ELEVATING THE PATIENT'S VOICE IN RESEARCH

Final Report

of a 2019 PCORI Eugene Washington
Engagement Award Project

Submitted by the CAPriCORN Patient Community Advisory Committee
Prepared by Earnest Davis

EXECUTIVE SUMMARY

The Eugene Washington PCORI Engagement Award Program helps "encourage the active integration of patients, caregivers, clinicians/providers, industry, payers/purchasers, researchers, and other stakeholders in the research process."

Our Workgroup formed the Elevating the Patient Voice in Research Project to better develop existing, strategic relationships with patients, community partners, key stakeholders, and governmental leaders ("consumers"). Our goal was to create patient-driven research questions which could lead to systems changes and address gaps in care delivery. Through the dissemination of our findings and research questions, we hope to:

- Inform the public about PCORI and comparative effectiveness research
- Inspire patients to become engaged in health research by charting a path for researchers
- Instigate new meetings, symposia, and conferences among advocates that facilitate patient-driven research

The Workgroup faced many challenges in delivering on our goals from reaching patients to navigating and adjusting our workplan as a result of the coronavirus pandemic. The initial approach of face-to-face discussions and large group community meetings proved untenable, and we required revision. To the credit of our team, we made that pivot and hosted our final convening and follow up discussions virtually. Low response rates to our survey required a midstream correction to provide an incentive for its completion. This project would never have reached completion without the time, effort, and talents of a dedicated group of individuals and organizations who believed in the value of this work. Our partners were flexible, our fiscal agent was responsive, and our target audience was eager to engage despite the challenges we faced. We are excited to have met our deliverables, but also feel there are many lessons to be learned from the community engagement process itself.

This Final Report serves three purposes:

i. Capture key findings from the online survey and community input sessions administered by the Workgroup
ii. Provide lessons learned, insight and guidance for patient-driven groups
iii. Suggest a set of patient-informed research questions that reflect policy and practice implications for future research.

Through our interactions with patients, caregivers, clinicians, health system leaders – and each other – we learned a great deal about our broad-based consumer community. We encountered the challenges in presenting an outreach and engagement project and, in doing so, unearthed the true voice of a community. A Dissemination & Implementation Plan for this Report is included in our submission materials to ensure broad dissemination to clients, providers, advocates, researchers and beyond. We feel the method and outcomes are equally powerful and should be widely shared with diverse audiences.

Respectfully Submitted,
The CAPriCORN Patient Community Advisory Committee

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BACKGROUND

The Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN) is one of 13 original clinical data research networks (CDRNs) funded by the Patient-Centered Outcomes Research Institute (PCORI). Through PCORI funding, CAPriCORN successfully linked data from the electronic health records of more than 7 million patients across 11 different healthcare systems in metropolitan Chicago and is continuing to successfully deploy that data through PCORI-funded projects/clinical trials. CAPriCORN's Patient Community Advisory Committee (PCAC) was established at CAPriCORN's founding in 2013, pursuant to PCORI guidelines, to enable CAPriCORN to achieve PCORI's vision of incorporating the patient and clinician voice in all aspects of research. The CAPriCORN PCAC remains committed to helping ensure evidence from clinical research is disseminated to key constituencies, while supporting healthcare decision-makers adapt their delivery models to better meet the needs of their patients.

The PCAC meets regularly to provide feedback and recommendations related to CAPriCORN activities and research. The membership believes that early engagement of patient and community voices is necessary. Discussion of projects during formation leads to research designs that better reflect the needs of patients and providers. Patient-centered outcomes research leads to the generation and synthesis of evidence that helps patients, clinicians, advocates and health systems make informed decisions that will improve health care at all levels. CAPriCORN and its sister CRNs are actively soliciting questions for further research. This approach begins with "… reaching out to other key stakeholders – patients, caregivers, clinicians, and health care policy makers – to solicit the questions that matter most from these users." (Fleurence, 2014)

In Fall 2018, PCAC leadership identified the Eugene Washington Engagement Award for Conference Support as a way to build its standing within the surrounding community. The intent was to better develop existing, strategic relationships with community partners, key stakeholders, and governmental contacts. Based on their positioning in the marketplace and dedication to promoting health equity, the PCAC selected Health and Medicine Policy Research Group (HMPRG) to serve as the Fiscal Agent for the *Elevating the Patient Voice in Research Project*. HMPRG proved to be a qualified and capable external partner, with the necessary infrastructure, proven experience, and available capacity, to excel in that role. The PCAC and HMPRG were awarded a $50,000 grant in August 2019.

DELIVERABLES

The project summary proposed to PCORI included engagement with a broad-based stakeholder community, consisting of patients, caregivers, and clinicians. The primary objective was to generate topics for research, help the Institute prioritize those topics, and ensure patient involvement in research design. A newly formed Project Team was to draw on the expertise of its partners to launch multiple input sessions in communities with the least access to healthcare The team's primary focus area was identified as Cook County, Illinois with specific focus on the South and West regions of the county. All activities of the project were to result in data, recommendations, and organizational structures to: enhance long-term internal and external stakeholder commitment to appropriate, accessible, quality health care for all; synthesize perspectives across stakeholder groups, prioritizing patient/consumer input and voice; guide future research by developing community-informed research priorities for CAPriCORN's data set; and identify and document current health system weaknesses and strengths.

The Project would last 12 months, including the following key activities:

- Facilitating three consumer input sessions;
- Disseminating a survey of community needs;
- Holding a full-day Community Convening;
- Coordinating a communications plan; and
- Publishing of a Final Report that summarizes findings.

Timeline

The project was initially designed to include three phases: Planning (August to October 2019), Implementation (October 2019 to April 2020) and Analysis & Reporting (April to July 2020). Joseph M. Harrington, Co-Lead of the PCAC, was chosen to serve as the Project Lead. The Project commenced with the development of a Planning Team that included members of the PCAC as well as representatives from partner organizations, patients, and other community stakeholders. Appendix A catalogs the membership of the team. The Planning Team was charged with overseeing the design and implementation of each step in each phase of the project.

The Planning Team held its first meeting on July 9, 2019 where they reviewed the objectives and key milestones of the proposed project. They began by conceptualizing a consumer assessment designed to rank health and social issues of concern to the target population and gain input from community members who could not participate in in-person sessions. The survey was then used to shape the agenda for community input sessions so that the data obtained from each mode of engagement would be comparable. The team created a script for the community input sessions so that all facilitators could elicit responses in a uniform way at each convening.

As per the Project Plan, the survey was used to develop an effective playbook for community convenings on the South and West Sides of Chicago. These areas were targeted due to the rich diversity of ethnic and racial populations – populations historically under-served by the healthcare system – and established relationships with key community partners in the area. The first two sessions were hosted in January and February of 2020 with attendance below the anticipated 30 participants per session. On March 20, Illinois Governor J.B. Pritzker issued a 'stay at home' order in response to the COVID-19 pandemic gripping the state. The order required cancelation of all planned in-person meetings, including the scheduled April 16 Final Convening at Malcom X College. While this intervention likely saved countless lives, it certainly interrupted exceptional work across PCORI partners, including the *Elevating* project. The third community convening scheduled for March 2020 was canceled.

