soda Cysters

Living with Cancer and Other Long Term Conditions

Lived Experience Consultation Summary Report

Soda & Cysters for Macmillan Cancer Support

MACMILLAN. CANCER SUPPORT

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Project Background

Context

Most people living with cancer - around 70% - are also living with at least one other long-term condition, whether that's a physical or mental health condition, a learning disability, frailty, chronic pain, or sensory impairment. People with Cancer and Other Long Term Conditions often face delayed diagnosis, less or different treatment, and decisions that don't reflect what matters most to them.

Macmillan Cancer Support's recent literature review found that people with Cancer and Other Long Term Conditions are:

- More likely to be diagnosed at a later stage when there are fewer treatment options available.
- Once diagnosed, more likely to receive delayed treatment, or treatment that differs from clinical guidance.
- Less likely to be involved in decision making about their treatment and care.

There is also evidence that shared-decision making (SDM) is associated with improved patient knowledge about treatment options and increased satisfaction with the overall care experience. This consultation set out to understand:

- Whether treatment decisions are aligned with what patients actually want
- What factors lead to worse outcomes for people with Cancer and Other Long Term Conditions
- How living with multiple conditions affects daily life - including living with pain and fatigue, and how it affects people's mental and physical wellbeing
- How shared decision making (SDM) could reduce unwarranted variation.

Purpose of this Report
This is a summary of a UK-wide lived experience consultation for Macmillan Cancer Support carried out by Soda and Cysters, exploring what it is like to live with Cancer alongside other Long Term Conditions. It draws on conversations with 65 people across England, Scotland, Wales and Northern Ireland - people living with cancer and other long term conditions, their carers and family members, and healthcare professionals.

Soda was selected by Macmillan Cancer Support as a partner to lead this work, alongside our delivery partner, Cysters. The project was rooted in design justice principles: shifting power to communities, recognising systemic inequities, and treating people with lived experience as experts.

This summary is for anyone interested in this work: people living with cancer and other long-term conditions, carers and families, healthcare professionals, charities, researchers and the wider public. A longer, internal version of this report was produced for Macmillan Cancer Support. Macmillan Cancer Support is also producing an insight report that will include our findings, which will be published on the charity's website.

Soda

Macmillan partnered with Soda to deliver this work.

Soda works with healthcare organisations to embed the insights of people with lived experience of disability, long term conditions and neurodivergence directly to the design of healthcare services and products. Our mission is to ensure that people with lived experience are recognised and engaged as experts in research, design, and innovation, focusing on ensuring care delivered is inclusive, accessible and equitable for all. We have previously worked with Macmillan's Impact Investment Fund and Participation Teams to co-design an approach with people with lived experience, ensuring their voices are centred in decision making, funding and design of solutions for cancer care and treatment.

Our work is rooted in design justice, shifting power dynamics, recognising systemic inequities, and ensuring underserved communities shape innovation. This means involving people with lived experience while addressing the structural barriers that limit representation, access and agency. Accessibility principles guide all aspects of delivery, from engagement formats to reporting, ensuring processes and outputs meet a wide range of human needs. We are trained in trauma informed engagement and facilitation.

Our team was founded with lived experience of disability and living with long term conditions at its core, and specifically prioritises delivery and engagement by teams of experts with lived experience. We have extensive expertise supporting commercial, public sector and charity organisations through engaging people with lived experience in participatory processes, including through research, consultation, design, testing and implementation of healthcare solutions.

Soda worked with our brilliant project partners, Cysters, to deliver this work.

Cysters

Cysters were brought in as project partners by Soda, drawing on long standing, trusted relationships within communities to support both recruitment and meaningful dissemination of this work.

Cysters is a grassroots, community led organisation working at the intersection of health inequalities striving for health justice by centering the most marginalised person. Founded to address gaps in care and systemic barriers faced by marginalised communities, Cysters centres the voices of those often excluded from research, policy and service design. Their work spans an array of conditions, with a strong focus on racial and social inequities in healthcare access and outcomes.

Cysters plays a critical role in enabling inclusive research by building trust where systems often cannot. Through deep community engagement, culturally competent approaches and lived experience leadership, they ensure that research reaches and reflects those most impacted. This includes supporting ethical and representative recruitment, creating safer spaces for participation, and ensuring findings are shared back with communities in accessible and meaningful ways. Cysters are trained in Mental Health First Aid, and trauma informed engagement.

