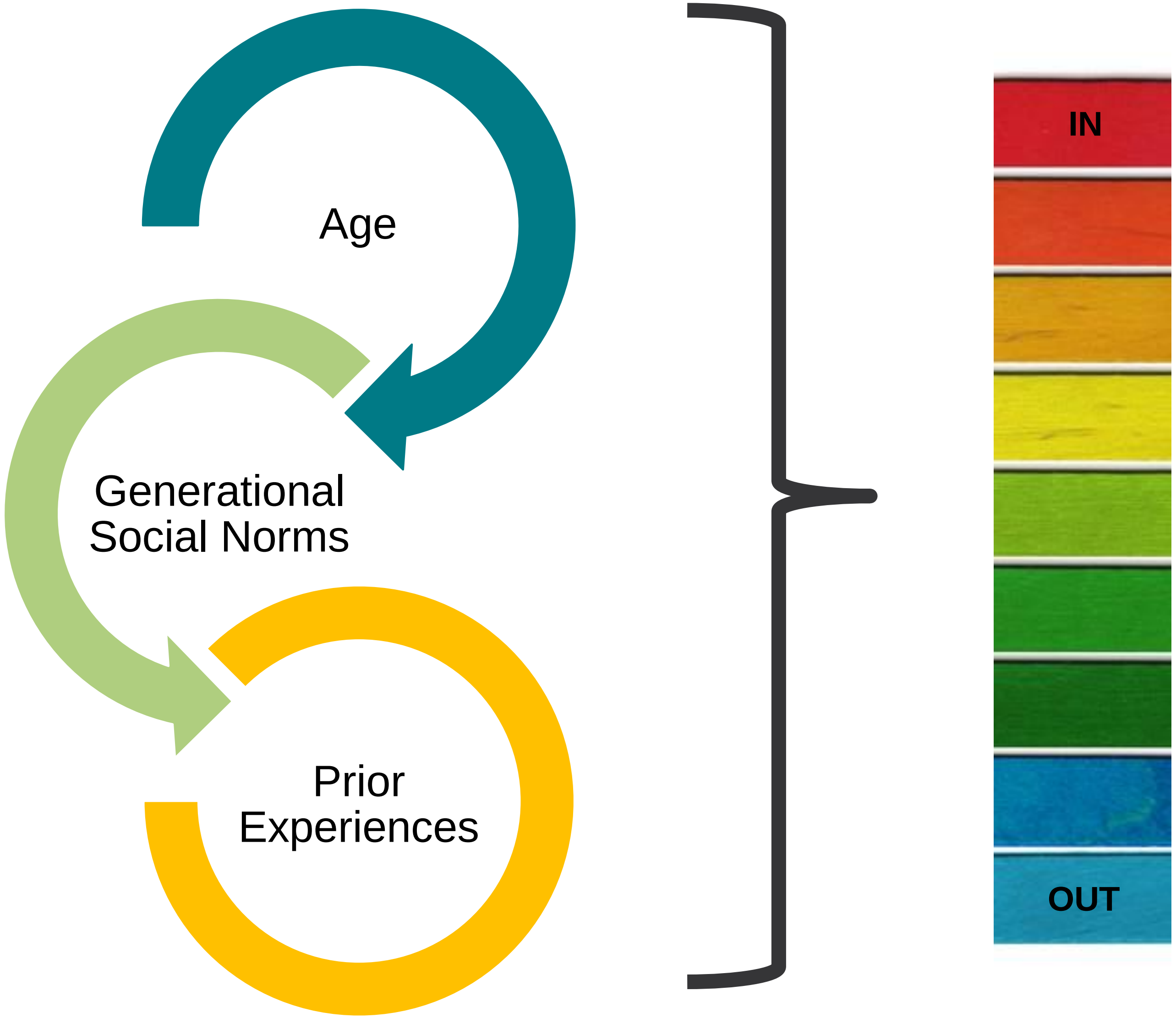
“…the part that’s toxic is you always have to wonder... Just the fact that you even have to think about it is kind of where the toxicity comes from. It’s almost an internal problem because you have no way of actually knowing, unless somebody comes up and calls you a dyke to your face and punches you. People are smarter than that, usually. It’s really insidious—it’s just a factor. It’s an added stress factor in all your interactions.” – Lesbian Patient

