Co-Developing a Public and Community Involvement and Engagement (PCIE) Plan for the Sussex Cancer Research Centre (SCRC): A Community-Researcher-Led Approach

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Table of Contents

List of Acronyms *2*

Acknowledgements *4*

Executive Summary *5*

Introduction *10*

Methodology *12*

Key Findings *13*

Demographic Data and Outreach 13

Thematic Findings and Analysis 17

I. Cancer Care Services 17

II. Cancer Research 21

Recommendations *24*

Public and Community Involvement and Engagement Action Plan for the Sussex Cancer Research Centre (SCRC) *27*

Appendices *30*

Appendix I: A Note on Methodology 30

Appendix II: Interview Script (REN Cancer Project) 34

Appendix III: Participant Information Sheet and Consent Form 37

Appendix IV: Ethical Guidelines Document 38

Appendix V: Sussex Cancer Research Centre (SCRC) Introduction Note 40

List of Acronyms

CR	Community Researcher
DRI	Diversity Resource International
GP	General Practitioner
ICB	Integrated Care Board
NHS	National Health Service
PCIE	Public and Community Involvement and Engagement
REN	Research Engagement Network
SCRC	Sussex Cancer Research Centre
SIS	Sussex Interpreting Services
TDC	Trust for Developing Communities
UK	United Kingdom
VAAC	Voluntary Action Arun and Chichester
VCSE	Voluntary, Community and Social Enterprise

List of Tables and Figures

Table I: Locations across Sussex and number of participants 15
Table II: Public Community Involvement and Action Plan for the Sussex Cancer Research Centre 27

Fig I: Level of awareness of SCRC (%) 8
Fig II: Willingness to engage in cancer research (%) 8
Fig III: Gender breakdown of participants (%) 13
Fig IV: Age composition of participants (%) 14
Fig V: First language of participants (%) 14
Fig VI: Types of cancer experienced by participants (%) 15
Fig VII: Type of lived experience reported by participants (%) 16
Fig VIII: Cancer type by participant lived experience (number) 16
Fig IX: Cancer type by participant age (number and cumulative %) 17

List of Infographics

Infographic I: Challenges vis-à-vis cancer care services 6
Infographic II: Snapshot of highlighted challenges for cancer care services 7
Infographic III: Challenges vis-à-vis cancer care research 7

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Executive Summary

Situating the Report

This Report is a consolidated account of the experiences gathered from diverse community members on their experiences of cancer care services and research. At its core is the long-term aim to advance health equity. It is one of many co-produced strategic documents from the Phase Two project of the pan-Sussex Research Engagement Network (REN). The Report presents a community engagement plan for the Sussex Cancer Research Centre (SCRC), co-designed by Voluntary, Community and Social Enterprises (VCSEs), community researchers, and other stakeholders. It outlines the Public and Community Involvement and Engagement (PCIE) plan as a process that positions communities as equal partners in research. Its primary goal is to improve the value, relevance, and conduct of research, and to address issues that affect the community. The Report includes insights from 47 interviews conducted by 15 community researchers (CRs) in their own communities or the communities they work with.

The COVID-19 pandemic shone light on and exacerbated decades of health inequities in the region, with different outcomes for communities. It especially compounded vulnerabilities for communities living in areas of deprivation and minoritised populations. This necessitated that services and research address the specific needs of multiply marginalised communities and groups. This Report is an attempt to centre their voices and their ability to effect change through sustained engagement with healthcare research, processes and interventions designed both *with* them and *by* them.

Across the reports, the CRs emphasised two factors that made it possible for the interviewees to have these conversations safely and with a sense of comfort:

1. The fact of researchers coming from the same communities and sharing a language.
2. Both the interviewers and the interviewees sharing some form of lived experience of cancer, making speaking with and between them relatively easier.

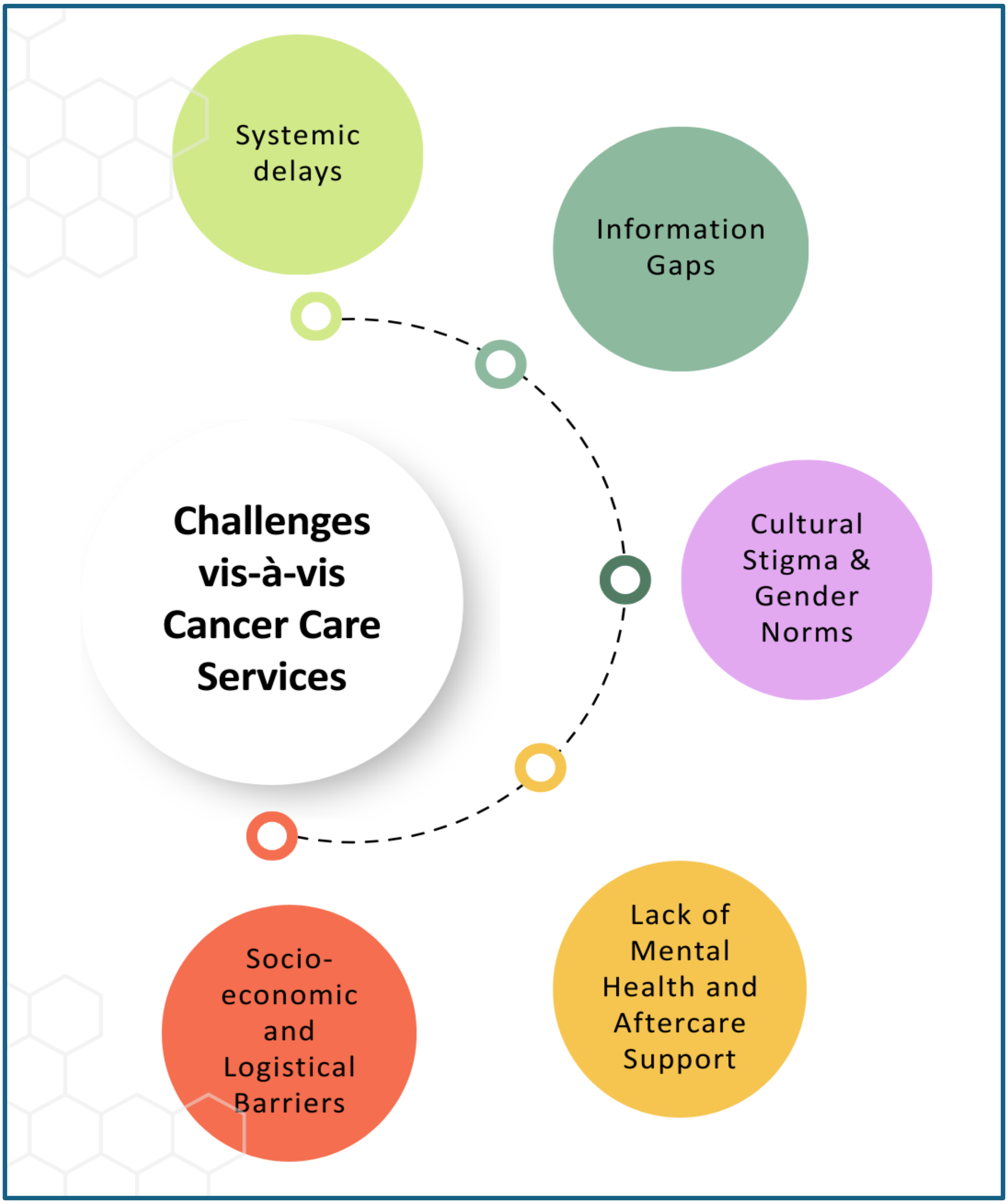
As community members gained familiarity with the SCRC through the community researchers, many saw this as a “unique opportunity to break away from the outdated ways of working.” To them, it opens pathways towards an alternate model of “inclusive, equitable, and community-led research and care.” Such research and interventions that move care closer to communities and devolve power over decision-making, are fundamental to empowering people. They help shape the outcomes of research and practice amid a nurturing environment of care and solidarity.