Their approach is rooted in equity, co production and accountability to the communities they serve. By working with Cysters, organisations are able to move beyond tokenistic engagement towards research that is truly inclusive, intersectional and grounded in real lived experiences.

Research Topics

The consultation broadly focused on four thematic areas:

1. General experience managing Cancer and Other Long Term Conditions and the impact on daily life (how conditions interact, what it's like to manage multiple conditions);
2. Experience in clinical spaces (communication with healthcare professionals, understanding and knowledge of multiple conditions);
3. Support in community settings (support beyond hospital or GP settings, what works or could improve); and
4. Shared decision making (desire to be involved, what an ideal process would look like, and who would be involved).

Workshops and 1-1s with healthcare professionals explored a parallel set of questions, exploring: healthcare professionals' understanding and tools for supporting patients with Cancer and Other Long Term Conditions; communication and information sharing, both with patients and between healthcare professionals; and the barriers to, and ideal practice of, shared decision making.

Recruitment and who was involved

Recruitment was intentionally community-centred rather than extractive, shifting power and resources into the hands of communities themselves. It was facilitated through trusted, existing relationships and grassroots networks led by both Soda and Cysters, including community organisations, faith spaces, social media, WhatsApp groups, peer support networks, and partnerships with charities such as OUTpatients, Dementia UK, Alzheimer's Society and the UK Learning Disability Network.

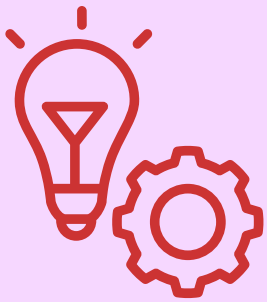
Participants represented people with cancer from across the UK; Black, Pakistani and Bangladeshi communities; Deaf and disabled people; people with learning disabilities, dementia, frailty, diabetes and other long-term conditions; LGBTQIA+ people; carers and family members; and healthcare workers. Most participants lived across several intersecting identities and conditions at once.

The consultation engaged people with long-term conditions according to the NHS's six major conditions and other common long-term conditions, as well as other self-declared conditions and disabilities.

- 65 people with lived experience of living with cancer alongside other long term conditions took part: 60% from England, 17% from Scotland, 16% from Wales and 7% from Northern Ireland
- Cancer types represented included Breast, Cervical, Colon, Endometrial, Leukaemia, Lung, Lymphoma, Prostate, Skin, and Thyroid Cancer.
- Long-term conditions and disabilities represented includedArthritis, Asthma, Bladder Retention, Chronic pain, Dementia, Diabetes, Dyslexia, Epilepsy, Fibromyalgia, Fibromuscular Displasia, Hearing Impairment, Heart Failure, Hypertension, Hypothyroidism, Chronic Kidney Disease, learning disabilities, Long COVID, Myalgic Encephalomyelitis, mental health, mental health due to side effects of cancer treatment, Migraine, Neuropathy, OCD/anxiety, Osteoarthritis, Parkinson's, Rheumatoid Arthritis, Spinal Scoliosis, Thrombocytopenia, Vasculitis, Visual Impairment.

All participants lived across an intersection of several of the above conditions and identities at once.

Definitions



For the purpose of this work, the following definitions were used:

Shared decision making: Shared decision making (SDM) is a collaborative process that involves a person and their healthcare professional working together to reach joint decisions about their care.

NICE has produced guidelines on shared decision making here.

Engagement Methods

Engagement was designed to be accessible, relational, and rooted in community spaces. We shared the research opportunity through community talks and attended local in person drop ins to meet people where they already are and build trust.

We chose not to deliver in person workshops, as the majority of participants had already signed up to online sessions. This approach supported safer spaces for open dialogue, particularly for those facing systemic barriers, stigma, or exclusion within traditional research settings. For people who preferred 1-1 settings, we set up 1-1 interviews.

Headline Findings

Experiences across all groups living with cancer and other long term conditions were resoundingly similar, regardless of population group, resulting in a clear set of cross-cutting findings across all thematic areas.

