

## Plenary 3 - Engaging with communities and patients: Native Sisters (Native Patient Navigators; Survivorship Navigators)

### Connecting, Communicating and Collaborating across the Globe

## Plenary 3 - Engaging with communities and patients: Native Sisters (Native Patient Navigators, Survivorship Navigators)

Linda Burhansstipanov, MSPH, DrPH  
(Cherokee Nation of Oklahoma)

President, Native American Cancer Initiatives, Inc. (NACI)  
Founder, Native American Cancer Research Corporation (NACR)

3022 South Nova Road  
Pine, CO 80470-7830

Phone: 303-838-9359; 1-800-537-8295

<http://www.NatAmCancerInitiatives.org>

<http://www.NatAmCancer.org>

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### Objectives: The participant will be able to:

- 🥁 Identify selected lessons learned since 1994 for community-based Native Patient Navigation programs



*BRIEF overview  
of AI/AN data???*

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### Native American Cancer Research Corporation (NACR) and Native Patient Navigators (NPNs)

🥁 NPNs (also called “lay health advisors”, “Native Sisters”, “Survivorship Navigators”)



🥁 NACR = 1<sup>st</sup> *American Indian* Navigator program in the US (1994)

⊕ Help from Joanne Tsark from Papa Ola Lokahi

⊕ “Guidance” from Dr. Harold Freeman



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### Background

🥁 Based on Harold Freeman’s Navigator model as orally described during meeting in 1992

🥁 Started as “Native American Women’s Wellness through Awareness” (NAWWA) 1994

⊕ NAWWA in Denver and L.A.

🥁 Funded by Robert Wood Johnson Foundation



Harold Freeman, MD  
Harlem Hospital, NY



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### NAWWA Background / History / Evolution

- 🥁 1994 to present NAWWA [RWJF, Komen] →
- 🥁 1998 “Increasing Mammography for Urban American Indian Women” [NCI R25 CA77665] →
- 🥁 1999 to present “Colorado Women’s Cancer Control Initiative” [Colorado Department of Public Health and Education] →
- 🥁 2002 “Increasing Mammography Screening among Medically Underserved Women” [NCI R25 CA 96540] →
- 🥁 (1996 Network) 2004 “Native American Cancer Education for Survivors” [Komen #POP0503920, #POP0202135, NCI R25 CA 101938]
- 🥁 2006 Prevention / Early Detection Native American Tobacco Education (NATE) Coalition;
- 🥁 Native American Prevention of Obesity (NAPO)) [Colorado Department of Public Health and Education]
- 🥁 “Native Navigators and the Cancer Continuum (NNACC)”  
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### Characteristics of the Native Sisters

- 🥁 Native (preferred)
- 🥁 Respected by the community (credibility in the community)
- 🥁 Model healthy behaviors
- 🥁 Passion for helping community members
- 🥁 Education varies (service vs. grant)



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**People don't care  
how much you  
know until they  
know how much  
you care.**



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### **Why “Native” Patient Navigators?**

🥁 Issues of trust due to prior mistreatment in healthcare and other life situations.

⊕ AI sterilization

⊕ Havasupai

⊕ specific tribal populations (e.g., Muscogee (Creek) Nation versus Dakota Nation).



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## Why “Native” Patient Navigators?

- 🥁 Cultural perceptions common to a specific tribal nation, band or clan.
  - ⊕ Words “cancer”, “positive”
  - ⊕ Invitation of disease into individual, family, community
  - ⊕ Tobacco as a sacrament for ceremonial purposes
  - ⊕ Owl “icon” on walls on CO clinic
  - ⊕ Chair in hallway



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## Why “Native” Patient Navigators?

- 🥁 Spirituality (Traditional Indian Medicine unique to specific tribal Nations or geographic regions).
  - ⊕ “Details” vs. Green Corn, vision quest, Sun Dance
  - ⊕ New Agers vs. Ceremonies
  - ⊕ Water v. Corn pollen
  - ⊕ Spiritual protection for NPNs



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## Why “Native” Patient Navigators?

