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Improving Diversity in Cancer Research Trials: The Story of the Cancer Disparities Research Network

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Abstract The participation of racial and ethnic minorities and underserved populations in clinical trials is a critical link between scientific innovation and improvements in health care delivery and health outcomes. However, these population groups continue to be underrepresented in research. We describe the development of the Cancer Disparities Research Network (CDRN) to improve minority and underserved populations' participation in biobanking research. Between February and October 2011, we conducted a regional assessment to identify challenges and opportunities for cancer trials and biobanking research across the CDRN. Representatives from ten CDRN biorepository facilities completed an online survey assessing their facilities' minority biospecimen collection, biobanking practices, and education/outreach initiatives. Representatives of eight facilities also participated in stakeholder interviews. The majority (70 %) of facilities reported that specimens were available for research, although only one tenth of these specimens were from non-White patients. Most facilities collected a patient's age, gender, race, medical history, and ethnicity with samples; however, less than half also collected family health history, education level, household income, or primary language spoken. In addition, few

This paper is dedicated in loving memory to Piotr Kulesza, a true inspirational leader in the pathology and clinical research field who was committed to advancing research and addressing cancer health disparities. His genuine enthusiasm and love for teaching and mentoring were contagious.

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institutions collected Asian or Hispanic subgroup information. Only a few reported biospecimen collection outreach programs specifically targeting minority and underserved populations. Biospecimen directors and administrators indicated that funding, biospecimen sharing procedures, and standardization barriers limited their facilities from collaborating in biospecimen collection programs, despite their great interest. These findings suggest that the CDRN can provide opportunities for collaboration, resource sharing, and fostering of research ideas to address cancer disparities in biospecimen research.

Keywords Biobanking · Clinical trials · Cancer research · Minority and underrepresented populations

Introduction

Tailored cancer prevention and therapeutic options drive research output and translation in the era of patient-centered medicine. Unfortunately, limited diversity in research participation reduces output and yields applications that do not speak to the complexity and heterogeneity of cancer and its impact on minority populations [1]. The participation of racial/ethnic minorities and underserved populations in clinical trials is a critical link between scientific innovation and improvements in health care delivery and health outcomes [2]. However, these population groups often do not participate in clinical trials and in biobanking research due to distrust of the medical system, lack of awareness of clinical trials among patients and physicians, limited opportunities to participate, inadequate health insurance, and logistical burdens of trial participation (e.g., cost, transportation, study duration) [3–8].

Closing the gap in clinical trial participation among minority and underserved populations requires a significant paradigm shift in how researchers conduct research, training, and community engagement [9–15]. Building on these principles, the National Cancer Institute's (NCI) Center to Reduce Cancer Health Disparities (CRCHD) has funded the Geographic Management Program/Biospecimen Management Program (GMaP/BMaP) Network. This five-region network aims to build critical "hubs" to support and efficiently manage cancer health disparities research, training, and infrastructure programs.

In this paper, we describe the challenges and opportunities of cancer trials and biobanking research involving underrepresented populations in the Midwest and Northeast states that constitute Region Five—renamed the Cancer Disparities Research Network (CDRN). We present findings from surveys and interviews using our Comprehensive Needs Assessment Tool (CNAT) to illuminate biospecimen scientists, pathologists, and biorepository facility managers' perspectives on infrastructure and relationship building processes, including barriers, facilitators, and needs/opportunities for the CDRN. We examine how this partnership drives our next steps in developing a collaborative network of stakeholders to address cancer disparities in biospecimen research.

Methods

The Development of the CDRN

Established in the fall of 2009, the CDRN brought together 13 CRCHD-funded institutions to create transdisciplinary teams of community-engaged researchers, NCI's Continuing Umbrella of Research Experiences (CURE) trainees, basic scientists, biospecimen experts, pathologists, bioinformatics researchers, community health educators, and community members and organizations to address disparities in clinical and biobanking research. In alignment with national and international efforts, our network aims to create the infrastructure to centralize standards for collecting, processing, and archiving biospecimens and annotated data [16, 17] while reducing cancer disparities through community outreach [18, 19]. The cancer trial and biospecimen research arm of this network, BMaP, seeks to improve minority and underserved populations' participation in biobanking research while also facilitating biospecimen scientists' integration of these populations into their research.

