Ethical Considerations for Data Collection Using Surveys

Marilyn J. Hammer, PhD, DC, RN

Surveys are instruments used to quantitatively evaluate subjective data. Through the addition of open-ended questions, qualitative data can also be obtained (Eysenbach & Wyatt, 2002). Technically, survey is a general term used to describe the collection of information but is often used interchangeably with questionnaire—a list of focused questions. In oncology, assessing symptoms and quality of life (QOL) through surveys aids in providing feedback to optimize patient care. The collecting and analyzing of patient information is integral to research and patient care. One of the National Institutes of Health’s initiatives within the Roadmap for Medical Research was the development of the Patient-Reported Outcomes Measurement Information Systems (PROMIS®) (Ader, 2007). Domains within PROMIS specifically target symptoms and QOL issues of patients with cancer (Garcia et al., 2007). Aside from PROMIS, numerous valid and reliable instruments are used to gather patient experiences and needs in oncology. These instruments have also been paired with biomarkers to investigate associations between patient perceived experiences and underlying mechanisms. For example, the research program conducted by Miaskowski (2016) and others (Alfaro et al., 2014; Dhruba et al., 2014; Merriman et al., 2014) highlights genetic variants and symptom clusters.

Although there can be multiple variations of simple surveys and complex questionnaires paired with biomarker data, research ethics should be universally maintained. When using surveys, two areas to consider are obtaining informed consent and maintaining scientific integrity.

Obtaining Informed Consent

Obtaining informed consent may vary in format. Often, in-person participant enrollment in studies includes a discussion and signing a consent form. Mailed or web-based surveys, however, have implied consent or “passive” consent by virtue of participants completing them (Buchanan & Hvizdak, 2009). However the survey is delivered, participants should understand that they have the right to participate without compromise of care. In addition, they should have the right to not answer specific questions. This is not an issue when using paper surveys, but sometimes electronic surveys do not allow participants to skip questions. Participants may not be allowed to move on to a subsequent question without responding to the current question, or, in some cases, they may not be able to submit a survey without responding to all questions. If answers are not allowed to be skipped, participants may not complete a survey or may provide false information that is not representative of their specific situations. Aside from actual content,