

This section is meant to be a mutual effort. If you find an article you think should be abstracted in this section, do not be bashful—submit it for consideration to feature editor Kenneth V. Iserson care of *CQ*. If you do not like the editorial comments, this will give you an opportunity to respond in the letters section. Your input is desired and anticipated.

Buchanan EA, Hvizdak EE. Online survey tools: Ethical and methodological concerns of human research ethics committees. *Journal of Empirical Research on Human Research Ethics* 2009;4(2):37–48.

In recent years, online survey products have emerged as convenient research tools. Despite the growing prevalence of online surveys in empirical research, literature focused on ethical and methodological issues surrounding the use of online surveys remains limited. The study reviews U.S. Human Research Ethics Committees' (HRECs) review processes related to online surveys. Surveys were sent to 750 HRECs, and data were collected from November 2007 to May 2008. Two hundred and thirty-four (31.2%) of polled HRECs responded, and answers were analyzed both quantitatively and qualitatively. Ninety-four percent of respondents indicated that online survey research was the type of Internet research most often reviewed, with HRECs typically reviewing zero to five Internet-related protocols per month. Almost all of the Internet surveys reviewed fell into the exempt category of review, suggesting that the nature of the data was not overly sensitive, nor were vulnerable populations being targeted. Nearly 35% of HRECs did not regard the privacy and security policies of commercial Internet survey tools as part of their standard review process. Approximately 74% of respondents did not have a designated review person to examine Internet research-based protocols. Five percent of HRECs required researchers to participate in Internet-based research ethics training, and 19.2% required HREC members to receive training in Internet research ethics. To qualitative questions regarding perceived strengths and weaknesses of online survey tools, respondents gave mixed perspectives on various topics including Security/Storage, Anonymity/Confidentiality, Sampling, Consent, Design, HREC Regulations, and Spam. What some

respondents found to be weaknesses, others found to be strengths. Additionally, whereas some respondents sought specific guidelines for Internet-based research, others saw no explicit need for guidelines beyond those that currently exist. *As online research assumes more prominence, a better understanding of online research ethics as well as more consistent HREC review of online surveys will help to ensure appropriate human subjects protections.*

Feldman JA, Rebholz CM. Anonymous self-evaluation of performance by ethics board members: A pilot study. *Journal of Empirical Research on Human Research Ethics* 2009;4(1):63–9.

Much has been penned about various aspects of Institutional Review Boards' (IRB) functioning and composition in the literature over the past decade. However, there are almost no data available regarding IRB members' perception of their own performance. There has been a great deal of focus in recent years on IRBs, especially regarding the members and what mechanisms are in place for reporting conflicts of interest and the like. In this study, the authors attempted to compile data regarding IRB members' own impression of their performance as well as their degree of satisfaction with the mission, functioning, and time commitment associated with their own participation on the Boards.

This study involved anonymously surveying each member from three different IRBs within one institution (Boston University Medical Center) and gleaned information regarding individual experience of the actual meetings as well as the time required to prepare for, discuss, review, and present protocols under consideration. The survey was developed by those conducting the study and utilized a 6-point Likert scale related to eight questions about the quality of the IRB meetings and a 5-point Likert scale related to five prompts regarding the

amount of time required to perform different IRB tasks. Qualitative comments were also solicited on how the IRB process could be improved. The surveys were given to 43 IRB members at three different sites within the same institution and were completed by 38 members. Responses indicate positive marks for each question on the survey. For example, in response to the prompt "Board meetings make efficient use of my time," two panels' average response was 5 (agree) and one panel's average response was 6 (strongly agree). And in response to a time prompt "Duration of meetings" all three panels responded with an average of 3 (about right). Qualitative suggestions for improvement included responses such as "Some of the discussions do not sort out the major risks to subjects from bureaucratic issues."

Because information regarding IRB members is so limited, this study attempts, on a small scale, to determine individual thoughts about IRB members' own performance on the panels. The authors acknowledge some of the most obvious limitations to their study, including the fact that there may be no association between self-perception of IRB members and their actual performance, the fact that it was conducted at only one institution, the fact that it had a limited number of participants, and the fact that the surveys may have encouraged positive responses. Importantly, other factors causing individuals to be leery of making too many assumptions about the results of this paper include a lack of proven reliability for the instruments used as well as the fact that IRBs may function differently at various institutions throughout the country, meaning IRB members in other locations may or may not be as satisfied with their specific institution's policies and procedures, which could affect IRB members' responses to the survey. *Overall, this is a worthy attempt at learning more information about the IRB process, but the results of this study tend to create more questions than are answered in this paper, which may have been the intent of the authors in the first place.*

Weitzman ER, Kaci L, Mandl KD. Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. *Journal of Medical Internet Research* 2009;11(2):e14.

