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Ethics of Clear Health Communication: applying the CLean Look approach to Communicate Biobanking Information for Cancer research

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Abstract

Cancer innovations, such as biobanking technologies, are continuously evolving to improve our understanding and knowledge about cancer prevention and treatment modalities. However, the public receives little communication about biobanking and is often unaware about this innovation until asked to donate biospecimens. It is the researchers' ethical duty to provide clear communications about biobanking and biospecimen research. Such information allows the public to understand biobanking processes and facilitates informed decision making about biospecimen donation. The aims of this paper are 1) to examine the importance of clear communication as an ethical imperative when conveying information about cancer innovations and 2) to illustrate the use of an organizing framework, the CLean (Culture, Literacy, Education, Assessment, and Networking) Look approach for creating educational priming materials about the topic of biobanking.

Keywords

Biobanking; health communication; ethics

Cancer-related research innovations and technologies are continuously developing, yet, the public often remains unaware of these advances. A *biobank*, an example of a cancer-related innovation, is a repository where biospecimens such as saliva, urine, blood, tissue, or other bodily materials are collected, stored, and cyro-preserved at freezing temperatures to be used

for scientific research. Within cancer studies, research using biospecimen donations can lead to discoveries related to cancer prevention, cures, and personalized medicine.¹ Currently, a number of health care institutions with biobanks request cancer surgical patients consider donating tissue from the procedure for biospecimen research.² Although this request is typically asked of patients, more research that utilizes biospecimens with a healthy control group (the public) is being conducted nationwide.² Clear and understandable health communications can keep the public abreast of new research developments and make innovations such as biobanks “trustworthy institutions of long-term social durability.”³[p.430]

Biospecimen research raises a number of ethical concerns for the public. This includes personal health information privacy, protocol and processes of donating biospecimens for research, concerns about the management of donated biospecimens, and access to the results of biobanking research outcomes.⁴ Biobanking concepts, procedures, and research can be so complex that few non-experts understand the science behind it without translation.⁵ However, the general public receives little information about biobanking and biospecimen research until asked to donate in a medical setting.^{4,5,6,7} This can violate the principles research ethic of autonomy, that is, being able to make decisions with a sufficient amount of information. Thus, a need exists to create priming educational materials to inform the public about biobanking. Therefore, the goals of this article are 1) to examine the importance of clear communication as an ethical imperative when conveying information about cancer innovations, and 2) to illustrate the use of an organizing framework, the CLEAN (Culture, Literacy, Education, Assessment, and Networking) Look approach for creating educational priming materials about the topic of biobanking.

Biobanking and research ethics

By law, before a study may commence, researchers who use biospecimens must obtain study approval from an Institutional Review Board (IRB) to demonstrate how their proposed work will adhere to ethical principles of research. Although bioethicists have suggested alternative ethical considerations to genome research (e.g., shift from focusing on individuals’ gain from participating in research to the citizenry of genomic research findings),^{8–11} traditionally the IRB makes its decision on the basis of the study’s fidelity to the three principle tenets of the *Belmont Report* which include Respect for Persons (honoring participants’ autonomy to participate in research), Beneficence (minimization of study-related risks and maximization of benefits), and Justice (equal distribution of study costs and benefits to research participants).¹² Clear and understandable communication is at the center of each of these ethical principles, particularly Respect for Persons since comprehension of study information is research participants’ first step in making an informed decision.^{13,14} Researchers can enhance potential participants’ autonomy in making informed decisions about research participation by communicating appropriate information about the study’s potential risks, benefits, and processes to potential participants, which, in the case of biospecimen research, is the public. Appropriate priming information will allow potential donors to learn about biobanking and biospecimen research prior to informed consent, thus ensuring their autonomy in making well-informed decisions about whether to donate biospecimens.

Research shows patients’ overall willingness to consider donating biospecimens, yet it also notes several reasons for declining participation which include privacy concerns and perceived lack of time to make a truly informed decision.¹⁵ Other reasons for not participating include unfamiliarity with biobanking technology, lack of understanding the value of biospecimen research, fear of genetic testing and cloning, fear of privacy breach (specifically to health insurance companies), and perceived costs of donation.¹⁶ Additionally, prior knowledge and beliefs about biobanking may have an effect on potential

participants' ability to make an informed decision about donating biospecimens. This is compounded by lengthy informed consent documents, the meaning of which is not always conveyed clearly.^{15–18} Therefore, it is researchers' ethical duty to inform the public about new innovations by deconstructing technical information using clear and understandable linguistically and culturally relevant communications. This mindset may help to engage the public in new cancer innovations.