Conditional Openness or “Outness”

(When asked if open about her sexuality)… “No, not really. I don’t walk around with a sign. When I’m with someone, I don’t even know that we’d hold hands. I’m always careful about my safety. I’ve never felt totally safe. That’s just the way it is.” – Lesbian Patient

“It’s not consistent being able to be out. It’s been challenging to come out to certain people, doctors. I was a mental health counselor for (organization). They knew I was in a relationship with a woman, but would not mention it. It was rather awkward.” – Lesbian Patient

Conditional Openness or “Outness”

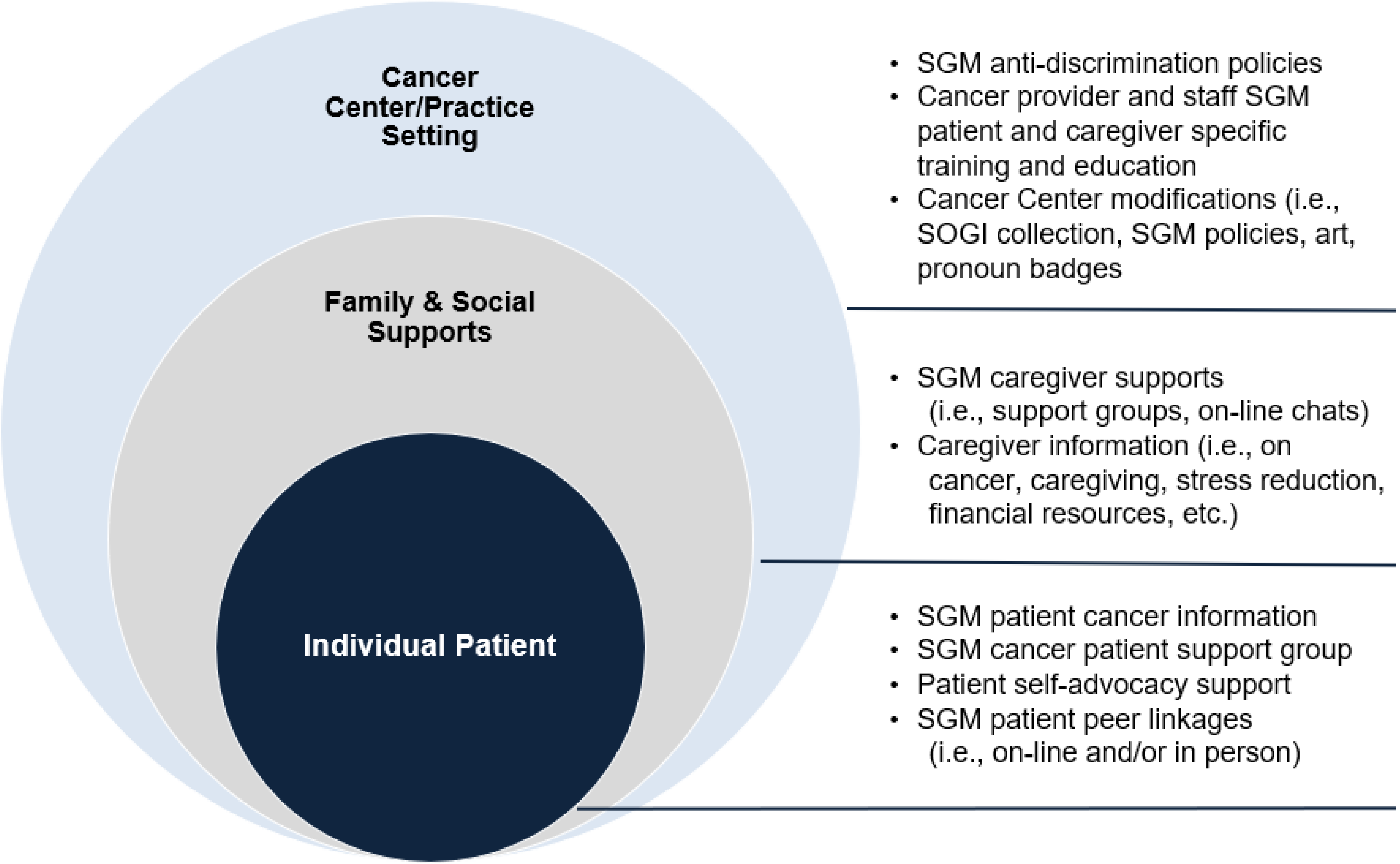


Prior Experiences Informed Cancer Care

"We asked our provider, 'Are you okay working with a lesbian couple?' Because neither of us really trusted that she, or any medical professional is, because people have all kinds of stuff. There is a lot of religiosity even among doctors and healthcare professionals, where they have biases; those biases come out…we wouldn't have done that if we were a straight couple." – Genderqueer, Lesbian Patient