The Planning Team pivoted in three ways. Following careful consideration of all possible options, a renewed focus was put on attaining survey responses which required no in-person contact during the 'stay at home' order. Soon after the Project Lead requested and recieved a 6-month no-cost extension from PCORI. Finally, a small workgroup worked to augment the community input session script for a virtual platform. The team worked with experts at HMPRG to integrate Zoom functionalities (group presentation, polling, chat, and breakout rooms) into the structure of the sessions. The partner from the previously scheduled March session was again engaged and the final community input session was held in a virtual format in September 2020.

The team agreed to plan final member check with the community. The purpose of the meeting was to bring together representatives from each session with researchers to present the aggregated project data. Appendix B lists the Final Group Convening attendees. A Zoom meeting was held which resulted in the development of four research questions and a 'research statement' to improve health status and research participation within the targeted communities. Community members provided confirmation that the themes were representative of collective opinions within the communities.

Survey

The Planning Team engaged with the Illinois Public Health Institute's (IPHI) Alliance for Health Equity, which released its Community Health Need Assessment (CHNA) in early 2019. Their CHNA summarized the health needs facing the communities served by hospitals, health departments, and community organizations. Through their CHNA process, they received 5,000 responses to their survey and completed over 50 focus groups. Figure 1 illustrates the findings of the IPHI work. The Planning Team decided to use IPHI's CHNA as a guiding source for the survey, building the data collection around the 6 social issues and 13 health conditions in the document. Open-ended items were incorporated throughout to uncover patient-driven research themes. The 19-item survey was launched on SurveyMonkey in October 2019 and broadly disseminated to HMPRG's 5,000+ listserv, as well as to organizations and partners identified by PCAC and the Planning Team. Appendix C lists the organizations involved in the survey dissemination. The data points were generated by questions designed to assess the following: i) importance of certain social issues and health conditions to the respondent's community; ii) what education is desired concerning these issues; iii) who is impacted by the issues; and iv) community interest in participating in health-related research.

Figure 1. Alliance for Health Equity CHNA

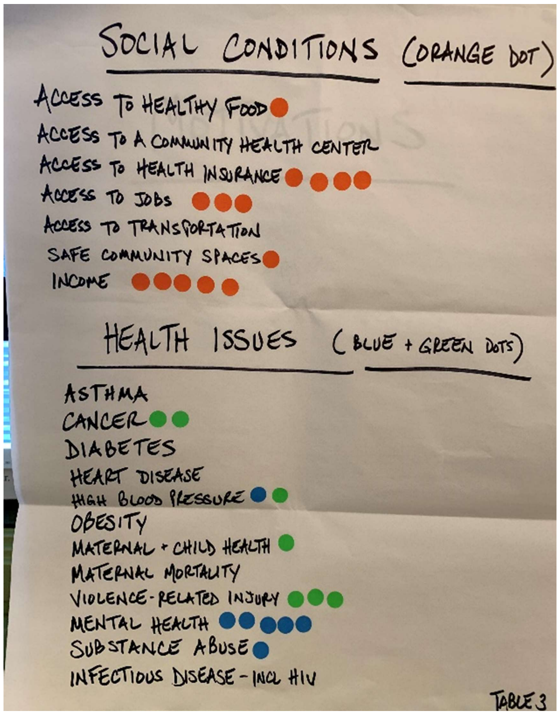
The questionnaire consisted of 5 demographic items, 4 attitude statements assessed on a 4-point Likert-type items, 2 rank order items, 2 factual items and 6 open-ended questions. Each data point is rich in both its quantitative sampling (e.g. ranking of social issues affecting community conditions, ranking of health conditions affecting community health, etc.) and qualitative sampling (e.g. what would you like to know about these issues, what community education is necessary, etc.). The initial method of recruitment - relying on community partners to coax participation among their networks - produced a lackluster response rate. The team pivoted to individual correspondences within their networks and an external campaign with Bronzecomm, again with limited success.

The COVID-19 pandemic presented a new opportunity for promoting the survey as group interviews became less likely. The team offered to present information about the study to community groups virtually to promote the survey. The Planning Team also repurposed budgeted dollars towards $10 gift card payments to each of the first 200 completed surveys, which elicited a substantial response. Approximately half of the total responses were compensated for their time through this mechanism.

Community Convenings

The Planning Team scheduled three consumer input sessions branded as 'Small Group Convening Sessions' in the South, West, and Southwest regions of Chicago. These communities were selected to coincide with areas of highest health need based on health disparities and lack of diversity in research. The team endeavored to hold events at community hubs such as health centers, community centers, and universities. Recruitment was initiated by the Planning Team and affiliated community partners. Special attention was paid to individuals of color in the recruitment of participants, though persons from any background were eligible for the project. Partners at Lawndale Christian Health Center, Chicago State University (CSU), and Governors State University (GSU) offered space to hold the small group convenings in the first quarter of 2020. A continental breakfast and gift card raffle were offered as enticements for volunteers. The Lawndale group (January 2020) produced 22 attendees with none abstaining from the convening activities and ran for approximately 2.5 hours. The Chicago State University (February 2020) group, which ran 2 hours and happened to take place the day of a snowstorm, resulted in 14 attendees though 3 chose to abstain from the convening activities. The Governors State University convening was canceled due to the COVID-19 outbreak and resulting quarantine orders for the state of Illinois but was rescheduled for September 2020 with 60 attendees. Participants for each group were enticed to attend through a raffle for multiple Amazon gift cards and, for GSU students attending the third convening, extra credit was awarded for participation. The active participant total was 93.

The larger convenings (Lawndale and Governors State) were broken into small groups (3 and 9 respectively) to encourage robust discussion and ample narrative data. The questions posed by the facilitator in each group remained consistent across all three convening for data cohesion, though time constraints limited convening data to ranking of social issues and health conditions to the top two for each group member versus ranking all thirteen as in the survey. Data was collected via a color-coded sticker system during in-person events. Figure 2 is an image captured during the Lawndale session which illustrates the data collection mechanism. The virtual convening utilized Zoom features to collect parallel information. All data represents the individual opinions of participants concerning health and social issues affecting the health of their communities.



SOCIAL CONDITIONS (ORANGE DOT)

ACCESS TO HEALTHY FOOD ●
ACCESS TO A COMMUNITY HEALTH CENTER
ACCESS TO HEALTH INSURANCE ●●●●
ACCESS TO JOBS ●●●
ACCESS TO TRANSPORTATION
SAFE COMMUNITY SPACES ●
INCOME ●●●●●

HEALTH ISSUES (BLUE + GREEN DOTS)

ASTHMA
CANCER ●●
DIABETES
HEART DISEASE
HIGH BLOOD PRESSURE ●●
OBESITY
MATERNAL + CHILD HEALTH ●
MATERNAL MORTALITY
VIOLENCE-RELATED INJURY ●●●
MENTAL HEALTH ●●●●●
SUBSTANCE ABUSE ●
INFECTIOUS DISEASE - INCL HIV

TABLE 3

Figure 2. Lawndale Voting

Final Group Convening

Participant validation is a necessary to confirm the credibility of results and check for resonance with experiences when collecting community specific data. The Planning Team held the Final Convening Group in October 2020 after all data had been collected and analyzed by the Project Consultant. The themes from the data were presented to a group of five community members (each participated in one of the community listening sessions) and four researchers. Of note, two of the researchers also participated in the community listening session, one researcher was a Planning Team member, and the other two researchers held leadership positions within CAPriCORN.

