

# A Tale of 2 Constituencies

## Exploring Patient and Clinician Perspectives in the Age of Big Data

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**Background:** Patient and clinician stakeholders are inadequately engaged in key aspects of research, particularly regarding use of Big Data to study and improve patient-centered outcomes. Little is known about the attitudes, interests, and concerns of stakeholders regarding such data.

**Research Design:** The New York City Clinical Data Research Network (NYC-CDRN), a collaboration of research, clinical, and community leaders built a deidentified dataset containing electronic health records from millions of New Yorkers. Guided by a patient-clinician advisory board, we developed a question guide to explore patient and clinician experiences and ideas about research using large datasets. Trained facilitators led discussions during preexisting patient, community, and clinician group meetings. The research team coded meeting notes and identified themes.

**Results:** Fully 272 individuals participated in 19 listening sessions (139 patients/advocates, 133 clinicians) at 6 medical centers with diverse NYC communities: 76% were female and 63% were nonwhite. Clinicians and patients agreed on all major themes including the central role of clinicians in introducing patients to research and the need for public campaigns to inform stakeholders about Big Data. Stakeholders were interested in using granular data to compare the care and clinical outcomes of their neighborhoods with others across NYC, but were also concerned that data could not truly be deidentified.

**Conclusions:** Clinicians and patients agree on potential benefits of stakeholder-engaged Big Data research and provided suggestions for further research and building stakeholder research capacity. This evaluation demonstrated the potential of brief meetings with existing patient and clinical groups to explore barriers and facilitators to patient and clinician engagement.

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Supported by contract CDRN-1306-03961 from the Patient-Centered Outcomes Research Institute and UL1TR001433 from the National Center for Advancing Translational Sciences, National Institutes of Health.

The authors declare no conflict of interest.

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ISSN: 0025-7079/18/5610-0S64

**Key Words:** patient engagement, clinician engagement, Big Data, patient-centered outcomes

(*Med Care* 2018;56: S64–S69)

Promotion and support of stakeholder involvement in research can influence health care decisions, organizational design, governance, policy making, and health outcomes.<sup>1,2</sup> Actively engaged patients, caregivers, advocates, and clinicians can identify novel questions and approaches, enhance the success of research initiatives and the translation of findings into sustainable practices.<sup>3–5</sup> However, diverse patients and busy practicing clinicians have not been adequately engaged in study design, implementation, and analysis.<sup>6–9</sup> There is a growing body of data on barriers to engagement of these stakeholders, even in research that may intuitively be more understandable and attractive, for example, comparative effectiveness and community-engaged research. Barriers include competing demands for time and attention, research mistrust, and inadequate understanding of the promises of research, especially among individuals from underserved populations, and those without previous research exposure.<sup>10–13</sup>

Although roadmaps to appropriately engage stakeholders in research are emerging,<sup>14</sup> there is very limited understanding of how to engage stakeholders in the rapidly evolving and increasingly complex field of Big Data (data science). Big Data efforts, including the Patient-Centered Clinical Research Network (PCORnet) funded by the Patient-Centered Outcomes Research Institute,<sup>15–17</sup> the National Institutes of Health's Big Data to Knowledge program<sup>18</sup> and the Precision Medicine Initiative<sup>19</sup> aim to gather data from multiple sources to study and improve health care and health. These large national initiatives are beginning to study whether and how stakeholders understand the concepts, uses, promises, and perils of Big Data, are prepared to contribute to and shape Big Data initiatives, where their interests lie, and to begin to build networks or communities of engaged stakeholders.

The New York City Clinical Data Research Network (NYC-CDRN), a member of PCORnet, brings together over 20 organizations, including 6 independent health systems contributing data to a central deidentified data repository. Its collaborative governance model leverages members' expertise and experience to inform patient-centered, comparative effectiveness research.<sup>20</sup> The NYC-CDRN focuses on socioeconomically, racially, and ethnically diverse patient

populations and clinicians in a geographically defined urban area. Like other members of Big Data initiatives, our seasoned researchers, clinicians, advocates, technology, privacy, and security experts rapidly recognized the lack of an established framework for patient and clinician engagement in Big Data research. To inform our engagement strategies and prioritize research topics, we aimed to gain insight from stakeholders into their understanding of Big Data, interest, and concerns in contributing to this research and questions they would like to answer.