"I didn't feel seen. I kept trying to connect with (name of doctor) in a way that would validate me, acknowledge me. I said, 'I work in the hospital; I know this system. I lost my sister to cancer and I was her caregiver.' But I never got recognized as somebody….it wasn't worth fighting to try to impress my point. I just held onto my observation. I walked out of there feeling like I did everything but stand on my head to get acknowledged as somebody. It made me so angry." – Lesbian Caregiver

Mapping Spaces for Interventions that would Promote Shared Decision Making



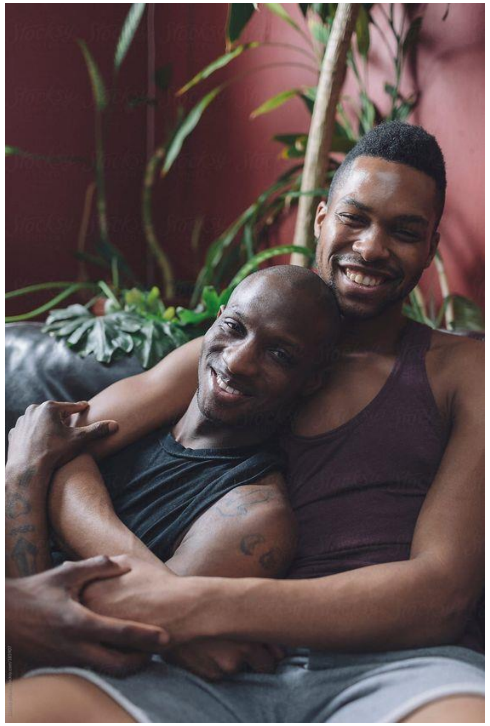
- SGM anti-discrimination policies
- Cancer provider and staff SGM patient and caregiver specific training and education
- Cancer Center modifications (i.e., SOGI collection, SGM policies, art, pronoun badges

- SGM caregiver supports (i.e., support groups, on-line chats)
- Caregiver information (i.e., on cancer, caregiving, stress reduction, financial resources, etc.)

- SGM patient cancer information
- SGM cancer patient support group
- Patient self-advocacy support
- SGM patient peer linkages (i.e., on-line and/or in person)

Kano et.al. *Frontiers in Oncology*. 2022.

Promoting Justice Through Community Engagement



“Nothing about us without us”

