

Title: Keep or Destroy? Attitudes of Patients With Inflammatory Bowel Diseases on Biospecimen Handling at Biobank Closure

Authors: R. Jean Cadigan, Michael Kappelman, Ajay S. Gulati, Suzanne Cook, kaaren haldeman, Kriste Kuczynski, Robert S. Sandler, Christopher F. Martin, Wenli Chen, Millie D. Long

Background/Aims: Studies have explored the ethical, legal, and social implications of biobanking. Although biobank closures occur, no study has examined participants' attitudes regarding continued use of samples after closure. We aimed to evaluate attitudes surrounding biobank closure and to determine factors associated with allowing continued use of samples after closure in a population of patients with inflammatory bowel diseases (IBD).

Methods: IBD patients in the CCFA Partners internet cohort participated in a 1:1 telephone interview on the risks and benefits of contributing specimens for research. These interviews informed a survey instrument evaluating perceptions of biobanking. We identified 3 themes which were used in the survey: "personal ownership of specimens" (degree to which specimens remain an individual's property after donation), "specimens as a commodity" (specimens considered material goods that can be sold) and "fear of discrimination" (belief that results from specimens will allow for future discrimination). We used bivariate analyses and logistic regression models to examine the relationships between disease and demographic factors, these themes and allowing continued sample use for IBD research after closure.

Results: A total of 26 interviews were conducted, and 1007 individuals completed the survey (57% response rate). The majority wanted to know, prior to contributing samples, what would happen to their samples and genetic information if the biobank were to close (88%). Participants were comfortable with destruction of the samples (90%) and genetic information (88%). They were also comfortable giving their samples and genetic information for studies on IBD (89% and 87%, respectively). Most participants were uncomfortable with selling samples and genetic information after closure. Neither disease type (Crohn's disease vs. ulcerative colitis), nor activity was associated with allowing continued use of samples after closure. Themes significantly associated with allowing continued use of samples after closure on bivariate analysis included personal ownership of specimens (<0.001), specimens as commodity (<0.001) and fear of discrimination (0.001). On adjusted analyses, only the theme of personal ownership of specimens (OR 0.27 (95% CI 0.17-0.43) was significantly associated with allowing ongoing sample use after closure

Conclusions: While willingness to participate in the proposed biobank was high, most respondents wanted to know upfront what would happen to their samples and genetic information if the biobank were to close. Those who perceived personal ownership of specimens were less likely to allow ongoing use of samples after biobank closure, independent of other factors. Creating a plan for specimens in the event of closure is important, as is disclosing this plan to participants during the informed consent process.