In every group, people felt living with Cancer and Other Long Term Conditions (COLTCs) was not considered holistically, that cancer diagnoses were delayed as a result of a dismissal of symptoms being attributed to a pre-existing condition. Once diagnosed, the impact of a long term condition on the presentation of cancer, and vice versa, were not considered. Where long term conditions or disability arose as a secondary effect of cancer treatment, these caused significant complications and effects on quality of life, and people did not feel they had support to manage secondary impacts further down the line.

Most participants did not have access to multidisciplinary teams that considered their cancer alongside their long term condition or disability, or shared decision making as an option. Where this was an option, it had a significant positive impact on clinical outcomes, as well as peoples' quality of life and confidence.

Primarily, people felt that the impact of treatment and care decisions on the quality of their daily life should hold importance alongside the clinical impact of cancer treatment.

A summary of headline findings by thematic area, with solutions directly offered by people during this consultation can be found in the table below.

General experience living with COLTCs

Challenges:

Mental and physical effects

- The mental and emotional strain of living with COLTCs is heavy and not addressed
- Managing COLTCs is overwhelming and exhausting, people with dementia and learning disabilities, specifically require specialised carer or family support
- Managing COLTCs is isolating

Effect on daily life

- Chronic fatigue is often an issue that presents across all cases and is unaddressed
- Impact on socio-economic factors, such as ability to work and support families are not addressed
- Non-professional carers do not feel equipped to support

Solutions:

Provide:

- Direct counselling and mental health support to address mental and emotional toll (free of cost) for people with Lived Experience and carers/ family members
- Peer-to-peer support, specific to population group and cancer type to reduce isolation
- Referral to pain management and fatigue management programmes
- Signposting to support beyond clinical settings for guidance on issues such as employment, benefits, and family care (this may be in the form of social prescribing, community health advocates, VCSE support)
- Training for non-professional carers and family members on supporting people with COLTCs, specific to disability/ access needs

Clinical experience with COLTCs

Challenges:

Treatment priorities

- Cancer treatment is often treated as the main priority over care for another LTC or disability
- Information is not always presented clearly in a way that illustrates the impact of a treatment decision on the quality of daily life
  - People feel the impact of a treatment decision on quality of life should be treated with importance alongside the clinical impact of treatment

Communication and information sharing

- Communication with Healthcare professionals feels rushed
- Communication with Healthcare professionals feels fragmented
- Communication with Healthcare professionals feels led by a power dynamic, there is a lack of open-ended communication
- Information is often not presented in plain language, or easy to understand accessible formats
- Having an advocate present is vital for people with additional needs, though not everyone has access to a carer or family member to do this

Treatment and medication

- The impact of cancer treatment and medication changes, or drug interactions are not always considered alongside treatment or medication used to treat LTCs
- Information about medication side effects is not always presented sufficiently for people to feel they are confident managing medication or decisions linked to medication
- The responsibility of who should present information about medication side effects is not clear amongst healthcare professionals
  - Where healthcare professionals are responsible for this (e.g. pharmacists), they do not feel they have sufficient time with people to present this information

Ongoing care after acute care

- Once cancer treatment is over, the secondary impacts of treatment, which may not present until months, or years, after are not addressed
- After acute/ urgent clinical treatment is complete, people feel they are left out of the system with no referral route to return to should secondary conditions or disability arise from cancer treatment

Solutions:

Treatment priorities

- Train healthcare professionals in person-centred engagement
- Train healthcare professionals to be equipped to ask questions and manage information about living with Cancer and Other Long Term Conditions
- Train healthcare professionals to ask open-ended questions such as **'what is important to you?' or 'what would you like to get out of your treatment and care?'**

Communication and information sharing

- Train healthcare professionals in communication methods that centre plain language, and accessible formats
- Produce easy read materials for information sharing, where these are already available, provide better signposting
- Provide an advocate specifically for people who have additional access needs

Treatment and medication

- Develop or signpost to guidance specific to managing multiple medications with COLTCs for patients and healthcare professionals
- Integrate more time with pharmacists to discuss medication protocols and side effects
  - Develop or signpost to guidance specific to managing multiple medications with COLTCs

Ongoing care after acute care

- Provide support through a direct line for advisory and signposting in cases that are specific to the secondary impact of cancer treatment on existing LTCs or developing additional LTCs

Community support for people with COLTCs

Challenges:

- Community support was not present/ offered in any formal way for many people
- Families and carers are often the main source of support in community settings, and where untrained, do not feel equipped to support individuals with very specific needs

