

Does Engagement Matter?

A Supplement To:
Authentic Engagement Of Patients And Communities Can Transform Research, Practice, And Policy



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The engagement of patients and other stakeholders is increasingly emphasized in health research. Involving diverse stakeholders has intuitive benefits, and the expectation of engagement is becoming more common among funders (e.g., the Patient Centered Outcomes Research Institute [PCORI]).¹ Yet empirical evidence that the hard work of engagement yields meaningful changes in either study design or outcomes is limited. This supplement provides further details about our experience with “authentic” engagement, as described in the core *Health Affairs* article, “Getting to know you: authentic engagement of patients and communities can transform research, practice, and policy.”² The article provides examples of the engagement of patients in practice-based research and of the community in health equity research. Further details about these experiences follow.

Engagement Of Patients In Practice-Based Research

In a two-year pilot study funded by PCORI, we adopted an intensive stakeholder engagement approach to develop an “informed decision-making (IDM) module” designed to capture data on how patients approach decisions about cancer screening (see Figure 1). The IDM module was hosted on a portal used by more than 72,000 primary care patients. We devoted a full year (February 2012-January 2013) to the design of the IDM module before it went live and sought broad engagement of patients and other stakeholders, including clinicians, health system leaders, and scientists (Table 1). The intensity of the stakeholder engagement was expanded beyond the original protocol after its usefulness in developing the IDM module grew more apparent. Patients were engaged via focus groups, a patient working group, and an advisory board. Clinicians, health care administrators, and scientists were engaged via a clinician working group, health systems working group, and an expert advisory panel.

Focus Groups

Out of 102 patients screened, 79 primary care patients (35 men, 44 women) participated in ten, two-hour focus groups split between Northern Virginia and metropolitan Richmond (VA). The focus groups sought to clarify issues

Table 1. Stakeholder groups that provided input

| Patient Engagement |
|-----------------------------------------------------------------------------------------------------------------------------------------------------|
| 10 two-hour focus groups (N = 79 patients) |
| Patient Working Group (N=46 patients) <ul style="list-style-type: none"> ▪ Online discussion board ▪ Two in-person meetings |
| <i>MyPreventiveCare</i> Advisory Board (N=14, 8 meetings) |
| Cognitive testing (N=13) |
| Usability testing (N=7) |
| Practice Engagement: |
| Clinician Working Group (N=14) |
| Expert Advisory Panel Engagement: |
| 3 clinical decision psychologists (PhDs), 1 behavioral scientist (PhD), 1 expert on patient-clinician communication (MD) |

of importance to patients in approaching cancer screening decisions. Participants represented a socio-demographically diverse population with varied educational attainment (above high school = 57; high school or below = 20), and insurance status. Focus group facilitators used a semi-structured focus group guide, developed by the research team, and naturalistic inquiry methods. Discussions were audio-recorded and transcribed and then subjected to qualitative coding and analysis in Atlas.ti by a multidisciplinary team of qualitative researchers using a grounded-theory approach. The findings were used to create an initial version of the IDM module.

Patient Working Group (PWG)

To enhance patient engagement in the study design process, focus group attendees were invited to participate in the Patient Working Group (PWG). This group was devel-

oped to continue the dialogue that had begun in the focus groups, to ensure that we captured the patient voice in the formative work of developing the IDM module, and to review drafts of the instrument. Participants in the PWG were treated as coinvestigators and coequal partners in the development of the IDM module, not as human subjects. Initially, 46 patients registered for an online discussion board (Figure 2). However, this method of engagement did not work as well as intended, and participation in the online discussion diminished over time. Members reported that the online medium was onerous, so we adjusted our engagement methods and held two in-person meetings with the PWG in northern Virginia and Richmond.

MyPreventiveCare™ Advisory Board (MPCAB)

We convened a 14-member advisory board composed of patients who were users of MyPreventiveCare™ (MPC),

Figure 1. The Informed Decision Making (IDM) Module

MyPreventiveCare™, an online portal used by more than 72,000 primary care patients led a subset of patients (N = 2,355) through a series of questions to learn how they approached cancer screening decisions. The system identified:

- Women age 40-49 who had not had a mammogram within 2 years.
- Men age 55-69 who had not had a prostate-specific antigen (PSA) test within 2 years.
- Adults age 50-74 who were not up-to-date with colorectal cancer screening.

Patients in these groups were invited to complete a 17-item informed decision making (IDM) module (*MyQuestions™*).

The IDM module addressed how patients make decisions about such screening tests, their priorities for receiving information, preferences for how the data should be presented, expectations for the upcoming office visit with the primary care clinician, and patients' desired role in the decision-making process. See Appendix for screen shots of the 17 questions as they appeared online.



the interactive personal health record that served as the platform for this study. MPCAB members were recruited from eight primary care practices in northern Virginia and met monthly to discuss questions related to this study. The patients' input brought an important perspective to counterbalance the advice of academic experts. The MPCAB went on to have a significant ongoing role, meeting quarterly to offer a consumer perspective on a variety of projects and challenges surrounding MPC. It has continued to evolve and guides the practices more broadly, addressing multiple issues related to patient engagement in care, particularly via online engagement activities. The MPCAB has even merged with the Clinician Working Group (described below) to increase the synergy between these two groups.

Health Systems Engagement

We established a Health Systems Working Group (HSWG) to represent stakeholders with a role in managing the health systems involved with this study: Inova-Fair Oaks Hospital, Inova-Fairfax Hospital, Valley Health and Valley Physician Enterprises, and Bon Secours Health System – Richmond Region. The HSWG was comprised of five chief executive officers or chief medical officers of these health systems who met twice by conference call to lend advice on the project and discuss the larger implications of the project for care delivery.

Expert Advisory Panel

An expert panel of thought leaders from the United States and Canada, including clinical decision psychologists, a behavioral scientist, and an expert on patient-clinician communication, advised on study design. Members included Ronald M. Epstein, MD, University of Rochester; Dominick Frosch, PhD, Gordon and Betty Moore Foundation; Annette M. Cormier O'Connor, PhD, University of Ottawa; Mary C. Politi, PhD, Washington University of

Figure 2: The Patient Working Group (PWG)



In January 2013 we launched an online Discussion Board (howidecancer.org), which was created to elicit periodic feedback from members of the PWG. The members had secure, closed online access to this site, where researchers presented focus group findings and shared draft language for the questions on the IDM module.

