Exploring consumer engagement experiences

A research project co-led by the National Consumer Scholars

Evelyne Kane, MPH, Program Manager for Community Engagement, Camden Coalition
Danielle Hodges, MHS, Program Manager for Data & Quality Improvement, Camden Coalition
Olivia Richard, National Consumer Scholar
Stephanie Burdick, National Consumer Scholar
Suzette Shaw, National Consumer Scholar

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Introduction

Consumer engagement is becoming a popular concept in healthcare, with organizations increasingly understanding the value in working closely with those they serve in order to improve their programs and outcomes. But what are the experiences of the program staff and consumers who take part in consumer engagement activities? This joint project between staff at the **Camden Coalition of Healthcare Providers** (Camden Coalition) and complex care consumers taking part in the Camden Coalition's National Consumer Scholars program sought to learn more about on-the-ground experiences of consumer engagement, and to extrapolate those experiences into recommendations for the complex care field.

We used an online survey to collect responses from complex care consumers and from staff/providers at complex care organizations. Survey responses elucidated the importance of understanding consumers' intrinsic motivations for participation, setting clear expectations and roles for consumer participants, and always closing the loop by sharing back the outcome of consumers' work and input. Responses also highlighted the need for organizations to address common barriers to consumer participation.

We hope this research project in-and-of-itself is a replicable model for how organizations can benefit from consumer partnerships, and that the findings described here provide insight and guidance for how complex care organizations — and others — can and should build authentic and mutually beneficial partnerships with their consumer stakeholders.

Background: The National Consumer Scholars

It is vital that the experiences of people with complex health and social needs and their caregivers inform the direction of the **complex care** field. Since its launch in 2016, the Camden Coalition's **National Center for Complex Health and Social Needs** has purposefully engaged consumer leaders from organizations across the country through our **National Consumer Scholars program**. National Consumer Scholars have first-hand experience living with or caring for someone with complex health and social needs, experience with systems-level transformation, and leadership involvement with an organization that provides complex care or advocacy. Each cohort of Consumer Scholars takes part in peer-led leadership development activities, plays an active role at the annual **Putting Care at the Center** conference, and brings lessons back to their local communities. The program aims to create mutually beneficial partnerships with consumers[1] by tapping into their lived experiences and other expertise, while offering opportunities to foster professional and personal

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[1] *In this report, we use the terms "consumer" and "person with lived experience" interchangeably to refer to individuals who identify as having first-hand experience as a person (or caregiver of a person) with complex health and social needs. These terms are also often used synonymously with "patient," "client," or "community member." We recognize that all of these terms can be* **limiting***, lacking in specificity, and/or carry potentially* **negative** *connotations. In speaking with Consumer Scholars about this, we have heard that most feel less concerned with the use of this terminology than they are with other ways in which they hope to be authentically included in this work. Because of this, we hope that our use of these terms will not detract from the other ideas about consumer engagement contained in this report.*

development, as well as chances to build connections with other organizations and consumers across the country working to improve care and services for communities with complex needs.

Through the generous support of the **Robert Wood Johnson Foundation**, the Coalition expanded the role of the National Consumer Scholars beginning with the 2019-2020 cohort. In addition to supporting Consumer Scholars' attendance and participation in two annual conferences, teams of Consumers Scholars were paired with staff across several departments within the Camden Coalition. These teams collaborated on projects including: developing technical assistance content, leading virtual learning sessions, authoring blog posts, participating in the **working group** that developed the **complex care core competencies**, and co-designing *Amplify: A consumer voices bureau*. The Consumer Scholars listed as authors on this report elected to co-lead a research project to explore current consumer engagement practices and opportunities to strengthen partnerships between consumers and organizations that provide health and social services.

Methods

The research team, comprised of three Consumer Scholars (Stephanie Burdick, Olivia Richard, and Suzette Shaw) along with two Camden Coalition staff (Danielle Hodges, a Program Manager of Data and Quality Improvement and Evelyne Kane, a Program Manager of Community Engagement) began their work together in November 2019. The team met several times over the following months to collectively discuss the goal and timeline of the project, choose a research topic, and agree on research questions and methodology.