CDRN is led by Northwestern University (BMaP—PI Simon) and Fox Chase Cancer Center (GMaP—PI Fleisher), with a Coordinating Committee of CDRN investigators guiding the strategic efforts. Since inception, CDRN has undergone the following several phases of expansion: phase 1—original 13 partner institutions (October 2009), phase 2—six new partner institutions and one new state (January and May 2011); and phase 3—seven new institutions and seven new states (May and June 2012) see Fig. 1. CDRN currently comprises 28 partner institutions, including 1 community cancer center, 2 NCI Community Cancer Center Programs (NCCCP), 6 academic medical centers, 4 minority-serving institutions, 2 NCI-designated cancer centers, and 13 NCI-designated comprehensive cancer centers [see Table 1]. This network spans 15 states from the Midwest to the Northeast (CT, IA, IL, IN, MA, MI, MN, ND, NJ, NY, OH, PA, RI, SD, WI). CDRN encompasses diverse racial/ethnic communities including African Americans, Latinos, Asians, Appalachians, and American Indians.

The Comprehensive Needs Assessment Tool (CNAT)

Following the first regional annual meeting, a working group comprised of GMaP/BMaP investigators and NCI's CRCHD was convened to develop Region Five's CNAT, including its goals, core areas, themes, and methodology. The resulting CNAT consists of four instruments (available upon request):

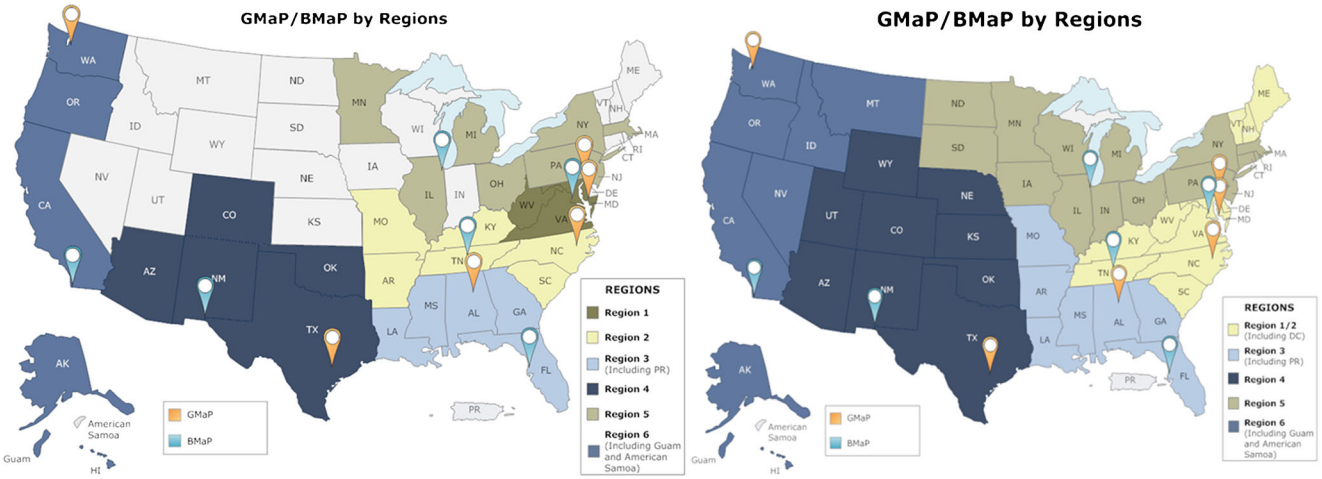

Fig. 1 GMaP/BMaP Region 5's expansion: Left map original 13 partner institutions across 9 states (October 2009). Right map current 28 partners across 15 states (April 2013)