Building Health Equity through Partnership

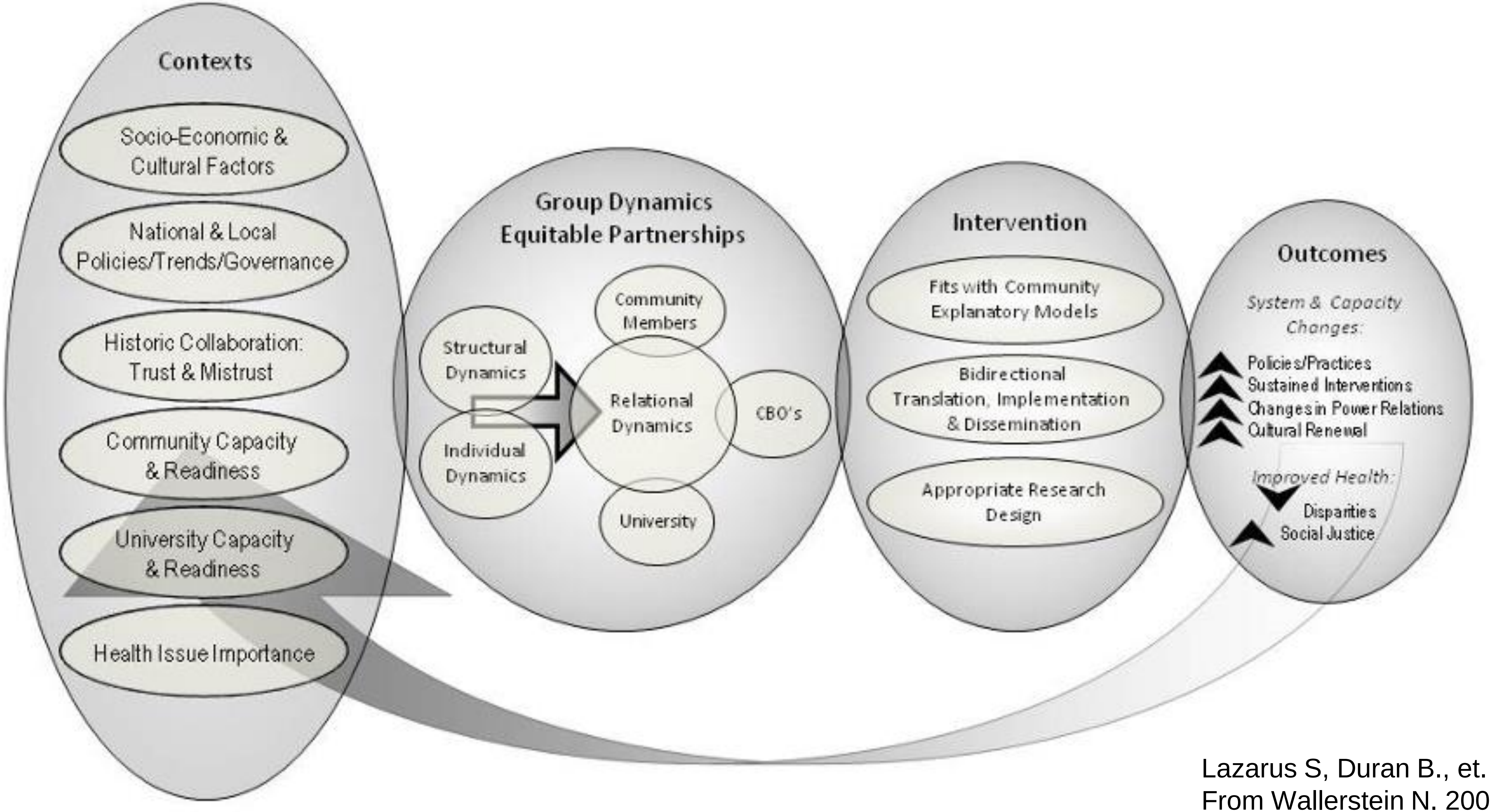
We crafted a Community Advisory Board to create equitable relationships between:

- SGM communities
- Broader local communities
- Health advocates
- Researchers
- Healthcare providers
- Policy makers and more

Developing Trust

Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies. 2022.

Developing Community Engagement for Each Level of Research



Lazarus S, Duran B., et. al. 2012
From Wallerstein N. 2008.

We sought advice on:

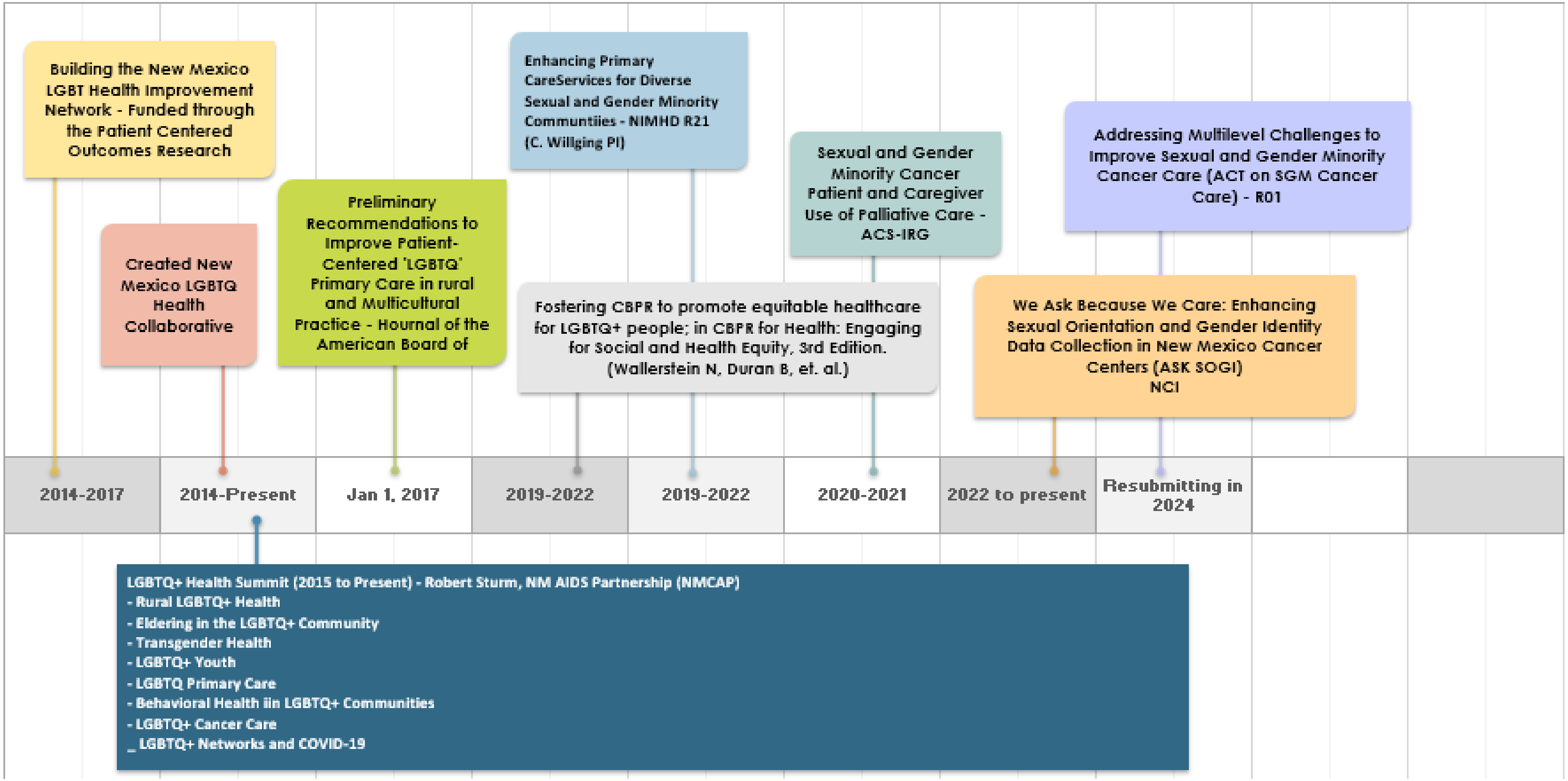
- Refining the research question
- How to recruit for the study
- What language to use
- How to explain the study
- Where to hold meetings
- How to interpret and use data

Image by Freepik (Google Creative Commons Licenses)

How Community Engagement Drives Research

LGBTQ+ Engagement Activities and Research Transformation and Development

04/2014 to present



Building the New Mexico LGBT Health Improvement Network - Funded through the Patient Centered Outcomes Research

Created New Mexico LGBTQ Health Collaborative

Preliminary Recommendations to Improve Patient-Centered 'LGBTQ' Primary Care in rural and Multicultural Practice - Hournal of the American Board of

Enhancing Primary CareServices for Diverse Sexual and Gender Minority Communtiies - NIMHD R21 (C. Willging PI)

Fostering CBPR to promote equitable healthcare for LGBTQ+ people; in CBPR for Health: Engaging for Social and Health Equity, 3rd Edition. (Wallerstein N, Duran B, et. al.)