Based on the many personal experiences — both positive and negative — that they have had as consumer advocates and advisers, the Consumer Scholar team members suggested exploring what factors make consumer engagement more meaningful and more likely to occur. The team's hope was that their findings could be used to strengthen consumer engagement practices and improve consumers' experiences.

The team decided to create and disseminate two surveys[2] aimed at illuminating the varying perspectives of those doing consumer engagement work: one version collected the experiences of consumers ("consumer survey"), and the other collected the experiences of the staff of health and social service organizations who presently or previously partnered with consumers in their work ("staff/provider survey"). The survey questions, a mix of both multiple-choice and open-ended questions, were written collaboratively by team members. Each survey collected information including: demographic information of the respondent, the type of consumer engagement activities they or their organization had taken part in, ways in which consumers were connected to/recruited for projects/events, experiences with receiving/offering compensation, issues of accessibility, and barriers they had experienced in this work.

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[2] See Appendix A & B

For ease of dissemination, particularly during the COVID-19 pandemic, the surveys were built into an online survey collection tool. The research team participants sent the survey links by email and text to contacts within their professional and personal networks. Survey responses were collected from May to August 2020. In total, our consumer survey received fifteen responses, and our staff survey received seventeen.

Summary of major themes

Many models of consumer engagement

Both versions of the survey asked respondents about the types of consumer engagement activities they had experience with (i.e., the "consumer survey" asked respondents what types of activities they had participated in, while the "staff/provider survey" asked respondents what type of activities they/their organization had engaged consumers in). Across both surveys, respondents reported experience with a wide range of different consumer engagement activities, with the most common activity being inviting consumers to share their personal stories and lived experiences. Other common activities included:

- Having consumers participate in a conference workshop or panel presentation,
- Engaging consumers in focus groups or interviews, and
- Consumer advocacy work such as speaking with elected officials, consumers attending rallies or doing community organizing work.

Somewhat less common activities included Community Advisory Board participation and working with consumers in the creation or review of reports, program plans, and/or community outreach materials.

It is encouraging to see a wide variety of consumer engagement experiences reported by both consumers and staff/provider respondents. A common concern raised by our Consumer Scholars is that too often they are asked to share their personal stories — particularly those that highlight the "problems" they have experienced — but are not invited to participate in other solution-oriented work, which can contribute to a sense of **tokenism.** At the Camden Coalition, we wanted to partner with Consumer Scholars on a variety of different projects not only to strengthen our own work through the inclusion of consumer voices, but also to pilot various models of consumer engagement work that we believe could be replicated by other organizations.

Building mutually beneficial partnerships

The consumer survey asked respondents to report the factor(s) that most influenced their decision to participate in consumer engagement work. The most common reason given was "opportunities to connect with other individuals with lived experiences." The next most common reasons were "to improve my understanding of the medical and social barrier to quality healthcare" and "for my own personal and professional development."

To us, these results highlight the importance of building partnerships with consumers that are truly *mutually* beneficial by taking time to understand and address the needs, goals, and interests of consumer participants. Organizations should not only devote time to considering how they hope consumer engagement will benefit their program or event, but should also consider how consumer participants will benefit. While providing compensation can be one means of supporting consumer involvement, it is often not the only benefit from participation that consumers are interested in. Rather, organizations that intentionally build relationships with consumers and seek to understand their personal interests and goals may find additional opportunities to give back through efforts such as mentorship, professional development, and networking opportunities. These activities can also be helpful in terms of recruiting and retaining consumer participants.

