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

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

*all times 12-1pm MT unless otherwise noted
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
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

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.
Considerable Gaps in Recommended Care for Peripheral Artery Disease

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

<table>
<thead>
<tr>
<th>Class of recommendation</th>
<th>Level of recommendation</th>
<th>Recommendation</th>
<th>Adherence reported in literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>A</td>
<td>Aspirin or clopidogrel alone to reduce risk of myocardial infarction, stroke, and vascular death in patients with symptomatic PAD</td>
<td>57.7%–62.8%[172,174]</td>
</tr>
<tr>
<td>I</td>
<td>A</td>
<td>Statin therapy for all patients with PAD</td>
<td>30.5% (asymptomatic)[173]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Antihypertensive therapy for all patients with hypertension and PAD to reduce risk of myocardial infarction, stroke, heart failure, and cardiovascular death</td>
<td>48%–60% use of angiotensin-converting enzyme inhibitor in symptomatic PAD[176,178]</td>
</tr>
<tr>
<td>I</td>
<td>A</td>
<td>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 (i.e., varenicline, bupropion, and nicotine replacement therapy) or referral to a smoking cessation program</td>
<td>16% were referred to smoking cessation counseling. 11% received pharmacological treatment[176]</td>
</tr>
</tbody>
</table>

PAD indicates peripheral artery disease.
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.”
Thank you

Stay in touch

demetria.bolden@cuanschutz.edu
520-250-5606
Demetria M. McNeal, PhD MBA

Demetriamcneal.com
www.linkedin.com/in/demetriammcneal
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
• 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
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)

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

 CORE PRINCIPLES

Co-equal

Co-created

Ongoing

Shared governance

Multi-knowledge

Equitably financed

Bi-directional

Inclusive

Culturally-centered

Trust

COMMUNITY ENGAGEMENT

Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies. 2022.
Developing Community Engagement for Each Level of Research

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
How Community Engagement Drives Research

LGBTQ+ Engagement Activities and Research Transformation and Development

04/2014 to present

Building the New Mexico LGBTQ 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 - Journal of the American Board of

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.)

Enhancing Primary Care Services for Diverse Sexual and Gender Minority Communities - NIMHD R21 (C. Willging PI)

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) - RO1

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

Resubmitting in 2024


LGBTQ+ Health Summit (2015 to Present) - Robert Sturm, NM AIDS Partnership (NM CAP)
- Rural LGBTQ+ Health
- Eldering in the LGBTQ+ Community
- Transgender Health
- LGBTQ+ Youth
- LGBTQ Primary Care
- Behavioral Health in LGBTQ+ Communities
- LGBTQ+ Cancer Care
- LGBTQ+ Networks and COVID-19
Next Steps – Resubmitting R01

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

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

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

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

Move to intervention development planning

If adaptable EBIs are available
If no adaptable EBI is available

DATA COLLECTION AT SIX NCI-DESIGNATED CANCER CENTERS

Next Steps
This work takes a village – Thank you!!!
For questions or comments, please reach me at miria.kano@cuanschutz.edu

Thank you!
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!

# of People Interviewed (n = 32)

<table>
<thead>
<tr>
<th>Month</th>
<th>0</th>
<th>6</th>
<th>20</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>October</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>November</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>December</td>
<td></td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>January</td>
<td></td>
<td></td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

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

• 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

https://www.smithsonianmag.com/
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
Carline Tietbohl, PhD
Micah Pascual, MS4
Gilberto Alvarez, MD
Adam Knappe, MD
Jon Ratmeyer, MD
(IHS Pediatricians)
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.