ASCO Practice Leadership Series

Diversity & Inclusion in Oncology

Thursday, May 20, 4:00pm
Speakers

Sybil Green, JD, RPh, MHA
Diversity and Inclusion Officer
American Society of Clinical Oncology

Charles Kamen, PhD, MPH
Assistant Professor of Surgery, University of Rochester
Assistant Director of Community Engagement, Wilmot Cancer Institute
Chair of Health Equity Research, URCC NCORP Research Base
Diversity & Inclusion in Oncology

Sybil Green, JD, RPh, MHA

Practice Leadership Call
May 20, 2021
Historical Overview: A Longstanding Commitment to Equity and Diversity

Dr. Jane C. Wright,
One of ASCO’s seven founders
2020 Mission Statement Upgrade

MISSION STATEMENT:
Conquering cancer through research, education, and promotion of the highest quality, **equitable** patient care.
Diversity, Broadly Defined

Goal: to ensure diversity of expertise, perspective and ideas

- Race/Ethnicity
- Underrepresented in Medicine (Blacks, American Indians/Alaska Natives, and Latinos)
- Gender
- Sexual and Gender Minorites
- Age
- Disability
- Geography
- Global Distribution
- Career Advancement and Promotion
- Oncology Sub-specialties
- Practice Setting
DIVERSITY
of people, perspectives

EQUITY
in policy, practice & position

INCLUSION
via power, voice & organizational culture
Equity, Diversity and Inclusion at ASCO

EDI encompasses our internal efforts, as well as our member/patient-facing efforts.
Cancer Disparities and Health Equity Statement

ASCO’s Health Equity Goals

- Addressing Structural Barriers
- Increasing Awareness and Action
- Ensuring Equitable Access to High-Quality Care
- Ensuring Equitable Research

Source: Published in: Manali I. Patel; Ana Maria Lopez; William Blackstock; Katherine Reeder-Hayes; E. Allyn Moushey; Jonathan Phillips; William Tap; Journal of Clinical Oncology 2020 383439-3448.DOI: 10.1200/JCO.20.00642
Health Equity Strategic Goals


Eliminating Structural and Institutional Barriers

Ensure Equitable Access to High Quality Care

Ensure Equitable Research

Increase Awareness and Action


## ASCO’s Longstanding Commitment to EDI

| Education and awareness of inequities for the oncology community. | Workforce Diversity & Development: Developing a workforce that represents the population at large and is equipped to care for disparate populations. |
| Quality assessment and improvement to facilitate the reduction of disparities in cancer care and treatment outcomes. | Policy & Advocacy: Advocating for policy, programmatic analysis and development of resources to ensure equitable access to cancer care for every patient, with a special emphasis on reducing insurance and economic barriers to care. |
| Research focused on cancer care disparities and representation in cancer clinical trials. | Conquer Cancer Research Awards: Funding research through grants for investigators of underrepresented groups and for investigators focused on disparities research. |
Current Equity, Diversity and Inclusion Initiatives

Diversity in Committee Volunteers

- Medical Student Rotation
- Annual Meeting Research Award
- Supporting Needs of Providers Caring for Underserved
- ASCO-ACCC Collaboration
- Diversity Mentoring Program
- Health Equity Awareness Campaign
- Career Development Award
- Research Professorships
- Impact of Social Determinants of Health
- Niarchos: Improving Cancer Care in Underserved Communities
- Advanced Clinical Research Award
- Young Investigator Award
- SGM Minority At-A-Glance Data Dissemination
- Oncology Summer Internship

Do we have all the answers for reaching equity?
Of course not…

Sometimes it is not about having all the answers, but rather posing the right questions and searching for the answers together.

This is a journey.
Next Steps

• Organizational EDI Priority Setting
• Health Equity Awareness Campaign
• Understanding Impact of Social Determinants of Health in Cancer Care
• Research and Data Collection on Sexual and Gender Minorities
Individual and institutional predictors of sexual orientation and gender identity (SOGI) data collection in oncology practice

Charles Kamen, PhD, MPH
Assistant Professor of Surgery, University of Rochester
Assistant Director of Community Engagement, Wilmot Cancer Institute
Chair of Health Equity Research, URCC NCORP Research Base
...and I have nothing to disclose.
Three questions:

• How can you treat a patient you can’t see?

• Why not now?