## METHODS

The NYC-CDRN's organizational structure includes a Governance Board, and 4 subcommittees: patient/clinician engagement, privacy and security, technology, and comparative effectiveness/research. Engagement subcommittee leaders conceived of and led this study, but worked closely with the other subcommittees, the governance board, and a newly formed 16-member Patient-Clinician Advisory Board on all aspects of the study. First, leaders held discussions with each subcommittee to gather the questions they would like to ask of patients, advocates, and clinicians to accomplish their aims. These discussions also allowed us to introduce, in detail, the purpose and benefits of stakeholder engagement. Second, we reviewed these questions with the Advisory Board, who added additional questions and worked with us to develop a recruitment strategy.

Rather than conducting formal 60–90-minute focus groups, we decided to conduct “opportunistic” listening sessions, asking clinician, patient, and community advocacy groups who were identified by the Advisory Board. These groups have regularly scheduled, well-attended meetings, to allow us to join their meetings and engage their members in discussions for up to 30 minutes. The clinician groups consisted of faculty/staff meetings. The patient/advocacy groups consisted of advocacy groups, social service organizations, patients and disease groups (rare and chronic). The rationale was to garner input from more representative stakeholders, including those who may not attend a separate focus group, such as the busiest stakeholders, those with limited trust and initial interest in Big Data or research. By answering open-ended questions, the group could think about this new area, and share ideas that do not emerge from surveys with their prepopulated answer choices for pre-selected questions.

In partnership and with approval of the Patient/Clinician Advisory Board and the Governance Board, the subcommittee developed moderator guides including questions about previous participation in research, attitudes, pros and cons about Big Data research and the NYC-CDRN. The questions included: what they would want to ask using the data, ways they would share information about the Clinical Data Research Network (CDRN), how to garner patient and clinician participation in CDRN and ways to reach out to patients in the CDRN to solicit their participation in future studies. We also developed, a 1-page introduction for attendees of listening sessions, describing the NYC-CDRN and Big Data research. The Advisory

Board worked with the privacy committee to address concerns regarding consent. They both agreed consent was not necessary given that no identifying data from participants was being collected. Also, the study was deemed exempt from informed consent by the IRB. Those who chose not to participate were given the opportunity to leave the session. Participants were notified that any results from the session would be used in publication(s) and disseminated to all groups who participated.

To recruit groups for listening sessions, we worked with members of all CDRN subcommittees, and the Advisory and Governance Boards, to identify preexisting groups and ascertain their interest in taking part in listening sessions. We aimed to recruit geographically, demographically, and clinically diverse groups. Because the initial focus of our CDRN was on 2 common, chronic conditions (diabetes, obesity) and 1 rarer chronic condition (cystic fibrosis), we tailored recruitment to reach relevant groups. All groups solicited chose to participate.

Trained qualitative researchers led each session, and trained note-takers recorded key elements of each discussion and basic demographics of participants (sex, geographic location, race/ethnicity, and for clinicians, their specialty). We began with a brief discussion of the NYC-CDRN, then led participants through the questionnaire guide, asked for feedback on our 1-pager, and ascertained their interest in being involved with future CDRN-activities.

We analyzed discussion notes and field notes taken by the researchers using thematic analysis,<sup>21,22</sup> and 2 independent coders assigned codes to the notes and compared codes between patient/advocate and clinician groups. We then reviewed the codes to develop themes unique to each group (patient/advocate and clinician) and common to both, used member checking to ascertain validity,<sup>23</sup> and calculated interrater reliability (with  $\kappa$  statistic of 92%).

## RESULTS

There were 19 listening sessions. The 11 clinician groups had 133 (range, 10–30/group) academic and community physicians from cardiology, endocrinology, family medicine, internal medicine, nephrology, pediatrics and pulmonary, as well as nutritionist and nurses. The 8 patient/advocate groups had 139 participants (range, 8–20 people/group) from free-standing community organizations and disease support groups from various NYC neighborhoods with disease including diabetes, obesity, cystic fibrosis, cardiovascular disease, hypertension, and depression. Most (63%) were nonwhite (91% of patients, 44% of clinicians) and 76% were female (85% of patients, 67% of clinicians). Few reported experience as participants in research studies (33% of patients; 0% of clinicians).