An important theme that surfaced across multiple questions was consumers' perception that too often, few changes were made as a result of their input and work. Comments to this effect included:

> *"[It's] exhausting to see little or no change in health outcomes - long-lasting epidemics and poor health outcomes for Americans who are Black, Brown and/or poor."*

> *"No changes for all the effort, time, resources, and energy I expended when asked to participate."*

> *"The objective is for change and to better the circumstances and welfare of my people at risk, but those changes have been slow to occur."*

In reviewing survey results with the Consumer Scholar team members, they validated these experiences and expressed that too often consumers experience the frustration of not seeing outcomes from their efforts. This happens for a variety of reasons such as:

- Organizations asking for consumer feedback and input in areas where they do not have direct ability or intentions to make a change (e.g., collecting community perspectives on behavioral health access for informational purposes, not because the organization can, intends, or is able to use these perspectives to directly improve access);
- Organizations asking for consumer feedback and input, without a clear plan or intention for if and how feedback will be used (e.g., a grant requires an agency to collect client satisfaction surveys, so the organization does this to meet the requirement, but not with the intention to act on this data);
- An organization seeks community input to inform their position, but does not have direct control over whether community input is incorporated by decision-makers (e.g., an organization seeks community input on the site of a new community health center and promotes their preferences, but ultimately the decision lies with elected officials or other external stakeholder groups);
- An organization does not clearly communicate to consumers how feedback will or will not be used at the onset of a project (e.g., consumers participate in a focus group but are not explicitly informed about the reason the organization is seeking their feedback, or if and how their feedback will be used to make improvements); or

- An organization does use consumer input to make improvements, but does not close the loop with consumers who contributed to the project to let them know how their feedback was used.

These examples describe some — but not all — of the ways in which consumers may end up feeling that their work and contributions were of no effect. This may discourage them from future participation with that organization, or decrease the likelihood that they continue in consumer engagement work in general.

The consumer survey also collected responses to the question "Overall, how satisfied are you with your experience participating in consumer engagement activities?" Fourteen out of seventeen respondents (82%) indicated that they were either "satisfied" or "very satisfied." The Consumer Scholar team members all found this result surprising, stating that in their experiences, many consumers, including themselves, have had negative experiences in consumer engagement work. In interpreting this result, they suggest that consumers that had too many negative experiences were likely to have "burned out" or stopped participating altogether and may therefore have been underrepresented in survey results. The Consumer Scholars also suggested that many consumers may simply have low expectations, or as one of the Scholars put it: "[consumers] are used to having so little, they tend to be much more grateful and may not expect or ask for more." While disheartening, this insight is important when interpreting "satisfaction" feedback (in engagement as well as service delivery) from members of communities that have long histories of being marginalized and under-resourced.

To foster robust consumer engagement, it is important for organizations to take steps to avoid consumer frustration and burn-out, including:

- Only seeking feedback when there is an ability to respond to it. Being responsive to consumers does not mean your organization must do exactly what they advise. Rather, it is important to clearly communicate why their input was not integrated, or clearly communicate in advance if feedback is being sought for purely informational purposes.
- Setting expectations for whether or not the organization that is seeking feedback has direct ability to make changes. For instance, an organization may be advocating for change, but the decision may lie in the hands of policymakers that the organization cannot exact control over.
- Closing the loop with consumers — regardless of the outcome. When changes are made as a result of consumer input, it is essential that organizations share this back with participants so they are aware of the impact of their work. However, there will be many times that changes are not enacted based on consumer input. In these instances, organizations may understandably feel hesitant to let consumers know the outcome, but closing the loop still remains essential. Consumers should be informed of the outcome, even when it is not favorable or aligned with their preferences. These discussions can include educational components where organization staff discuss the "whys" of slow or no change, including diverse stakeholder opinions or the iterative nature of policy change.

Overcoming barriers to engagement

Both versions of the survey included questions about potential barriers to consumer engagement. The staff/provider survey asked, "Have you ever experienced barriers in any of the following areas when attempting to engage consumers in your work?" 79% of respondents reported one or more barriers with the most common barriers being: "recruiting consumers to participate," and "identifying consumers with the skills and experience needed to participate in a given project or event."