Table 1 CDRN members

CDRN members[a]		
Institution	State	Investigator(s)
Boston University[d]	Massachusetts	Tracy Battaglia
City College of New York[b]	New York	Karen Hubbard
Columbia University[d]	New York	Mary Beth Terry & Parisa Tehranifar
Dana Farber/Harvard Cancer Center[b]	Massachusetts	Karen Emmons & Karen Burns White
Fox Chase Cancer Center Temple Health[b]	Pennsylvania	Linda Fleisher, J. Robert Beck, & Nestor Esnaola
Hartford Hospital (NCCCP)[d]	Connecticut	Andrew Saldner
Indiana University[d]	Indiana	Victoria Champion
Karmanos Cancer Center (Wayne State U)[b]	Michigan	Terrance Albrecht
Lincoln University[b]	Pennsylvania	Anna Hull
Loyola University[d]	Illinois	Emily E. Anderson
Mayo Clinic Cancer Center[b]	Minnesota	Judith Kaur
Memorial Sloan Kettering Cancer Center[b]	New York	Tim Ahles & Francesca Gany
Mercy Medical Center (NCCCP)[d]	Iowa	Richard Deming
Northeastern Illinois University[d]	Illinois	Moira Stuart & Marian Gidean
Northwestern University[b]	Illinois	Melissa Simon, Julian Schink, Raymond Bergan, Piotr Kulesza, Warren Kibbe, June McKoy, Marla Clayman
Ohio State University[b]	Ohio	Electra Paskett & Peter Shields
Pennsylvania State University Hershey[c]	Pennsylvania	Eugene Lengerich
Purdue University[d]	Indiana	Sulma Mohammed
John T. Vucurevich Regional Cancer Care Institute, Rapid City Regional Hospital[d]	South Dakota	Daniel Petereit
Roswell Park Cancer Institute[c]	New York	Deborah Erwin
Temple University[b]	Pennsylvania	Grace Ma
Tufts University[c]	Massachusetts	Karen Freund
University of Chicago[c]	Illinois	Karen Kim
University of Illinois at Chicago[c]	Illinois	Elizabeth Calhoun
University of Massachusetts Boston[b]	Massachusetts	Adán Colón-Carmona
UMDNJ—Cancer Institute of New Jersey[c]	New Jersey	Shawna Hudson
University of Pennsylvania[c]	Pennsylvania	Tim Rebbeck
University of Wisconsin at Carbone[d]	Wisconsin	Alex Adams

[a] Current and past members

[b] Phase 1—original 13 partner institutions (October 2009)

[c] Phase 2—six new partner institutions and one new state (January and May 2011)

[d] Phase 3—seven new institutions and seven new states (May and June 2012)

(1) Principal Investigator (PI) Survey, (2) PI Interview, (3) Cancer Biospecimen Research Survey, and (4) Biobanking Stakeholder Interview. These instruments were designed to examine current practices, resources, and needs of each participating GMaP institution; evaluate capacity building to conduct cancer health disparities (CHD) research; assess collaborative potential among the region for conducting CHD research; and assess minority biospecimen collections and biobanking practices. This paper draws on data from the Cancer Biospecimen Research Survey and Biobanking Stakeholders Interview instruments. The Cancer Biospecimen Research Survey specifically assessed the minority biospecimen collection (i.e., specimens that were available for research), biobanking practices, and education and outreach initiatives of the institutions' core facilities. To reduce respondent burden, facilities were asked to report the specimen data that were readily available. The survey underwent cognitive testing with representatives from several biobanking facilities to verify readability and item comprehension. Biobanking Stakeholder Interviews were designed to identify opportunities and challenges for health disparities research.

Data Collection

CDRN institutions eligible to complete the Cancer Biospecimen Research Survey were those that collect and bank specimen (n=11). The remaining CDRN institutions were either ineligible (i.e., did not collect/bank specimen) or joined after the assessment phase. CDRN Principal Investigators identified the biorepository leaders who manage the primary pathology core facility at their respective institutions and facilitated the completion of the survey. These leaders included pathology directors, clinical trial administrators, and biorepository facility administrators. Biorepository leaders received a link to a web-based survey in February 2011. Facility leaders completed the surveys between February and March 2011. Between July and October 2011, CDRN project staff conducted Biobanking Stakeholder Interviews by phone with the same facility leaders who had completed the survey. Interviews lasted an average of 45 min and were audio recorded and transcribed. The Institutional Review Boards of the Fox Chase Cancer Center and Northwestern University approved all study protocols.

Analysis

We used descriptive statistics to analyze data from the Cancer Biospecimen Research Survey on CDRN's minority biospecimen collection, biobanking practices, and education and outreach. The Biobanking Stakeholder Interviews were transcribed and then coded using ATLAS.ti software to identify and extract common themes. These themes were discussed until consensus was reached. Coding discrepancies were resolved through discussion with the team. Results were interpreted in conjunction with our GMaP regional partners.