Call to action: Creating Clear Health Communications about Biobanking

In 1999 the National Cancer Institute's Office of Biorepositories and Biospecimen Research identified the need for the development of educational communication tools and resources related to biospecimen collection as a strategic priority.¹⁹ At the local level, community partners of the Tampa Bay Community Cancer Network (TBCCN), Moffitt Cancer Center's National Cancer Institute-funded Community Network Program, expressed an interest in learning about new cancer innovations such as biobanking, toured Moffitt's biobanking facilities, and identified knowledge gaps about this technology by the community at large. In response, TBCCN implemented a series of community-engaged processes to develop English and Spanish-language educational toolkits to create awareness and address public concerns about participating in biobanking research. To guide this process we applied the CLEAN Look approach (Culture, Literacy, Education, Assessment, and Networking), an organizing framework previously developed by the team for creating culturally and language appropriate cancer educational materials (Box 1).²⁰ We describe in the next section how this approach can be a useful tool for researchers seeking to inform the public about new cancer innovations. By following a systematic approach that strove for clear and relevant communication and understanding, researchers are able to uphold the ethical imperatives of Respect for Persons/Autonomy, Beneficence, and Justice.

Culture

In this model, *culture* refers to the cultural sensitivity of health education materials.²⁰ Researchers should consider the two dimensions of cultural sensitivity: *surface structure* (e.g., observed characteristics of a culture such as people, food, or color preferences), and *deep structure* (e.g., social, psychological, religious, and cultural values that influence a health behavior) when developing health promotion materials or planning interventions.²¹ To address surface and deep structure dimensions of cultural sensitivity, TBCCN assembled a Biobanking Community Advisory Board (CAB), which consisted of culturally diverse leaders of community-based health institutions and grassroots organizations. The CAB helped to create a focus group guide to assess community members' knowledge and understanding of biobanking and biospecimen research. TBCCN conducted 12 focus groups with a total of 95 Tampa Bay community adults to gauge their pre-existing knowledge and understanding of biobanking.⁶ Focus group feedback identified the need to communicate information to the public regarding the purpose of biobanking and its procedures, relevance, and confidentiality issues. Findings also suggested the public's need to understand the relationship between biospecimen donation and cloning and ways that researchers can ensure research participants' privacy and confidentiality. Focus group members also expressed the need for the educational materials to be easy-to-understand, concise, entertaining, and engaging. Research staff and the CAB considered these preferences when developing ideas for the biobanking educational toolkit.

Literacy

Developing effective health education communications requires that a reasonable match must exist between the material and the logic, language, and experiences of the intended audience.²⁰ Literacy, the consideration of language, education, and skill in interpreting and

understanding written and verbal communication, was considered when developing and evaluating the educational toolkit. During the formative focus groups, community members were asked to provide their age, educational experience, preferred language, and preferred channel of health communication (e.g., print media, interpersonal education) for receiving biobanking information. Based on this feedback, researchers elected to develop a DVD and supplemental informational pamphlet. Further, to address language needs of a diverse audience, researchers decided to create English and later Spanish versions of the materials using plain language for the educational toolkit. Prior to creating the DVD and pamphlet, bilingual staff pre-tested the language of the materials, especially key terms, with other Spanish speakers. For example, when selecting the Spanish term for biospecimens and biobank, different terms were tested among both bilingual community and CAB members, and they preferred the terms *muestras biológicas* instead of *materiales biológicos* and *biobanco* instead of *depósito*, respectively.

Education

Addressing the target audience's information and educational needs and preferences is important to creating health communications.²⁰ Creators of such communications should assess what pre-existing health materials are available to the public and determine whether or not to use these materials or incorporate information from them in the creation of new, more appropriate communications targeted to the intended audience. Research staff and CAB members identified and reviewed three educational brochures intended for the public including 1) the National Cancer Institute's brochure, *Providing Your Tissue for Research: What You Need to Know*, 2) Moffitt Cancer Center's *Donating Human Tissue for Research*, and 3) Dana-Farber Cancer Institute's *Advancing Cancer Care: Tissue Banking*. These materials varied in length, target audience, language readability, and general appearance. Upon reviewing the community focus group data, researchers and the CAB concluded that new materials were necessary to prime the public about biobanking technologies and biospecimen research. Research staff and the CAB collaborated with cultural and media organizations to develop the educational toolkit.