St. Louis; and Brian J. Zikmund-Fisher, PhD, University of Michigan. The panel members were integral partners in the research team and helped to plan the study design and interpret results.

Practice Engagement

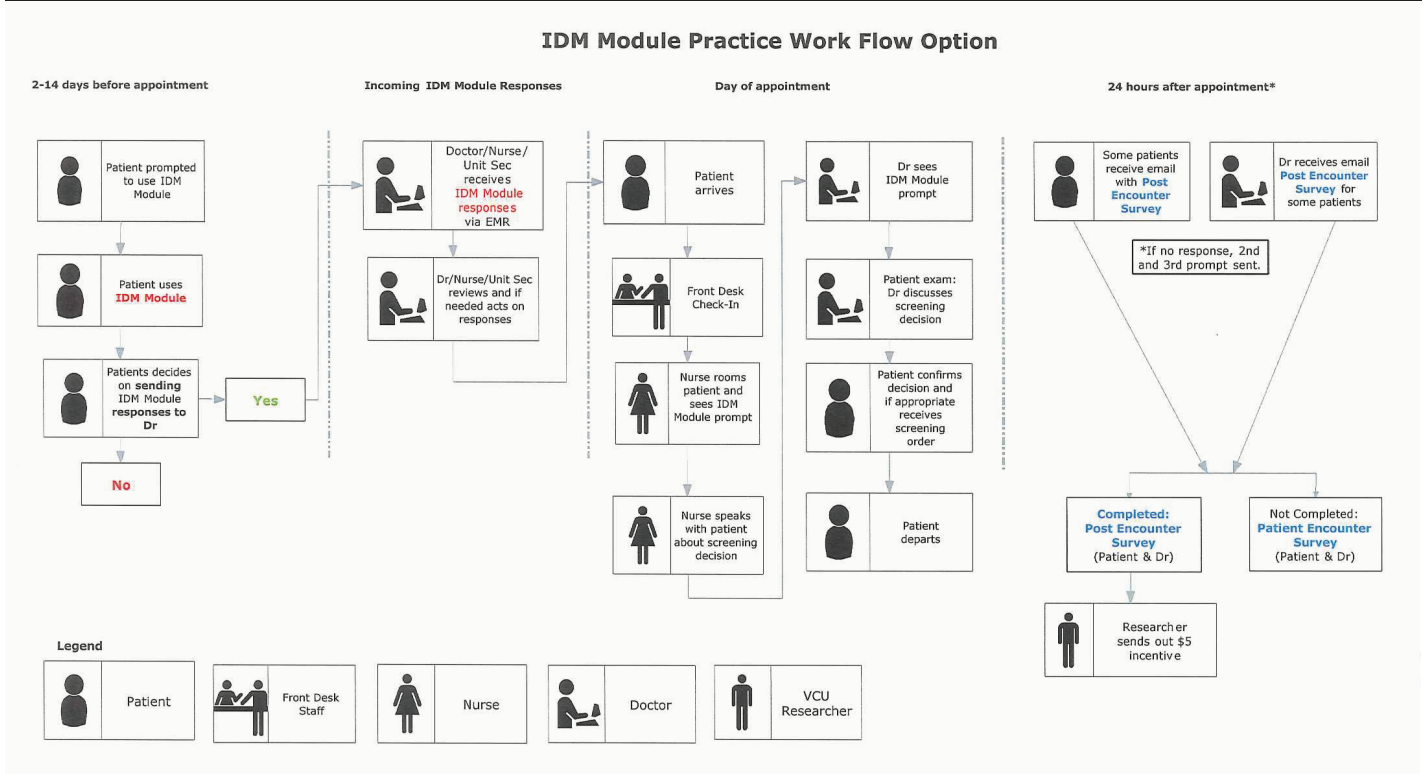
We established a Clinician Working Group (CWG) to engage practitioners in designing the study and, later, in interpreting the results. This 14-member working group included physicians, nurses, and other key personnel from the primary care practices that would field the intervention in year 2. These practices initially included Fairfax Family Practice Centers (consisting of 10 different office sites), Front Royal Family Practice, VCU Nelson Clinic, and Bon Secours Health System Richmond-Tidewater Region. In addition, we established new relationships with 10 practices in northern Virginia, Washington DC, and Greater Richmond. These 10 new practices—from urban areas of Richmond and rural and suburban areas of Northern Virginia—assisted us with focus group patient recruitment.

The CWG met monthly and became fully engaged in (a) reviewing the content of the IDM module, (b) determining what information to forward to the electronic medical record (EMR), (c) reviewing the protocol for audio-recording visits, (d) planning the customized “workflow” their practices would implement to process requests and complete surveys, and (e) holding 15 orientation meetings at each practice to prepare staff for fielding the intervention and eliciting feedback on how to improve the project plan. The goal was to engage practices as full partners in design and implementation. The CWG determined that the message to clinicians about the patients’ preferences needed to arrive as a prompt, appearing in the EMR as an incoming task, stored as structured data as is done for laboratory test results. The practices also worked intensively on tailoring workflow in their practices to accommodate input from the IDM module (see Figure 3). Finally, the CWG developed the protocol for audio-recording 30 office visits.

Finalization of the Informed Decision-Making (IDM) Module and Post-Encounter Surveys (PES)

The IDM module (see Appendix) was finalized based on iterative feedback from the research team, the Expert Advisory Panel, and the PWG, MPCAB, CWG, and HSWG. More than seven iterations of the IDM module were developed. The IDM module underwent two waves of cognitive testing, eliciting feedback from 13 patients (6 men, 7 women) on the understandability of questions. Beta-testing of the online version of the IDM module was performed by the research team, MPCAB, and CWG. Post-encounter surveys, to be completed by patients and clinicians after clinical encounters, were also developed using a similar process of multi-stakeholder input. More than five iterations were developed with input from the research team, the Expert Advisory Group, and the PWG, MPCAB, CWG, and HSWG. CWG (and MPCAB) input was equally critical in deciding how to invite and encourage clinicians and patients to complete the post-encounter surveys.