Opportunities

- Faith and community groups were a key source of community support, where they were relevant and available
- Occupational Therapy support was considered invaluable where it was available
- Community Nurse at home, or in-neighbourhood support was considered invaluable where it was available
- Peer support, was considered invaluable where it was available

Solutions:

- Provide training for carers and family members who are not specifically qualified as carers to support individuals with COLTCs, specifically learning disabilities and dementia
- Provide better signposting to peer support groups that already exist for carers
- Provide tailored peer support groups for carers
- Build better support for, and signposting to, Occupational Therapy teams who work in-situ
- Build better support for, and signposting to, Community Nurses

“The Macmillan online forum has been invaluable - it’s been outstanding.”

Shared Decision Making

Desire to be involved

Participants overwhelmingly wanted to be involved in decisions about their care, linking involvement to increased confidence, a sense of control, and reduced anxiety. This desire was rooted in the belief that individuals understand their own day to day needs, symptoms, and priorities better than clinicians, particularly when managing multiple conditions. Involvement was also seen as a way to ensure care aligned with what mattered most to them, including quality of life, and to avoid rushed or poorly understood decisions.

Preferences for involvement were not uniform. Some participants preferred less involvement in urgent or high risk situations such as lifesaving surgery, or where they had strong trust in clinical expertise. Others chose to delegate decisions to carers or family members, while some explicitly did not want carers to have final decision making authority. Across groups, there was a clear need for flexible approaches that allow individuals to vary their level of involvement depending on context, capacity, and personal preference.

What are the Barriers to Genuine SDM?

Despite the strong desire to be involved, shared decision making was often described as inconsistent or conceptual, rather than practical.

System level barriers played a significant role. Fragmentation across healthcare services, including a lack of shared records and poor communication between professionals, meant that no single clinician had a full picture of a person’s situation. This limited the ability to have informed, holistic discussions and often left patients acting as coordinators of their own care. The absence or invisibility of multidisciplinary teams further restricted meaningful involvement, with decisions frequently made within silos and focused on cancer alone rather than its interaction with other conditions. The lack of a clear care coordinator or advocate reduced patients’ ability to engage, particularly for those with complex or additional needs. Where an occupational therapist was present in an advocacy role, appointment flow and decision making was improved significantly.

Communication barriers were also prominent. Many participants described interactions as rushed, unclear, or one directional, with treatment plans presented as fixed rather than open to discussion. There was limited use of open questions about what mattered to the patient, and some participants felt unable to challenge clinicians due to power dynamics or cultural norms. Complex medical language and inaccessible information made it harder to understand options, particularly for those with learning disabilities or cognitive impairments.

Power imbalance between Healthcare Professionals, meaning more senior healthcare professionals' views are taken in precedence over roles that may work more often and closely with a patient. Power imbalance also exists in communication methods between Healthcare Professionals and patients, making patients feel they have not been consulted in decisions.

Practical and emotional factors further constrained involvement. Participants often felt overwhelmed, especially when presented with complex information or statistics, reducing their ability to engage in decisions. Time pressure was a recurring issue, with people feeling forced to make decisions during appointments without adequate opportunity to reflect or seek support.

Carer involvement limited by practical barriers, such as not being informed about appointments or lacking access to relevant patient record information.

Differing priorities meant there was a consistent lack of focus on quality of life, with decisions framed primarily around clinical outcomes rather than how treatments would affect daily living

> **"I haven't had a choice in what medication I'm on. I've just been told that [this is] the rest of your life... this is my life, and you just kind of dictated to me."**

What Ideal Decision Making Looks Like

Participants described **ideal decision making as a collaborative, ongoing process** rather than a one off event. Central to this was coordinated care, with regular joint discussions involving a full multidisciplinary team so that all conditions and their interactions could be considered together. There was a strong emphasis on valuing the input of carers and family members where appropriate, while still centring the voice of the individual. Having a professional who understood the whole case and could guide conversations across services was seen as critical to improving continuity and trust.

Clear, accessible, and personalised communication was essential. Participants wanted full explanations of options, including risks, side effects, and impacts on quality of life, presented in plain language and accessible formats. They valued being explicitly invited into conversations and asked about their priorities, with the ability to adjust their level of involvement over time.

Time and flexibility were also key. People wanted space to ask questions, reflect, and return to discussions rather than being pressured into immediate decisions. Decision making was seen as something that should evolve as circumstances, preferences, and health needs change.