As electronic medical records make greater inroads into medical practices, personally controlled health records (PCHRs) have been advocated. Promoting individual

patient rights, PCHR proponents claim that this type of system would lessen problems related to fragmented health records and disengaged and disempowered patients while simultaneously supporting public health monitoring and research. PCHRs, a version of personal health records, enhance users' control over a record's access and content. Recently launched PCHR platforms include Google Health, Microsoft's HealthVault, and the Dossia platform, based on Indivo.

These authors used observational and narrative data to assess the familiarity with and the impact, expectations, and acceptance of PCHRs. Using focus groups, semi-structured individual interviews, and review of e-mail content, they collected data from healthcare administrators, clinicians, and community members. This was done while an early version of their system was also being evaluated. Two independent analysts coded the data from their subjects' narrative texts.

They found that participants had little familiarity with the PCHR system, but still had high expectations for its capabilities, even though it was only in development. The participants felt that PCHRs' greatest benefits would be having physical control of their own medical records and being able to view and update them, as well as being able to share health information with healthcare providers. These subjects felt that PCHRs' benefits outweighed any perceived risks, including those related to inadvertent or intentional information disclosure. The authors identified barriers to implementation as being older patients, resistance to change among providers, inadequate health and technology literacy, ensuring accuracy and integrity of health information, and understanding confidentiality and privacy risks. *Although using technology to enhance patient autonomy is tempting, this study again demonstrates that solutions must be found to both technological and social barriers before these enticing ideas are foisted on the public or the healthcare system.*

Sofaer N, Kapiriri L, Atuyambe LM, Otolok-Tanga E, Norheim OF. Is the selection of patients for anti-retroviral treatment in Uganda fair? A qualitative study. *Health Policy* 2009;91:33-42.

Attempting to achieve universal access, Uganda introduced free antiretroviral therapy (ART) for HIV/AIDS in 2004, but only 46% of Ugandans who needed ART

received it in 2006. Life expectancy and quality of life can be improved with ART. Because the need for ART will likely continue to outstrip supply in Uganda, decisions regarding selection of ART recipients should be fair. The authors used the accountability for reasonableness (A4R) as a framework for evaluating allocation decisions because it is a leading framework for making healthcare decisions. This framework evaluates decisions based on (1) relevance, (2) publicity, (3) appeals and revisions, and (4) enforcement. *Relevance* means that those affected by a selection decision could agree that the reasons for the selection decision are relevant to that decision. *Publicity* means that those affected by the selection decision know the reasons the decision was made. *Appeals and revisions* refer to a process that enables people who have been denied treatment to present reasonable objections to the selection decision or the policies that led to the decision. Finally, *enforcement* refers to the regulatory process to ensure the above are carried out. The authors conducted 39 interviews with 41 health professionals in 2007 in several institutions or programs providing ART in Uganda. In addition, the authors convened five focus groups with 47 HIV/AIDS patients, most of whom were receiving ART. Four focus groups were single sex but one was of mixed sex because of insufficient recruitment. The single sex focus group was considered preferable because mixed groups were thought to potentially inhibit free expression. Interviews typically lasted on average 45 minutes and focus groups lasted approximately 75 minutes.

The authors applied the data collected to each of A4R's conditions. Several institutions selected patients according to a first-in/first-out (FIFO) criteria, with some institutions considering very sick individuals, staff, or ART recipients' families not having to meet the FIFO criteria. Criteria also commonly included a CD4 count between 50 and 250, with the additional requirement that there not be other major medical problems such as tuberculosis. There was also psychosocial criteria such as disclosure of HIV status to spouse, having a treatment supporter and an adequate long-term food supply, not be depressed, not be alcoholic, and live permanently within a certain distance of the providing/treating institution. Both patients and health professionals thought FIFO was fair and there was generally widespread acceptance of the other criteria and