Key Findings

The findings reveal an interrelated and intersectional set of challenges (see Infographics I, II & III) and opportunities (see Recommendations) in cancer care research and engagement.

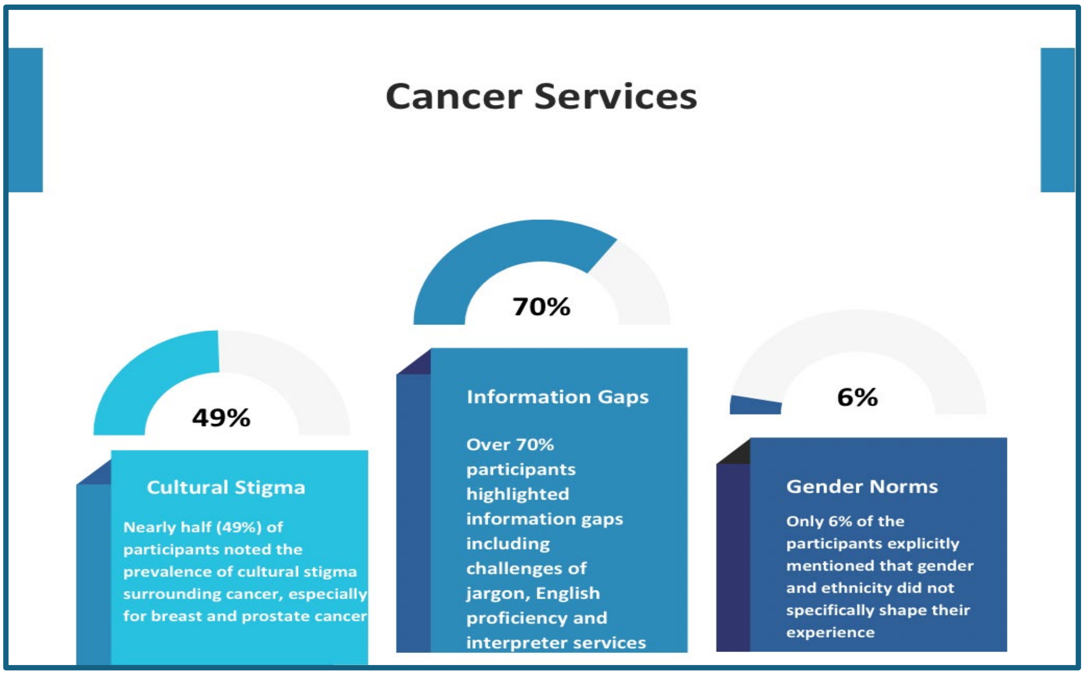
Snapshot of Findings Across Cancer Care Services and Research

Infographic I: Challenges vis-à-vis cancer care services



Among the findings regarding cancer services, the Report identifies systematic delays, information gaps, cultural stigma and gender norms, a lack of mental health and aftercare support, socio-economic and logistical barriers as key issues hindering access to services (see Infographics I & II).

Infographic II: Snapshot of highlighted challenges for cancer services (%)



Cancer Services

49%

Cultural Stigma

Nearly half (49%) of participants noted the prevalence of cultural stigma surrounding cancer, especially for breast and prostate cancer

70%

Information Gaps

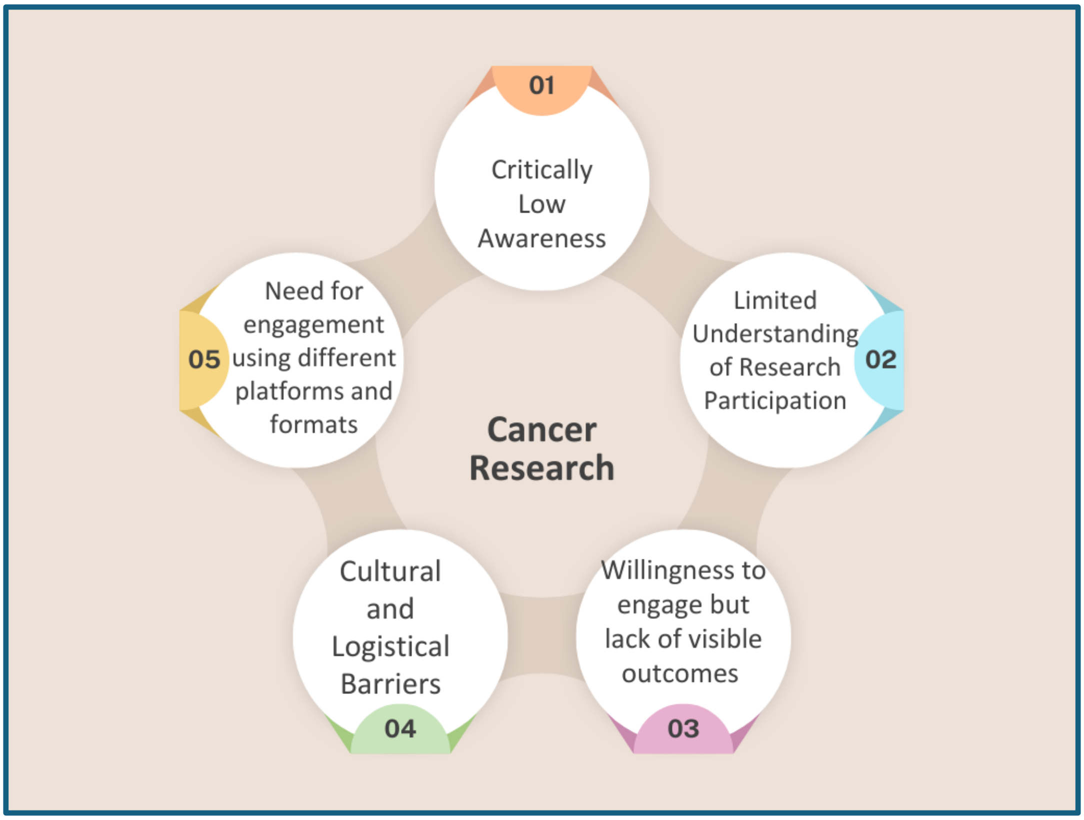
Over 70% participants highlighted information gaps including challenges of jargon, English proficiency and interpreter services

6%

Gender Norms

Only 6% of the participants explicitly mentioned that gender and ethnicity did not specifically shape their experience

Infographic III: Challenges vis-à-vis cancer research



Cancer Research

01 Critically Low Awareness

02 Limited Understanding of Research Participation

03 Willingness to engage but lack of visible outcomes

04 Cultural and Logistical Barriers

05 Need for engagement using different platforms and formats

Among findings regarding cancer research, the Report identifies key concerns around critically low awareness limited understanding of research participation, willingness to engage but demoralisation due to a lack of follow-through or visible outcomes, cultural and logistical barriers, and the need for engagement through different platforms and formats (see Infographic III and Figs I & II).

