Background

Dr. Sarah Birken is a researcher who has conducted surveys on patterns and determinants of survivorship care plan (SCP) use, and offered technical assistance to Comprehensive Cancer Control (CCC) programs and coalitions on data collection.

Question and Answer Discussion

What are CCC programs and coalitions doing around survivorship data collection?

- Activities
  - Paid for implementation of the Center for Disease Control and Prevention’s (CDC) Behavioral Risk Factor Surveillance System (BRFSS) survey cancer survivorship module in the state.
  - Modified cancer survivorship module on the BRFSS to ask more specifically about SCP use.
  - Conducted surveys collecting data about SCP use.
    - Among cancer hospitals/programs (sometimes CoC-accredited only, sometimes all)
    - Among primary care providers
  - Using data to inform cancer plan objectives and strategies to help hospitals meet SCP guidelines.
  - Using data to compile a toolkit of best and promising practices around SCP use.
  - Conducting a review of survivorship surveys (e.g. American Cancer Society and LiveSTRONG).
  - Conducting a survey of survivor needs and variations by demographics and individual characteristics.

- General strategies
  - Spearheading activities with dedicated survivorship workgroups.
  - Working with universities and involving public health students.
  - Leveraging a coalition organization’s contacts to identify and connect with people to be surveyed.

How can CCC programs and coalitions promote SCP use?

- Understand barriers and determinants to SCP use in order to develop relevant strategies and interventions.
  - Dr. Birken’s article describes potential provider determinants of SCP use, including:
    - Beliefs about consequences of SCP use (benefit to survivors, professionals and system);
    - Motivation and goals (advocating SCP use, time constraints);
    - Environmental context and resources (information technology, funding, system support, SCP delivery during a dedicated visit); and
    - Social influences (prioritization of SCPs at the organization, leadership support).

- Empower patients and engage their support to request and push for SCPs from their providers.
• Dr. Birken and GW Cancer Institute are looking for survivorship success stories to share, to disseminate successful strategies and promising practices for promoting SCP use. Submit your survivorship success story [here](#) or by emailing cancercontrol@gwu.edu.

What are some factors to consider in deciding whether you **should** conduct a survey at all?

- **Need:** Will survey information be useful and meet the needs of your organization and stakeholders?
- **Cost/Benefit:** Is the information gained worth the financial and time commitment of conducting the survey?
- **Stakeholders:** Do stakeholders agree that a survey is the right approach to meet their needs?
- **Existing data sets and surveys:** Are there existing data sets sufficient to meet your information needs?
  - Using an existing data set saves time and money and reduces survey burden on respondents.
  - Understand the original purpose, methodology, context, limitations and biases of the data set.
  - Example sources of existing data: registry data, published research, BRFSS, CoC data

How do you identify who to survey?

- Your survey purpose should determine your sampling frame, or who is surveyed.
  - Who are you trying to help or affect? What is the level and scope of the information that you are looking for? Who would know this information?
  - For example, a survey may target hospital directors to understand organizational determinants, providers for provider attitudes or survivors for survivor experiences with SCP use.
- **Brainstorm associations or affiliations that would have lists of target organizations or respondents.**
  - Dr. Birken used: CoC, Association of Community Cancer Centers (ACCC), National Comprehensive Cancer Network (NCCN), and Quality Oncology Practice Initiative (QOPI)
  - Identify a coalition partner with the desired network and reach.
- Consider whether your respondents are representative of your population of interest.
  - For example, CoC-accredited hospitals may systematically differ from non-CoC hospitals.

How do you develop a survey instrument?

- “Garbage in, garbage out”: Make sure your questions are designed to collect the information that you need.
- Do not reinvent the wheel: Whenever possible, look at existing surveys to borrow questions, get ideas, and see what and how questions are asked. Potential sources of questions or items include:
  - Published research literature. Psychometrically tested measures may be validated and may make your data comparable to that of other studies using the same measures.
  - Network of interested people collecting the same types of data. Dr. Birken welcomes use of her survey (contact her at sarah1@email.unc.edu to request a copy). Consider reaching out to other CCC programs/coalitions who have conducted surveys in the past.
- Consult with stakeholders: Stakeholders familiar with your target respondents and issues can provide crucial insights about what should be asked and how it should be asked.
- Conduct cognitive interviewing when possible: Have some target respondents complete your survey with you, to help you understand how respondents are interpreting your questions and experiencing the survey.
- Pay attention to logistical minutia: Pilot surveys can identify issues at all levels that could impede survey completion (e.g., incorrect addresses or poor packaging). Call participants to check on their survey experience.