While these challenges are common, there are a variety of **resources** available on consumer recruitment, as well as several organizations nationally that operate consumer speakers bureaus (including the Camden Coalition's consumer voices bureau, *Amplify*), that exist to facilitate these connections.

Despite the availability of resources to support consumer recruitment, the issue of representation — especially among complex care sub-populations (such as individuals living in long-term care facilities, individuals who are home-bound, individuals experiencing incarceration, etc.) — will likely remain an ongoing challenge. While there is no simple solution to the challenges of recruitment and representation, organizations can improve their community connections in several ways, including:

- Intentionally fostering mutually beneficial relationships with consumers based on an understanding of consumers' motivations, interests, and personal aims for involvement;
- Investing time into building authentic relationships with consumers, rather than transactional exchanges;
- Employing the recommendations listed above to reduce the likelihood of burn-out and ensuring consumers are made aware of the outcome of their work; and
- Understanding and addressing the root of potential community mistrust and engaging in **trust-building** activities with the community at large.

In many ways, the issue of identifying consumers with the right skills and experience needed for a given project is also a challenge of recruitment. Systemic racism and socio-economic inequalities have resulted in the unavoidable fact that certain communities have less access to the educational resources and experiences that are expected in many traditional professional roles and settings. While certainly, there are members of any community that already possess the skills and knowledge needed to participate in system- or policy-level work, it is unlikely that truly representative consumer engagement can be achieved without some commitment from organizations to provide training, mentoring, and other supports to build consumers' skills and knowledge in particular areas of work.

Much like the process for hiring a new employee, organizations will benefit from spending time prior to a project involving consumers mapping out what skills, knowledge and experience — in addition to lived experiences — are required for someone to successfully participate in the event or project being planned. Once these required competencies are identified, organizations must determine what their capacity is to support individuals in developing these competencies, with the understanding that skill- and knowledge-building are often iterative and long-term efforts. An investment in training, mentoring, and development (for both consumer partners and paid staff members) is an important

component of furthering equity and inclusion, and combating the detrimental impacts of long-standing racial and socio-economic disparities.

In the consumer survey, we asked several questions related to potential barriers to participation including: "Has your health ever impacted your willingness or ability to participate in consumer engagement activities?" To this question, 64% of respondents reported that their health had impacted their willingness or ability to participate. While perhaps unsurprising, this result highlights an important challenge of engaging with consumers with complex health and social needs. By definition, complex care consumers are likely to face health-related barriers to engagement. To support representative engagement across complex care populations, it is important for organizations to understand how health can impact an individual's ability to participate and ensure that projects and events — to the fullest extent possible — support the participation of people with diverse needs and health challenges. Considerations such as **trauma-informed** practices, accomodations for people living with disabilities, and flexibility in timelines and expectations can all aid in the ability of people with complex health and social needs to participate in events and projects.

In addition to health-related barriers, the consumer survey also asked questions about the common barriers of transportation and access to technology: "Have you ever needed help obtaining transportation to any consumer engagement events or activities?" and "Have you ever needed help accessing or using technology in order to participate in an online consumer engagement activity?" 76% of respondents reported that they had needed assistance with transportation and 52% of respondents reported that they had needed help accessing technology. Those who indicated a need in these areas were asked follow-up questions about whether they had requested assistance with accessing these resources, and if they had received assistance as requested. In both categories, nearly 78% of respondents did receive assistance accessing these resources when they requested it from organizations. While encouraging to see that the majority of consumers received assistance, there were still some consumers who reported that this was not the case. In considering ways to improve consumer engagement, and particularly ways to ensure representation from marginalized and under-resourced populations, organizations should take time to consider what resources and/or accommodations may facilitate participation and plan to be able to address these needs.

Limitations

While we believe that our survey results reveal some important considerations for building mutually beneficial partnerships between consumers and complex care organizations, we also acknowledge limitations to our findings. Most importantly, both surveys received relatively few responses (our consumer survey received 15 responses, and our staff/provider survey received 17). Distribution of the surveys was limited to just the personal and professional networks of the members of the research team and did not include any widespread distribution through email listservs or social media. Fortunately, it remains possible to continue distributing the survey to wider audiences in

the future in order to obtain additional responses and to understand if these initial results are representative of the experience of the wider community.