The themes identified via descriptive statistical analysis of survey and convening group data were presented by the Project Lead and Project Consultant. Community members verified the results were congruent with the pulse of the community while the researchers noted that the data collection methodology (i.e. direct engagement with community members) and resulting analysis were enlightening. The Principal Investigator for CAPriCORN offered a brief education in creating effective research questions before a brainstorming session commenced. In all four research questions were formulated by the group. The convening group participants were adamant that, while the voice of the customer is obligatory to effective patient-centered health studies and clinical effectiveness research, it is not sufficiently adequate to effect change given the enormity of the health crises in their communities. They indicated that any research done with these targeted populations must:

- Focus on accomplishing tangible change in the participating communities that goes beyond scientific learning,
- Focus on prevention as a priority while acknowledging mitigation is necessary,
- Include community leaders and residents as paid members of the research team, and
- Respect the culture and lived experience of the community.

Each of these requirements are supported by the survey and convening group data as community-wide sentiments. They are also supported by the literature in public health and social sciences spaces. Though not a deliverable in the original project plan, the Planning Team felt it appropriate to develop a research statement on behalf of the participant communities as it is key to PCORI's success in future research. The research questions and research statement were vetted by the Project Team and affiliated researchers. Appendix D catalogs the research questions/statement and associates supporting themes from the project with each question. Of note, a significant proportion of the project participants believed that 'community coalitions' were the best way to study the health conditions. The Collaborative Research Teams listed in Appendix D are examples of the community and professional roles provided during the project and paired with each Research Question by the Project Consultant.

FINDINGS

The data from the first two convening groups was collected by facilitators on whiteboards and provided to the Project Consultant. Data from the third convening was collected via Zoom polls, chats and facilitator notes, then forwarded to the Project Consultant. The SurveyMonkey questionnaire was closed in October 2020. Appendix E is a representation of the survey as participants viewed it in online. Data from the survey was downloaded to a spreadsheet, which was used as the skeleton for data collection. All data from the three convening groups was added to survey spreadsheet for statistical coherence. All data points with ZIP codes outside of the target population were excluded, as was any survey responses with bad data (i.e. all social and health conditions ranked in order). The cleaned data set was converted to a comma delimited file and transferred to SPSS for analysis.

Participants

A total of 465 people engaged with the Project either through one of the three community input sessions or the online survey. Of all the participants, 369 were included in the data analysis. Figure 3 provides a breakdown of responses by engagement point. The column labeled 'Adjusted Participants' removes survey participants from the North Side of Cook County (n=19), participants from other states (n=73), responses with bad data (n=1) and CSU attendees who did not participate in convening voting or discussion activities (n=3). Anecdotally the convenings included a mix of ages, ethnicities, professional and blue-collar community residents, though no demographic information was collected during the input sessions or on the survey.

Data Source	Date	Participants	Adj. Participants
Survey	9/2019 - 10/2020	369	276
Lawndale Group	1/2020	22	22
CSU Group	2/2020	14	11
GSU Group	9/2020	60	60

Figure 3. Participant Sources

Quantitative Data Themes

The closed-ended questions in the convenings and on the survey (5, 6, 7 and 12) collected from the survey and convening groups created the most data. Survey participants ranked social issues 1 through 7 with 1 being the issue most important to them. Figure 4 shows the responses in terms of mean ranking (lower mean indicates more important condition), how often participants ranked it first or second, and how often participants ranked the issue sixth or seventh. Convening participants were instructed to select their top two conditions, thus their preferences are included in the top frequencies but not the lower. Based on the responses, the Planning Team **suggests access to health centers and health insurance** are the two social issues that should be included in studies, though there may be some validity to researching access to healthy food and jobs based on how closely the responses were ranked. Social determinants of health seem to play a significant role in the target communities.

Conditions	Mean	Freq. 1-2	Freq. 6-7
Access to Healthy Food	3.35	34.2%	17.4%
Access to a Health Center	3.2	37.6	15.4
Access to Health Insurance	3.32	30.4	11.4
Access to Jobs	3.44	28.4	10.8
Access to Transportation	4.93	8.4	32.2
Safe Community Spaces	4.18	21.2	26.8
Income	4.09	29.8	30.1

Figure 4. Social Issues Rankings

The data analysis found **cancer, diabetes and heart disease** are the health conditions most important to residents of the South and West Sides of Cook County. Survey participants ranked health conditions 1 through 13 with 1 being the condition most important to them. Figure 5 shows the responses in terms of mean ranking (lower mean indicates more important condition), how often participants ranked it first or second, and how often participants ranked the condition in the bottom three. Convening participants were instructed to select their top two conditions, thus their preferences are included in the top frequencies but not the lower. In this exercise, while asthma had a significant proportion of responses ranking them in the top two spots, a significant frequency of responses had it in the lower three rankings. Mental health had a similar assessment to asthma however a number of participants astutely mentioned how poor mental health, like diabetes, could lead to other health and social issues. This realization led the Planning Team to report **mental health** as a possibility for research in the target communities though it was not taken into account in the research questions.

Conditions	Mean	Freq. 1-2	Freq. 10-13
Asthma	5.52	25.2%	20.3%
Cancer	4.17	38.8	12
Diabetes	4.58	23.6	12.2
Heart Disease	5.08	13.5	11
High Blood Pressure	5.58	11.9	10.6
Obesity	5.81	14.6	11.7
Mother/Child Health	7.49	5.2	26.2
Maternal Mortality	8.53	2.4	37.4
Infant Mortality	8.94	2.4	52
Violence-related Injury	8.00	12.9	50
Mental Health	6.71	21.4	34.2
Substance Abuse	8.09	14.1	47
Infectious Disease	9.23	7.9	55.8

Figure 5. Health Conditions Rankings

When asked what they would like to know about the social issues and health conditions participants overwhelmingly desired to learn **ways they can be prevented**. The four specific questions shown in Figure 6 were only asked on the survey. However the question 'what would you like to learn about these issues' was posed in the convening groups and answers were captured in qualitative form.

Research Topics	Yes	No
The causes and factors that contribute to them	59.4%	40.6%
Ways they can be prevented	75%	25%
Information on the types of people and communities affected	51.8%	48.2%
What people in my community think about them	37.3%	62.7%

Figure 6. Desired Learning Preferences

Qualitative Data Themes

The data points from questions 7, 8, 9, 10 and 12 were collected in word form from the survey and convening group participants. They include answers to open ended questions on the survey, answers to facilitator questions during the convening, and stories told about participants, communities, and community resources (i.e. doctors, hospitals, grocery stores, etc.) during the convening. Their comments were coded for analysis by the Project Consultant, but their sentiments were captured in their entirety and added context to the development of research questions.

Survey and community input session participants were posed the question 'what would you like to know about these issues', referring back to the ranked social issues and health conditions. **Community education & channels** was the preferred knowledge goal as illustrated in Figure 7. This grouping includes desires for education concerning health conditions and for *innovative, impactful methods* of communicating that education. Examples include the traditional education goals of signs & symptoms and importance of screening as well as novel learning like what institutional conditions foster these conditions, how to advocate for yourself in the healthcare system, and how to infuse more "energy" into health education. Similarly the second priority was to learn about care delivery and *innovative, impactful methods* of delivering care. Some examples were learning about care alternatives outside of the health industry, treatment options available inside and outside the community, and how to better integrate community health workers.