Results

Representatives from 10 of the 11 biorepository facilities completed the Cancer Biospecimen Research Survey. Representatives of eight of these ten facilities who completed the Biospecimen Survey also participated in the Biobanking Stakeholder interviews. Interview participants included five pathology directors, one clinical trials administrator, and four biorepository facility administrators. In two institutions, we interviewed a pair of individuals who jointly completed the survey. We describe key findings below, organized into three domains: resources, infrastructure, and relationships.

Resources Available Through CDRN

Availability of Specimens for Research Seven (70 %) facilities reported specimens were available for research, totaling 36 cancer types. Of specimens collected from 130,386 patients in seven facilities that included race/ethnicity data, only 11 % were from non-White patients (Table 2). The non-White patients included African Americans (8 %), Asians (<1 %), Hispanic/Latinos (<1 %), and other (<1 %). Six facilities reported 235,097 cumulative samples banked, with most being from White patients (88 %). Although most facilities reported that they collected age, gender, race, medical history, and ethnicity, few collected the patient's family health history (4/10), education level (4/10), household income (2/10), and primary language spoken (2/10). Very few institutions reported collecting other epidemiological risk factor data and ethnic subgroup information for Asians and Hispanics (Table 2).

Specimens, while generally available, had program policy restrictions for use. Use of specimens required institutional approval at the majority of sites (n=7). In one site, use was also subject to Institutional Review Board approval if personal health information was needed. One facility reported that samples could be made available to outside institutions with collaboration of in-house investigators. In two facilities, outside institutions could use samples if they do not belong to other protocols. One facility had fees associated with the samples.

Facilitators for Institutional Collaboration Sixty percent of the biorepository facilities reported having existing institutional links or sharing agreements such as specific protocols and cooperative group agreements. One site reported that legal Memorandums of Understanding or Material Transfer Agreements could be established when necessary. Another facility's sharing agreements were under the oversight of a Scientific Advisory Committee, with internal researchers receiving priority use of specimens.

Table 2 Resources available in the CDRN network

Categories	Specific elements identified
Cancer types collected	• 36 cancer types collected • Most common cancer types—breast, colorectal, lung, gynecologic (uterine, ovarian, etc.), pancreatic, hepatic, urologic (bladder, kidney, prostate, testicular), melanoma, and non-melanoma skin cancers
Type of specimens collected	• Most common specimens—healthy and diseased tissues • Least common specimens—bodily fluids • Most common specimen conditions: fresh frozen, FFP blocks, FFP slides (unstained) • Least common conditions—frozen tissue sections and frozen in preservatives
Race and ethnic groups associated with specimens collected (n=8)	• Facilities collect specimen for the following racial and ethnic groups: Native Hawaiian/Pacific Islanders (6 sites), American Indian/Alaskan Native (7 sites), Asian (7 sites), Black/African American (8 sites), White (8 sites) and Hispanic/Latino (8 sites) • Reported Asian subgroup information—Chinese, Korean, Japanese (3 sites) • Reported Hispanic/Latino subgroups—Mexican, Mexican American, Puerto Rican (one site)
Samples reported by race and ethnicity (n=7)	• specimens were collected from 130,386 patients • 89 % (n=116,417) White patients • 9.4 % (n=12,321) Non-White patients • 1.3 % (n=1,648) Hispanic patients • Non-White included African Americans (n=9,840), Asians (n=1,920), Native Hawaiians (n=95), and Native Americans (n=466)

Infrastructure to Support High-quality, Well-annotated Biospecimens for Research

Organizational Structure of Biorepository Facilities All biorepository facilities were managed by a central facility, but across institutions, there were biorepositories specific to projects or investigators not under the purview of the central facility. Half of the institutions had multiple repositories with a wide array of cancer types (Table 2).

Bioinformatics-electronic Annotation Systems All facilities used electronic annotation systems for biospecimen collection. The most common were Oracle® and OnCore®. Other data systems or platforms included: caTissue Suite, Powerpath, Freezerworks, Java™, Microsoft NOTIS, and those developed in-house.

Quality Assurance and Quality Control Procedures Seven facilities reported the percentage of specimens that passed quality control. Four sites disclosed that they had a 100 % specimen quality control pass rate, one site confirmed a 92 % pass rate, while the remaining two sites reported 30 % and 20 %, respectively. Nearly all facilities (9/10 sites) had quality assurance/quality control procedures. Pathologists reviewed tissue samples to confirm tumor diagnosis before they were released for research in four sites.