Sexual and Gender Minority Cancer Patient and Caregiver Use of Palliative Care - ACS-IRG

Addressing Multilevel Challenges to Improve Sexual and Gender Minority Cancer Care (ACT on SGM Cancer Care) - R01

We Ask Because We Care: Enhancing Sexual Orientation and Gender Identity Data Collection in New Mexico Cancer Centers (ASK SOGI) NCI

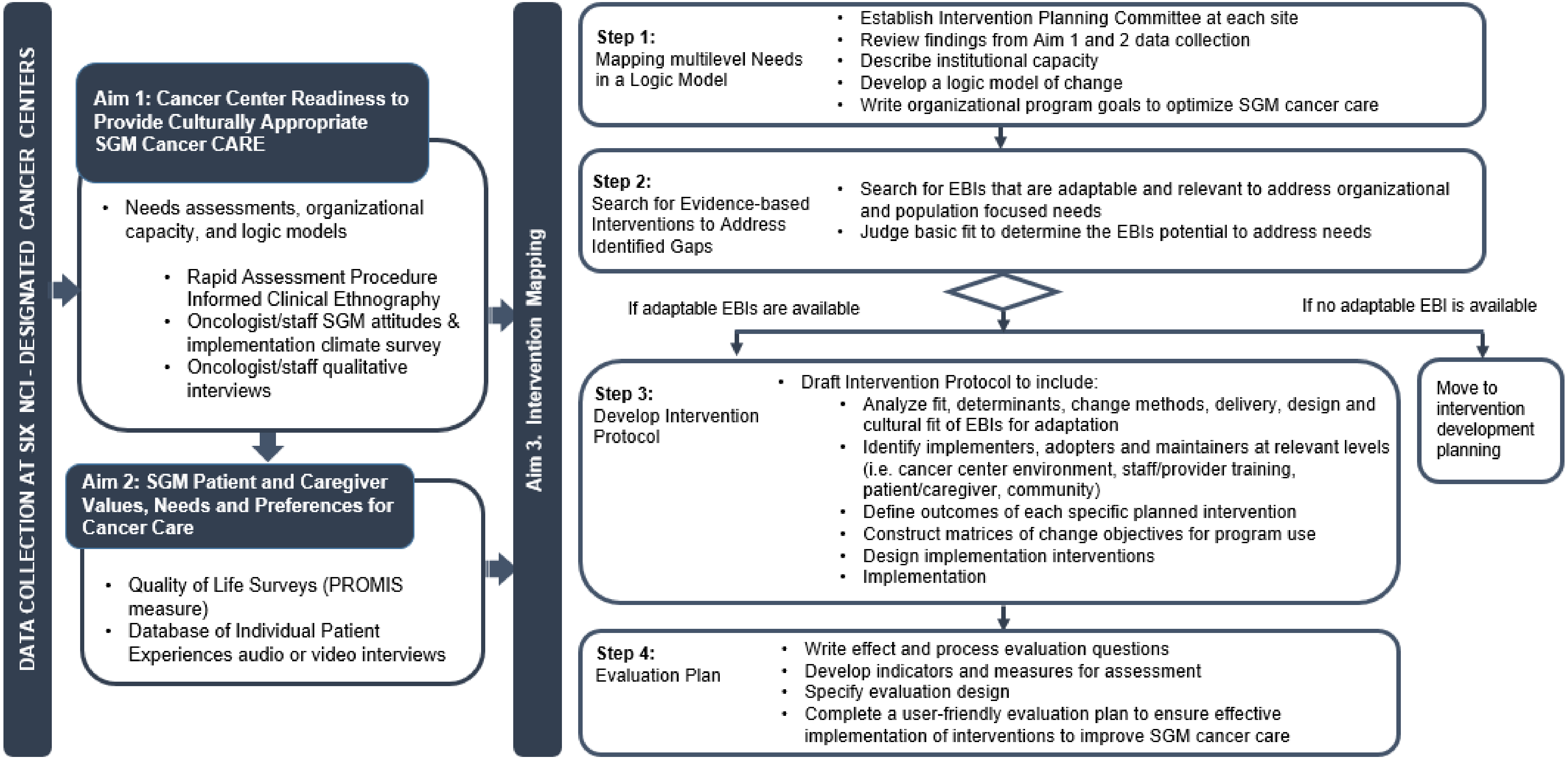
2014-2017	2014-Present	Jan 1, 2017	2019-2022	2019-2022	2020-2021	2022 to present	Resubmitting in 2024