Participants also highlighted the importance of **practical tools to support shared decision making**, including shared electronic records, symptom journals, and decision aids to help clarify options and trade offs.

Finally, **ongoing access to support was critical**, with participants wanting clear ways to contact healthcare professionals after appointments to ask follow up questions or raise concerns. Overall, ideal shared decision making was characterised by coordination, clarity, flexibility, and genuine partnership between individuals, carers, and professionals.

Overview of Findings by Group

For the purposes of this summary, a brief overview of headline findings, and linked recommednations from the research with each population group can be found below. We hosted workshops specific to each population group, to dig deeper into lived experiences of each group respectively. If you would like to find out more about detailed population group findings, please contact Soda directly.

People with learning disabilities alongside cancer

- The role of a trained carer is vital in coordinating cancer care alongside Learning Disabilities - in most cases, carers supporting individuals with cancer are not trained.
  - There is an opportunity to develop tailored training that supports carers of people with Learning Disabilties and cancer.
- Information in clinical contexts is often not presented in an accessible way that allows a person to be involved in conversations about their own care. Easy-read information is not necessarily shared, or is only in one format.
  - Design information, communication and decision-making aids that come in a variety of accessible formats.
  - Train healthcare professionals in accessible and inclusive language and communication practices.
- Tools that support communication and tracking between Healthcare professionals, someone with a Learning Disability and carers were seen as useful.
  - Develop accessible aids for symptom tracking, and/or signpost to accessible digital tools that support these processes.

People with dementia alongside cancer

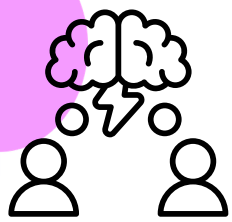
- The role of a trained carer to supporting and coordinating cancer care alongside dementia, is vital. Carers felt they didn't have access to professional training that was tailored to them.
  - Develop tailored training that supports carers of people with dementia and cancer.
- Clinical environments and travel to hospital is particularly complex due to needs to stay in familiar environments and recognise familiar faces - different staff and locations on top of managing dementia, can cause difficulty in management.
  - Provide in-community care for people with dementia, so people can be met in their own home.
  - Ensure continuity in Healthcare professionals to reduce confusion and possibility of non-adherence.
- Those who had access to an advocate or care coordinator role, often through community nurse roles or Occupational Therapy roles, benefitted immensely.
- In decision-making settings, while the role of a carer or family member is vital, the person with dementia is often overlooked. In many cases, with the right communication methods and tools, they can and should have a role in decisions about treatment and care.

Overview of Findings by Group

Carers and family members

- In many cases, people with long term conditions who develop cancer, or people who have cancer that causes the development of long term conditions, rely on family members or untrained carers to support them.
- Carers and family members feel unequipped to deal with both Cancer and Other Long Term Conditions.
- Carers felt they would benefit from:
  - Training that is unique to dealing with particular cancer needs, alongside long term conditions.
  - Peer-to-peer support from other carers or family members dealing with the same thing
- Carers felt they did not have sufficient access to health information that allowed them to act as a key coordinator and decision-maker alongside the person they care for.
- Where available, they benefitted from digital tools that enabled them to access and manage this information

> "It becomes overwhelming because I'm not professionally trained to handle this."



Healthcare professionals

- Healthcare professionals reported feeling equipped to manage cancer care, but less equipped to understand complexities of treatment of long term conditions interacting with cancer care. This reflected the experience of people with lived experience.
- Medication interactions were highlighted as a key area where Healthcare professionals, especially pharmacists, felt ill-equipped to deliver tailored information that is vital to treatment/ management working effectively in complex cases that involve long term conditions and other medication interactions.
- Healthcare professionals would like to be able to carefully consider the impact of decisions on quality of life, but do not feel they have the time, resources or tools to do this.
- Tailored support that addresses overall impact of long term conditions and cancer, as well as impact on quality of life, work best:
  - **Case study**: The Christie's clinic, specifically designed for people with cancer and dementia, where care is tailored, and Occupational Therapy act as coordinators and advocators for every patient.
  - **Case study**: Bath Centre for Fatigue Services providing wrap around support for the impact of cancer and long term condition related fatigue on daily life.