Access issues	6
Care Delivery & Channels	10
Community Education & Channels	24
Community Impacts	7
Community Led	3
Low cost/Natural Solutions	5
Other	5
Prevention Training	6

Figure 7. Specified Desired Learnings

Participants were vocal in defining what researchers should study regarding the health conditions. Unsurprisingly the responses of **community education & channels** and **prevention techniques** dominated all other responses. The findings were very much in line with the results above. Figure 8 indexes answers to the question "what are some specific things we should try to learn about the health conditions that are important to you and your community?".

Care Delivery & Channels	20
Community Education & Channels	51
Disparities	15
Drug Abuse/Violence Prevention	21
Environmental Stress/Impacts	27
Mental Health Impacts	17
Other	9
Prevention Techniques	53
Transferable Skills	5

Figure 8. Community Informed Research Goals

Community	32
Elderly	4
Everyone	65
Families	9
Health & Healthcare Industry	10

Other	7
Racial Minorities	5
Underprivileged	29
Unhealthy	22
Youth	20

Figure 9. Parties Impacted By Health Conditions

Item 9 asked participants 'who in the community do these issues effect'. While **everyone** was the primary response, it does not give any additional specificity to the goals of the *Elevating the Patient Voice in Research* project. It does however speak to the pervasiveness of cancer, diabetes and heart disease in the community and the overarching desire for education and prevention techniques to build resistance and resilience towards the conditions. Data from this question is represented in Figure 9. Responses to 'Who do these issues impact' included some specific wording that differentiated everyone (inclusive of populations outside the community) from community (exclusive of populations outside the community). Community was not defined by the Planning Group as based in geographic, racial or socioeconomic status. If participants defined the community as an area with low socioeconomic status, then inclusion of 'underprivileged' with 'community' codes would indicate a desire to study the community exclusive of other populations. Without any further enlightenment on the mindset of participants the Planning Team accepted 'everyone' as the intended sentiment and did not include any target population in the resultant research questions.

Similar to the desired learning question, participants provided some traditional and some fresh ideas when asked 'who should be involved in studying these issues'. The results are presented in Figure 10. **Community coalitions** received the most attention with respondents listing novel coalition members (corner stores, block clubs, civil rights organizations, teachers, etc.) to go along with the traditional researcher roles. Contributors expressed a common sentiment that collaborations were effective means of research, but funding agencies and principal investigators should expand community partnerships beyond churches and hair salons. The *Health & Health Industry* grouping, including hospitals, medical schools, medical researchers, etc., narrowly missed the top two. If added to quotes that specifically mentioned physicians, this grouping would be top two. Finally, a strong opinion that community research team members be paid was expressed in the convening groups and the survey.

Community	42
Community Coalitions	48
Everyone	38
Government Agencies	13
Health & Healthcare Industry	37
Other	4
People of Poor Health	14
Physicians	10

Figure 10. Suggested Researchers

The final data point analyzed concerned participants' interest levels in contributing to certain types of research. The summary presented in Figure 11 only includes survey participants because convening group members were not asked this question. At least 77% of respondents were at least somewhat interested in talking and sharing data with researchers or even testing a new solution to the health and social issues faced in the community. But there was an 18 to 31% decrease in the number of people that were at least somewhat interested in trying a new medication as part of a research study. It is important to note that the more than half (59%) of participants were at least somewhat interested in testing a new drug. Researchers should not shy away from cultural inclusiveness in pharmacological studies as it is a requirement in clinical effectiveness research. However they should expect a need for additional outreach and education to identify willing subjects.

	Very Interested	Somewhat Interested	Not Interested	Neutral
Sharing your opinion about the health issues	43%	47%	8%	3%
Testing a new solution that is not a medication	41%	37%	18%	4%
Sharing data with researchers who are trying to address the health issue	39%	38%	20%	3%
Trying a new medication	24%	35%	36%	5%

Figure 11. Types of Research Preferred by Residents

Community-Informed Research Questions

A group of project participants and researchers met in a final convening facilitated by the members of the Project Lead. The Planning Team for *the Elevating the Patient Voice in Research* proposes the following community developed and community informed research questions:

1. What are the learned protective factors that instigate resistance to cancer, diabetes and heart disease in residents of communities with increased prevalence?
2. What is the immediate and enduring role of stress? allostatic load in the development of cancer, diabetes and heart disease?
3. In what ways do the effects of environment weathering and epigenetics alter the manifestation of cancer, diabetes or heart disease in minority communities?
4. Which common understandings of health and healthcare can be proven/disproven using the CAPriCORN data set?

Additionally, according to project participants, there is a demand in communities for education even more than health research. When research does not exist to provide education, participants require participatory action research. Investigations should emphasize action, include paid members of the community as research team members, and seek to understand the health condition while changing it.

Among the 86 current PCORI-funded projects in Illinois there is some congruence in the *Elevating* project findings in that 14 concern the health conditions participants found most important (10 cancer, 1 heart disease, 3 diabetes) and 11 projects were focused on education or prevention. However, of those 86 projects awarded between 2012 and 2020, only one incorporated the Project's stated community informed health conditions, research goals, and community coalition leadership. Funding of the proposed or similar research questions has a high propensity for increased patient-centered research activity in areas like the South and West Sides of Cook County.

SUMMARY

The grant period was interrupted by the COVID-19 crisis of 2020 and required adjustment to the project plan and deliverables. However, a robust data set was created based on the data compiled during the three consumer input sessions and via the online survey. Once analyzed the information led to the formation of themes that can help scientists and funding agencies better design research that is both scientifically and culturally relevant in diverse communities like the South and West Sides of Cook County. The Planning Team also feels the design and methodology used to execute the *Elevating* project could be a model for PCORI-funded community engagement activities. They include:

- Managing the project through a Planning Team with diversity of age, ethnicity, professional background, geography, and interests,
- Regular meeting and structured work assignments for accountability and efficiency,
- Utilizing existing relationships and networks to reach community residents,
- Educating community participants while engaging them in the project, and
- Paying community participants for their time when engaging with the project.

Given the wealth of learning that can come from this project, the Planning Team has included a Dissemination and Implementation Plan as Appendix F.

The *Elevating the Patient Voice in Research* Planning Team would like to thank PCORI for its generous funding and flexibility in these unprecedented times and the 421 people that participated in the project. Thank you to Health & Medicine Policy Resource Group for going above and beyond to support an extended timeline for the project. We would also like to thank all the partnering organizations for their social marketing in support of the convenings and survey; Lawndale Christian Health Center, Chicago State University, and Governors State University for volunteering space; the researchers that volunteered their time to review and evaluate our findings; and Joseph Harrington for his adept and persistent leadership of the group.

Respectfully submitted,

The **Elevating the Patient Voice in Research** Planning Team

Reference:

Fleurence RL, Beal AC, Sheridan SE, Johnson LB, Selby JV. 2014. Patient-powered research networks aim to improve patient care and health research. Health Affairs 33(7) 1212-1219.