We also acknowledge the impact of selection bias on these results. Our online survey — available only in English — would most likely exclude both respondents who did not have access to or comfort using the internet and those who do not speak English. As the Consumer Scholar members of the research team suggested, it is also possible that individuals who had too many negative experiences with consumer engagement work may have been less likely to complete the survey due to "burn-out" and/or a sense that their input would not result in any meaningful changes. In addition to these groups that we can expect were underrepresented, we also are aware that there are always many other voices that are missing from the conversation as a result of limited time and energy to participate as well as health challenges that disproportionately impact many communities, notably Black, Indigenous, and communities of color.

Summary of findings

In summary, we believe the findings from these surveys elucidate several important considerations for how organizations can and should build authentic and mutually-beneficial partnerships with their consumer stakeholders, including:

- Involving consumers early and often through the process of program design, implementation, and evaluation improves complex care programs ability to truly understand and meet the needs of the consumers they serve.
- In addition to inviting consumers to share their personal experiences through storytelling, organizations can and should engage consumers in solution-oriented work through focus groups, feedback surveys, consumer advisory boards, and consumer participation in work groups, conferences, and advocacy campaigns.
- In terms of recruitment and retention of consumer participants, it is important for organizations to build relationships with their consumer participants and to understand and address their motivations for participation.
- Too often consumers feel that their work and contributions have not made a difference. To avoid this, organizations should clearly set expectations about the purpose and goals of seeking consumer input, and always close the loop with consumer participants to let them know the outcome of their work. This is important even when consumer input did not result in changes being made.
- Organizations must dedicate time and resources to overcome barriers to consumer participation, particularly to ensure representation of consumers from marginalized and under-resourced communities. This includes providing accommodations like transportation and technology access, employing a trauma-informed approach to consumer engagement work, dedicating staff time to support consumers in their work, building trust with communities, and compensating consumers fairly for their time and effort.

Conclusion

Through our work with Consumer Scholars over the past eighteen months, we learned many valuable lessons about the opportunities — as well as some challenges — inherent in partnering with people who bring diverse experiences and skill sets to the table. In the course of this research project, we found that Consumer Scholars brought particularly valuable contributions to the process of refining the consumer survey as well as providing context to survey results. Consumer Scholars were able to consider survey language and questions from the lens of desired respondents and, in this way, could advise on the best phrasing and framing to ensure questions would be clear and easily understood, much in the same way that community health workers are able to provide cross-cultural "translation" to improve communication between patients and providers. As organizations craft messages and materials intended for consumers, it can be extremely valuable to receive feedback on these messages and materials from consumers themselves. Secondly, in reviewing the survey results, the Consumer Scholars were able to offer insights from their own experiences that provided important context to findings, and share hypotheses for surprising results that may not have been clear otherwise. As organizations review the results of evaluation efforts, engaging consumers can be important when analyzing and interpreting results and findings, as well as when using results to identify opportunities for improvement efforts.

Overall, we believe one important finding — from the results of the survey as well as the experience of the project team — is that there are many **models** of consumer engagement and many **resources** available to support organizations who wish to deepen and diversify their partnerships with consumers. During the development phase of **Amplify**, we worked with our consumer design team on the creation of **Value Statements** that we believe reflect many of the lessons we at the Camden Coalition have learned from working with our Consumer Scholars over the past several years. We hope the findings from this research project as well as the project model itself serve as inspiration for organizations to continue to devote time and effort to the often challenging — but always worthwhile — work of creating authentic and mutually beneficial partnerships with the consumers they serve.

Contributions and acknowledgments

Appendix A: Consumer survey

Many healthcare and social service organizations believe that it is important to work with community members, who are often called "consumers," "patients," or "people with lived experience." Similarly, many people from the community ("consumers") would like to help to improve how health care and social services are provided to their community. We are giving this survey out to to better understand how organizations and consumers can work together. When answering the questions in this survey, please think about any "consumer engagement" work that you have experience doing.