Fig I: Level of awareness of SCRC

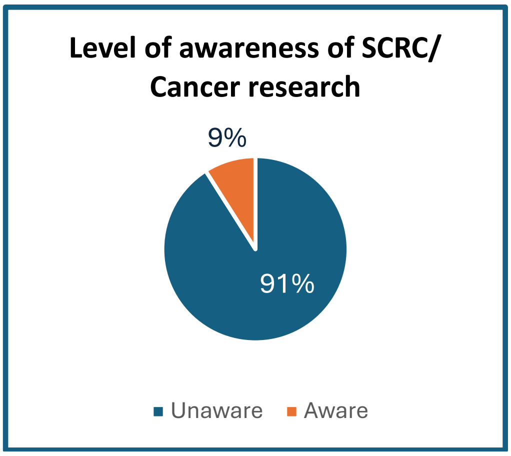
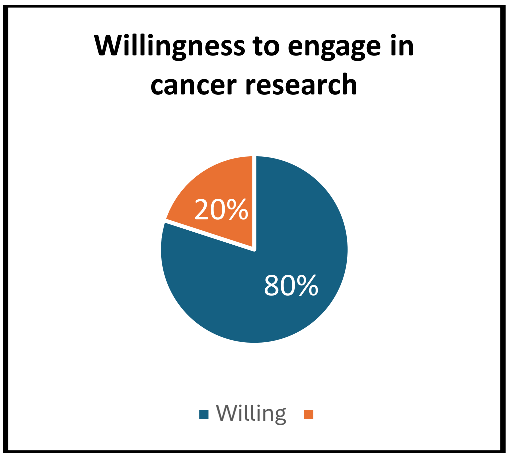


Fig II: Willingness to engage in cancer research



Intended Readership

While this Report is written to be a guiding document for planning around cancer research and services in Sussex, it is also developed for a diverse readership including public health professionals, policymakers, academics, and technical experts in planning, monitoring and evaluation.

Recommendations

- **Multilingual Outreach Campaign, including technology-based innovative tools**: Using translated leaflets, posters, and social media videos (e.g., TikTok, WhatsApp) in Arabic, Cantonese, Ukrainian, and other community languages to raise SCRC awareness. Place materials/QR codes in GP surgeries, pharmacies, and community hubs.
- **Peer Support Groups:** Establish peer-led groups for survivors and carers, focusing on mental health and shared experiences, where people can talk about their past or current experiences for emotional support.
- **Bilingual Community Liaison Teams:** Recruit bilingual staff to conduct regular outreach in community spaces, building trust and sharing SCRC's work. Compensate ambassadors equitably to formalise their role as bridges between institutions and communities.
- **Community Advisory Panels:** Create panels of survivors, carers, and advocates to co-design research priorities and materials. Compensate participants to value their expertise.

- **Culturally Safe Workshops:** Host workshops and awareness events in community hubs, mosques, temples, and churches, led by bilingual healthcare professionals and survivors. Provide childcare, food, and interpreters to ensure accessibility.
- **Social Media Engagement:** Develop short, multilingual videos featuring survivor stories and research updates, shared via Instagram, TikTok, and WhatsApp groups.
- **Early Detection Research:** Prioritise studies on improving screening access, particularly for over-60s and minoritised groups, including mobile units and pharmacy-led initiatives.
- **Mental Health Support:** Integrate psychological support into care pathways, with bilingual counsellors and post-treatment follow-ups to address emotional needs.
- **Faster Diagnostic Pathways:** Research strategies to reduce referral and treatment delays addressing systemic bottlenecks, and how to integrate with alternative/complementary medicine and treatment.
- **Culturally Competent Care Models:** Study integration of traditional remedies with biomedical treatments, addressing cultural preferences.
- **Accessible Research Participation:** Offer flexible engagement options (e.g., phone, drop-in sessions) with transport and childcare support to overcome logistical barriers.
- **Shift from consultation to collaboration with communities:** Foster partnerships with trusted figures, collaborate with GPs, pharmacists, and faith leaders to disseminate information and recruit for research, leveraging their credibility.
- **Publicly report back**: to communities on how their input shapes research and services.
- **More Funding:** Advocating for and shaping policy towards funding to help local hospitals provide facilities and resources to support new research with communities.
- **Provide support and signpost** cancer survivors and their families to organisations that can help them, e.g. Macmillan, Cancer Research UK.

Overall, we present this Report as a crucial contribution towards improving cancer research and cancer care in a more inclusive way - one that centres the voices and needs of marginalised communities and supports pathways towards dismantling health inequities.

Introduction

This Report centres the voices and lived experiences relating to cancer screening, diagnosis, treatment, and caregiving for minoritised ethnic communities across Sussex. Research indicates that despite lower overall cancer incidence among minoritised ethnic communities compared to White British populations in the United Kingdom (UK), they experience worse outcomes, persistent inequalities, and are less likely to report positive healthcare experiences. These disparities stem from a range of factors, including cultural beliefs, limited awareness, and systemic issues such as racism.[1] More evidence is emerging on how community engagement and empowerment are highly effective strategies for addressing these health inequalities among minoritised ethnic and socio-economically disadvantaged populations in the UK.[2] There is broad consensus that approaches like co-designing health initiatives with communities, delivering services through trusted local networks, and empowering community members as peer support workers significantly improve health outcomes. Strategies that prioritise local expertise, cultural sensitivity and autonomy build trust, reduce barriers like stigma and access issues, and promote equitable health outcomes, particularly for ethnic minorities who face worse health outcomes. This Report pays explicit attentiveness to such approaches and aims to be a strategic document that guides the vision of the SCRC to improve engagement in cancer services and research to tackle health inequalities.

Community engagement is at the core of the SCRC, a pioneering research centre in Sussex launched in June 2024. It is dedicated to improving cancer treatment and outcomes through innovative research. The SCRC's work spans from laboratory research to clinical applications, focusing on translating scientific discoveries into real-world benefits for people affected by cancer. Central to the Centre's vision is the active involvement of the public and communities by building meaningful connections with diverse Sussex communities, ensuring that research and services reflect their needs and experiences. It is in this spirit that REN, building on earlier learnings, set out to co-develop a PCIE plan for the SCRC. The aim of this co-designed plan is to guide services, research, and other projects at SCRC.

The Sussex REN founded in October 2023[3] is a collaboration between Sussex Integrated Care Board (ICB), Brighton and Sussex Health Research Partnership, and seven local VCSEs. In the first phase, REN trained a diverse cohort of community researchers who worked with and engaged minoritised communities from areas of deprivation in Sussex to investigate how to improve their participation in health and care services and research. Building on the recommendations of the initial phases, REN is invested in strengthening and embedding community research within the health and care research life cycle to tackle health inequalities.

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[1] Abraham et. al., 2022. Inequalities in cancer screening, prevention and service engagement between UK ethnic minority groups. *British Journal of Nursing*, 31(10), pp. S14-S24.

[2] MacDonald H., et. al., 2024. What works: Community engagement and empowerment to address health inequalities. *Health Inequity Evidence Centre.*

[3] The Sussex REN is one of the many regional networks of the National REN development programme that was launched in 2022. For more on this, see https://www.bsms.ac.uk/research/support-and-governance/shcrp/ren.aspx.

It is in this background that REN co-designed this community engagement plan for the SCRC. This Report is one of the many co-produced strategic documents of the REN Phase Two.