APPENDIX A

Project Planning Team Membership

Earnest Davis	Independent Consultant, EJD Consulting
Dr. Paris Davis	Pastors4PCOR
Dr. Rupert Evans	CEO, Thapelo Institute, Inc
.	
Charon Gladfelter	
Janice Glenn	PCAC Co-Lead, Diversity and Inclusion Consultant
Mac Grambauer	Senior Consultant, McAlpine Consulting for Growth, LLC
Joseph M. Harrington	PCAC Co-Lead
Kevin M. Hull, JD	Executive Director of the West Side Institute for Science and Education
Shabina Khan	Patient Advocate
Dr. Doriane Miller	Director of the Center for Community Health and Vitality, UChicago Medicine
Dr. Fred Rachman	CEO, AllianceChicago
Margie Schaps	Executive Director, HMPRG
Shannon Sweetnam	Director of Development and Communications, HMPRG
Dr. Karriem Watson	Director of Community Engaged Research, UI Health Cancer Center
Natalie Watson	Community Relations Program Manager, The Institute for Translational Medicine, University of Chicago

APPENDIX B
Final Group Convening Attendees

Dr. Booker Davis	Scientist, Northwestern University Community Convening #3
Earnest Davis	Independent Consultant, EJD Consulting
Brave Fung	Payroll Specialist, Governors State University Community Convening #3
Joseph M. Harrington	PCAC Co-Lead
Dr. Wilnise Jasmin	Medical Director of Behavioral Health, Chicago Department of Public Health Community Convening #2
Charles Jenkins, Jr	Community Convening #1
Dr. Abel Kho	Principal Investigator, CAPriCORN Director, Center for Health Information Partnerships
Dr. Raj Shah	Steering Committee, CAPriCORN Associate Professor, RUSH Alzheimer's Disease Center
Shannon Sweetnam	Director of Development and Communications, HMPRG
Natalie Watson	Community Relations Program Manager, The Institute for Translational Medicine, University of Chicago
Dr. Karriem Watson	Director of Community Engaged Research, UI Health Cancer Center
Charlie Wilson	Community Convening #1

APPENDIX C
Survey Dissemination Partners

Peer Plus Education and Training Advocates
Rush University Road Home Program for Veterans
Sinai Community Institute
Skokie Health Department
Stickney Health District
UIC Office of Community Engagement and Neighborhood Health
VNA Foundation
Inner City Muslim Network (IMAN)
Men Making a Difference (MMAD)
National Black Nurses Association, Chicago Chapter
Oak Park Health Department
Cook County Health Department
Cook County Physicians Association
Dean of Health Sciences at Malcolm X College
Fr. Michael Pfleger (St. Sabina Church)
Foxglove Alliance
Congressman Danny K. Davis–7th District Office
Gift of Hope
Habilitative Systems, Inc.
Housing for Health
Illinois Foundation for Quality Health Care
Center for Faith and Community Health Transformation
Chicago Department of Public Health
CommunityHealth
Center for Community Health Equity
Alliance for Research in Chicagoland Communities (ARCC)

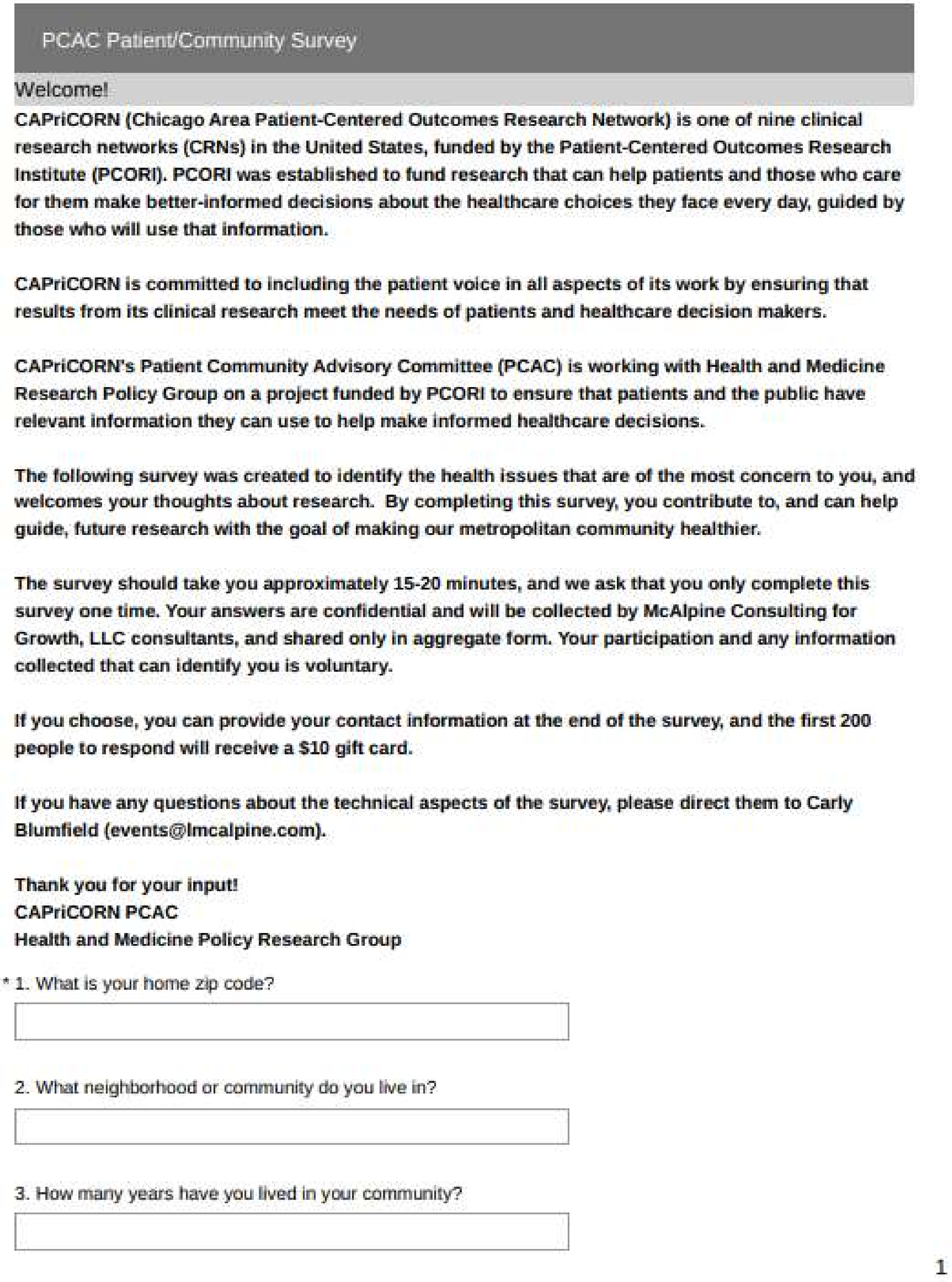
APPENDIX D
Community Informed Research Questions

According to *Elevating the Patient Voice in Research* participants, there is a demand in communities for **EDUCATION** even more than health research. When research does not exist to provide education, participants require ***Participatory Action Research***. Investigations should emphasize action, include paid members of the community as research team members, and seek to understand the health condition while changing it.