- Logistical issues unique to Indian Health Service (IHS) Contract Health Services (CHS)
  - ⊕ Oncologist = referral to CHS
    - ⌚ Average interval from biopsy to initiation of cancer care for females = 6 months (for males = 9 months)
  - ⊕ Diabetes MD and oncologist typically share no interactions/ files /medical records but 32% of survivors also have diabetes



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## NNACC Research Question

- Can a Native specific comprehensive Navigator-implemented community cancer education intervention improve health behaviors among Native American community members?



Honoring Dance for Survivors,  
NACR PowWow, 2009



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### NNACC uses Patient Navigation for:

- ⌘ Prevention
- ⌘ Early detection
- ⌘ Diagnosis
- ⌘ Treatment
- ⌘ Survivorship quality of life
- ⌘ Palliation / End-of-Life



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### Locations of the NNACC Partners -- Community based

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### Example of Success (NNACC) see publications for details

- 🥁 Study was designed to work with 738 AI community members
- 🌐 Ended up with 1,964
- 🥁 70% females
- 🥁 77 participants diagnosed with cancer during the study and helped by NPNs



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### Excerpt from Online Evaluation: Navigation Report from **NACR** Database (17 patients during NNACC)

#### Navigation Activities - Report Totals - pg3

Time: hrs	#	Screening:
1.75	3	Help finding a healthcare provider/ clinic
1	5	Help setting up medical appointment
1	1	Reminder call (or visit) for appointment
2.1	7	Accompany patient to appointment
.55	2	Help with paperwork for IHS
.3	3	Help with paperwork for Medicaid
0	0	Help with paperwork for Medicare
.58	4	Help w/ paperwork for St/Foundation program
.25	1	Help with paperwork for Private Insurance
0	0	Help with paperwork for VA
.13	4	Help with transportation to screening
0	0	Help with lodging for screening
0	0	Help w/child/elder supervision during appt
.25	1	Reminder Call - Medical Appointment

#### End of Life:

.17	1	Help w/ Advance Directives Resources
0	0	Help w/ End of Life/Hopice Resources
0	0	Help with final will
0	0	Help with traditional Indian ceremonies
0	0	Help with transportation to/from Hospice setting
0	0	Help w/nutrition supplements for EOL/Hospice
0	0	Help with daily living
0	0	Help with family caregivers' needs

3.33 4 Others

Time: hrs	#	Diagnosis:
1.75	3	Help following up the positive screening results to make an appointment for diagnostic test
.25	1	Help getting a second opinion
1.75	4	Help patient and family to better understand prognosis and treatment options
1.53	4	Help with transportation for diagnostic appt
0	0	Help w/ Lodging - Followup
.75	2	Accompany patient to diagnostic appt test(s)
1.58	7	Help w/Setting Medical Appointment-Followup
.75	4	Help w/Finding a doc or oth Hlth Professional Res

#### Prevention:

0	0	Help with improving diet
0	0	Help with weight control
0	0	Help with physical activity
0	0	Help clean up the environment
0	0	Help with tobacco prevention
0	0	Help with tobacco Cessation

#### Palliation:

.17	1	Help with cancer pain resources
0	0	Help with nutrition resources
0	0	Help w/professional counseling support services
0	0	Help with info about clinical trials opportunities
.17	1	Help obtaining recommended cancer meds
0	0	Help with cancer rehabilitation

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### Excerpt from Online Evaluation: Navigation Report from NACR Database (17 patients during NNACC)