We use the term "consumer engagement" to describe the many activities that community members do to support the work of health and social service organizations, including (but not limited to) sharing personal stories, sitting on Advisory Boards, attending conferences, advocating, giving speeches or presentations, or doing consulting or advising work with health or social service agencies.

Your participation is voluntary and we won't be able to connect any of your answers back to you.

If you have any questions regarding this survey or the research project, please contact Danielle Hodges at dhodges@camdenhealth.org.

Checking "Agree" below means:
▪ You have read and understand the above information
▪ You are 18 years of age or older
▪ You consent to complete the survey

___ Agree

___ Disagree

1. **What level of experience have you had participating in consumer engagement activities as a person with lived experience (e.g. focus groups, storytelling, speaking on panels, research)?**
   - ☐ I have not been part of any consumer engagement activities.
   - ☐ I have occasionally participated in consumer engagement activities.
   - ☐ I have often participated in consumer engagement activities.

2. **Please select which reasons had the most influence on your decision to participate in a consumer engagement activity. [Check all that apply]**
   - ☐ Improving my understanding of the medical or social barriers to quality healthcare
   - ☐ Exposure to policy strategies for transforming the American healthcare system
   - ☐ Opportunities to connect with other individuals with lived experience
   - ☐ Personal or professional development
   - ☐ Reputation of the sponsoring agency/healthcare organization
   - ☐ A desire to help others or give back to my community
   - ☐ A personal experience I had with my own circumstances motivated me to get involved
   - ☐ Other (please specify):_____

3. **Which of the following types of consumer engagement activities have you been involved in? [Check all that apply]**
   - ☐ Participated in focus groups, informational interviews, or filled out feedback surveys
   - ☐ Shared my personal story in front of an audience, or had my written story shared with the public
   - ☐ Led a workshop or other learning/training session
   - ☐ Attended a conference
   - ☐ Participated in public speaking events such as giving a speech, presentation, or speaking on a panel
   - ☐ Been a member of a Community Advisory Board or Advisory Committee
   - ☐ Worked with an organization to review materials such as reports, program materials, marketing materials, or outreach materials
   - ☐ Participated in advocacy work such as speaking to elected officials, attending or organizing rallies, or doing community mobilizing work
   - ☐ Represented the consumer perspective on steering committees or a working group
   - ☐ Other (please specify):_____

4. **Which of the following BEST applies to how you first heard about the consumer engagement activities you've been involved in?**
   - ☐ Social media
   - ☐ Website (not social media)
   - ☐ Staff person at an agency that provided services to me told me about the opportunity and asked me to participate

☐ Another consumer told me about the opportunity
☐ I heard about the opportunity on the radio/TV or in the newspaper
☐ Other (please specify): _____

5. **Has your health ever impacted your willingness or ability to participate in consumer engagement activities?**
   ☐ Yes (please explain)_____
   ☐ No

6. **Have you ever been offered money, or other forms of compensation to participate in consumer engagement activities?**
   ☐ Yes
   ☐ No

7. **Have you needed help obtaining transportation to any consumer engagement events or activities?**
   ☐ Yes
   ☐ No

8. **(If previous answer was YES) Did you ask for help with transportation from the organization, agency or other professional organizing the event/project?**
   ☐ Yes
   ☐ No

9. **(If previous answer was YES) Did you receive transportation services?**
   ☐ Yes
   ☐ No

10. **Have you ever needed help accessing or using technology in order to participate in an online consumer engagement activity (e.g. webinar, survey, etc.)?**
    ☐ Yes
    ☐ No

11. **(If previous answer was YES) Did you ask for help accessing or using technology from the organization, agency or other professional organizing the event/project?**
    ☐ Yes
    ☐ No

12. **(If previous answer was YES) Did you receive help to access or use necessary technology?**
    ☐ Yes
    ☐ No