Research Question (*Study Language*)	**Research Question** *(Community Language)*	**Collaborative Research Teams** *(Examples)*	**Project Results Supporting the Research Question**
What are the learned protective factors that instigate resistance to cancer, diabetes and heart disease in residents of communities with increased prevalence?	What are people doing to keep from getting sick?	CAPriCORN Hospitals & Health Centers Home Health Workers Personal Retailers (e.g. Barbers) Sociologists & Social Workers (need bullets, etc.)	**77%** indicated they would be interested in 'sharing data with researchers who are trying to address health issues' **75%** desired to learn prevention techniques
What is the immediate and enduring role of stress? allostatic load in the development of cancer, diabetes and heart disease?	How does stress make you sick?	Geneticist Psychologist Specialty & Primary Physicians Non-military PTSD Residents Community Support Groups Government Agencies	'Environmental stress impacts' ranked **3rd** most desirable area of learning among participants
In what ways do the effects of environment weathering and epigenetics alter the manifestation of cancer, diabetes or heart disease in minority communities?	Do symptoms look the same in poor neighborhoods as they do in rich neighborhoods?	Geneticist Psychologist Specialty & Primary Physicians Healthy and Diagnosed Patients	Cancer, diabetes, and heart disease ranked **'Most Important'** health conditions
Which common understandings of health and healthcare can be proven/disproven using the CAPriCORN data set?	Can you believe what you've always been told about your health?	Churches Community Organizers Schools Professional Researchers	'Community education' ranked **2nd** most desirable area of learning among participants

APPENDIX E

Elevating the Patient Voice in Research Questionnaire



PCAC Patient/Community Survey

Welcome!

CAPriCORN (Chicago Area Patient-Centered Outcomes Research Network) is one of nine clinical research networks (CRNs) in the United States, funded by the Patient-Centered Outcomes Research Institute (PCORI). PCORI was established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information.

CAPriCORN is committed to including the patient voice in all aspects of its work by ensuring that results from its clinical research meet the needs of patients and healthcare decision makers.

CAPriCORN's Patient Community Advisory Committee (PCAC) is working with Health and Medicine Research Policy Group on a project funded by PCORI to ensure that patients and the public have relevant information they can use to help make informed healthcare decisions.

The following survey was created to identify the health issues that are of the most concern to you, and welcomes your thoughts about research. By completing this survey, you contribute to, and can help guide, future research with the goal of making our metropolitan community healthier.

The survey should take you approximately 15-20 minutes, and we ask that you only complete this survey one time. Your answers are confidential and will be collected by McAlpine Consulting for Growth, LLC consultants, and shared only in aggregate form. Your participation and any information collected that can identify you is voluntary.

If you choose, you can provide your contact information at the end of the survey, and the first 200 people to respond will receive a $10 gift card.

If you have any questions about the technical aspects of the survey, please direct them to Carly Blumfield (events@lmcalpine.com).

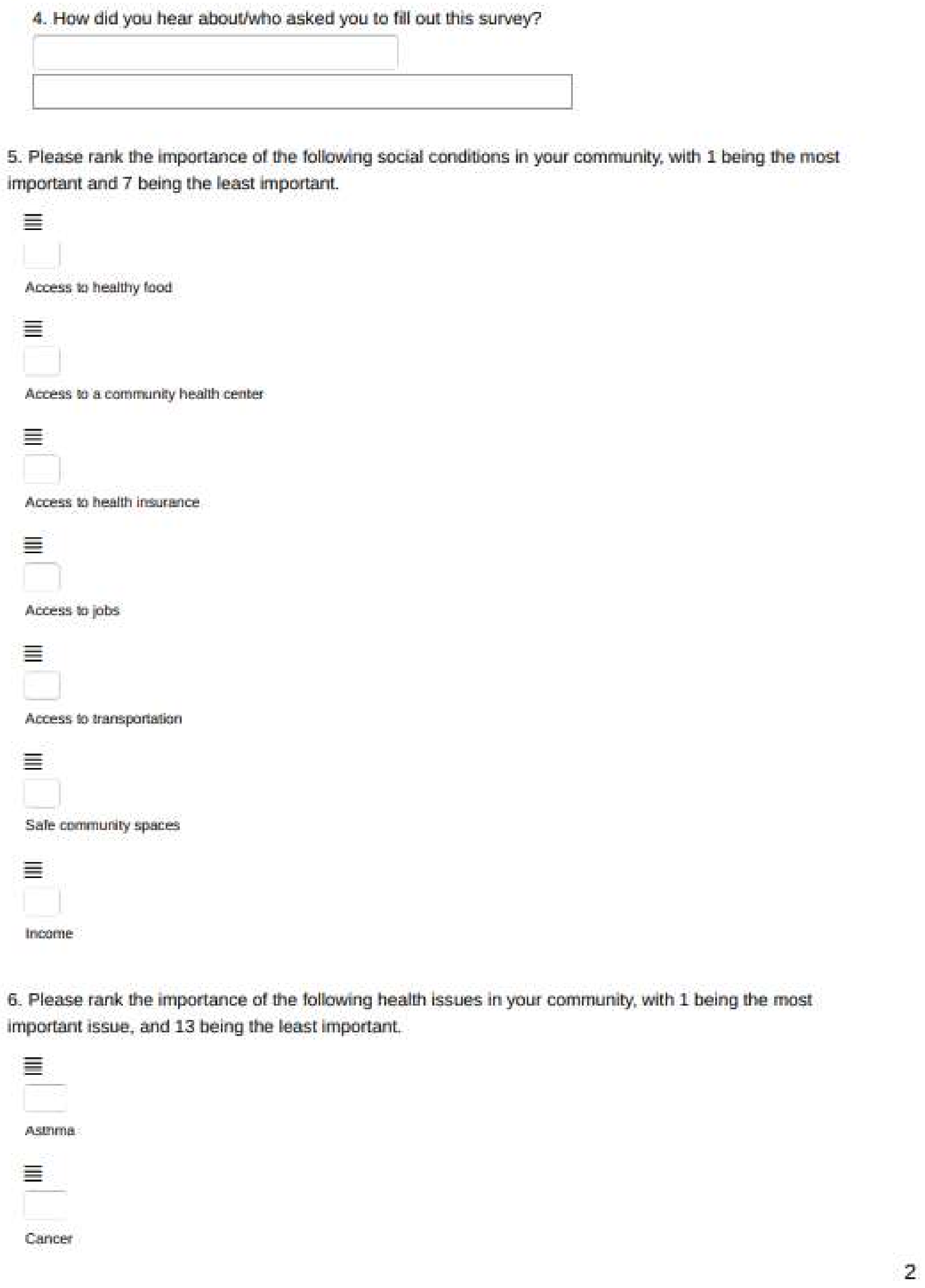
Thank you for your input!
CAPriCORN PCAC
Health and Medicine Policy Research Group

* 1. What is your home zip code?