Figure 3. Work flow designed by practices for implementing IDM module



Outcomes of patient engagement

The impact of stakeholder engagement was evident throughout the process. In response to stakeholder input (including a total of 772 comments), the IDM module underwent 23 revisions over the planning year. Of the comments received, patients provided the greatest share (46.1%), followed by the core research team (35.5%). The clinicians and expert panel each contributed less than

10% of total comments (4.1% and 6.9%, respectively).

The majority (N = 320; 89.9%) of patient comments were received in months 5-11, during cognitive testing and usability testing.

Patient input was critical in the development of the IDM module. The patients questioned the overall objectives, pointed out problematic wording, and identified omissions.

Table 2. The Informed Decision Making Module (IDM)

| IDM Item | Core research team | | Experts | | Patients | | Clinicians | | RTI | | TOTAL |
|--------------------------------------------|--------------------|--------------|-----------|-------------|------------|--------------|------------|-------------|-----------|-------------|------------|
| <i>General comments</i> | 24 | 38.7% | 3 | 4.8% | 29 | 46.8% | 6 | 9.7% | 2 | 3.2% | 62 |
| <i>Item-specific comments</i> | | | | | | | | | | | |
| Q1. Awareness of recommendations | 7 | 21.9% | 2 | 6.3% | 19 | 59.4% | 2 | 6.3% | 2 | 6.3% | 32 |
| Q2. Stage of decision | 3 | 14.3% | 1 | 4.8% | 12 | 57.1% | 1 | 4.8% | 4 | 19.0% | 21 |
| Q3. Immediate next steps | 10 | 31.3% | 4 | 12.5% | 13 | 40.6% | 2 | 6.3% | 3 | 9.4% | 32 |
| Q4. Desired information | 23 | 34.3% | 8 | 11.9% | 26 | 38.8% | 6 | 9.0% | 4 | 6.0% | 67 |
| Q5. Desired format for information | 20 | 32.8% | 9 | 14.8% | 25 | 41.0% | 2 | 3.3% | 5 | 8.2% | 61 |
| Q5SL. slider | 9 | 64.3% | 1 | 7.1% | 3 | 21.4% | 0 | 0 | 1 | 7.1% | 14 |
| Q6. Preferred sources for reading/research | 14 | 38.9% | 1 | 2.8% | 19 | 52.8% | 0 | 0 | 2 | 5.6% | 36 |
| Q7. Presenting statistics | 8 | 20.5% | 2 | 5.1% | 22 | 56.4% | 1 | 2.6% | 6 | 15.4% | 39 |
| Q8. Cognitive decisions vs gut feelings | 11 | 30.6% | 6 | 16.7% | 16 | 44.4% | 0 | 0 | 3 | 8.3% | 36 |
| Q9. Fears and worries | 10 | 27.0% | 2 | 5.4% | 20 | 54.1% | 2 | 5.4% | 3 | 8.1% | 37 |
| Q10. Stage of decision | 0 | 0 | 0 | 0 | 6 | 100.0% | 0 | 0 | 0 | 0 | 6 |
| Q11. Next steps | 6 | 25.0% | 1 | 4.2% | 16 | 66.7% | 0 | 0 | 1 | 4.2% | 24 |
| Q12. Comfort with decision (SURE) | 6 | 27.3% | 0 | 0 | 15 | 68.2% | 0 | 0 | 1 | 4.5% | 22 |
| Q13. Interest in discussing with doctor | 10 | 37.0% | 1 | 3.7% | 14 | 51.9% | 0 | 0 | 2 | 7.4% | 27 |
| Q14. Desired topics to discuss with doctor | 6 | 30.0% | 0 | 0 | 12 | 60.0% | 0 | 0 | 2 | 10.0% | 20 |
| Q15. Desired level of control (Degner) | 5 | 26.3% | 0 | 0 | 10 | 52.6% | 1 | 5.3% | 3 | 15.8% | 19 |
| Q16. Audiorecording consent | 6 | 54.5% | 0 | 0 | 5 | 45.5% | 0 | 0 | 0 | 0 | 11 |
| Q17. Feedback on survey questions | 10 | 38.5% | 1 | 3.8% | 12 | 46.2% | 0 | 0 | 3 | 11.5% | 26 |
| AP-I. Action page (initial) | 22 | 48.9% | 3 | 6.7% | 18 | 40.0% | 1 | 2.2% | 1 | 2.2% | 45 |
| AP-F. Action page (final) | 6 | 37.5% | 2 | 12.5% | 7 | 43.8% | 0 | 0 | 1 | 6.3% | 16 |
| TQ4 | 5 | 71.4% | 0 | 0 | 2 | 28.6% | 0 | 0 | 0 | 0 | 7 |
| TQ5 | 1 | 33.3% | 0 | 0 | 2 | 66.7% | 0 | 0 | 0 | 0 | 3 |
| TQ8 | 2 | 40.0% | 0 | 0 | 3 | 60.0% | 0 | 0 | 0 | 0 | 5 |
| Subtotal (Extant items) | 224 | 33.5% | 47 | 7.0% | 326 | 48.8% | 24 | 3.6% | 49 | 4.6% | 668 |
| Extinct items (N, %) | 50 | 48.1% | 6 | 5.8% | 30 | 28.8% | 8 | 7.7% | 10 | 9.6% | 104 |
| TOTAL | 274 | 35.5% | 53 | 6.9% | 356 | 46.1% | 32 | 4.1% | 59 | 7.6% | 772 |

Extant items = retained in final instrument; *Extinct items* = deleted in final instrument; *TQ* = Transition question; *RTI* = Research Triangle Institute (web developer)

Their extensive input on multiple drafts resulted in substantial shortening of the instrument by removing 13 questions and 4 transition statements. In addition, they suggested rewording to improve readability for lay users, proposed innovative strategies to address issues of concern to patients facing cancer screening, and provided creative suggestions for administering questions in an interactive online format.