rationale such that it appeared relevance was satisfied. Although widely accepted, some of the criteria used have been criticized as unfair or based on faulty information in other research. Regarding the next component of A4R, namely, publicity, many patients reported that the selection decision and the criteria they failed to meet were always communicated. All patients knew that eligibility depended on the CD4 count, with some expressing the CD4 criteria in lay terms. One rural all-women group only knew that the CD4 count mattered and did not understand the other criteria. Generally, individual patients could recall fewer criteria than the health professionals. In conclusion, the authors believed that the publicity criteria was probably satisfied in most institutions; however, the conclusion was qualified as probably because patients generally recalled fewer reasons than the health professionals and there was concern that in some institutions, such as with the rural women group, that the criteria were not available to them. The third component of the A4R process, appeals, was observed by the authors to not be satisfied. Although health professionals and patients referred to suggestion boxes and people available they could voice concerns to and health professionals mentioning an "open-door policy" for patients to express concerns, neither health professionals nor patients challenged denial decisions or the criteria. It was noted that patients reported that appeal mechanisms were unnecessary. Finally, regarding the fourth component of the A4R process framework, enforcement, the authors believed that on the basis of their data, the enforcement condition was not met. Many institutions had standardized disclosure of information on the selection process, and many required all or difficult decisions to be made in a "case conference," which sometimes included patients, yet the data indicated there was no enforcement of effective means to appeal decisions. *The authors conclude that in Uganda there is a widespread practice of communicating selection decisions and rationales to health professionals and patients in ART programs, but acceptance of criteria and rationale by both patients and health professionals that is not up to date and complete underscores the importance of effective appeal mechanisms.*

Shippee TP. "But I am not moving": Residents' perspectives on transitions within

a community care retirement community. *The Gerontologist* 2009;49:418–27.

Continuing care retirement communities (CCRC) have emerged as an option for senior living instead of nursing homes or assisted living residences. There are about 2240 CCRCs in the United States, with about 745,000 residents as of 2007. The number of residents in such facilities has more than doubled in 10 years. These facilities allow movement between levels of care: independent living (IL), assisted living (AL), and nursing living (NL). Shippee lived in a Midwestern CCRC for 2 years to conduct her study. Residents were told that Shippee was conducting research. The CCRC that was the subject of the study was similar to other institutions across the country. There were 272 residents with 75% women, mean age of entry of 75 years and mean age for all residents of 86 years. Most residents (224 of the 272) were IL with smaller numbers (18 in AL and 30 in NL). Residents could only enter the CCRC by initially moving into an IL living situation. This ethnographic research included 23 months of observation and 35 semi-structured interviews lasting 40–90 minutes with IL, AL, and NL residents. Residents interviewed had been in the CCRC from between 1 and 30 years, and the age range was between 76 and 99 years of age. Residents did not have a choice about moving from IL status to AL or NL status. Usually the CCRC director, with advice from a small committee, made these transition decisions.

Shippee identifies three major themes emerging from the data she collected regarding the CCRC residents: autonomy, fatalism, and social disengagement. Residents feared and did not like being told to move from IL to AL or NL; rather, they saw this forced move as a threat to their sense of self, a sign that they could no longer take care of themselves, and of becoming sick or dependent. A number of residents in their former careers had substantial authority and responsibility and were extremely reluctant to give up their independence and auton-

omy, which the transition to AL or NL signified to the residents. Upon being moved to AL or NL, residents also lost privacy. Instead of having their own apartment, they were moved to a smaller studio apartment or a shared room. One resident noted she could not “think of anything worse than to spend the rest of my life in a room with a stranger.” Some used the remainder of their assets to purchase a private room in AL or NL to preserve their sense of privacy. Residents spoke of frustrations over the rules causing a move to AL or NL because they were perceived as unclear, ambiguous, and applied inconsistently. Further, in AL or NL, there was more regimentation, such as meals occurring at specific times, being awakened at a specific time, and not being allowed to have many personal possessions. This structure led residents in AL or NL to feel stripped of even basic decisionmaking authority. Residents also perceived the move to AL or NL in fatalistic terms. The move signified that their life was over and they would die soon. The arrangement of the CCRC tended to isolate AL and NL residents from IL residents. Resigned to die, AL and NL residents felt alone and typically did not develop social relationships with others in AL or NL.

To address these dilemmas Shippee recommended CCRCs’ facility administrators and staff (1) better publicize and inform residents about the rules governing transitions between levels of care, (2) provide more mixed activities for IL, AL, and NL residents, (3) identify socially active residents to act as liaisons to promote better integration among residents of the different levels, and (4) do more work to try to create privacy and personal space across all levels of care. *Shippee points out that “research on transitions between levels of care in CCRCs is almost non-existent; yet, these transitions represent a fundamental microcosm of the aging process in general.”* This type of study demonstrates how studying transitions within CCRCs can promote more constructive approaches and policies for running CCRCs.

These Abstracts of Note were written by Aimee Kaempf, Steven T. Herron, Ken Iserson, and Barry Morenz.