Five major themes emerged. All are common to patient and clinician groups (Tables 1–4): (1) clinicians should be central to the process of engaging patients in research; (2) there is a need to build capacity for stakeholders to translate their thoughts and ideas into research questions; (3) there are primarily interested in using data to compare different health centers/hospitals, or different

**TABLE 1.** Pros and Cons of NYC-CDRN

Pros of CDRN	
Exposure to research that is going on	P
Give doctors right tools to better patient care	P
Can inform policy	P
Can provide more accurate data*	P, C
Can make important information accessible and understandable*	P, C
Can use data to activate community and doctors*	P, C
Tool to organize communities to ask and answer questions*	P
Shed light on diseases, treatments*	P, C
Long term can use to reduce redundancies in testing	C
Cons of CDRN	
Data can never be truly deidentified	P
Do not want people from other hospitals to have their data	P
Worry cannot control how many times patients could be contacted	P
Not sure will trust that data are accurate (doubt other datasets like A1c registry)*	P, C
Do not trust info will be shared with communities*	P, C
May share info with insurers*	P, C
Labor intensive*	P, C
Do not see direct benefit for patients*	P, C
IT personnel already overwhelmed at institutions	C
Priority is patient care not research	C
Not very interested in the data that will be generated*	P, C
Will never get frontline clinicians to give regular input	C
Concern that data from CDRN will conflict with what doctors recommend to patients	C
Would not help with what they need (ie, reducing 30 d readmission, evaluating treatment effectiveness)	C

\*Patient and clinician agreement.  
C indicates clinician; CDRN, Clinical Data Research Network; NYC-CDRN, New York City Clinical Data Research Network; P, patient.

neighborhoods characteristics and outcomes to learn how and why their site/community differs from others; (4) they recommend a city-wide, or even nation-wide campaign to explain to the public why Big Data matters; and (5) although Big Data studies holds promise, there are concerns about privacy and transparency.

**Theme 1: Clinicians are Important to Engage Patients in Research**

The first theme is that clinicians should be central to patient engagement in research, particularly because benefits of research are not readily apparent. Clinicians should consider the merits of studies, grant access to their patients, and

**TABLE 2.** Suggestions for Publicizing the NYC-CDRN

Publicizing CDRN	
Use local ethnic media to send messages	P
Develop excellent Public Relations campaign, multipronged so people are familiar*	P, C
Share research 101	P
Give out family/patient/clinician-friendly portal to search for research studies*	P, C
Share positive research stories that are relatable*	P, C
Tell people where data will sit, how it will be secured*	P, C
Send clinicians emails with periodic updates about CDRN and trials of potential interest	C

\*Patient and clinician agreement.  
C indicates clinician; CDRN, Clinical Data Research Network; NYC-CDRN, New York City Clinical Data Research Network; P, patient.

**TABLE 3.** Suggestions for Research Projects

Research suggestions	
Topics that match community concerns	P
Comparing treatments*	P, C
Identify and compare neighborhoods with good and bad outcomes and determine related factors*	P, C
Need capacity building to translate perceived problems into research questions*	P, C
Need to have policymakers at table so research also meets their needs	P
Social media for young, face to face for older	P
Hold research forums to generate ideas with patients	C
Use data to create research registry for New York State for providers	C
How to reduce disease transmission in families	C
Cystic Fibrosis- infertility, Management Care Agency, pancreatitis	C
Get ideas through research forums	C
Need to prepare people before meetings so come with ideas*	P, C
Percentage of weight loss with postbariatric surgery compared with age	P
Correlation of bariatric surgeries and attendance a support groups	P
Success rates of surgeries at various institutions	P
Complication rates based on type of surgery and year postsurgery	P
Pregnancy complications postsurgery	P
Fertility issues postsurgery (male/female)	P
No. patients postbariatric surgery w/plastic surgery	P
Medications postsurgery	P

\*Patient and clinician agreement.  
C indicates clinician; P, patient.