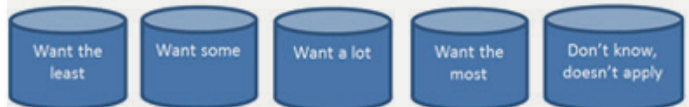
Certain classes of input were especially impactful, or were prescient. For example, some problems that were flagged by patients but not initially addressed by the developers subsequently plagued the project upon implementation. For example, we received 26 comments from patients about a specific question in the IDM module which required users to use interactive graphic tools to prioritize the types of information they considered most important. The patients were concerned about the length and complexity of the question and the level of computer literacy it would require (see Figure 4). Ten out of 26 patients indicated they could not understand the question. Some refinements were made before the IDM module went live, but we later determined that patients who abandoned the survey often did so after encountering that question.

Overall, investing time and effort in two forms of stakeholder engagement—short-term, episodic engagement via focus groups, and ongoing longitudinal engagement via advisory boards—yielded substantive improvements in the design and conduct of this study. The less intensive, short-term engagement introduced input from a wide range of patients, while the more intensive, longitudinal engagement provided much needed depth, but from a smaller cohort of patients. The combined approach created an environment that helped empower patients to provide meaningful direction to improve the study design and enhance the usability of the IDM module and related survey questions.

Figure 4. Edits to draft question 4 of IDM module

4. Drag and drop: **Put these in one of the five cans:** To decide about [cancer screening test], how much would you want to **learn know** about the following? **Click on each of the following items and drag each one into the can that best matches how much you would want to know.**

- The choices:** What are my options for screening?
- Effectiveness:** How much does screening reduce my chances of dying from cancer?
- Comparative effectiveness:** Does one kind of screening test work better than another?
- Risks:** What possible problems can be caused by screening?
- Guidelines:** What do organizations recommend for screening?
- The procedure:** How is the screening performed?
- Success rates:** How good are my doctors at doing the screening?
- The cancer itself:** How common is it, and how dangerous?
- Other Something else (please specify):**
_____ [fill in]



Core research team

"How good are my doctors at doing the screening?" As I have said, I do not like this option. It is illogical to say I want to know how good my doctor is at doing a blood test (or in a patient's eyes doing a mammogram). Would this be more correct to word as "How good is the screening test?" (CT-AK-Q4-522-522)

Experts

Maybe specify that you mean expert organizations or national organizations or other groups? (should you provide an example?) (EAP-MP-Q4-44-44)

Patients

I'd rather see less options. I think you could combine some things into one category. Not sure which to do that with, but, for example, information regarding your doctor and facilities seem like they could be combined. (PWG-HD-Q4-417-421)

There are a lot of questions in 4. I would cut the question on how good are my doctors. I also think the question "what possible problems can be caused by screening" and "how common is the cancer and how dangerous is it" could be combined. Maybe "what are the pros and cons of the screening?" ...I agree with you 100% that things like how is the procedure performed, how effective is it, what are the different options, etc. are important but how long and how many questions do we want to ask in this survey? I believe questions and answers like the ones below are more important...

I do not feel that there are too many questions in questions 4-8. It is the patient who will decide what they want and I would rather see too many questions so the patient will be able to select exactly what they want. I like the drag & drop... (PWG-DW-Q4-425-427)

Will there be boxes or something to drag and drop my selections?...Is the space for fill-in character limited or unlimited?...Will the fill in answer be included in the summative responses? Will the summative responses be ranked in priority, alphabetically, etc.? (PWG-DW-Q4-516-64)

Something else (please specify): Will someone be there to help me understand my next steps (not clinical) after a negative screening? (PWG-GW-Q4-66-617)

Engagement Of The Community In Health Equity Research

Participatory research frameworks, such as community-based participatory research (CBPR), put the intended beneficiaries of research at the heart of the research process.³ While some CBPR partnerships are formed around a specific goal or intervention, others have a more flexible research agenda. Quantitative data may inform the process, but CBPR often involves qualitative research methods, such as focus groups and key-informant interviews. Other tools for capturing the lived reality of participants, such as PhotoVoice and use of social media, are becoming increasingly important (see Figure 5).

Community voice is an important component of conducting community needs assessments that reflect residents' concerns, experiences, and values. Community assessments are becoming more prominent due to legal requirements for nonprofit hospitals to conduct community health needs assessments (CHNAs), and the leadership role that some public health departments are taking in guiding these efforts.² Using CBPR to identify community priorities can move these assessments beyond reliance on secondary data or surveys of community leaders.

[The Center on Society and Health](#) at Virginia Commonwealth University received funding from the university's Center for Clinical and Translational Research to produce a health equity report for the Richmond area. In order to incorporate community voice into the report, we convened a CBPR team ([Engaging Richmond](#)) to identify community priorities related to social determinants of health. Our goals were to (1) identify community

Figure 5. Community-Based Participatory Research

CBPR is a collaborative partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process. Participants contribute their expertise and share responsibilities and ownership of the research process. They incorporate the knowledge gained with action to enhance the health and well-being of community members. CBPR is characterized by shared decision making, co-learning and capacity building, relevance to the community, ecological approach, dissemination of findings, and sustainability.

Authentic engagement of the community using CBPR can give voice to affected populations and contribute new insights using a variety of research approaches and communication tools. For example, in a study conducted in collaboration with the Urban Institute, our CBPR team ([Engaging Richmond](#)) employed individual interviews and PhotoVoice to assess the impact of firearm violence on Richmond City residents and communities. These methods empowered residents to describe their experience in their own words and to select photographic images that highlighted key themes that emerged from the research (see example here and at <http://societyhealth.vcu.edu/work/the-projects/the-cost-of-firearms-violence.html>).



"I started carrying guns myself...I was willing to hurt somebody if they try to hurt me. Nobody was going to do that to me again."

priorities by engaging residents and service providers as partners; (2) build trusting relationships between the university and the community (which had a history of both positive and negative encounters); and (3) promote community capacity to assess and address health priorities. To focus our efforts we selected a particular community in the East End of Richmond as the basis of the partnership. Although poverty, education, and scarcity of jobs are major concerns in the neighborhood, it was chosen for this project largely due to its strengths, which included a well-developed network of service providers and advocates and a roster of community development initiatives. Here, we report on the involvement of the CBPR team in identifying community priorities, focusing specifically on their role in analyzing and interpreting focus group data.