Infrastructure Necessary for Procurement of High-quality, Well-annotated Samples Four main categories of infrastructure for procuring high-quality, well-annotated samples were identified as the following: SOPs, laboratory, bioinformatics, and buy-in from surgeons and principal investigators. Having a laboratory that worked closely with surgeons to procure specimens was deemed essential. Collecting well-annotated samples from communities, however, was noted as a significant challenge. One biorepository administrator described, "Through the medical center we have built the structure to electronically get medical records through the tumor registry and link them to our biorepository. For clinical annotation, we have those data fields. With minority samples, procured through community groups, from individuals who are not patients at our institution, we don't have these data elements and we need to rebuild the same data structure to link with the samples." Collecting specimens in the community presented additional challenges; some types of specimen collected were relatively easy to collect (e.g., blood, saliva) whereas other types of specimens (i.e., tissue) required greater effort and resources to process and annotate.

Efforts to Address Legal and Ethical Issues These efforts focused on the regulatory process, educating local IRBs, biospecimen protocols, infrastructure at the medical center, and an honest broker system. Facilities noted that the regulatory process and biobanking protocols were key to protecting patients and establishing guidelines for the future use of samples. According to one biospecimen facility administrator, "Patients sign off on the consent form [and] the specimens are de-identified and bar coded. All specimens are coded in a system so there is no chance for any kind of transfer of HIPAA information. Specimens have a link that we will share, but it has multiple layers of de-identification." Several facilities noted that an honest broker system was a crucial means to assure IRBs and patients that samples are de-identified and patient information is protected. A few facilities noted additional activities to address legal and ethical issues, such as having support from a legal team, privacy officers on regulation changes, and educating local IRBs on biospecimen collection processes.

Relationships and Outreach with the Community

Education and Biospecimen Collection Projects Many facilities (60 %) partnered with investigators to collect specimens for health disparities research. The projects cited include the

breast and prostate SPOREs, as well as programs that targeted Chinese, American Indian/Alaskan Native women. Nearly half (40 %) of the facilities have collaborated on education and outreach efforts to promote the collection of biospecimen in communities; four other facilities indicated a "high interest" or "moderate interest" in participating in these programs. However, few reported education and outreach programs promoting biospecimen collection specifically in minority populations.

Facilitators and Barriers for Community Outreach and Specimen Collection Respondents indicated a high interest in biospecimen collection and biobanking collaborations, but barriers included limited funding and resources, lack of standardization across institutions, and specimen ownership and sharing procedures. Facilitators for biospecimen collection and banking varied. Nearly all facilities believed community engagement was essential to building the trust necessary to complete the consent process, questionnaires, and collection of samples. Many sites also perceived educational resources for patients, physicians, and the community to increase awareness of clinical trials as indispensable. Also critical was institutional infrastructure that permitted collection, storage, and recovery, including dedicated staff to retrieve samples onsite/offsite. According to a pathology director, the type of specimen collected is one contributor to successful minority biospecimen collection, "Prostate-Specific Antigen (PSA) test for prostate is a beautiful example, we can show up with a van, have a phlebotomist and our staff, we can approach a person for screening test for cancer, we can draw the blood which takes about 10 minutes. Other specimens are more difficult; we cannot go in and ask someone in the community to come in our hospital for surgery." Another facility described strategies they used for successful biospecimen collection, "When we talk with people about the purpose of the study and it's for participation in something in particular [such as a specific study], and they understand, regardless of race or ethnicity, they will do anything to prevent someone from going through this. When it is just biorepository collection, it's a little bit harder to recruit the minority patients. There is more suspicion. [Patients ask], what is going to be done with my samples because of the whole legacy of Tuskegee and other things that have happened in the past. What we find with cancer patients is that having the doctor talk to the patient first about biorepository and biobanking and then [having] our staff also doing the in-depth consent process helps."

Strategies to Overcome Misconceptions Regarding Bio-sampling Related Research The three main strategies identified by respondents to overcome misconceptions were institutional safeguards (i.e., multiple levels of protections and confidentiality), engagement of patient advocacy groups, and educational efforts. The latter included educating the public on genetic research (e.g., to clarify that genetic information is only accessible to investigators) and educating staff. As summarized by one facility, "We need to be able to have everyone—people who register the patient, seek consent from the patient, person doing the vitals, physicians—all able to articulate the right message. It only takes one person to say that they are going to do something weird with it to get it off track."