0 Help finding a healthcare provider/ clinic	0 Help w/ lodging and trans for family during patient's treatment (away from home for days, weeks, months)
0 Help setting up medical appointment	0 Help w/child/elder supervision during appointment
0 Reminder call (or visit) for treatment appointment	1 Help w/family education about the patient's cancer
0 Accompany patient to appointment	0 Help w/employment/career counseling for patient
.5 1 Help w/Obtaining Health Information	0 Help w/obtaining a Treat Plan from HC provider/clinic
0 Help w/Childhood cancer resources Resources	0 Help w/support for children/elders during cancer treat
2 Help patient and family ask questions	.58 3 Help with addressing patient's side effects from cancer or treatments
0 Help patient communicate with provider about co-morbidity	0 Help w/Trad Indian Med healers/Med Man/Woman
0 Help with paperwork for IHS	.25 1 Help w/information about clinical trials opportunities
0 Help with paperwork for Medicaid	1 Help w/Info on dealing with insurance issues Resources
0 Help with paperwork for Medicare	0 Intervening w/ IHS
0 Help w/paperwork for St/Foundation program	.83 1 Intervening w/ Medicaid
0 Help w/paperwork for Private Insurance	0 Intervening w/ Medicare
0 Help w/paperwork for VA	0 Intervening w/ Private Ins.
2 1 Help with transportation to treatment	0 Intervening w/ VA
0 Help with lodging for treatment	
<b>Quality of Life / Recovery:</b>	
.5 2 Help w/ Cancer Rehabilitation	0 Help with nutrition resources
.67 1 Help finding cancer support info programs	.33 2 Help w/professional counseling support services
.33 2 Help w/ Peer Support Resources	1 1 Help with transportation for follow-up services (screenings for other diseases, other cancers)
1 Help w/ Quality of Life and supportive care Res	.5 2 Help w/addressing patient's side effects from cancer or treatments (fatigue, skin reactions, amputations)
.17 1 Help w/ Complementary and Alternative Treat	.42 0 Help w/cult issues related to recovering from cancer experiences (temporary surrender of sacred pipe during hair loss side effect from treatments)
0 Help w/Trad Indian Med healers/Man/Woman	1 Help with information about clinical trials QOL / supportive care opportunities
0 Help w/Employment issues	0 Help w/daily living issues
0 Help with Fertility issues	.17 1 Help obtaining recommended cancer medications
.75 2 Help with NACR's Memorial Fund Applications	
1.17 2 Help with Financial Assistance resources	
0 Help finding a healthcare provider	
.25 2 Help with legal assistance and information	

Native American Community Education Workshops will increase the knowledge and intended behaviors among the Native American participants by at least 20%.

Table 2. Increased Knowledge and Overall Workshop Evaluation

	Total
Average % of participants that answered pre-session knowledge items correctly	40.3%
Average % of participants that answered post-session knowledge items correctly	65.4%
Difference between the average percentage correct for the pre- and post-session knowledge	28.4%



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### Overall Workshop Evaluation by Partner's Sites

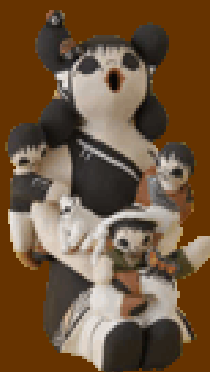
Table 3. Overall Workshop Evaluation

	Total
Average % of participants that rated the workshop content as "understandable"	89.0%
Average % of participants that responded "I agree" about the workshop providing useful information	91.7%
Average % of participants that answered "yes" they would recommend the workshop to others	92.3%



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### Summary / Key Points

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## Solutions / Lessons Learned: Audience Response System (ARS)

- 🥁 ARS, once learned, works well for workshop evaluations
  - 🌐 Because of higher than anticipated participation, NACR needed to loan ARS keypads to partners
- 🥁 Most partners have purchased more keypads



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## Summary of Key Points

- 🥁 NNACC intervention based on solid research methodology
- 🥁 Community-based Participatory Research Design among NACR, ITCMI, RCRH (GPTCHB), MCN=very successful
- 🥁 Each Partner creates MoA-O with other local AI organizations to coordinate, implement and evaluate FFE and WS interventions