Referred to here as the PCIE plan[4], we define the goal of a PCIE plan as improving the value, relevance and conduct of research, and ensuring research addresses issues that affect the community. We understand PCIE as a process that involves communities in the research as equal partners. The different levels within the spectrum of community engagement include Informing, Consulting, Involving, Collaborating, and Empowering (International Association of Public Participation, 2014).[5] Thus, at the heart of this phase was the co-production of this PCIE plan with active community involvement to draw out pathways for collaborative interventions that empower the community by placing the power of decision-making in their hands.

The Report presented here is a consolidated account of the knowledge and experiences gleaned from diverse community members on aspects of cancer care services and research, with the long-term aim to advance health equity.

While the Report is meant to be a guiding document for planning around cancer research and services in Sussex, it is developed for a diverse readership, including public health professionals, policymakers, academics, and technical experts in planning, monitoring and evaluation. The COVID-19 pandemic shone a light on, and exacerbated, decades of health inequities in the region. It compounded vulnerabilities for different communities, especially affecting areas of deprivation and minoritised populations (Sussex NHS Commissioners, 2021).[6] This necessitated that services and research address the specific needs of multiply marginalised communities and groups. This Report aims to centre their voices and their ability to effect change through sustained engagement with healthcare research, processes and interventions designed with them.

Co-developing a PCIE plan is seen as key to framing SCRC's engagement strategy and ensuring it is shaped by communities across Sussex. Thus, the primary question that the project started with was, how do we ensure all people with experience of cancer can be stakeholders of the SCRC? This question translated into the following aims of the project:

- To ensure people with lived experience of cancer are at the heart of research at the SCRC
- To find out how the community members across Sussex would like to engage with cancer research happening locally
- To develop a community engagement plan for the Sussex Cancer Research Centre (SCRC).

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[4] For the sake of this project and seeking to replicate this elsewhere, we do not use the word patient for people living with cancer. The word has its origins in the biomedical model which has been criticised as it "(mis)represents an individual seeking healthcare as one who is simply a passive participant and recipient of care." (Whyte, Elias & Cook, 2024). This was brought to the attention of the project team by Markus Taylor- lived Experience Lead - who worked on this project in the advisory capacity on behalf of SCRC.

[5] International Association for Public Participation. (2014). *IAP2 Public Participation Spectrum*. https://iap2.org.au/resources/iap2-published-resources/.

[6] Sussex NHS Commissioners. (2021). Tackling Health Inequalities: Progress Report 2020/21 and Action Plan 2021/22. https://www.westsussexccg.nhs.uk/wp-content/uploads/2021/04/Health-Inequalities-Progress-Report-2020-21-and-Action-Plan-21-22.pdf.

We were particularly interested in engaging with underserved and minoritised ethnic populations. This was necessitated as existing research has shown significant gaps in this regard and more specifically based on the feedback from SCRC. Prior to the commencement of this project, critical thinking by SCRC Directors on previous attempts at PCIE revealed that existing engagement activities were readily engaging people from demographic majorities, retired individuals, and high-income individuals. Therefore, there was a motivation to enrich this study's cohort for members from minoritised and marginalised. To ensure the project remained embedded in communities, REN selected Diversity Resource International (DRI), one of the core VCSE partners of REN, to lead the project.

The Report covers a range of themes from cancer research to care practices, starting with a methodology section that underlines how this study was community-led and co-produced. The next section collates and presents the key findings of the Report. This includes demographic data illustrating the project's diverse reach in terms of people, places, and lived experiences. Five key themes are then presented and analysed vis-à-vis cancer care research and services. This is followed by recommendations and a targeted public and community involvement and engagement (PCIE) action plan for the SCRC.

Methodology

This project's methodology is grounded in a community-led and co-produced research approach that centres the lived experience and knowledge of CRs and participants. CRs were identified and recruited based on their lived experience of cancer screening, diagnosis, treatment, and/or caregiving, as well as their strong connections with diverse and minoritised communities across Sussex. This ensured that the project remained embedded within the communities it sought to engage. It also meant the insights collected reflected a wide range of experiences, places, and backgrounds.

The study employed a qualitative methodology using semi-structured interviews with participants who had lived experience of cancer either personally or as caregivers. CRs conducted interviews within their own communities or networks, with particular focus on individuals from minoritised backgrounds and those who do not speak English as a first language. Interviews explored experiences of cancer care services, barriers to screening and diagnosis, and perceptions of research and engagement with SCRC. An in-house ethics protocol guided the project including the interview process. All participants received information about the study, gave informed consent, and were offered a ‘thank you’ honorarium. Interviews were recorded, transcribed and stored anonymously.

CRs transcribed and analysed their interviews using thematic analysis. Each CR produced a summary report detailing demographic information and key themes emerging from their interviews. These individual reports were then synthesised into the consolidated findings presented in this Report. Demographic analysis was limited to indicators for which data was consistently provided across all interviews. A few indicators, such as ethnicity, were missing therefore they were not analysed or visualised.

A methodology note that details the process of co-designing and co-production of this project is presented in Appendix I. The in-depth methodological approach is also a reflection of the collaborative and iterative nature of this research. Therefore, this Report presents methodology itself as a critical intervention towards collaborative knowledge production with communities and as a way of integrating an ethics of care and mutuality in this endeavour.

Key Findings

The findings presented here emerge from 47 interviews conducted between April and May 2025 by 15 community researchers. Each CR produced a 3–4-page report with a largely common format consisting of three main sections: anonymised demographic data of the participants, key findings organised by themes, and recommendations. This section provides insights into demographic data and the broader emerging themes. The aim is to showcase both the extent to which the goal of reaching out to diverse underserved groups and communities was achieved, as well as the issues that the participants identified in the cancer care and research ecosystem in Sussex.

Demographic Data and Outreach

The demographic data from the interviews, as presented in the figures below, show that the project succeeded in recruiting across demographics and enriching outreach to underserved populations. All presented data are either counts (numbers of participants) or percentages (%) of participants out of 47.

Figure III presents the breakdown by gender for the research participants, showing that the participants were majority female.

Fig III: Gender breakdown of participants (%)

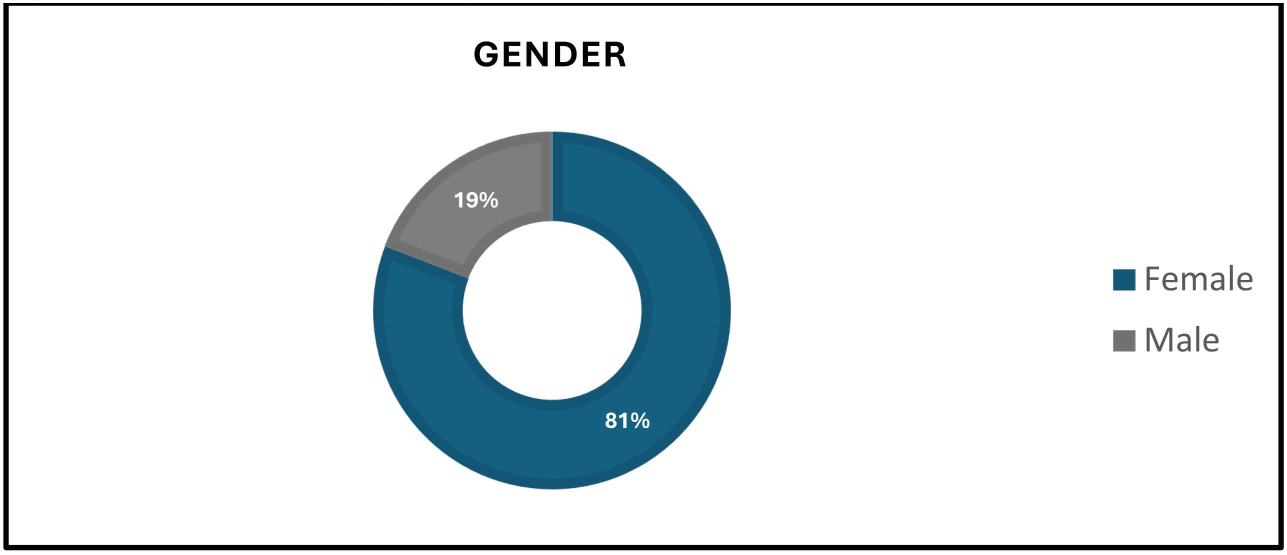


Figure IV presents age-wise breakdown for the research participants and shows that the age group of 40-49 years was the most recruited.