inform patients about research opportunities. In large part this is because many participants believe that research in general is a good idea, but something is “lost in the translation” in engaging patients and clinicians in research. One patient said, “Researchers are in outer space from what patients are going through.” Patients and clinicians did not appreciate a significant impact of much of research done to date. Clinicians discussed how findings and guidelines keep changing and studies sometimes offer little new actionable information. Thus it may be wiser to spend the limited time they have with patients doing things they know they need to do, than to spend time on research, with unproven benefits. They are also concerned that patients from diverse backgrounds, with limited literacy or formal education will not respond well to researchers, will refuse to participate in important studies if not approached by their clinicians first, and therefore research findings will not be meaningful to these populations. Patients noted that they cannot readily think of examples of how their lives and health improved based on research, making it less attractive. And, as they did not separate their attitudes toward clinical care and research, if they have a negative clinical experience, they assume they will have a negative research experience. These concerns could be mitigated for patients who trust their clinicians, by receiving a “warm handoff” from their clinician to the research staff. Clinicians would be more comfortable if patients are not asked to participate in a research study without their knowledge, and if they first have time to understand the research and its potential patient burden, risk, and impact. Both groups also noted that positive past research experiences would foster positive future experiences, and vice versa.

**TABLE 4.** Possible Recruitment Suggestions and Challenges

Recruit suggestions	
Doctors as gatekeepers (pros and cons about this)*	P, C
Community health worker/coordinators to introduce research and engage patients*	P, C
Social service, clergy, advocates as gatekeepers	P
Go through trusted organizations	P
Transparency with possible benefits to patients*	P, C
Identify and honor language preferences	P
No texts: do not trust from stranger (could use for follow-up)	P
Text and email patients	C
Mail or phone call from someone from their institution	P
Approach person in waiting room if recruiter from that site	P
Do not cold contact patients	C
Use fundraisers for recruitment	P
Use local research champions within practices	C
Have dedicated research staff to speak/enroll patient (warm handoff)	C
Research staff should look like patients	P
New consent strategies (video consent)	C
Social media to advertise for research (especially for young)*	P, C
Create referral tool and process for doctors to use	C
Incentives for patients	C
Recruit challenges	
No clinical/research separation (baby/bathwater)	P
Research futilism (research to date has not made impact)	P
Trust: petridish/victimization concerns	P
Acknowledge past abuses in research before taking part	P
Do not trust people outside their own hospital/clinic	P
Do not direct contact: will scare people that their info was released	P
Want to know who sponsors research before take part*	P, C
Socioeconomic patient issues (several comorbidities)	C
Consenting when patients have an appointment is too time consuming	C
Consenting by electronic medical record is too time consuming for provider	C
Patients scared of term “research”	C
Disruption to clinical workflow	C
Time burden on patient	P

\*Patient and clinician agreement.  
C indicates clinician; P, patient.

**Theme 2: Build Capacity for Stakeholders to Translate Ideas into Research Questions**

The second theme is that both groups need assistance in learning how to translate their concerns and ideas into concrete research questions. Big Data research is a relatively new concept to many, and when asked what kinds of questions they would like to ask using Big Data, they stated they did not know how to convert the many ideas they had into solid research questions that would pique the interest of researchers. Many stated that with appropriate effort, researchers could demystify research, help people develop ideas and thereby create positive research experiences which would facilitate future engagement efforts.<sup>24</sup> Clinicians are worried their patients will refuse to participate in a study due to a lack of research literacy, particularly in the new world of Big Data.

**Theme 3: Use Data to Compare Different Health Centers/Hospitals/Neighborhood Characteristics and Outcomes**

The third theme was that when asked to provide ideas for research, nearly all ideas involved comparing how their

clinic or neighborhood compared with other clinics or neighborhoods. How do care and outcomes differ for a given condition? Are patients in some neighborhoods sicker than in others, and is this due to clinical or neighborhood factors? Do some clinical sites offer better treatments for a given disease that lead to better outcomes? Rather than groups honing in on specific research questions, they honed in on conducting comparison studies.