LGBTQ+ Health Summit (2015 to Present) - Robert Sturm, NM AIDS Partnership (NMCAP)

- **Rural LGBTQ+ Health**
- **Eldering in the LGBTQ+ Community**
- **Transgender Health**
- **LGBTQ+ Youth**
- **LGBTQ Primary Care**
- **Behavioral Health iin LGBTQ+ Communities**
- **LGBTQ+ Cancer Care**

_ LGBTQ+ Networks and COVID-19

Next Steps – Resubmitting R01



DATA COLLECTION AT SIX NCI - DESIGNATED CANCER CENTERS

Aim 1: Cancer Center Readiness to Provide Culturally Appropriate SGM Cancer CARE

- Needs assessments, organizational capacity, and logic models
    - Rapid Assessment Procedure Informed Clinical Ethnography
    - Oncologist/staff SGM attitudes & implementation climate survey
    - Oncologist/staff qualitative interviews

Aim 2: SGM Patient and Caregiver Values, Needs and Preferences for Cancer Care

- Quality of Life Surveys (PROMIS measure)
- Database of Individual Patient Experiences audio or video interviews

Aim 3. Intervention Mapping

Step 1:
Mapping multilevel Needs in a Logic Model

- Establish Intervention Planning Committee at each site
- Review findings from Aim 1 and 2 data collection
- Describe institutional capacity
- Develop a logic model of change
- Write organizational program goals to optimize SGM cancer care

Step 2:
Search for Evidence-based Interventions to Address Identified Gaps

- Search for EBIs that are adaptable and relevant to address organizational and population focused needs
- Judge basic fit to determine the EBIs potential to address needs

If adaptable EBIs are available

If no adaptable EBI is available

Step 3:
Develop Intervention Protocol

- Draft Intervention Protocol to include:
    - Analyze fit, determinants, change methods, delivery, design and cultural fit of EBIs for adaptation
    - Identify implementers, adopters and maintainers at relevant levels (i.e. cancer center environment, staff/provider training, patient/caregiver, community)
    - Define outcomes of each specific planned intervention
    - Construct matrices of change objectives for program use
    - Design implementation interventions
    - Implementation

Move to intervention development planning

Step 4:
Evaluation Plan

- Write effect and process evaluation questions
- Develop indicators and measures for assessment
- Specify evaluation design
- Complete a user-friendly evaluation plan to ensure effective implementation of interventions to improve SGM cancer care

This work takes a village – Thank you!!!

University of New Mexico and UNM Comprehensive Cancer Center

- Dolores Guest, PhD, RD
- Amy Farnbach Pearson, PhD
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- Kendal A. Jacobson, BA
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- Andrew Sussman, PhD, MCRP
- Bernard Tawfik, MD
- Zoneddy Dayao, MD
- Robin Johnston

The American Cancer Society
(ACS-IRG-17-178-22)

The LGBT Cancer Network

- Scout, PhD
- Jessica Abeita

The Pacific Institute for Research and Evaluation

- Cathleen Willging, PhD

The National Cancer Institute
(NCI 3P30CA118100-17S4)

THANK YOU!

For questions or comments, please reach me at miria.kano@cuanschutz.edu

Thank you!

Ethics, Challenges, and Messy Decisions in Shared Decision-Making seminar series

Working *with* and *in* Diverse Communities in Research

Lucinda Kohn, MD MHS
Assistant Professor of Dermatology
Division of Pediatric Dermatology
Department of Dermatology
Centers for American Indian and Alaska Natives Health
Children's Hospital of Colorado

My path here

- Chinese American
- Adopted by the Crow Tribe
- Run a dermatology clinic in the Indian Health Service Chinle Service Unit