• Does it work?
HOW CAN YOU TREAT A PATIENT THAT YOU CAN’T SEE?
SOGI Data Collection in Oncology

- Allows us to track and monitor disparities in cancer outcomes
- Allows us to refer patients to tailored supportive care
- Allows us to recruit patients for cancer research
- Is a component of patient-centered care
- Is a component of emerging national guidelines
Disparities in cancer prevalence

TABLE 3. Invasive cancers among men in registered homosexual partnerships, Denmark, 1989–1997

<table>
<thead>
<tr>
<th>Site of cancer</th>
<th>All homosexually partnered men (n = 3,391)</th>
<th>Homosexually partnered men without AIDS* (n = 3,054)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Observed</td>
<td>RR*</td>
</tr>
<tr>
<td>All cancers†</td>
<td>139</td>
<td>2.1</td>
</tr>
<tr>
<td>Cancer other than Kaposi's sarcoma, non-Hodgkin's lymphoma, and anal squamous carcinoma</td>
<td>65</td>
<td>1.0</td>
</tr>
<tr>
<td>Anus, squamous cell carcinoma</td>
<td>4</td>
<td>31.2</td>
</tr>
<tr>
<td>Kaposi's sarcoma</td>
<td>38‡</td>
<td>136</td>
</tr>
</tbody>
</table>

Table 3. Multiple Logistic Regression of the likelihood of Having a Diagnosis of Cancer Among California Women and Men

<table>
<thead>
<tr>
<th>Predictor in the Model</th>
<th>Female Population, n=71,112</th>
<th>Male Population, n=51,233</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AOR</td>
<td>95% CI of OR</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lesbian/gay vs heterosexual</td>
<td>1.066</td>
<td>0.792-1.435</td>
</tr>
<tr>
<td>Bisexual vs heterosexual</td>
<td>1.107</td>
<td>0.782-1.566</td>
</tr>
</tbody>
</table>

Frisch et al., 2003

Boehmer et al., 2011
Disparities in cancer outcomes

Drinks/30 Days
Moderate Exercise
Vigorous Exercise
Psychological Distress

Heterosexual
Gay

* p<0.05, ** p<0.01

Kamen, Palesh, et al., 2014
Tailored supportive care

1. 11.4% vs. 17.5%, p=0.03  
2. 63.3% vs. 81.8%, p=0.05

Kamen, Blosnich, et al., 2015; Kamen et al., 2016; Matthews, 2009
Research recruitment

If You Would Like More Information Regarding This Study Please Contact:

Nikki Murray, MS
Health Project Coordinator
Surgery-Cancer Control
263 Crittenden Blvd
Rochester, NY 14642
Phone: (585)276-4638
Email: nicole_murray@urmc.rochester.edu

Charles Kamen, PhD
Research Assistant Professor
Surgery-Cancer Control
263 Crittenden Blvd
Rochester, NY 14642
Phone: 585-275-9558
Email: charles_kamen@urmc.rochester.edu

Exercise Intervention
For LGBT Cancer Survivors & Caregivers

Frequently Asked Questions

- **How long will the visit take?**
  The total time for the baseline/post visit is approx. 3 hours

- **How long will I be in the study?**
  Your participation in the study will last approx.
  7-8 weeks

- **How many people will participate?**
  140 participants will be enrolled.

- **Is there any cost to participating?**
  There will be no cost to you.

- **What risks are involved?**
  There are little to no risks to being involved.
  Specifics will be discussed if you enroll.

- **Are there any benefits to participating?**
  You may or may not benefit from this study.

- **Will I get any payments for participating?**
  You will be paid $35 for completing both assessments.
  Each participant will receive an EXCAP exercise kit.

- **Can I leave the study?**
  You may discontinue participation at any time
  without making loss of present or future care.
A component of patient-centered care

“It would be nice, I think, if they would've asked first...Because I think people...just think, is this your sister? Or, is this...a relative? I don't think they really got the picture...because when we went back, even though [the provider] knew us, I was with someone different ...and they would not let [C7] in. I literally went through everything, and she was furious... We were like, how do you not have her in our records?”  (S7, cis white lesbian, 56, breast cancer)
ASCO Position Statement 2017

1. Patient education and support
2. Workforce development and diversity
3. Quality improvement solutions (data collection)
4. Policy solutions (non-discrimination)
5. Research strategies (funding and methods)
National Academies (NASEM) 2020 Report

1. Add measures of sexual orientation, gender identity and intersex (SOGII) status to data collection
2. Improve measures of SOGII and other factors
3. Fund new types of SGM studies
4. Link datasets that contain SOGII
5. Test and disseminate programs for SGM wellness
NIH SGMRO 2021-2025 Strategic Plan

1. Advance research on SGM communities

2. Expand SGM research partnerships

3. Foster SGM research workforce

4. Encourage SGM-focused data collection
WHY NOT NOW?
SOGI data collection in community oncology

- What percentage of community oncology sites (N=227) ask about sexual orientation?

23.3% (n=53)

- What percentage ask about gender identity?

10.1% (n=23)

Cathcart-Rake...Kamen, 2019
ASCO Survey Methodology and Respondents

• From Oct to Nov 2020, an anonymous 54-item online survey was distributed to ASCO members via direct outreach, co-authors, listservs and social media.