**Theme 4: Recommend a City/Nation-wide Campaign to Explain Importance of Research**

The fourth theme shared by patients and clinicians was the need for larger campaigns to introduce their stakeholder groups to Big Data research. Many patients are unaware that clinical information ever goes beyond their doctors’ offices to places such as insurers or regulators. As the introduction to the NYC-CDRN was the first time they learned of this, they had an initial negative reaction to the CDRN’s plans. One patient said, “Let me know what hospitals do not share their data with anyone, so that I can go do a doctor at one of them.” Interestingly Kim et al,<sup>25</sup> discuss in their study that trust is still a very real issue for people and it can affect a person’s perception of who they should allow access to their health care information. However, as they learned how data are safely and securely shared, many patients and clinicians warned that people like them may have a similar negative reaction if they are not first informed about how their data are currently used outside clinical settings. They think it is too much to ask the NYC-CDRN to educate all of NYC on why this matters, and suggest that national agencies develop educational campaigns. They also suggest that having patient and clinician-friendly portals to the data will help people see the promise of such endeavors (particularly if they can be used to compare their group to others, as in theme 3), and help gain wide support for Big Data research. Both groups also suggest having Big Data portals be linked to information about the diseases being studied and how diagnoses and treatments are informed by past research, to help patients understand how research can change lives.

**Theme 5: Big Data Studies Hold Promise, But Concerns About Privacy and Transparency**

The fifth theme is that while recognizing some of the promise of Big Data, both groups express concerns about potential for breaches of privacy. This is similar to Ancker’s Cornell Study where survey participants cited privacy and security of their data as serious concern.<sup>26</sup> Clinicians are also concerned that the data collected will not be accurate (ie, the problem lists and demographics may have inaccuracies), will lead to inaccurate findings and inappropriately impact treatment guidelines. Similarly, patients/advocates state that “bad” data can have negative implications and create stigma for communities, especially among low socioeconomic populations. Both groups also state that the findings from research may be kept within ivory towers, not benefitting frontline clinicians or patients from diverse communities. In addition, patients are worried data can never be truly deidentified and other hospitals or parties will have access to their data without their knowledge.

Interestingly, there is only 1 area where patients and clinicians differed, namely how to reach out to patients to solicit research participation. Generally, patients stated they prefer to be contacted through regular postal mail and phone calls from their clinicians or sites of care. Many were uncomfortable with the idea of receiving emails or texts from strangers. In contrast, clinicians suggested engaging patients by text message and email, even expressing disagreement when facilitators mentioned that patients had concerns about this. Clinicians believed that, with the increase use of technology, research staff will have more success engaging patients in research.

## DISCUSSION

Stakeholder engagement is a crucial piece of the research puzzle and is largely unexplored in the area of Big Data. Before embarking on comparative effectiveness research using a centralized, deidentified large clinical dataset, NYC-CDRN leaders conducted listening sessions with patients, advocates and clinicians to understand their concerns, ideas, and suggestions. Themes uncovered were held in common by both clinicians and patients.

Both groups prefer clinicians have a central role in engaging their patients in research, as trusted judges of good research and protectors of their patients. Others have suggested it is neither necessary nor advisable for clinicians to have this role, and patients can and should decide for themselves.<sup>27</sup> Interestingly, patients do not seem to distinguish between research and clinical care from the same site, such that positive clinical experiences may facilitate participation, but negative clinical experiences may thwart participation. To overcome research inertia, not having time or not seeing sufficient benefit to taking part in research, particularly in the new and harder to understand world of Big Data, stakeholders believe clinicians hold a very important role.

Stakeholders also want more information to help them understand Big Data and formulate their own questions, because they do not know if research already exists for what they are interested in. The populations most impacted by this research, diverse patient and the clinicians who care for them, have the best understanding of what the challenges and potential solutions are to improve health, so it is crucial to facilitate their input. Clinicians and patients may require assistance with clarifying their clinical focus and translating ideas into a research question.<sup>28</sup> Several organizations, including ours, are building programs to increase capacity for this input into big data analytics, and ongoing research will determine which approaches are most effective.<sup>29</sup>

Patients and clinicians suggested that research leaders explain that clinical data are used outside of doctor's offices for many purposes. CDRN-like organizations aim to distinguish themselves by ensuring that patient and clinicians are at the table to use these data wisely and effectively. However, if stakeholders hear, for the first time, that these data are not held solely by their clinicians, their negative reaction to sharing data may be singularly focused on groups who are simply making the most effort to make sure stakeholders understand when and how their data are used.