Relationships across Cancer Biospecimen Facilities

Existing Biospecimen Facility Collaboration At the onset of the partnership, seven biorepository facilities reported that researchers participated in various NCI Clinical Trials Cooperative Groups. For instance, one facility noted that while it did not individually track all projects, many CDRN partnering institutions collaborate and use specimens, conduct statistical analyses and pool samples from different communities. This same institution acknowledged that much disparities research has resulted from sharing biospecimens and participating in pilot projects, including those associated with SPOREs and the Breast, Head and Neck, Lung, and GI collaborations. Another site expressed interest in collaborating with CDRN in the formative testing of Cancer 101, a biospecimen community education module, originally developed by the Spirit of Eagles (U54 153605) in collaboration with the Northwest Portland Area Indian Health Board. Finally, a third institution mentioned that while it did not collaborate with any outside institutions, it was interested in new collaborations and opportunities.

Barriers and Opportunities for Future Collaboration Through This Network Our group of stakeholders noted numerous barriers for collaboration within the network, including limited resources to support collection efforts, lack of standardization across institutions, and issues related to ownership and sharing of specimen. Nevertheless, respondents expressed interest and enthusiasm in collecting additional specimens, engaging in collaborative projects, sharing resources, and pursuing opportunities to expand banks. Respondents voiced willingness to exchange insights on best practices with other institutions, as captured by one biospecimen administrator, "…we are at the startup phase in our biorepository, [we are interested in] best practices with software, equipment, procedures, Standard Operating Procedures, etc. We are willing to share our experiences." The following comment from a facility administrator exemplified the synergy that can provide opportunities for all of our participating institutions and the field of banking research, "Right now all these groups work independently; so we all speak different data languages. It would be great if we could annotate samples in similar manners and have certain data elements available so that researchers could go to a central place to see who has what…

They could pool materials from multi-repositories to get their research done. It would be great to have a central virtual databank of these samples."

Discussion

The CNAT's biobanking survey and interviews yielded valuable information regarding the CDRN's current and potential capacity to increase minority and underserved populations' participation in cancer research. The data presented are the first to aggregate such capacity across our region. These data identified barriers and opportunities for collaboration within and among pathology facilities, highlighted existing practices related to successful minority collection efforts, and provided recommendations for resource sharing and collaboration across our network as well as nationally.

The CNAT data demonstrate depth and breadth in the types of cancer specimens collected in Region Five. Although most of the facilities reported that they collected age, gender, race, medical history, and ethnicity, less than half collected the patient's family health history, education level, household income, and primary language spoken. In particular, race and ethnicity information were not often collected as separate variables and few institutions reported collecting ethnic subgroup information for Asians and Hispanics. Recently, the College of American Pathologists Diagnostic Intelligence and Health Information Technology Committee's Biorepository Working Group issued a call to standardize basic annotation information for specimens banked for research to maximize utility [20]. To harness the full potential of samples, detailed patient annotation information needs to be associated with the specimen [1]. Gaps in standardized annotated data provide opportunities for collaboration across sites [21]. Respondents and other Region Five partners have indicated desire to share and standardize patient information tools.

Among biospecimen facilities, multiple levels of collaboration and capacity exist to support collaborative research projects, including research networks, screening initiatives, trials, and large cooperative groups. We found that only a small percentage of collaborative education and outreach programs promoted biospecimen collection in minority and underserved populations, which is noteworthy because there are few biospecimens available from these populations. Lack of clinical trial infrastructure and resources for community collection, biorepositories' constraints in accommodating evening and weekend hours, and misconceptions regarding biospecimen research contributed to minority and underserved population recruitment challenges encountered by our institutions. Strategies used by facilities to overcome misconceptions regarding biospecimen research among these populations focused on education efforts, institutional safeguards, and engagement of patient advocacy groups. Key factors of successful specimen collection include community engagement, consent process, and awareness and education—but such infrastructure that facilitates biospecimen collection that promotes underrepresented population participation was often cited as non-funded or underfunded. Encouraging evidence indicates that racial and ethnic minorities in the USA are as willing as non-Hispanic whites to participate in health research [22]. As cancer trials and biobanking studies struggle to recruit minority and underserved populations, efforts need to focus on recruitment and retention.