The CBPR team was comprised largely of residents of a low-income, urban community with no previous research experiences. The 16 members included eight community residents, two area residents working as service providers in the community, one former community resident/graduate student, one graduate assistant, and four university researchers. Non-university CBPR team members were recruited at local school events and through local organizations. Meetings were held weekly at community locations, food and beverages were provided, and team members were paid an hourly rate for participation. Team members participated in research training covering a range of topics, including focus group methods.

The team conducted 17 focus groups (N = 170) to gather residents' perceptions of the most important social determinants of health in their community. Team members collaboratively coded and interpreted the data; drafted preliminary action plans to address top priorities; and presented data back to the community.

Table 3. Collaborative Coding Process

1. Focus group transcripts were distributed for each team member to read.
2. Each week coding group or groups were formed.
3. Each transcript was first coded individually. Then small coding teams worked together to reconcile coding differences.
4. The whole team came together to discuss and reconcile codes for each transcript.
5. New codes were added to the codebook as they were created.
6. As the codebook was developed and refined, the process moved from inductive to deductive coding.
7. University researchers reviewed coding (cross coding) and distilled themes to focus on identifying priorities.
8. Codes were entered into NVIVO.
9. NVIVO summaries were produced to work on the next step: identifying top community concerns.

Table 4. Sample codes from the codebook

| | | |
|----------------------------|-----------|-----------------------------------------------|
| Nostalgia for the past | Neighbors | Social conditions |
| Role models | Peers | Physical conditions |
| Hopefulness | Parents | Physical appearance of the neighborhood |
| Religion/faith communities | Media | Competing priorities |
| Pooling resources | Fear | Perceptions of the neighborhood |
| Residents' perceptions | Isolation | Outsiders' perceptions Neighborhood assets |

The qualitative coding process is described in Table 3. Each focus group was professionally transcribed, and the transcripts were systematically analyzed to code important themes. The group’s collaborative coding generally involved an open coding process, starting with inductive coding and allowing categories and themes to emerge from the data. Residents first worked individually and in small groups to read transcripts and enter notes and provisional codes. They then discussed the meaning and significance of the text and compared provisional codes within small groups. The full group then convened to discuss new codes that had been developed and to reconcile them with existing codes. The discussions addressed team members’ interpretations of the text, the appropriateness and naming of particular codes, and the fit with the group’s interpretation of the content. Table 4 displays a sample of codes from the codebook, reflecting a range of attitudes and perceptions, actors, situations, assets and challenges.

The benefits of engaging residents as research partners were apparent throughout this collaborative coding process. Informed by their lived experience, residents were able to recognize issues that had several related but distinct dimensions, a nuance not always apparent to researchers who came from other backgrounds. For example, one discussion unpacked the meaning of police presence in the neighborhood, which could mean over-policing, harassment, the degree of police presence, or mistrust (see Table 5 for examples).

Through a process of “cross coding,” the university researchers independently coded the text in order to identify new codes or different interpretations of the text and to collapse and simplify codes to help address the project-related research questions.

Table 5. Unpacking Meanings During Collaborative Coding

Police Presence

“I have a confused face because I’m confused about like if it’s over-policing, how is over-policing different from harassment? Like if you’re always there giving me a hard time all the time, is that the same? So constant presence, over-policing and harassment, those are like...”

“Well over-policing is too when people say ‘You’re stopping me on the sidewalk to check my ID to see if I really live here.’”

“Isn’t that harassment too then?”

“Yeah. That’s what they consider harassment.”

“So we can just get rid of [the code] ‘Over-policing’ and put that in ‘Harassment’?”

“Yes.”

“Okay.”

“Well this is interesting because in a way, what you’ve hit upon, is degrees of presence. ‘Presence of Police’ is like the broad category. That is the types. Is it too much, necessary, constant, over-policing?”

“But where do you then put mistrust of police?”

“You can put that under there too.”

“That could be there.”

“Is ‘Police’ as a code okay, though, or does it need to be changed to ‘Police Presence’?”

Resource Needs in the Community: Perception vs. Reality

“So under ‘Resource Needs,’ we just broke down what those were. And that could be something that maybe doesn’t get broken down, but we talked about health care because people talked about that specifically... People talked about things are better outside of their community, so you get the best food places, the best jobs. Things are always better outside of the community, and they wanted things to be in their community, but the reality was that things are better sort of on the other side.”

“Could that be under ‘Perceptions’ maybe, because it’s their perception, it may not be necessarily true?”

“Well no, it’s reality though, because there are no resources.” <continued simultaneously re: perception versus reality> ...

“Well we acknowledge that it is a perception, but there’s a lot of truth to it”

“But we’re not saying don’t code that. We’re just saying when you say ‘Resource Need’ that means that I’m looking for what people say they need.”

Outcomes of community engagement

We found several advantages to engaging CBPR team members in the collaborative coding process. First, it fulfilled the goal of CBPR to engage the community in the full lifespan of the research project, from helping to frame the focus group guide to recruiting participants, facilitating focus groups, and later presenting data and developing action plans. Second, it improved the interpretation of the data by incorporating the realities of lived experience. Cultural humility, as described by Israel et al. (2005) recognizes that an outsider cannot fully master another's culture. University researchers did not fully understand the cultural identity and meanings in play during the focus groups. By taking the lead in interpretation, community members provided the emic's or insiders' knowledge.⁵ This increased the validity of the analysis—tapping into residents' knowledge, personal perspectives, identity, and lived experiences—and expanding the research team's understanding of the themes and findings.⁶ For example, there were lengthy discussions of the cultural appropriateness of certain words (e.g., "projects" vs. "ghetto") and how police intervention differs for violence versus drugs (see Table 6). Community researchers added depth to the process through their willingness to explore and discuss the meaning and significance behind codes.

There were multiple other advantages of the collaborative coding process. The personal involvement of community members in coding and analysis of the transcripts made them feel more authentic when presenting the analysis or citing quotes. Team members noted that collaborative coding and interpretation made the research process feel more democratic and decreased their skepticism. The process of working intensively together fostered co-learning, mutual

Table 6. Lived experience of community members enhances validity of interpretation

The discussion started with a quote from the transcript, but community researchers put it in the context of their own experience:

"And then he talks about how police are big on drugs, but if you're fighting, they might let you fight for a couple of minutes and then they'll eventually come and break it up. But if it was something like drugs, the police seemed very..."