Patients do have privacy concerns with big data analytics.<sup>30</sup> Our patient partners suggested that larger entities introduce the concept of clinical data warehouses, so such information will not cause a backlash and damn our efforts to engage the stakeholders. In the *New York Times*, Steve Lohr said, "But the latest leaps in data collection are raising new concern about infringements on privacy—an issue so crucial that it could trump all others and upset the Big Data bandwagon."<sup>31</sup> It may be complicated to have people understand that their data are "out there" already, react to that, possibly negatively, and then follow on with supplemental point that this time, they can use it.<sup>32</sup> More research is needed on how to develop a systematic framework to open dialogs with patients about how to explain the use of clinical data in general, and for patient-centered research in particular.<sup>33</sup>

Our team found it interesting that on one hand, patients and clinicians wanted the very granular data, namely information about site of medical care and neighborhood patients live in, to compare risks, processes, and outcomes. Indeed, such groups were asking that data on social determinants of health be included in these explorations, much of which is only accurate in large cities, at block levels. In contrast, they are concerns that data cannot be truly deidentified, and this type of granular data makes deidentification challenging. The conflict between protecting privacy and answering patient and clinician-centered questions deserves further exploration. Privacy concerns can inhibit stakeholder engagement; however, transparency is necessary for trust and growth to flourish. It is imperative to be transparent with your stakeholders throughout the entire process. Some patient populations are increasingly interested in sharing their data to advance health, particularly for conditions they have, and feel that direct benefits from data they contribute outweigh protections of restrictive rules that may thwart research.<sup>34</sup> However, our stakeholders did not seem that enthusiastic.

Patients and clinicians also express concerns about the accuracy of clinical data. If data used are not accurate, they suggest it could stigmatize patients, or yield inadequate data on some populations (eg, by not accurately capturing racial, ethnic, language, or sexual minority groups), give doctors and their practices bad reputations and lead to inaccurate conclusions that could harm clinical care. Procedures leading to inaccurate or biased data may be damaging and are hard to detect.<sup>35</sup> Given these concerns; perhaps stakeholders could become allies in efforts to improve the accuracy and completeness of electronic health records.

Our study does have limitations. These were half hour group interviews, and while we took extensive notes, we did not audiotape and transcribe the sessions. The listening sessions were conducted in only 1 urban area and confined to the NYC-CDRN. However, this form of "quick and dirty" data gathering may have some advantages that deserve consideration. First, they may be having an efficient way to obtain information from groups who will not have the time or inclination to join formal focus groups, and do so in a setting and among people they are comfortable with. Participants have stated the major reason for lack of participating in focus groups was the time burden.<sup>36</sup> This only

reaffirms why listening sessions are a more efficient strategy to engage stakeholders.

We were also able to engage with diverse groups, garnering a wider spectrum of ideas, and from a larger network of individuals. In addition, all groups we met with agreed enthusiastically that we could return with further questions and to field future ideas. In this way, we may have created a network of networks: stakeholders who represent other stakeholders, with whom we can work, thereby garnering input way beyond the confines of the important, but rather small stakeholder boards traditionally involved in engaged research. We will disseminate to both clinician and patient/advocacy groups to facilitate knowledge gaps concerning research and large datasets. Also, we hope to gain feedback on the process and themes from these groups. Others working in research may want to consider this as a viable approach to garnering patient and clinician perspectives.

More research is needed to determine best ways to engage stakeholders in Big Data research. We did not find similar studies that addressed patient engagement and big data in the manner we chose. Our results may be generalizable to other CDRNs interested in patient/clinician engagement frameworks in Big Data. We found great agreement between clinicians and patients about how to engage and collaborate in research and are beginning to chart a road forward, forming network of networks. CDRNs can use these themes to create a research capacity building program for patients and clinicians and integrate their perspectives into research studies. The literature suggests that utilizing existing social networks can expand research knowledge and interest among stakeholders as well as create opportunities to engage diverse populations in research.<sup>37</sup>

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