Fig IV: Age composition of participants (%)

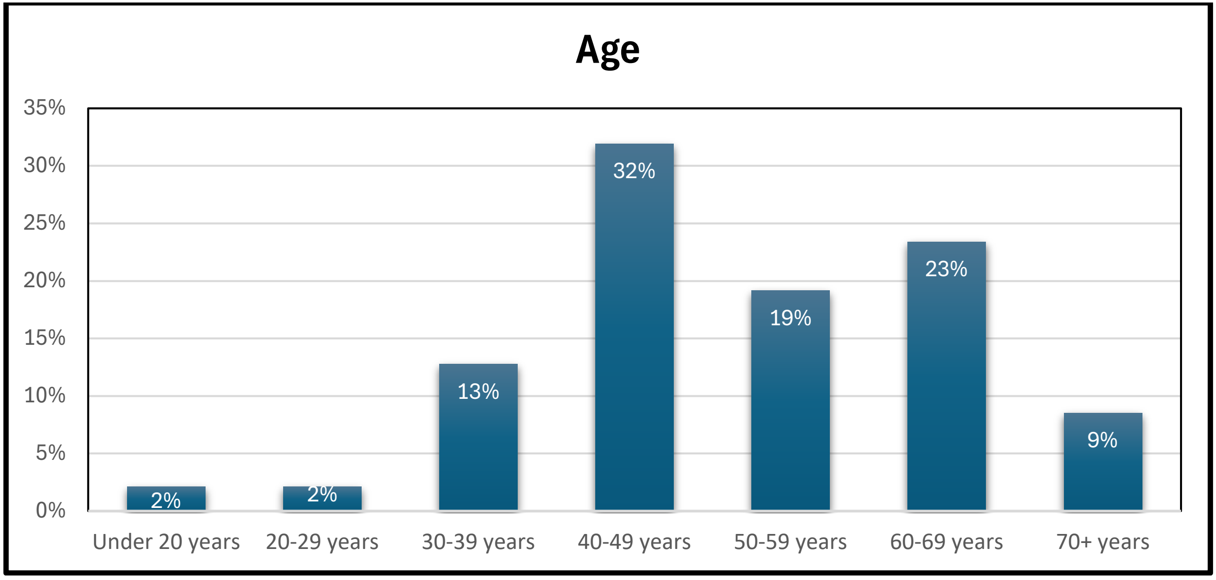
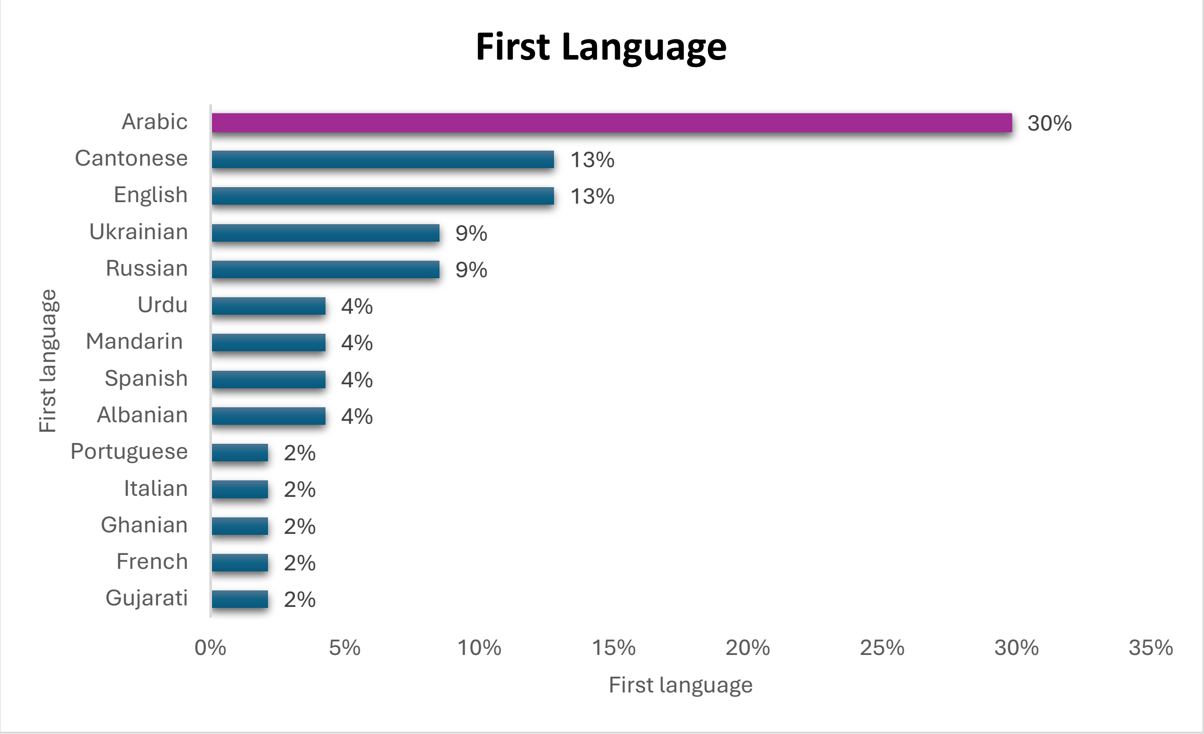


Figure V shows the percentage of participants against different first languages. The most common first languages of participants were Arabic, Cantonese, English, Russian, and Ukrainian.

Fig V: First language of participants (%)



In terms of the locations, Table I shows that participants were successfully recruited from across Sussex.

Table I: Locations across Sussex and number of participants

Bognor Regis (1)	Moulsecoomb (1)	Bevendean (1)	Portslade (1)	Angmering (1)	Hove (6)
Littlehampton (1)	Ferring (1)	Findon (1)	Worthing (1)	Crowborough (1)	Ringmer (1)
Hastings (2)	St Leonards (1)	Ore (1)	Chichester (1)	Arun (1)	Lewes (2)
Newhaven (2)		Crawley (3)		Brighton (17)	

There were diverse kinds of cancer that participants had experienced or had cared for, resulting in different forms of lived experience. These are highlighted in Figures VI and VII. As the figures show, most participants interviewed had lived experience of breast cancer, either through undergoing treatment, or as survivors or caregivers.