<table>
<thead>
<tr>
<th>Participant Demographics (N=257)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
</tr>
<tr>
<td>41-55</td>
</tr>
<tr>
<td>56+</td>
</tr>
<tr>
<td><strong>Race:</strong></td>
</tr>
<tr>
<td>Black</td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td>Other race</td>
</tr>
<tr>
<td><strong>Ethnicity:</strong></td>
</tr>
<tr>
<td>Non-Hispanic/Latino</td>
</tr>
</tbody>
</table>
Unadjusted Responses to Items

- **SO collected at institution**
  - Yes: 38%
  - No: 44%
  - Not Sure: 22%

- **GI collected at institution**
  - Yes: 48%
  - No: 18%
  - Not Sure: 34%

- **Consider SO when discussing care**
  - Always/Most of the time: 43%
  - Occasionally: 37%
  - Never: 10%

- **Consider GI when discussing care**
  - Always/Most of the time: 55%
  - Occasionally: 37%
  - Never: 9%

- **Important to know SO for best care**
  - Agree: 77%
  - Dissagree: 26%
  - No Opinion: 3%

- **Important to know GI for best care**
  - Agree: 85%
  - Dissagree: 14%
  - No Opinion: 1%

- **SOGI resources available**
  - Agree: 43%
  - Dissagree: 34%
  - No Opinion: 23%

- **Leadership support**
  - Agree: 57%
  - Dissagree: 18%
  - No Opinion: 25%
Regression Models Predicting SOGI Data Collection

Predictors of Collection of Sexual Orientation Data (adjusted model)

Leadership Support
Institutional Resources
Importance of Knowing Patient SO or GI

Predictors of Collection of Gender Identity Data (adjusted model)

Leadership Support
Institutional Resources
Importance of Knowing Patient SO or GI
Flow of SOGI data collection

1. **Data Input at Home**
   - Self report of information on sexual orientation (SO) and gender identity (GI)

2. **Arrival**
3. **Register Onsite**

4. **SO/GI Data Reported**
   - Information entered into EHR

5. **SO/GI Data Not Reported**
   - Provider visit input from history
     - **Yes**
     - Information entered into EHR
     - **No**
DOES IT WORK?
Addressing New Identities

• 23% of Yale freshmen, 18% of Harvard freshmen, and 16% of people aged 18-23 identify as SGM

• 20.6% of SGM people are with different-gender partners

• 3.3% of SGM people use a term other than LGBT to describe themselves

“Class of 2021 by the Numbers,” The Harvard Crimson, 2021
Gallup Poll, 2021; Image credit: Robin Muccari, NBC News
Assessing New Identities

Birth Sex
What sex were you assigned at birth?
- Female
- Male
- Intersex
  - A sex not listed here (please specify)
- Prefer not to state

Current Gender Identity
What is your current gender identity? (Please select all that apply)
- Woman
- Man
- Non-binary
- Genderqueer
- A gender identity not listed here (please specify)
- Prefer not to state

What is your gender?
- Female
- Male
- Non-binary
- Self-identify as: ________
- Decline to state

Do you identify as transgender or gender diverse?
- Yes
- No
- Decline to state
Integrating Intersectionality

Should I talk about [having breast cancer]? Because how many things could I have? You know black, lesbian - I'm like, I can't be the poster child for everything. At least with the LGBT issues we get a parade and a float and it's a party.

— Wanda Sykes —
An Example of Intersectionality

Distrust tertiles by race and sexual minority status (N=649)

- Low distrust
- Med distrust
- High distrust

<table>
<thead>
<tr>
<th>Race</th>
<th>Low Trust</th>
<th>Med Trust</th>
<th>High Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>White, NSM (N=285)</td>
<td>18.95</td>
<td>29.82</td>
<td>51.23</td>
</tr>
<tr>
<td>White, SM (N=123)</td>
<td>37.4</td>
<td>41.46</td>
<td>21.14</td>
</tr>
<tr>
<td>Black, NSM (N=156)</td>
<td>24.36</td>
<td>40.38</td>
<td>35.26</td>
</tr>
<tr>
<td>Black, SM (N=85)</td>
<td>49.41</td>
<td>28.24</td>
<td>22.35</td>
</tr>
</tbody>
</table>

Dean, Greene, et al., 2021
Conclusions and Future Directions

• In our survey, despite limited statistical power, the same three factors emerged as drivers of data collection:
  • Leadership Support
  • Institutional Resources
  • Individuals’ Attitudes

• We must attend to new identities, new methodologies, and intersectionality

• We need implementation studies!
Acknowledgements

• Deepest gratitude to the ASCO staff who made this work possible, including Kimberly Smith, Deanna DuLac, and Alex Swierz, as well as the ASCO SGM Task Force.
THANK YOU!

charles_kamen@urmc.rochester.edu
Next Call

• Virtual Roundtable, moderated by Dr. Lori Pierce
  From Diagnosis to Treatment: Ensuring Equity in Precision Cancer Care
  Tuesday, May 25, 2021
  11:30 AM to 1:00 PM Eastern

• June Practice Leadership Call
  Topic TBD
  Thursday, June 17, 2021
  4:00 PM Eastern

https://practice.asco.org/calendar
ASCO Quality Care Symposium

• September 24-25, 2021
• In-person in Boston and Online!

• Abstract deadline: June 1 at 11:59 (ET)
• Hotel and early registration: August 18 at 11:59 (ET)

https://quality.asco.org/