"Basically they reduced it. They reduced crime as far as drugs. But as far as violence, they'll come and break it up, if you need help. Then they'll leave. But as far as drugs, they're cracking down on that. It's just drugs and guns. But as far as fighting, I don't think they do too much cracking down on that"

Table 7. Community member observations about the process

"I really liked the coding, coding the transcripts. Because it was really the community's input, and I realized, especially, like when I was coding the transcripts of the focus groups, that I wasn't at, it's like you could actually really get a feel of what everyone was saying, as opposed to being there and, it took a whole lot of the frustration out. Because you actually got to focus on what was being said instead of trying to control the group or keep the groups or whatever. I liked that aspect of it because it was actually the community telling us what they felt the problems was, what they felt about the neighborhood, or whatever the case may be... I really liked the coding the transcripts, reading all the transcripts."

"One of the things that we had the opportunity to do was to create a coding process that we used with the focus groups. I think we did a pretty good job with that. I think we did a good job of coding. That kind of participation for a community researcher I think is invaluable, and that's the kind of stuff that I think we need to be, for those of us that want to, the opportunity is presented... I think that kind of participation would elevate the university in terms of how it engages and do business with the community."

"I'm excited about the coding process and our helping to create that work... We've helped design and drive all of that. This is certainly a collaborative effort and I think everybody gets to be a standout"

respect, and group cohesion. Collaborative coding fulfilled our aim to build community capacity by providing community researchers with new skills. The process helped them not only learn to handle data, but helped them to understand their communities better. Finally, the process of collaborative coding helped create a synergy of ideas and possible solutions as we moved onto the difficult next steps of identifying top community concerns and drafting action plans (see Table 7 for quotes from team members about the process).

The engagement of the community culminated in a list of community priorities (Table 8). Working from this list, we engaged collaboratively in priority setting exercises (asking questions regarding the themes residents identified in regard to frequency, importance, vulnerable populations, and ability to take action) and identified four top priorities:

- Mental health
- Parental participation
- Services for children
- Workforce development

For each of these priority areas, we worked with residents and service providers to develop detailed [action plans](#) (see Figure 6), which specified necessary inputs and outputs for action; short-term, medium-term, and long-term goals; and the relevant partners to engage. These action plans, developed in 2011, have continued to guide our work to the present, only some of which involves research. More details about the process are available in the health equity report produced by the Center on Society and Health based on this input.⁷

Our efforts to disseminate the research findings and action plans have emphasized feedback to the community. For example, Engaging Richmond produced a community newsletter that summarized the research process, key findings, and recommendations. These newsletters were distributed at various community locations and at a series of community

Table 8. Health equity priorities identified by Engaging Richmond

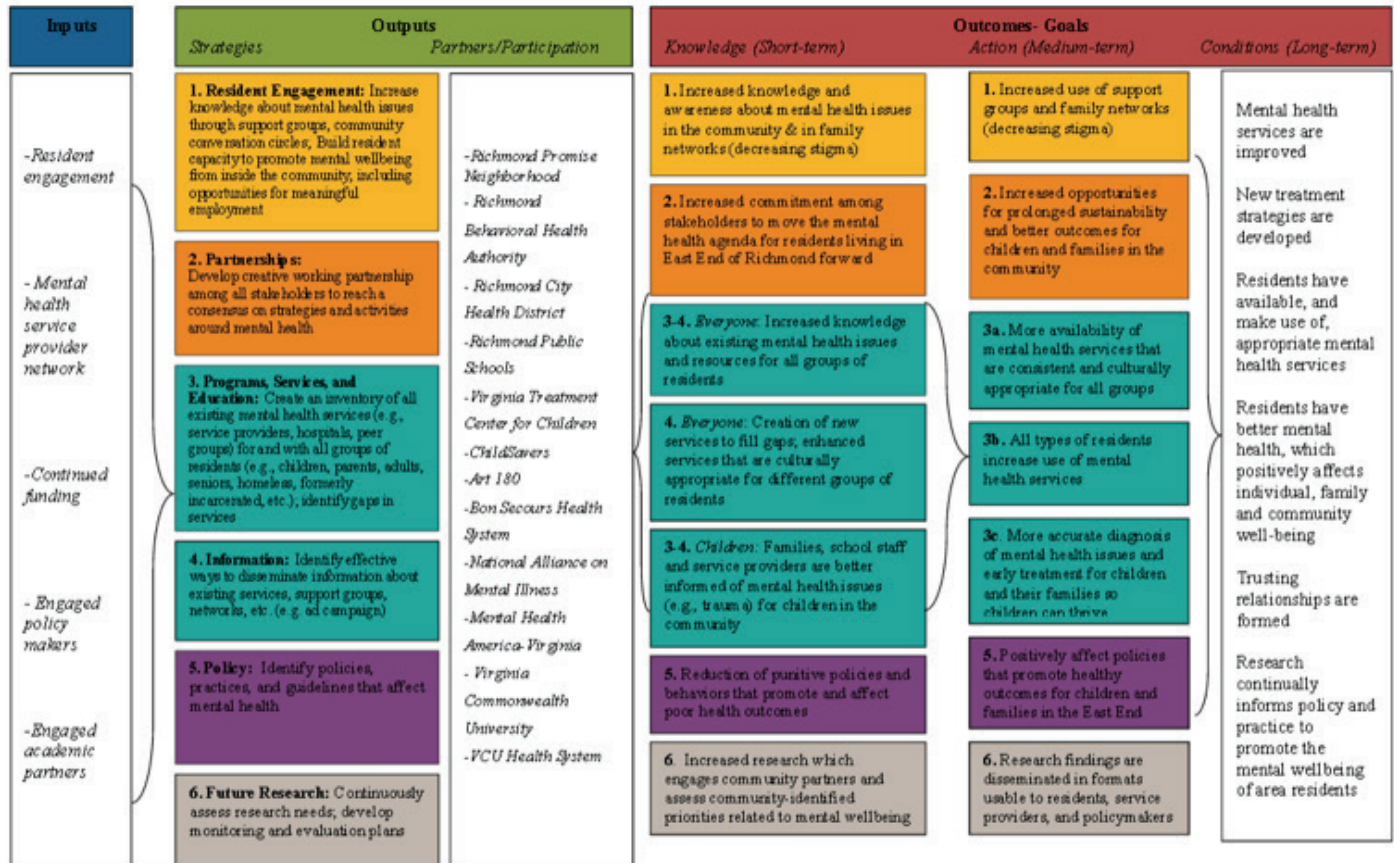
- Mental health
- Workforce development/jobs
- Services/recreational spaces for children
- Parental involvement
- Unity/community events/pooling resources
- Education
- Role models/mentoring
- Environment/physical appearance and cleanliness of neighborhood/upkeep
- Financial investment in neighborhoods
- Safety/policing
- Transportation
- Access to food/supermarkets
- Access to information/communication
- Access to and sustainability of services