Fig VI: Types of cancer experienced by participants (%)

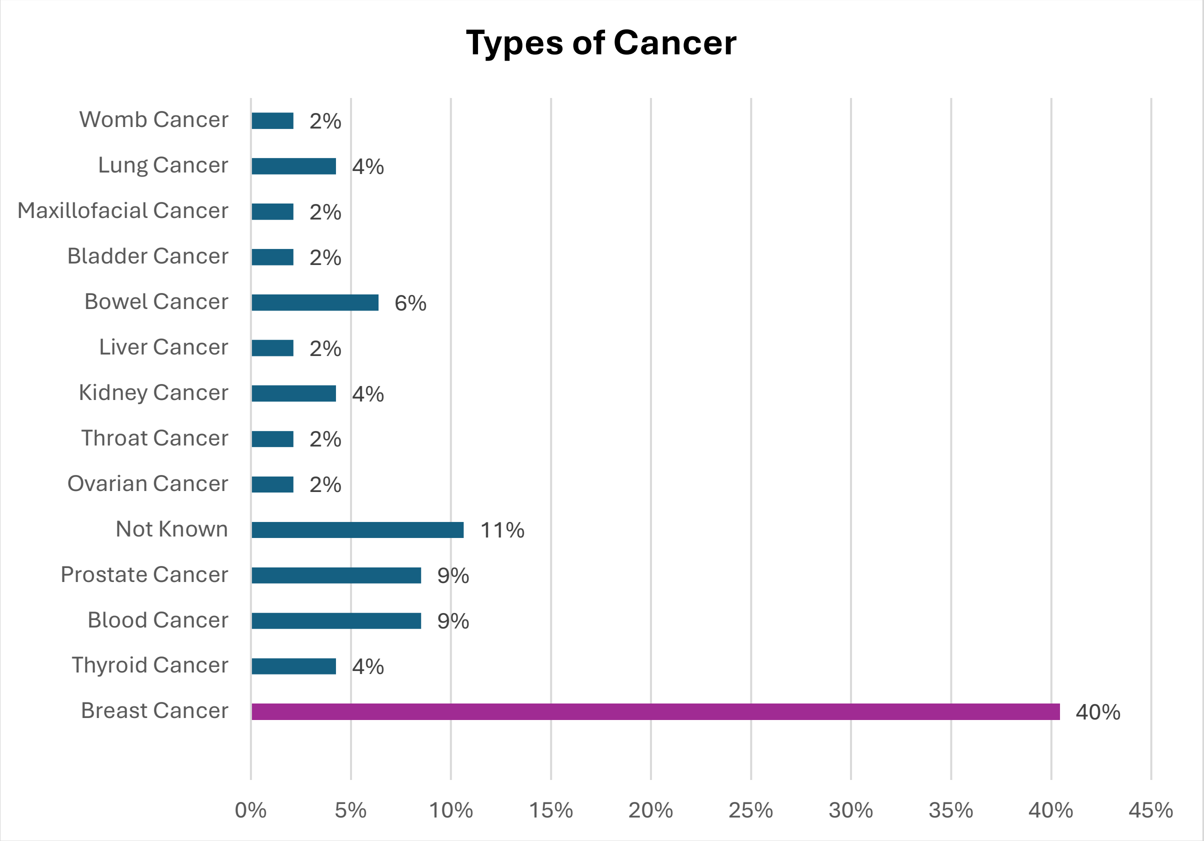
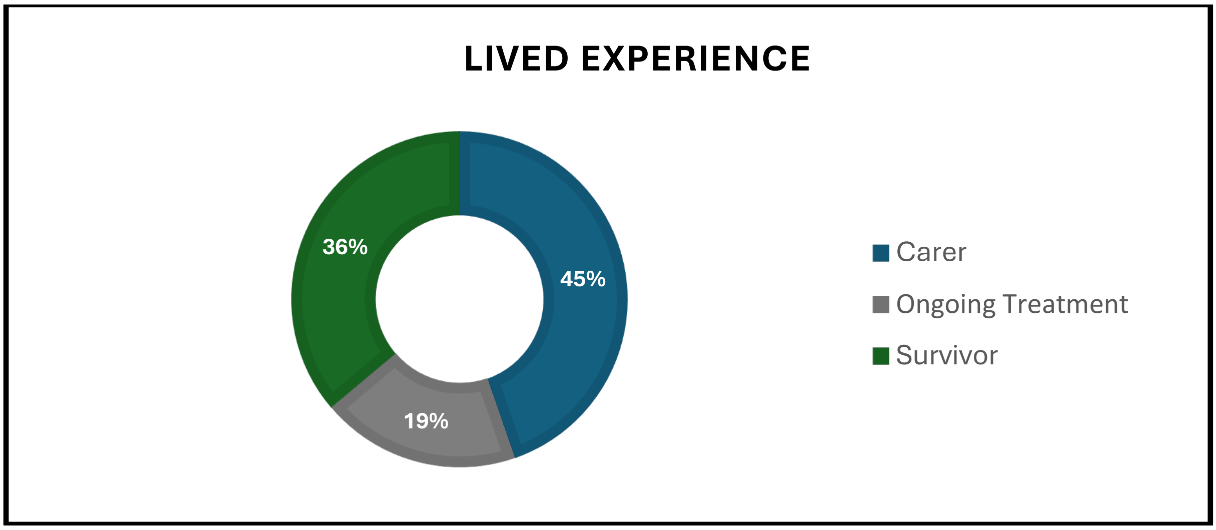


Fig VII: Type of lived experience reported by participants (%)



The following figures show the relationships between the type of cancer and the type of lived experience (i.e. carer, ongoing treatment or survivor; Figure VIII) and between the type of cancer and age (Figure IX). Taken together, this demographic data may demonstrate reasonably good engagement of minoritised groups and people with experience of multiple malignancies, broadly in line with cancer prevalence patterns in the general population. The absence of any respondents with lived experience of other cancer types, such as skin cancer or pancreatic cancer, will be important to map for future engagement to ensure coverage of all cancer types.

Fig VIII: Cancer type by participant lived experience (numbers)