2. What neighborhood or community do you live in?

3. How many years have you lived in your community?

1



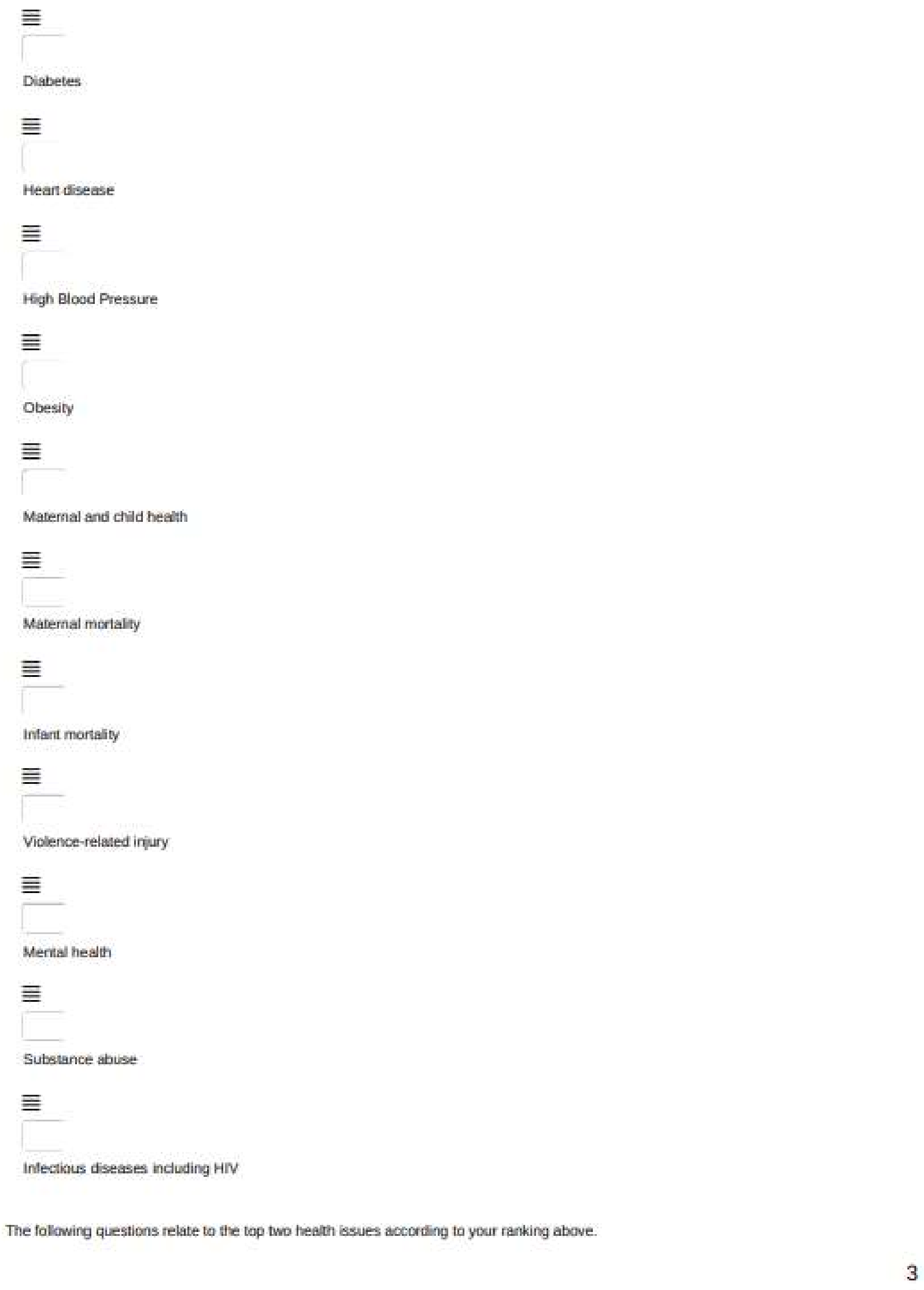
4. How did you hear about/who asked you to fill out this survey?

5. Please rank the importance of the following social conditions in your community, with 1 being the most important and 7 being the least important.

- ≡ ☐ Access to healthy food
- ≡ ☐ Access to a community health center
- ≡ ☐ Access to health insurance
- ≡ ☐ Access to jobs
- ≡ ☐ Access to transportation
- ≡ ☐ Safe community spaces
- ≡ ☐ Income

6. Please rank the importance of the following health issues in your community, with 1 being the most important issue, and 13 being the least important.

- ≡ ☐ Asthma
- ≡ ☐ Cancer



≡ ☐ Diabetes

≡ ☐ Heart disease

≡ ☐ High Blood Pressure

≡ ☐ Obesity

≡ ☐ Maternal and child health

≡ ☐ Maternal mortality

≡ ☐ Infant mortality

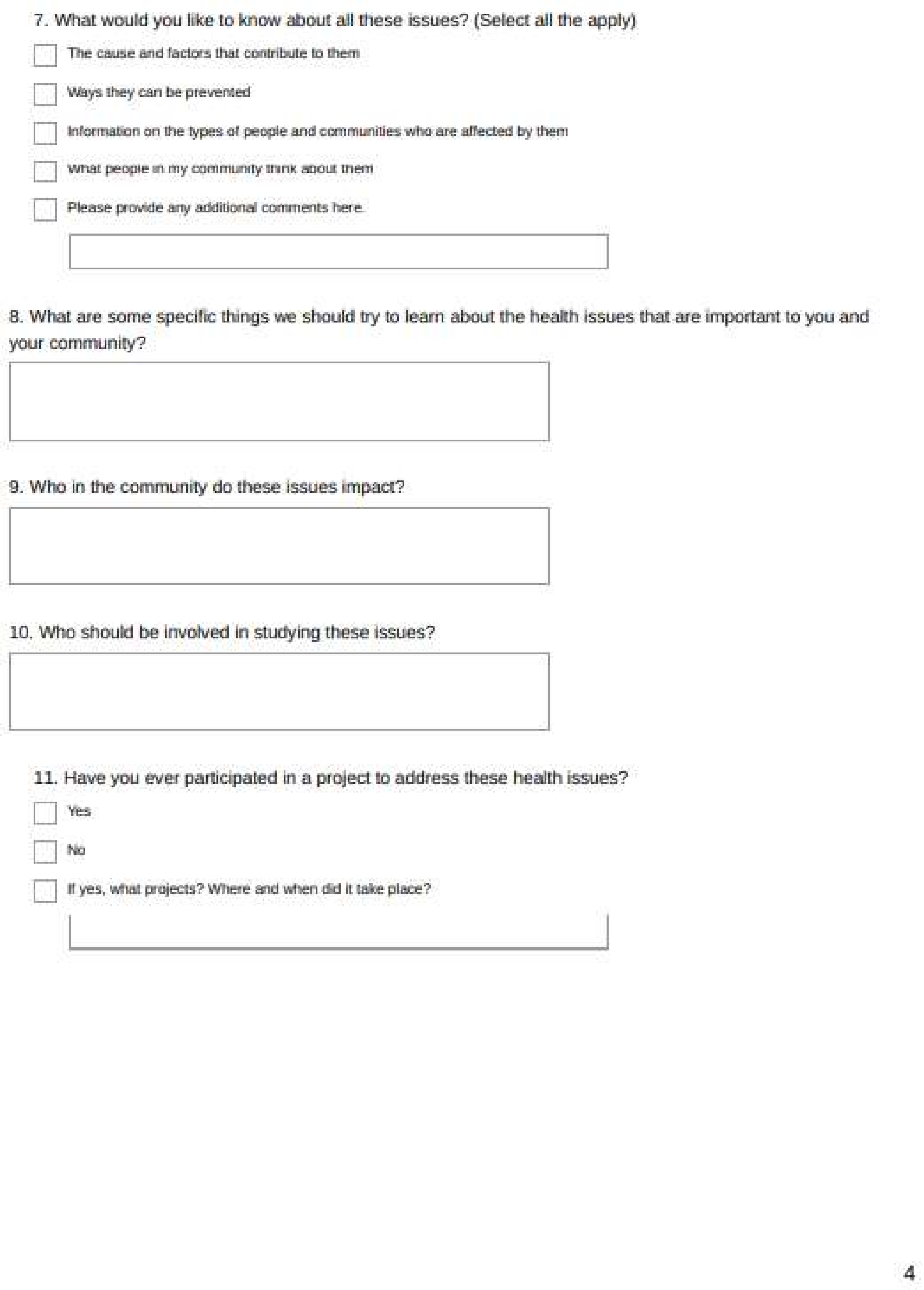
≡ ☐ Violence-related injury

≡ ☐ Mental health

≡ ☐ Substance abuse

≡ ☐ Infectious diseases including HIV

The following questions relate to the top two health issues according to your ranking above.