conversations. Meetings were held with local service provider organizations and community coalitions to explore opportunities for partnership based on the priorities identified. The plans have inspired policy initiatives in the community, ranging from work with the mayor's office to collaboration with local schools and with developers involved with [public housing redevelopment](#). One local coalition formally adopted Engaging Richmond's action plans to drive future programs and services. We regularly consult the action plans in vetting new research opportunities and to determine whether a proposed study will address identified community needs, not just the intellectual interests of investigators.

Figure 6.

Mental Health Action Plan

Developed by The Engaging Richmond Team



Assumptions: Establishing a culture of change is a necessary prerequisite for increasing individual opportunities, strengthening families and the community, and giving children a stable environment in which to thrive. Individuals having good mental health can create a community that prevents behavioral and emotional issues from occurring and where each resident reaches their full potential in a safe and peaceful environment.

External factors:

- The weak economy
- Cultural stigma
- Policy
- Different priorities which may conflict with increasing services for mental health in the East End

Conclusion

A primary goal of CBPR is to engage the community in all phases of a research project.⁸ CBPR projects vary widely in the extent of community participation in the research process. Most CBPR articles make little mention of the role of community partners in analysis.⁹ Few studies describe collaborative coding by all CBPR team members, including lay members as we report here, largely because most lay members do not enter the collaboration with skills or experience in coding. An exception is the Detroit Community-Academic Urban Research Center, which conducted focus groups and interviews and described a process for including community members in data analysis. Their summary analysis process included debriefing, holding summary analysis meetings to identify themes, and an in-depth analysis of transcripts to confirm the summary analysis and identify quotations.¹⁰ Other examples exist,^{11,12,13} but remain uncommon.

Meaningful stakeholder engagement is not easy and requires more than token efforts. For example, residents in our project sometimes struggled with the complexities, such as applying multiple codes to the same text. For some team members, coding felt redundant or slow. Collaborative coding requires extra time to train people with no previous research

experience and imposes a variety of demands that accompany true collaboration. These challenges, undertaken with limited resources, were hurdles but not barriers in our project.

As this supplement has documented, authentic engagement can markedly improve the quality of research and its alignment with the needs and priorities of the target population. Future research should provide evidence to better characterize the incremental benefit that accrues from the engagement of stakeholders and to clarify how to better match the intensity of engagement with the task. Some parts of the research process require brief, time-limited input from stakeholders, whereas others require their engagement throughout the process. A mismatch of these conditions can overlook the input of stakeholders or, conversely, overburden them. Learning how to enhance engagement is worth the effort to ensure that research ultimately serves the interest of those for whom it is conducted.

Acknowledgment

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Appendix

Screen shots of Informed Decision Making Module (questions 1-6)

Question 1: Awareness of recommendations

Question 2: Stage of decision

Question 3: Immediate next steps

Question 4: Desired information

| | Very important | Somewhat important | Not that important |
|------------------------------------------------------------------------------------------------------------------------------|----------------|--------------------|--------------------|
| What are my options (choices) for getting screened or not getting screened? | ● | ○ | ○ |
| How much would screening improve my chances of living longer? | ● | ○ | ○ |
| Does one kind of screening test work better than another? | ○ | ○ | ● |
| Are there problems that screening might cause, such as false test results, medical complications, or unnecessary treatments? | ● | ○ | ○ |
| What are the screening guidelines of expert organizations, such as the American Cancer Society? | ○ | ● | ○ |
| How is the screening test performed? | ○ | ● | ○ |
| How common or how dangerous is the cancer? | ○ | ○ | ● |
| What are the costs and what will my insurance cover? | ● | ○ | ○ |
| Please specify what else you would like to know about when deciding about cancer screening. | ○ | ○ | ○ |

Question 5: Desired format for information

| | Words | Pictures | Numbers | Stories | Level of Detail |
|------------------------------------------------------------------------------------------------------------------------------|-------|----------|---------|---------|-----------------|
| What are my options (choices) for getting screened or not getting screened? | ● | ○ | ○ | ○ | Slider |
| How much would screening improve my chances of living longer? | ○ | ● | ○ | ○ | Slider |
| Are there problems that screening might cause, such as false test results, medical complications, or unnecessary treatments? | ○ | ○ | ● | ○ | Slider |
| What are the screening guidelines of expert organizations, such as the American Cancer Society? | ○ | ○ | ○ | ● | Slider |
| How is the screening test performed? | ○ | ● | ○ | ○ | Slider |
| What are the costs and what will my insurance cover? | ○ | ○ | ○ | ○ | Slider |

Question 6: Preferred sources for research

| | Most helpful | Somewhat helpful | Less helpful | Doesn't apply to me |
|-----------------------------------------------------------------------------------------------------------------------|--------------|------------------|--------------|---------------------|
| Internet research or other online information (e.g. Mayo Clinic, WebMD, or Google) | ● | ○ | ○ | ○ |
| Television programs or commercial videos about screening | ○ | ● | ○ | ○ |
| Articles about screening in magazines or newspapers | ○ | ○ | ● | ○ |
| Educational materials from a doctor's office or health organizations, such as pamphlets, brochures, flyers, or videos | ○ | ● | ○ | ○ |
| Something else | ○ | ○ | ○ | ○ |

Appendix

Screen shots of Informed Decision Making Module (questions 7-12)

Question 7: Presenting statistics

You are here: MyQuestions

What is the best way for you to use statistics, like numbers and percentages, to learn what to expect from different screening options?