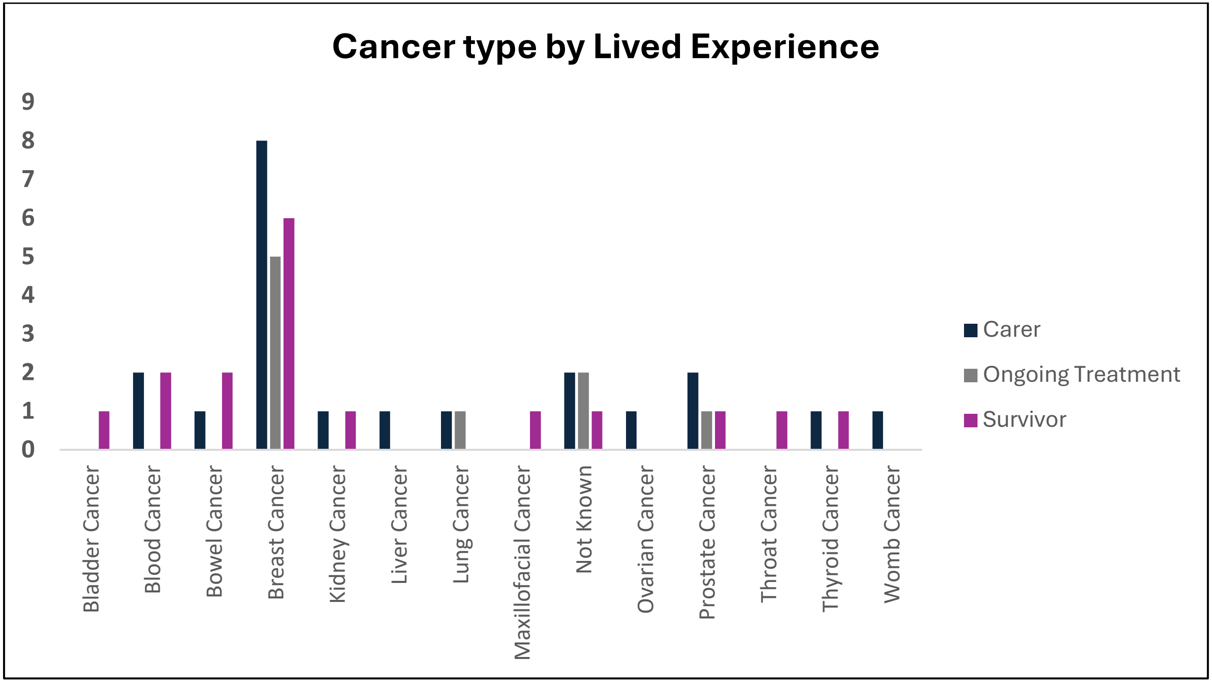
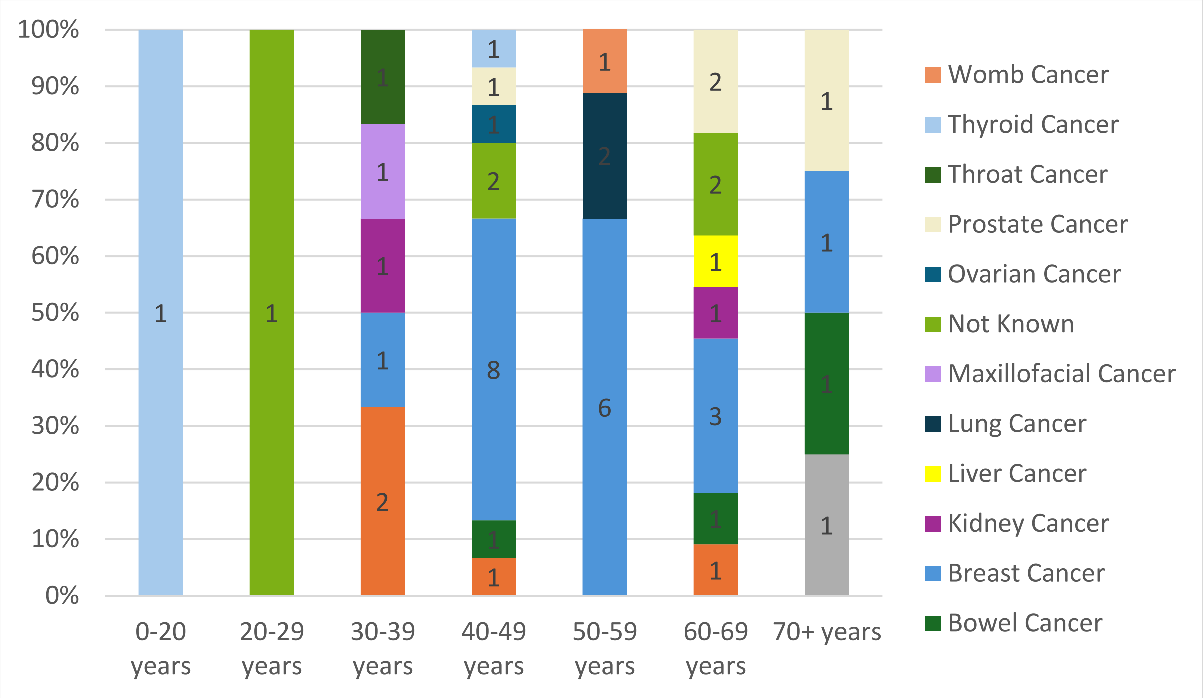


Fig IX: Cancer type by participant age (count and cumulative %)



Thematic Findings and Analysis

Across the 15 CR reports, five common themes emerged which were analysed and consolidated in this Report. These include:

- Awareness and Perceptions of SCRC and Local Cancer Research
- Willingness and Preferences for Sharing Lived Experiences
- Engaging Communities in SCRC's Work
- Community Challenges
- Research Priorities

In this analysis, we separate cancer services from cancer research, with a caveat that at times the two overlap as well.

I. Cancer Care Services

This Report operationalises cancer care services as the practical and systemic aspects of cancer care, including access to screening, diagnostic processes, treatment pathways, and post-treatment support. While not directly addressing engagement with research, the SCRC aims to address the needs of people with cancer in Sussex and therefore addressing challenges in their clinical experiences aids in identifying challenges to be addressed through research. The major issues outlined include:

A) **Systemic Delays**: Long waiting times for referrals, diagnosis, and treatment were a pervasive issue, causing anxiety, being perceived as enabling disease progression, and eroding trust. Participants across urban and rural areas reported delays ranging from

3-9 months, and they often linked this to GP (General Practitioner) dismissiveness, cultural disconnect, or hospital capacity issues. More than 60% (29/47) of the participants reported diagnostic delays. Illustrative quotes from the participants are shown:

> "They [GPs] are so stretched, I can see that, that *the wheels are falling off."* (emphasis added)

> "I remember my mother's case; they discovered it in May, did tests, and scheduled surgery for October. This delay gave the disease a chance to spread. It started as a 1cm lump in the breast, then spread to the lymph nodes. Even after surgery to remove the lymph nodes, it had still spread. *Early treatment is crucial; the earlier, the better the outcome*." (emphasis added)

> "After my surgery, I had to wait about five months for radiotherapy. The waiting made me feel very uneasy. I kept wondering if the cancer would come back."

Other participants highlighted a patronising or dismissive approach and the need to keep chasing the GP in order to get some attention and be enrolled for treatment,

> "She spoke to me like I was a child. I wanted to complain, but everything was spiralling out of control."

> "I was brushed away. If I didn't chase them, I wouldn't be here now."

> "Doctors dismissed my husband's symptoms... They said, 'it's just stress' until his blood thickened dangerously."

However, there was also a level of appreciation for the NHS, particularly at the treatment level for free services and for staff being 'caring and professional'.

> "…being treated in England. That has been really helpful, financially, it has been a relief, I get benefits that give me *financial respite*. I come from a country in Latin America where there is no welfare, so I really value this." (emphasis added)

B) **Information Gaps:** Inaccessible information due to language barriers, complex medical jargon, and lack of outreach emerged as a recurring theme across the fifteen reports. More than 70% (33/47) participants highlighted challenges related to medical jargon, limited English proficiency, and inadequate interpreter services.

One participant shared,

> "When I was diagnosed, the doctor gave me a phone number to call for support, but I never called. I didn't know who would be on the other end, and I wasn't comfortable talking to a stranger over the phone—especially in English."

A participant said they were not "taken seriously" and that "language delayed my diagnosis."

Another highlighted how the language barrier adds to shyness and lack of knowledge, making it difficult to access services.

> “Yes, there’s a language barrier. Also lack of knowledge of the system: how to make an appointment… You know that you’re here with the rights of a visitor and you’re shy, you’re scared to ask…”

Where provided, there were concerns raised about the quality and cultural appropriateness of these services. The situation for people living in isolated settings (e.g., emergency accommodation) was further aggravated as they felt they were least informed. There was a perception that the lack of culturally sensitive communication exacerbated confusion around diagnosis and treatment options.

