

Survey helps identify diagnostic misconception in Latino study participants

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Biological specimens are increasingly collected and stored for population health research.

Image provided by Dr. Sarah Knerr.

Researchers conducting observational studies are increasingly collecting biological samples to help understand and improve population-level health and disease management. While collectively useful, the results from any given participant's sample are generally not clinically meaningful, and so are generally not made available. Despite this distinction, some research participants mistakenly expect that donating biological samples may benefit them personally by providing meaningful health information. Identifying participants susceptible to such misconceptions would help ensure ethical recruitment in biospecimen research projects, particularly in underserved populations. In a recent report in *BMC Medical Ethics*, Drs. Sarah Knerr and Rachel Ceballos in the Public Health Sciences Division describe a new survey instrument they developed to systematically measure conflation of biospecimen-based research and clinical care for use with Latino communities.

Research participants' expectations of receiving personal health benefits when participating in observational studies have been termed diagnostic misconception. This is an extension of the concept of therapeutic misconception, most common in clinical trials, where trial participants misunderstand the different goals and principles governing research compared to clinical

care. These misunderstandings can alter participants' perceptions of the balance of potential benefits and burdens of research participation, which in turn can impact the effectiveness of the informed consent process and the decision whether to participate. "With the increasing focus on developing precision and patient-centered medicine the line between research and clinical care will likely get blurrier," said lead author Dr. Knerr. "It is important for the research community to think through the implications of what this means for our participants."

Of particular importance is evaluating the extent and impact of diagnostic misconception in communities that have limited health care access. These populations may be more strongly affected by the negative consequences of misunderstandings about research and clinical care, which could damage trust in both doctors and researchers. Furthermore, diagnostic misconception could potentially motivate project participation if health care is otherwise inaccessible due to false beliefs that research participation can substitute for medical care. Said Knerr, "We were inspired to create this instrument by observations we made analyzing data from a prior research study Dr. Ceballos conducted with Latinos living on the US-Mexico border. During interviews about biomedical research participation, people often described 'getting checked' as a main benefit of providing a sample for research, even though our interview guide had initially explained the differences between providing samples for research versus clinical care."

To enable future research on the causes and consequences of such misconceptions, the authors developed a quantitative survey instrument measuring conflation of observational biospecimen-based research and clinical care. This involved developing 20 questions pertaining to participants' understanding of the difference between observational research and clinical trials, the purpose of biospecimen-based research, and the perceived likelihood of benefiting personally from participation. By piloting these questions with 150 Latino adults in the lower Yakima Valley of Washington state and performing psychometric analyses, the authors identified the combination of questions that best measured conflation of research and clinical care. The authors also found that individuals with the highest scores on the final instrument, indicating the greatest conflation of biospecimen-based research and clinical care, were unemployed, spoke only Spanish, had no health insurance, had less access to traditional health care, and had good self-rated health. Future biospecimen-based research studies may be able to modify their recruitment and informed consent processes in order to help clarify misunderstandings about research and clinical care, particularly for subgroups that may be more likely to have misconceptions about research.

While a good first step, further research is needed to refine the instrument and assess its generalizability in more diverse communities and settings. Said Dr. Knerr, "the most pressing

questions that this work raises are ethical ones about research recruitment and informed decision-making in communities that have poor access to health care, who are often also underrepresented in population-based biobanks and targeted for special recruitment efforts. How much do they know about biobanking and observational research? How likely are they to conflate research and clinical care and does this influence their decisions to take part in research studies? Is this coercive? What can we do about it?" Answering these questions will be important for ensuring that all populations are able to appropriately participate and benefit from biospecimen research.

Citation:

[Knerl S, Ceballos RM](#). 2015. Giving samples or "getting checked": measuring conflation of observational biospecimen research and clinical care in Latino communities. *BMC Med Ethics*. 16:49. doi: 10.1186/s12910-015-0041-9.

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