13. **Overall, how satisfied are you with your experience participating in consumer engagement activities?**
   - ☐ Very satisfied
   - ☐ Satisfied
   - ☐ Neither satisfied nor dissatisfied
   - ☐ Dissatisfied
   - ☐ Very dissatisfied

14. **(for those who indicated dissatisfaction to previous question) Please explain why you feel dissatisfied:** _____

15. **Which state are you currently located in?**_____

16. **How old are you?**
   - ☐ 30 years of age or younger
   - ☐ Between 31 and 50 years of age
   - ☐ Between 51 and 65 years of age
   - ☐ 66 years of age or older
   - ☐ Prefer not to say

17. **Which of the following best describes your gender?**
   - ☐ Female
   - ☐ Male
   - ☐ TransFemale
   - ☐ TransMale
   - ☐ Other (please specify)
   - ☐ Prefer not to say

18. **Which of the following best represents your racial or ethnic identity? [Check all that apply]**
   - ☐ Asian American
   - ☐ Black or African American
   - ☐ Hispanic, Latino/a, or Spanish origin
   - ☐ Native American or Alaskan Native
   - ☐ Native Hawaiian or Pacific Islander
   - ☐ White or Euro-American
   - ☐ Other (please specify) _____
   - ☐ Prefer not to answer

19. **Please share any additional feedback you may have regarding your consumer engagement experience.**

20. **If you would like to be entered into a drawing to win one of five $10 gift cards, please provide this contact information. If you do not wish to be entered into the drawing you can skip this question.**

     Name:_____

     Email address:_____

     Phone number:_____

Appendix B: Staff/Provider survey

Many healthcare and social service organizations believe that it is important to work with community members, who are often referred to as "consumers," "patients," or "people with lived experience." Similarly, many people from the community would like to work with organizations to improve the services and care that they and other consumers receive. We are administering this survey to better understand the current "consumer engagement" practices of various healthcare and social service organizations.

We use the term "consumer engagement" to describe the many activities that community members do to support the work of health and social service organizations, including (but not limited to) sharing their personal stories, sitting on Advisory Boards, attending conferences, advocating, giving speeches or presentations, or doing consulting or advising work with health or social service agencies.

Your participation is voluntary. Your responses to this survey will only be reported in aggregate form; no one will be able to connect you to any of the results.

If you have any questions regarding this survey or the research project, please contact Danielle Hodges at dhodges@camdenhealth.org.

Checking Agree below means:
- ☐ You have read and understand the above information
- ☐ You are 18 years of age or older
- ☐ You consent to complete the survey

___ Agree

___ Disagree

1. **What setting/industry segment BEST describes your work? [Check all that apply]**
   - ☐ Hospitals (public and private)
   - ☐ Nursing and residential care facilities
   - ☐ Outpatient care centers
   - ☐ Home healthcare services
   - ☐ Mental/behavioral health provider/services
   - ☐ Ambulatory healthcare services
   - ☐ Social service agency
   - ☐ University/Academic institution
   - ☐ Community-based organization
   - ☐ Other (please specify):_____

2. **Which state is your primary work located in?_____**

3. **How often does your organization/agency engage consumers in your projects/work/ events? (e.g. focus groups, storytelling events, panels, research)?**
   - ☐ Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Never

4. **(If they select "Never" for the previous question) Is your organization interested in engaging consumers in your projects/work/events?**
   - ☐ Yes
   - ☐ No
   - ☐ Unsure
   (If they select "yes", "no" or "unsure" they will skip to question #11 and then exit the survey.)