7. What would you like to know about all these issues? (Select all the apply)

☐ The cause and factors that contribute to them

☐ Ways they can be prevented

☐ Information on the types of people and communities who are affected by them

☐ What people in my community think about them

☐ Please provide any additional comments here.

8. What are some specific things we should try to learn about the health issues that are important to you and your community?

9. Who in the community do these issues impact?

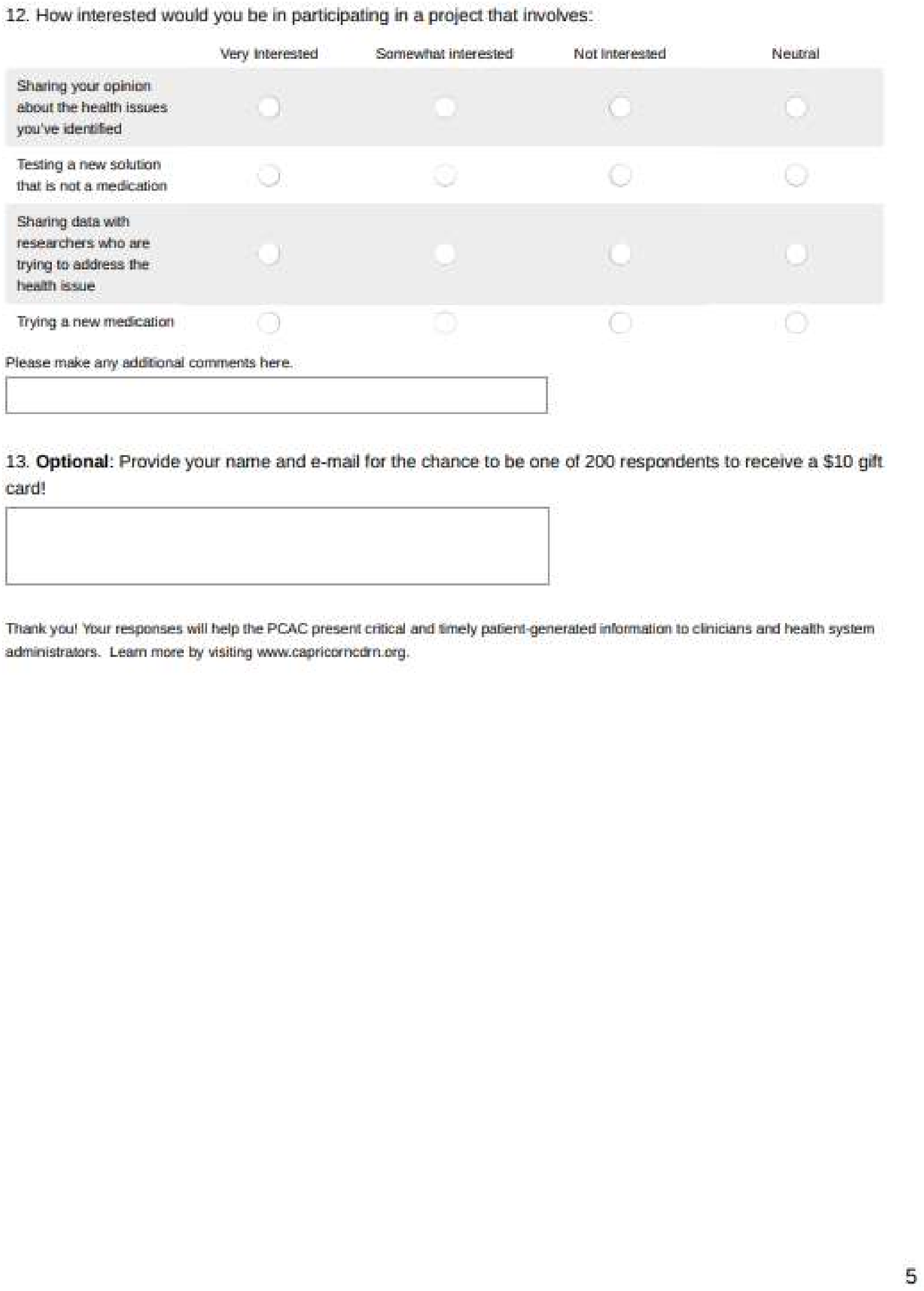
10. Who should be involved in studying these issues?

11. Have you ever participated in a project to address these health issues?

☐ Yes

☐ No

☐ If yes, what projects? Where and when did it take place?



12. How interested would you be in participating in a project that involves:

	Very Interested	Somewhat interested	Not Interested	Neutral
Sharing your opinion about the health issues you've identified	○	○	○	○
Testing a new solution that is not a medication	○	○	○	○
Sharing data with researchers who are trying to address the health issue	○	○	○	○
Trying a new medication	○	○	○	○

Please make any additional comments here.

13. **Optional**: Provide your name and e-mail for the chance to be one of 200 respondents to receive a $10 gift card!

Thank you! Your responses will help the PCAC present critical and timely patient-generated information to clinicians and health system administrators. Learn more by visiting www.capricorncdrn.org.

APPENDIX F

Dissemination and Implementation Plan

Initial Dissemination

Task	Goal	Description	Date
Final Convening Group	Results Validation	Share Data Analysis and draft Proposed Research Questions	10/29/2020
Email Affiliated Researchers	Results Validation	Share Final Report draft and request feedback	11/18/2020
CAPriCORN Steering Committee	Results Validation	Share Data Analysis and draft Proposed Research Questions	11/20/2020
Email Planning Team	Dissemination Prep	Share Final Report and Dissemination Plan	11/25/2020
Create Final Report Link	Dissemination Prep	Create a landing page for the Final Report on the CAPriCORN website	11/29/2020
Train PCAC Members	Dissemination Prep	Provide a short slide deck and talking points to PCAC members	TBD

Substantive Dissemination

Task	Goal	Description	Date
Email Partner Organizations	Targeted Dissemination	Send Final Report to affiliated organizations for review	11/30/2020
Email Planning Team Networks	Targeted Dissemination	Ask Planning Team to email Final Report to their networks	11/30/2020
PCAC Presentations	Targeted Dissemination	Trained PCAC members present short presentation to their networks	TBD
CAPriCORN Website	Targeted Dissemination	Create a Venn diagram of patients with top conditions and demographics	TBD

Broad Dissemination

Task	Goal	Description	Date
Social Media Blitz	Community Dissemination	Ask partner organizations to share Final Report link via social media	12/7/2020
Email Blitz	Community Dissemination	Ask partner organizations to share Final Report via email	12/7/2020
Issue/Policy Briefs	Industry Dissemination	Email Executive Summary to policy analysts and advocacy groups	12/7/2020
Present to Alliance for Health Equity C4	Community Dissemination	Present Data Analysis Slides	TBD

Implementation

Establish Measurement Strategy	Measurement	Measure the impact of D&I activities *Questions Researched* *Media Uptake*	TBD
Research Question Toolkit	Project Education	Develop a special toolkit for the CAPriCORN website for more engagement about proposed research questions	TBD