Assessment

Once health education materials are created, they must be pilot-tested with members of the target audience to assess audience satisfaction and understanding of the material's content.²⁰ After the educational toolkit was created, two research team members (MA, CDM) conducted learner verification interviews to evaluate participants' comprehension of biobanking and steps involved in the process of biospecimen donation. For example, participants were asked to elaborate on their understanding of specific sections of the DVD that dealt with privacy and confidentiality concerns, benefits of donation, and overall understanding of key terminology. Efficacy and persuasion of the messages were also assessed by asking participants to review the toolkit and report their perceptions of biospecimen donation, their receptivity to donating biospecimens, and their confidence about sharing the information with others. When asked about their satisfaction with the toolkit, participants reported appreciation of the diversity of races, ethnicities, and ages of the individuals featured in the DVD and pamphlet. Testimonials from community members also resonated with them. Future directions of the current biobanking communication assessment include examining the efficacy of the toolkit created for improving participant's knowledge, attitudes, and self-efficacy regarding to biospecimen donation and biobanking.

Networking

Networking refers to collaborating with community partners and other stakeholders who represent the intended audience and whose input is valuable in planning, creating,

evaluating, and sharing health education materials or programs.²² The research team sought partnerships with local key stakeholders and the Biobanking CAB from the inception of the idea to create the educational toolkit, and this continued through the evaluation process of the DVD and pamphlet. Stakeholders included marketing and media organizations, community-based organizations, community key informants, biobanking researchers, and clinicians. These partnerships provided considerable input in developing and evaluating the toolkit, making it accessible for the intended community. Members of the research team also worked with the National Cancer Institute's Biospecimen/Biobanking—Geographic Management Program (BMaP), a regional and national collaboration among cancer researchers and providers dedicated to reducing cancer health disparities as it relates to biobanking participation.²³ Specifically, they are exploring ways in which this locally produced biobanking communications materials for healthy community members may be used in educational initiatives for the general public among TBCCN partners and within BMaP-3 (Region 3) network.

Conclusion

Cancer innovations are occurring rapidly, and genomic research can advance our understanding of how cancer is prevented and treated. The development of clear communications about such innovations address the core ethical principles for enhancing potential research participants' understandings about whether or not to participate in research involving biospecimen donation. Clear communications about new cancer research innovations may empower individuals to make more autonomous and voluntary decisions about whether or not to participate in biospecimen research. Using systematic methodologies such as the CLEAN Look approach can facilitate the development of ethically sound and clear information about new cancer innovations.

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Box 1

APPLICATION OF THE CLEAN (CULTURE, LITERACY, EDUCATION, ASSESSMENT, AND NET WORKING) LOOK APPROACH TO CLEARLY COMMUNICATE BIOBANKING EDUCATIONAL MATERIALS

CLEAN Look Categories	CLEAN Look Considerations	Strategies to Address CLEAN Look Considerations
Culture Assess the cultural relevancy of the health education materials	<ul style="list-style-type: none"> • Does the program, services, or project aim to reach multicultural, multilingual groups? • In what way can the materials link to the group's beliefs, values, preferred language, and linguistics? 	<ul style="list-style-type: none"> • Created a Community Advisory Board to advise the development of the educational toolkit • Conducted formative focus groups with diverse community members to determine their beliefs and understanding of biobanking information
Literacy Assess appropriateness of language and readability of information	<ul style="list-style-type: none"> • What are the literacy levels of the target audience? • What are the language preferences for this audience? • How does the group prefer to receive health information (e.g. print materials, interpersonal communication)? 	<ul style="list-style-type: none"> • Asked the target audience about their language preferences and preferred channel of communication for health information • Created English and Spanish educational toolkits using clear, understandable language • Bilingual staff and community members reviewed language of all materials in educational toolkit
Education Address audience information needs and preferences	<ul style="list-style-type: none"> • What preexisting materials are available on the same or similar topic? • What are the biobanking information needs of community members? • What are other concerns (e.g. ethical concerns, fears) the audience wishes are addressed about the proposed topic? 	<ul style="list-style-type: none"> • Reviewed existing biobanking public education information • Relied on focus group data conducted with local community members about their current knowledge about biobanking and preferences for receiving biobanking information to inform the creation of the educational toolkit
Assessment Evaluate audience understanding of and satisfaction with health materials	<ul style="list-style-type: none"> • Does the audience understand the health education materials? • Is the audience satisfied with the overall educational products? • What changes are necessary to make the information more culturally and literacy relevant and acceptable? 	<ul style="list-style-type: none"> • Conducted iterative learner verification interviews with the target audience to ensure understanding and satisfaction of educational toolkit materials; subsequent changes due to audience feedback received additional community member review
Networking Create collaborations with health professionals create and later share health materials	<ul style="list-style-type: none"> • What other stakeholders' and health professionals' feedback should be considered prior to finalizing the health education material(s)? • What are best methods to sharing or disseminating the health education materials? 	<ul style="list-style-type: none"> • Collaborated with community members which included health professionals on a Community Advisory Board for the finalization of materials • In the future we will work with our community partners and partnering health organizations to disseminate this information to the public