



SURVEY SUMMARY

Dates: Survey sent out May 6; Deadline June 30

Number of Respondents: 102

Sponsors: Georgia Society for Clinical Oncology (GASCO) and Georgia Cancer Coalition (GCC)

ABOUT THOSE WHO RESPONDED

Geographic: Respondents were from 30 cities representing all the Regional Cancer Coalitions divisions in the State of Georgia. The largest number of respondents were from Atlanta (32%) and Savannah (13%). Others with 3.7% to 6.5% each are (from largest to smallest): Rome, Macon, Albany, Augusta, Athens and Decatur.

Position Funding: 93.2%-paid; 6.8% -voluntary

Of those paid:

- 62.8% -funded by their organization.
- 21.8%- other, including: grants, Avon Foundation, regional cancer coalition, organizational donation, paid employee of a physician practice, match between hospital & ACS
- 9% -funded by ACS
- 6.4%- funded by private donations

Education:

- 31%- RNs
- 19%- OCN
- 18% -Social Workers
- 32%- others, to include -MPH, RD, RT, MDiv, PhD, MBA, BA, BS, BS, MD...also, teachers, medical assistant, psychology degree, MEd/counseling, Survivor with corporate management experience, navigator training programs

Professional Organizations: (75 responses: 68%- belong to one; 32%- do not)

Specific organization membership: 57 responses, some with several memberships, to include:

- 18- Oncology Nursing Society (national & local chapters)
- 5- National Association of Social Workers
- 4- Association of Oncology Social Work
- 2- ACS

- 2- GASCO
- 2-Georgia Nursing Association
- 2- Association of Community Cancer Centers
- 2- Association of Cancer Executives
- Others: ANA, ASRT, ARRT, ATS, CMAP, HMA, OCN, NCBC, SOPHE, RCP, dietary associations, Sisters by Choice, International Assn of Administrative Professionals, etc.

Years Experience: (79 responses)

Average/Mean - 14.14 years; Median- 11 years; Mode- 10

Work tied to Cancer Patients

- 71%-totally cancer patients
- 16.9% -spend 75% of their time
- 3.6%- half of their time
- 8.4% spend 25% or less of their time with cancer patients

ABOUT THEIR ORGANIZATIONS

Specializing in Specific types of cancer:

- 32%- specialize in breast cancer
- 27%- no specialization;
- 14%- other
- 12%- general cancer
- 10% -specialize in lung cancer
- 5% -specialize in colorectal cancer;;

Information being collected/tracked: (67 responses/many with multiple items)

- 10- Numbers of contacts, patients seen, services given
- 8- collecting demographics (age/gender/race/cancer site)
- 7- Tracking referrals (date/agency/patterns)
- 5- Not tracking any data/just getting started
- 3- Tumor/Cancer Registry tracking data
- 3- Patient Satisfaction
- 3- Dates of procedures/time spent with patient
- 2- Tracking time from screening to diagnosis to treatment
- Clinical Trials
- *Other responses:* outcomes, treatments, patient, compliance, patient needs; changes in knowledge/attitude/behavior

Cancer Patient Navigation Functions: (in order of largest response; no limit on number individual could check)

- Connect Patients with resources and support systems (87%)
- Help patients identify and use appropriate social services/community resources (85.9%)
- Engage in community outreach and education (84.8%)
- Help to decrease patients' anxiety and fear (83.7%)

- Help patients identify and access financial services to pay for health care (79.3%)
- Facilitate interaction and communication with health care staff and providers (78.3%)
- Provide Necessary education to the patient/family regarding treatment plan/options (75%)
- Assess a newly diagnosed patient's psychosocial needs (68.5%)
- Streamline appointments and paperwork (59.8%)
- Help patients arrive at scheduled appointments on time and prepared (59.8%)
- Assist patients in meeting their spiritual needs (54.3%)
- Develop a care plan to address individual needs (53.3%)
- Track interventions and outcomes (53.5%)
- Notify individuals of clinical trials; facilitating enrollment upon request (38%)
- Discuss tissue banking (21.7%)

Defining Patient Navigation: Additional functions mentioned in respondents organizational definitions of cancer patient navigation include:

- Facilitating health/medical care access
- Connecting patients/families with medical, financial, psychosocial, spiritual resources & support
- Providing a patient-centered, outcome-focused process
- Diminishing barriers
- Smoothing the journey across the continuum of care
- Advocating, Coordinating Care and Resources, Solving Problems, Educating, Serving as Liaison
- Offer the empathy of a survivor; Listening; Peer-to-peer support
- Helping patients/families understand processes, expectations, realities
- Providing continuity of care
- Offering community and faith-based outreach
- Addressing prevention
- Recruiting patients for clinical trials
- Assuring optimal quality care is provided for the patient
- Discussing plans upon discharge from hospital: community resources, financial assistance
- Helping patients locate information, formulating questions to ask doctor
- Providing support with day-to-day concerns: transportation, lodging, local assistance
- Serving as the single point of contact
- Supporting the family
- Assuring seamless, personalized care

A GEORGIA CANCER PATIENT NAVIGATOR ORGANIZATION

Interest in joining/participating in a Cancer Patient Navigation organization in Georgia:
(80 responses) 90%- Yes; 10% - No

Interest in attending one-day conference: (83 responses) 95.2% -Yes; 3.8%- No

Interest in Networking Activities: (73 responses) 89%- Yes; 11% -No

Ideal conference length: (48 responses):

- 43% said 1 day
- 29% said ½ day
- 12% said 1-2 days
- 8% said 2 days
- 4% said more than 2 days.

Interest in networking activities: (73 responses) 89% Yes; 11% No

Issues respondents would like the Georgia Cancer Patient Navigator organization to address:
(in order of greatest interest; no limit on number individual could check)

- Share information on community resources (84.2%)
- Ensure all newly diagnosed cancer patients & caregivers have access to navigation (81.6%)
- Promote best practices (80.3%)
- Address quality of care issues (75%)
- Offer continuing education (75%)
- Reduce barriers to care (75%)
- Increase awareness of Oncology Navigator role (73.7%)
- Develop standards/principles/measurements for patient navigation (71.1%)
- Reduce health disparities in Georgia (71.1%)
- Promote development/expansion of Patient Navigation programs (69.7%)
- Promote collegiality through supportive network (61.8%)
- Using Information Technology to provide support for navigators (60.5%)
- Ensure sustainability of patient navigation programs (57.9%)
- Share outcomes measures which document return on investment (57.9%)
- Promote/participate in patient navigation research (52.6%)
- Embrace mission of Georgia's Comprehensive Cancer Control Plan (52.6%)
- Promote availability of Clinical Trials (48.7%)

Suggested Program contents/speaker/resource information needed: Topics mentioned most:

1. Networking
2. Financial resources/assistance
3. Data collection tools/methods
4. Follow-up care
5. Metrics/Patient Tracking
6. Clinical Trial promotion/access
7. Cancer Research
8. Available resources
9. Models/Best practices in Patient Navigation (guidelines/protocols)
10. Support for Patient Navigation program among physicians/staff;
11. Access/Entry into system
12. Supportive care (psychosocial, dietary, sexuality, survivorship)

Suggested speakers:

- Dr. Harold Freeman
- Jane Clark, RN
- Rep Hilda Solis (CA)
- Dawn Satterfield/CDC
- Dr. Nanette Turner/Mercer
- CHAN representative
- Erin Hernandez/Blue Ridge AHEC
- Christiana Care in NJ - Panel/Group on how Navigation works in their organization
- Judi Kneece
- Cheryl Kish, Georgia College & State University

OTHER COMMENTS/THOUGHTS & IDEAS ABOUT PATIENT NAVIGATION IN GA

The bulk of comments are praise: this is a wonderful initiative, long overdue, invaluable.

Some important concerns/issues that are raised include:

1. There are many different types of individuals in this role. The role of the navigator and the definition of the title vary so widely. We need to determine how to avoid “turf” wars.
2. Patient navigators are important as “physician extenders.”
3. The ongoing needs of cancer patients are extensive; sharing this role would be of great advantage to the patient and caregivers.
4. Navigation should include of marginalized populations-- limited English proficient; undocumented; the poor – who have additional barriers.
5. We exist only to care for the patient.
6. Networking and educational opportunities specific to oncology navigation have been difficult to find in some areas and a number of navigators work independently outside of a facility. An organization would be a welcome source of both.
7. Request for communication classes on subjects such as delivering the initial diagnosis, introducing clinical trials and when to begin to initiate dialogue about palliative care.
8. The value of having cancer survivors involved in the navigation process
9. The need for funding for navigation projects for all types of cancer patients, especially within the same cancer center. The patients do perceive a disparity in circumstances when this is not the case.
10. The roles and patient communication parameters need to be clearly defined and appropriate training provided when navigation services are being conducted using non-clinical personnel.
11. The organization should provide education to payers and physicians on how patient navigation is a cost effective and quality enhancing way to manage complex patients