With respect to infrastructure, 100 % of our facilities reported using electronic annotation systems for biospecimen collection. Use of a wide range of data systems and platforms makes standardizing electronic annotation systems challenging and raises issues of compatibility and operability. Related issues such as data reporting, data sharing and mining, data accessibility, and network security and personnel to manage data are critical areas that will be addressed in the next phase of planning the CDRN biospecimen network [1, 23]. The AACR-FDA-NCI Cancer Biomarkers Collaborative group recommended that a "system for harmonizing terminology and standards and a supportive bioinformatics platform" was necessary to promote the development of methodologies, infrastructure, and policies for the use of biomarkers during cancer therapy [21, 24]. Since bioinformatics and data management are central components of any research core or biobanking facility, efforts are underway across institutions to identify commonalities and data systems that can be integrated to address these needs. Furthermore, findings from the interviews highlight the need to establish data systems to link specimens collected in communities with clinical data. The majority of our institutions have established infrastructure to support collection efforts; however, they have also indicated a need for funding to facilitate future collection efforts.

All participating facilities possess the infrastructure to address legal and ethical issues. Regulatory processes and protocols serve as the backbone for guidelines on banking samples, using specimen in the future, and protecting patients. Facilities reported working closely with local IRBs, legal teams, and privacy officers. Nevertheless, there is still work to be done to centralize IRBs and standardize recruitment tools and protocols. Informed consent may be a major challenge in the use of biospecimen for cancer research. The AACR-FDA-NCI Cancer Biomarkers Collaborative group recommends a common informed consent document that standardizes biospecimen terminology and addresses patient privacy issues [21].

Overall, biospecimen directors and administrators reported funding, biospecimen sharing procedures, and standardization barriers that limit their facilities from collaborating in biospecimen collection programs. Despite these barriers, they expressed a great desire to engage in partnerships to collect

additional specimens and/or share samples. These stakeholders indicated that collaborating with CDRN would be a valuable resource for their institutions. They also indicated a willingness to share successful strategies from their institution and an interest in learning about best practices employed by other institutions. We have created linkages among multidisciplinary researchers, including behavioral and community investigators, that are critical for the long-term success of our network. For instance, the Cancer 101 biospecimen banking module is currently being pilot tested at 11 CDRN sites. In addition, a communication tool intended to facilitate conversation between clinical trial recruiters and research subjects is currently undergoing cognitive testing and will be pilot tested at several CDRN sites [25]. Moving forward, paradigm shifts are required to overcome the traditional barriers of funding, collaboration, and standardization. The CDRN network described herein is an example of leveraging the expertise of diverse stakeholders and institutional resources to create the momentum for this effort.

It is important to note several limitations of this study. As a convenience sample, these data do not represent all cancer research trials and biobanking collection efforts in Region Five. We provide a snapshot of only those biospecimens that were available for research, and these data are limited to the information biospecimen facilities were able to collect and share at the time of the survey. Additionally, these data represent only the perspective of academic centers, researchers, and biospecimen facility leaders. Further inquiry should include community members, community hospitals, and other stakeholder organizations. Nevertheless, these data shed light on an overlooked issue—the lack of minority and underrepresented population participation in cancer research and biobanking. Without broader representation of groups impacted by cancer, improvements in health care delivery and benefits from clinical trials will continue to elude our most vulnerable populations.

Conclusion

CDRN can enhance the work of individual facilities and provide opportunities for collaboration, such as sharing specimens, exchanging best practices, increasing participation in underrepresented populations and fostering research ideas. In the last two years, we have conducted site visits to our partner institutions to formally meet pathology directors, facility administrators, biospecimen researchers, clinical trials administrators, community health educators, and others to cross-fertilize the expertise of institutions and discuss opportunities and barriers for collaboration. Through these meetings, we have heard a resounding willingness to collaborate and a desire to meet other biospecimen stakeholders to set the stage for collaborative relationships.

A key ingredient for a collaborative network is the commitment of regional leaders and partnering institutions to increasing diversity of participation in cancer research and biobanking. This level of dedication is best supported through a basal funding infrastructure such as that provided by the NCI's CRCHD. Additional funding is required to maintain infrastructure, provide technical support, continue to provide education about cancer trials, foster cross-collaborations for future research, and to, most importantly, foster meaningful bidirectional and continued dialog and relationships with the communities and populations being studied.

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