How do you collect survey responses and encourage people to respond?

- Web-based surveys are a common option (e.g. SurveyMonkey, Qualtrics, REDCap).
  - Benefits: Inexpensive, wide reach, analysis features, eliminates need for data entry.
  - Challenges: May not reach clinicians with less computer use, oversaturation of web-based requests.
• Try mixed approaches to reach respondents (e.g. web survey, paper survey, phone calls).
• Be persistent and contact respondents multiple times, but do not harass.
• Consider participant incentives (e.g. raffle to win an iPad).
• More is not necessarily better. If the number of responses you have is sufficient to guide your program or answer your question, it may not be necessary to collect additional surveys.

What data exists on outcomes of SCP use? How are outcomes of SCP use measured and assessed?

• There have been several observational studies reporting positive outcomes (e.g. patient and provider satisfaction, survivor adherence to follow up). Two randomized controlled trials found no statistically significant benefits of SCP use; however, results may be inconclusive due to study limitations.
• Scan existing studies for ideas on indicators and measurement. For example, Chrischilles et al 2014 examined the following outcomes: patient-reported certainty about which doctor was in charge, follow-up checkup, MRI/PET/CT scan in the past 2 years, physician communication experiences, meeting exercise guidelines, and self-perceived health status.
• National Cancer Institute has a Grid-Enabled Measures Database which is a “web-based collaborative tool containing behavioral, social science, and other relevant scientific measures.”
• Consider your needs and purpose in choosing design and measures. Rigorous study design and data collection may be necessary for influencing insurance reimbursement or publishing in an academic journal, but may not be necessary or most useful for other practical “real world” needs.

How often should surveys on SCP use be administered, especially in light of shifting guidelines?

• Prevalence of SCP use is likely slow to change. Although guidelines change and cancer centers may know what they should be implementing, it is challenging and a long process for cancer centers to initiate SCP use.
• Consider your needs and purpose, and whether the time and expense of a repeated survey is worthwhile. Will an additional survey influence your program’s work?
• If a follow up survey is conducted, consider whether your data needs would be met by surveying only a subset of your population (e.g. especially high needs populations) or using a subset of your survey items.
Expert and participant-recommended resources:

Guidance on survivorship care/SCP standards:
- Institute of Medicine’s report: From Cancer Patient to Cancer Survivor: Lost in Transition
- American College of Surgeons: Accreditation Committee Clarifications for Standard 3.3 Survivorship Care Plan

Articles on patterns and determinants of SCP use:
- Survivorship care plans: Prevalence and barriers to use (Birken et al, 2013)
- Potential determinants of health-care professionals’ use of survivorship care plans: a qualitative study using the theoretical domains framework (Birken et al, 2014)
- Determinants of Survivorship Care Plan Use in US Cancer Programs (Birken et al, 2014)
- Following through: the consistency of survivorship care plan use in United States cancer programs (Birken et al, 2014)

Articles about survivorship care plan use and outcomes:
- Survivorship care planning and its influence on long-term patient-reported outcomes among colorectal and lung cancer survivors: the CanCORS disease-free survivor follow-up study. (Chrischilles et al, 2014)
- Who is receiving survivorship care plans? Findings from the 2012 Livestrong survey (Rechis et al, 2013)

GW Cancer Institute resources:
- Evaluating Cancer Survivorship Care Models
- Executive Training on Navigation and Survivorship: This online training is a nuts and bolts course on navigation and survivorship program development and implementation, including: program components, services, questions to consider, models of care, survivorship care plans, developing a protocol, and developing an algorithm. Continuing Education credits are available for nurses and social workers. To register for the program, use enrollment code ETrain (note, this is case sensitive).

Resources mentioned by participants:
- CoC Hospital Locator
- NCI's GEM (Grid-Enabled Measures) Database

Survey methods resources:
- Powerpoint on Response Rate in Surveys from University of Wisconsin-Extension
- Survey Fundamentals guide from University of Wisconsin-Madison Office of Quality Improvement