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## Summary of Key Points

- 🥁 More than 125 hours of initial NPN training
- 🥁 Although webinars work well, for some trainings no substitution for face-to-face trainings (and observed practical exercises)
- 🥁 Topics for refresher sessions or new topics (stomach, pancreatic) are identified by NPNs or members of the administrative team



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## Summary of Key Points

- 🥁 Online evaluation program working effectively (but steep learning curve)
- 🥁 Average increase in learning from WS pre- to post-test knowledge is >25%
- 🥁 Education intervention very well accepted by all of the communities
- 🥁 AIs diagnosed with cancer during NNACC accessed quality services quickly and efficiently
- 🥁 More than double the number of anticipated participants in the intervention.



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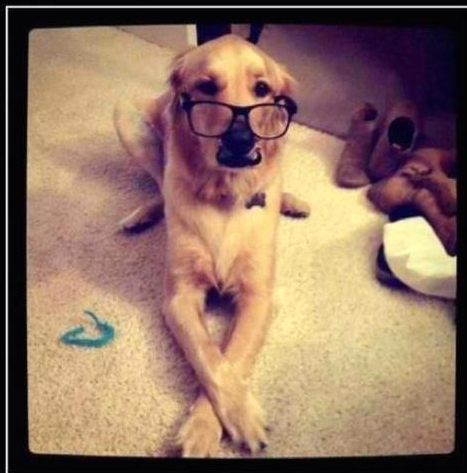
Thank you for  
inviting me and  
allowing me to  
share Patient  
Navigation  
Competencies with  
you



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## Discussion Topics



Have a seat and  
Let's talk about a few items

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### The Competencies




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### A1. Competency:

 Provide health education and coaching that enable patients to self-manage their health condition(s) using culturally-tailored public health theory and strategies.





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## B. Domain: Advocacy and Community Capacity Building


-  B1. Competency: Communicate barriers and human rights violations that patients experience in the health care system to providers and staff in order to assure that these setbacks or discriminatory events are addressed and optimally resolved.
-  B2. Competency: Seek and facilitate opportunities for community capacity building to address health inequities among populations.



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## C. Domain: Assessment and Referral

-  C1. Competency: Assist patients to access additional services and programs as needed to self-manage their health condition(s).



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## D. Domain: Communication

- 🛖 D1. Competency: Demonstrate the ability to effectively communicate with patients, families and members of the health care team.



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## E. Domain: Care Coordination and Case Management

- 🛖 Facilitate the appropriate and efficient delivery of services to bridge gaps, both within and across systems, to promote person-centered, optimal outcomes.




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## F. Domain: Reporting, Evaluation and Tracking


-  F1. Competency: Demonstrate effective “documentation” techniques including reporting, evaluating, monitoring, revising and tracking data related to patient care.



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## G. Domain: Cultural Responsiveness

-  G1. Competency: Demonstrate skills, establish and follow protocols, and exemplify behaviors that exhibit the value of diversity and intentionally promote effective and productive exchanges among clients and all employees or contractors of myriad cultural backgrounds within the healthcare system and its various settings.



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## H. Domain: Outreach Methods and Strategies

- 📦 Comprehend and demonstrate the ability to implement multi-prong approaches to engage un- and under-served communities through a variety of innovative strategies, as well as using established best practices (i.e., effective health promotion / behavior practices).



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## I. Domain: Use of Public Health Concepts and Approaches

- 📦 I1. Competency: Demonstrate an understanding of the larger, more complex issues of public health and their relation to the health care system in order to promote prevention, problem-solving, and policy change to achieve better health outcomes.



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## I. Domain: Use of Public Health Concepts and Approaches

- 🥁 I2. Competency: Support positive behavior change through culturally-tailored, promising and best-practices guided by public health theory and strategies.



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