INSTRUCTIONS: Enter the numbers 1, 2, and 3 next to the options in the order that best represents your preferences.

Tables

Listed in data tables with pros and cons

Tables

Pictures

Shows pictures with pros and cons for a great picture

Pictures

Plain English

Explains in plain English or the spoken word

Plain English

Question 7 of 17

Question 8: Cognitive vs "gut feeling" decisions

You are here: MyQuestions

How important to you are your gut feelings or instincts about cancer screening compared with weighing the pros and cons?

INSTRUCTIONS: Drag the slider below to the response that represents how you believe you would make your choice.

▲

|

▼

Gut feelings or instincts are most important
 Gut feelings or instincts are somewhat important
 Not sure or neutral
 Weighing pros and cons are somewhat important
 Weighing pros and cons are most important

Question 8 of 17

Question 9: Fears and worries

How important are the following fears or worries to your decision about colon cancer screening?

| | Very important | Somewhat important | Not that important |
|---------------------------------------------------------------------------------------------|----------------|--------------------|--------------------|
| Getting cancer or not catching cancer early enough. | ● | ○ | ○ |
| The pain or embarrassment of the test. | ○ | ○ | ● |
| Getting bad news when the results come back or finding out I have cancer. | ○ | ● | ○ |
| The costs of screening. | ○ | ● | ○ |
| Having complications (risks and side effects) from the screening test. | ● | ○ | ○ |
| Going to health care providers. | ○ | ○ | ● |
| Regretting my decision. | ○ | ○ | ● |
| Please specify what else you would like to know about when deciding about cancer screening. | ○ | ○ | ○ |

Question 9 of 17

MyPreventiveCare Home Dashboard

Helping you take care of your health

You are here: MyQuestions

What steps do you want to take next?

- I want to give it more thought.
- I have already decided to get a colonoscopy.
- I have already decided to get a stool blood test.

Question 10 of 17

Question 11: Next steps

Which of the following would you like to do?

- No next steps for now.
- Do more reading and research.
- Fill out a printed or online "decision aid" questionnaire that could help me weigh pros and cons.

Talk with . . . [check all that apply]

- . . . my regular health care provider.
- . . . a specialist for a second opinion.
- . . . my family, friends, clergy, or other people I trust.

- Prayer.
- Get a reminder to make this decision.
- Other next steps.

Question 11 of 17

MyPreventiveCare Home Dashboard

Helping you take care of your health

You are here: MyQuestions

Please click the button that best describes how you feel about your decision.

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |
|-------------------------------------------------------------------------------------------|----------------|-------|----------------------------|----------|-------------------|
| I know the benefits and risks of each option for getting screened or not getting screened | ● | ○ | ○ | ○ | ○ |
| I am clear about which benefits and risks from colon cancer screening matter most to me | ○ | ● | ○ | ○ | ○ |
| I have enough support and advice to make a decision about getting colon cancer screening | ● | ○ | ○ | ○ | ○ |
| I feel sure about the best choice for me | ○ | ○ | ● | ○ | ○ |

Question 12 of 17

Appendix

Screen shots of Informed Decision Making Module (questions 13-17)

Question 13: Interest in discussing with doctor

Would you like to discuss colon cancer screening at your next appointment? MyPreventiveCare™ can notify your healthcare provider.

Yes (If you choose this, MyPreventiveCare™ will send your answers to your provider)
 No (If you choose this, MyPreventiveCare™ will NOT send your answers to your provider)

Question 13 of 17

Question 14: Desired topics for discussion

What about colon cancer screening would you like to discuss with your health care provider?

What are my options (choices) for getting screened or not getting screened?
 How much would screening improve my chances of living longer?
 Does one kind of screening test work better than another?
 Are there problems that screening might cause, such as false test results, medical complications, or unnecessary treatments?
 What are the screening guidelines of expert organizations, such as the American Cancer Society?
 How is the screening test performed?
 How common or how dangerous is the cancer?
 What are the costs and what will my insurance cover?
 What do I need to know about logistics, such as preparation, where to go, scheduling, and transportation?
 Something else (please specify)

Question 14 of 17

Question 15: Desired level of control

For the colon cancer screening decision, slide the slider to the phrase that reflects the role you would prefer with your health care provider.

INSTRUCTIONS: Drag the slider below to the role you would prefer with your health care provider.

A. I prefer to make the decision about colon cancer screening.
 B. I prefer to make the final decision about colon cancer screening after seriously considering my health care provider's opinion.
 C. I prefer that my health care provider and I share responsibility for deciding which choice is best for me.
 D. I prefer that my health care provider makes the final decision about colon cancer screening but seriously considers my opinion.
 E. I prefer to leave much of the decision regarding colon cancer screening to my health care provider.

Question 15 of 17

Question 16: Audio-recording consent

Can you help us?

We want to see whether completing MyQuestions™ helps patients at their doctor's appointment. As part of a study, we are audio-recording about 30 appointments. All you would need to do is arrive a few minutes early for your next appointment to sign a consent form and allow your appointment to be recorded. In return we will thank you with a \$50 Target gift card.

Want to learn more? Please enter your information and a coordinator will call with more details.

I am interested in learning more
 I am not interested in learning more at this time

Please enter your information and a coordinator will call you with more details.

Name
 Number
 Best time to contact me

Question 17: Feedback on survey questions

Please give us feedback on MyQuestions™ by indicating how much you agree or disagree.

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Disagree strongly |
|------------------------------------------------------------------------------------------------------------------------|----------------------------------|-----------------------|----------------------------|----------------------------------|-----------------------|
| The questions were clear and easy for me to understand | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| It took too long to answer the questions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> |
| Completing MyQuestions™ helped me with my decision about cancer screening | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Completing MyQuestions™ could help other patients who have diabetes or other diseases and face complex medical choices | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Question 17 of 17

Thank you for completing MyQuestions™. Your answers will help us improve your care.

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