Overview of Findings by Group

Black, Pakistani and Bangladeshi communities

- Cancer diagnoses are sometimes softened, withheld, or not fully explained within families and communities which patients believe is due to culture, and feeling uncomfortable about talking about cancer in these groups.
- Even while receiving cancer treatment, many women remain expected to continue caregiving and uphold family responsibilities, shaped by cultural expectations.
- Some participants do not have the words to describe symptoms, especially for stigmatised body parts or conditions, this was particularly around breast cancer. Taboos around cancers (especially breast, prostate, reproductive health) limit open conversations and early intervention.
- Mental health in the context of living with cancer and long term conditions was often left unspoken, with language itself acting as a barrier. For example, in Punjabi, the closest translation is “crazy”, which reinforces stigma and discourages open conversation.
- Faith groups, charities, and peer networks are more trusted, culturally responsive, and accessible than formal services, with a heavy reliance on this.

“I lean on my family... and I've got a phenomenal medical team that I let them do the worrying and I do the healing.”

“We don't have a term or a phrase for breast, which amazed me, we have one for chest. So is it any wonder that we can't talk about it.”

LGBTQ+ community

- Across these groups, family, partners and friends were often central to navigating care. However, participants highlighted that not everyone has access to safe or affirming relationships, and relying on others can bring feelings of guilt, pressure, and fear of being a burden.
- LGBTQ+ individuals without family support have to rely on chosen family, peer networks, and community spaces instead of traditional family structures.
- Identity affirming peer spaces are often the only places where patients feel fully seen and understood.
- Patients describe their lives as dominated by healthcare systems, appointments, and symptom management, leaving little space for identity, joy, or normality.
- Patients repeatedly emphasised the fear of “disappearing” within the system.

“In the breast care world, your peers become like your breasties.”

Participant Quotes

"I would say some of my best support were other women going through or who had been through [the same thing as me]."

"I wasn't aware the late effects would be so profound, pelvic radiation disease, chronic, fluctuating nerve pain, limited mobility, a whole host of things."

"I have to explain my whole medical history to every new doctor or nurse. You see, it's really exhausting, repeating myself, and sometimes I worry that they won't see the whole picture. Diabetes doesn't just stop because you have cancer."

"Being human, but also living with long term illness, disability and cancer, is balancing being heard and not disappearing"

"It was worrying at the time is that the drugs that they were giving me to cure the Lymphoma can actually increase your risk of getting leukaemia."

"When you decline a certain treatment, clinicians are not very good at listening to why you don't feel it's right for you, and acknowledging that is a valuable decision. I think they find it an affront to their expertise, whereas you know you are the expert on you"

"Even after the healthcare professional has given their own opinion, you too should have the upper hand, the power to say yes or to say no."

"I lean on my family... and I've got a phenomenal medical team that I let them do the worrying and I do the healing."

What happens next

This consultation is the start of a longer process of turning these insights into action. Soda has provided Macmillan Cancer Support with a set of recommendations for short, medium, and long term impact.

Macmillan Cancer Support has already begun brilliant work to take action in this space. You can find out more about their strategic focus areas here.

Macmillan is already underway with work to explore Shared Decision-Making with the Royal College of Radiologists to improve how hospital teams collaborate on treatment planning, with a focus on incorporating patients' needs, preferences and circumstances into those decisions; they are also conducting research into digital self-management tools to address challenges like information overwhelm and navigating complex services; and informing a new advocacy project to design, test and deliver information and support solutions that help people with cancer who are at risk of experiencing the worst outcomes, including those with other long-term conditions to shape and participate in their cancer care.

Alongside these, the findings will be used to improve support through the Macmillan Support Line, develop resources and training to build healthcare professionals' skills and confidence, and shape funding to move care closer to home through partnerships with the NHS, local communities and voluntary organisations.

Credits and Thank Yous

We would like to thank Macmillan Cancer Support for engaging us in this work.

To the brilliant participants of this consultation, who provided immeasurably valuable insight to their daily experiences, sharing personal and difficult stories to bring richness to the challenges and ideas they have for this space. We are immensely grateful for your time and participation.

Thank you to all of the community organisations detailed on pages 8 and 9 of this report, who worked with us to reach grassroots community, and ensure such a broad intersection of identities were represented throughout this process.

Thank you to Sana Iqbal, of Studio Sana for working with us to design and layout this report.

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