5. **What role have you played relative to engaging consumers in your organization's work [Check all that apply]?**
   - ☐ I am in leadership and shape organizational priorities
   - ☐ I help to identify and recruit consumer participants for projects/events.
   - ☐ I lead projects/events that include consumer participants.
   - ☐ I work directly with consumers to provide training/support to enable them to participate in projects/events.
   - ☐ I play a supportive role in projects/events that include consumer participants.
   - ☐ Other (please specify):_____

6. **Which of the following examples BEST describes how you have worked with consumers to inform your work? [Check all that apply]**
    - ☐ Used consumers' first-hand experience/personal stories to inform and support our ***program development***
    - ☐ Used consumers' first-hand experience/personal stories to inform and support our ***policy/ advocacy work***
    - ☐ Used consumers' first-hand experience/personal stories to inform and support our ***fundraising***
    - ☐ Conducted focus groups, informational interviews, or administered feedback surveys to collect the perspectives of consumers
    - ☐ Lead a workshop or other learning/training session in partnership with a consumer(s)
    - ☐ Invited consumers to participate in public speaking events such as giving a speech, presentation, or speaking on a panel
    - ☐ Helped to organize Community Advisory Board or Advisory Committee meetings that included consumer participants
    - ☐ Asked consumers to review reports, program, marketing, or outreach materials
    - ☐ Invited consumers to speak to elected officials, attend or help organize rallies, or do community mobilizing work
    - ☐ Invited consumers to participate in steering committees or working groups
    - ☐ Other (please specify):_____

7. **Which of the following BEST applies to how you connect to/recruit individuals for the consumer engagement activities you've been involved in?**
    - ☐ Through social media
    - ☐ By inviting consumers who are current/previous clients or patients of my organization's care/service delivery efforts
    - ☐ Advertising opportunities on the radio/TV or in the newspaper
    - ☐ Conferences or other professional events
    - ☐ Through my personal or professional networks
    - ☐ Other, please explain: _____

8. **Please select the reason(s) that had the most influence on your decision to incorporate the consumer perspective into your work.**
    - ☐ Our funding source/grant required us to engage consumers in this work
    - ☐ Our organization has a specific mission/goal to routinely engage consumers in our work
    - ☐ We needed/saw value in having the unique perspectives consumers in this project/event
    - ☐ We recognize that consumer engagement is increasingly common and wanted to stay ahead of the curve
    - ☐ Some of our work/projects/events are specifically designed to be consumer-led
    - ☐ Other (please specify):_____

9. **Please indicate whether you have offered the following incentives or resources to individuals you have invited to participate in consumer engagement activities:**

- **Money or other forms of compensation**
  - ☐ Yes
  - ☐ No

- **Transportation to consumer engagement events or activities**
  - ☐ Yes
  - ☐ No

- **Assistance with accessing or using technology to participate in an online consumer engagement activity (e.g. webinar, survey, etc.)**
  - ☐ Yes
  - ☐ No

10. **Have you ever experienced any of the following barriers when attempting to engage consumers in your work? [Check all that apply]**
    - ☐ No, I have not experienced any barriers engaging consumers in my work
    - ☐ Faced challenges in identifying/recruiting consumers to participate
    - ☐ Faced challenges identifying/recruiting consumers with the right skills/experience needed to participate in a given project or event
    - ☐ Lacked adequate resources (staff time, funding, etc.) to support consumer engagement activities
    - ☐ Had negative experiences/did not find value in working with consumers in the past
    - ☐ Faced opposition to consumer engagement from my organization's leadership
    - ☐ Were not able to accommodate needs such as transportation, translation services, or childcare that consumer participants requested
    - ☐ Other (please specify):_____

11. **Please share any additional feedback you may have regarding consumer engagement.**

Camden Coalition
of Healthcare Providers

camdenhealth.org
P 856-365-9510
F 856-365-9520

The National Center
for Complex Health & Social Needs
An initiative of the Camden Coalition

nationalcomplex.care
P 856-365-9510 ext #2013

About the Camden Coalition

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of **complex care** by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our community-based programs deliver better care to the most vulnerable individuals **in Camden** and **regionally**.

The **National Center for Complex Health and Social Needs** (National Center), an initiative of the Camden Coalition, connects complex care practitioners with each other and supports the field with tools and resources that move complex care forward. The National Center's founding sponsors are the Atlantic Philanthropies, the Robert Wood Johnson Foundation, and AARP.