Lessons Learned from Current and Past Projects

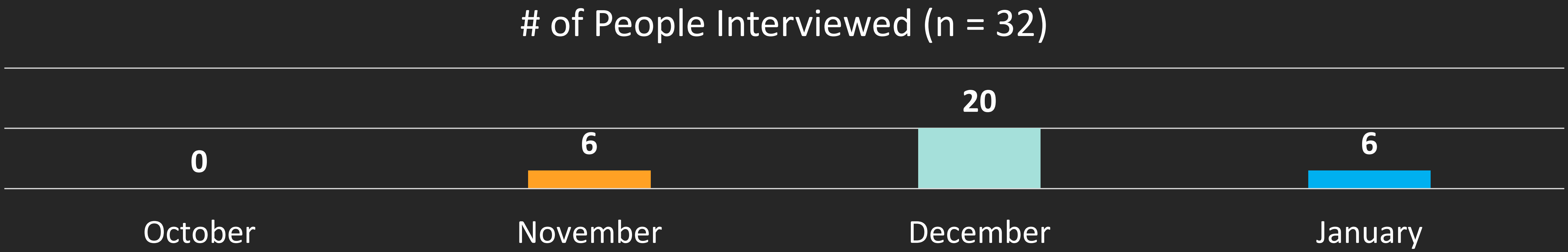
- Recruitment
- Compensation
- Community Engagement

Family Perspectives on accessing Pediatric Dermatology Clinics at CHCO

- Qualitative study on barriers and facilitators to accessing Pediatric Dermatology Clinics at CHCO

Recruitment

- This study recruited **parents of young children** from underserved and diverse **communities**
- Initially we struggled to recruit!



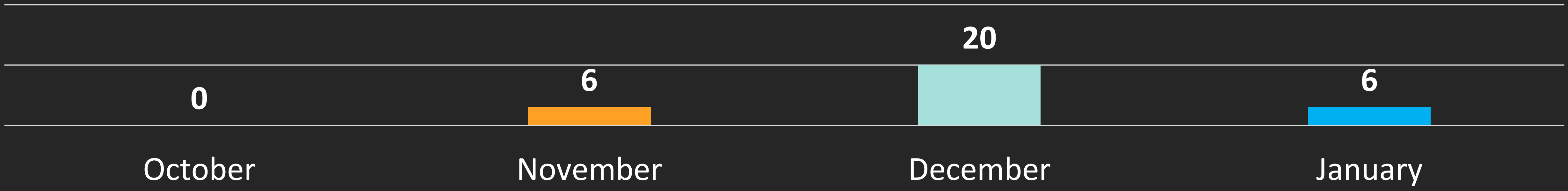
Recruited from October 17, 2023-January 23, 2024 (3 months)

Recruitment Tips

When we…

- Provided Calendly app to sign up so there was no back and forth
- Expanded our interview time offerings (evenings, weekends)
- Sent text reminders the night before

… we recruited & interviewed 20 families in 21 days



# of People Interviewed (n = 32)

Recruited from October 17, 2023-January 23, 2024 (3 months)

Compensate your participants the way that is most meaningful to them

https://www.smithsonianmag.com/

- Surveyed teens and adults at the Denver March Powwow on skin conditions and access to dermatology
- Since we were recruiting teens and adults, we gave out $10 cash for each survey filled
- It took 1-2 weeks to get all IRB and bursar forms approved
- Recruited 239 participants over 2 powwows

Give your research participants a voice

- Community Advisory Boards
  - Write it into your grant!
  - Pay them!
- Qualitative Research
- Patient/Family Advisory Boards

Forming a Patient Advisory Council

- Every institution has a process
- CHCO’s is to form a steering committee first
  - Our first step has been to do a **listening tour** of community leaders
  - We have learned that traditional monthly meetings in-person or by zoom may not work for our American Indian families
  - We must **compensate** our family experts for their time, and not waste their time by promising them change if change cannot happen
  - **Consensus** and **collaboration** are time intensive, energy intensive processes!

Respect the community's perspective and process for doing research – they are the experts and will be your biggest supporters

Summary

- Compensate people the way they want to be paid!
- Give your participants a voice. Their stories are powerful and their expertise in navigating their communities is crucial for the acceptance and sustainability of your work.
- Consensus building takes time. Be patient!
- Value community organizations and respect Tribal IRB processes

It takes a team!

- Thanks to


Sandra Garcia-Hernandez, MPH


Molly Thapar, MS3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Understand people may have different challenges than you – cost, time, strict jobs

- We needed to plan for **being able to have the money to make sandwiches for the trip and be able to pay for gas, lodging, things like that. […]** That way we were able to not be stuck up here without enough money to really survive.