> “When SCRC had new drugs and treatments, it should pass the information to the community and made leaflets to let people knew. It would be difficult for me with language barrier. I would not understand it if it were in English.” (sic)

> “I wanted to join community activities, but I didn’t know anything was happening. If someone had come to speak with us in Chinese, I would definitely have joined. *Most of us_won’t ask—we wait to be asked*.” (emphasis added)

A few participants, however, acknowledged the contribution of service and/or research-oriented organisations like Macmillan and Cancer Research UK in raising awareness of cancer and addressing information gaps. Three participants also highlighted the value of Cancer United as a vital support organisation and a potential bridge between the public and researchers in West Sussex. Moreover, the majority of participants saw this research project as positive and felt they were being heard. They hoped to see their “suggestions being implemented” in future.

C) **Cultural Stigma and Gender Norms:** Cultural stigma surrounding cancer was noted by nearly half [49% (23 out of 47)] of the participants, especially related to breast and prostate cancer. This stigma manifested as silence within families and communities, avoidance of screening, and fear of social exclusion. Cancer is seen as “shameful” or “contagious”. A few also cited discomfort with “opposite-gender care”. They noted,

> “Our community thinks Western medicine is ‘toxic’... They prefer herbal remedies but don’t tell doctors.”

> “…people in my culture are a little bit superstitious, and they try to stay away from anything related to cancer unless they are affected by it.”

This is particularly prevalent in participants from Arabic and Chinese speaking and South Asian communities. This viewpoint may highlight scepticism and the homogenising narratives often used to describe these cultures. A participant noted an unwarranted response stemming from a lack of cultural sensitivity:

> “If she understood the culture... she wouldn’t be having a go at me.”

Gender norms further complicated access, with reports of women avoiding mammograms and some men resisting prostate exams. Some women also thought that men were able to get better access just by being “loud”:

> “Loud males always get further forward than you, believe me.”

This stigma often prevented open discussion and delayed diagnosis or support seeking. A small number (3 out of 47; 6%) explicitly mentioned that gender and ethnicity did not specifically shape their experience.

D) **Lack of Mental Health and Aftercare Support:** Participants consistently reported insufficient psychological support during and after treatment, exacerbating emotional distress. As one participant noted, this was especially critical as “cancer is a psychological illness first, then a physical one.” Post-treatment follow-up was also lacking, leaving survivors feeling abandoned. Highlighting the importance of support especially during cancer treatment, a participant said,

> “*Mental support is extremely important* because some people, especially when undergoing chemotherapy, lose their hair, and their mental state suffers. They feel forced to hide it from others, or they can’t cope with it. So, when there are other people encouraging them, giving them confidence and empowering them, they can live and continue their lives normally.” (emphasis added)

Others wished for more information and emotional support during their experience,

> “I would have liked to have more info about how it all works with the oncologists, the hospital, and emotional support, this is very important for us to face this problem and deal with it. Sometimes there are really low points.”

> “I was on my own worrying about my mum's health and my children at the same time, *if only I knew there was support available*, my experience would have been better.” (emphasis added)

Participants expressed a strong need for ongoing mental health services embedded in culturally sensitive care pathways. Some participants, particularly those with caregiving responsibilities, talked about the caregiver burden and emotional toll they experienced, and highlighted the lack of practical support for caregivers.

> “It seems to me that people who deal with people who have cancer become afraid that they’ll get cancer, so they want to know more.”

E) **Socio-economic and Logistical Barriers:** Financial pressures, transport costs, and work commitments hindered access, particularly for low-income and rural participants. A participant remarked about the need to have carer's allowance to be able to afford access in terms of transport costs and other logistics.

Participants also reported financial burdens related to missed work and childcare. People with cancer accrue ‘huge costs’ on travel and private physiotherapy. This reflects how difficult it can be for families to provide proper care due to travel costs, accommodation or loss of income. Refugees faced additional visa-related uncertainties. A few participants acknowledged that higher socioeconomic status eased access to services for them. In the words of one participant, speaking about the major barrier to accessing cancer services:

> “The biggest barriers are in general: *Money, Money*!” (emphasis added)

II. Cancer Research

This section examines participants’ awareness, perceptions, and experiences of cancer research, including their understanding of participation, perceived benefits and risks, and willingness to engage with SCRC.

For this Report and analysis, cancer research encompasses awareness of SCRC, willingness to participate, engagement preferences, and community-driven research priorities. The key themes that this project identified relating to cancer research include:

A) **Critically Low Awareness:** Across all 15 reports, awareness of SCRC was nearly non-existent, with a striking 91% of participants (43 out of 47) unaware of the Centre or local research prior to the interview.

This was consistent across age groups and ethnic backgrounds, regardless of level of education or cancer experience, indicating a significant visibility gap in the Centre’s outreach. However, it is important to remember that, having been launched in June 2024, the SCRC is fairly new, which might partially explain these numbers. This project is one of the many steps that the Centre is taking to address this awareness gap in Sussex and to contribute crucial knowledge. In the words of one of the participants,

> “It's really sad because I work closely with cancer patients, but I never heard of any of that. I guess I know it's happening. There is research. And me and the kids, we've done a lot of events through the years to get funding through many mile races and few activities to get funding for the research. But it's always in my mind this research is out there in London, but not locally. So, I would say I really have not a lot of information regarding the Sussex Cancer Research Centre. I wasn't even aware of it and any research happening locally now.”

Such lack of awareness was more pronounced among participants whose primary language was not English. This could lead to feeling disconnected from the health system or relevant networks. The insecurity stemming from language barriers magnifies the lack of confidence in their ability to contribute meaningfully to SCRC, as three participants expressed. Only a small number of participants (two or three) knew about services provided by Macmillan UK or the research undertaken by Cancer Research UK, though they acknowledged their awareness-raising efforts.

B) **Limited Understanding of Research Participation:** Most participants had little to no understanding of what cancer research entails, what participation might involve, or how research findings are used. Many participants associated research exclusively with universities, clinical trials, or medical professionals, and thought their stories or views would not matter. Some reflections are noted here:

> "I thought research was only for scientists. *I didn't think my story mattered*." (emphasis added)
>
> "I didn't know *normal people could be part of it*." (sic) (emphasis added)
>
> "You don't really go out and research cancer unless it affects you or someone close."

This lack of understanding contributes to low levels of trust and participation. It also reflects a missed opportunity to frame research as inclusive, relevant, and grounded in real-life experiences. A participant, pointing to the need for age specific awareness and knowledge, said,

> "Raising awareness should also come in the form of educating young people and giving them simple information tailored to their age that cancer does not mean automatically death and that it is not as scary as it might seem, focusing on future generations so that people's perspectives and attitudes toward cancer change."

Suggesting that SCRC could create awareness by being at places where these treatments are sought, one participant noted,

> "…perhaps there could be someone from the SCRC in the places where people get treatment who could explain what they do, create awareness, and speak to patients about research and their involvement in research. It would be good to have an actual person talking about what they do, sometimes leaflets are read, sometimes not."

C) **Willingness to Engage:** Despite low awareness and limited understanding of research, more than 80% of the participants (38 out of 47) were eager to share experiences to shape research and interventions, provided key conditions were met. These conditions that many participants highlighted include, among others:

- use of preferred or first language
- a trusted intermediary or community facilitator
- clear jargon-free communication
- emotional and cultural safety
- anonymity
- data safety

A few participants also noted that sharing experiences is therapeutic, helps counter stigma and fosters solidarity. Here are some excerpts highlighting people's willingness to share their stories as well as concerns about lack of long-term follow-up:

> "I'd be happy to share *if I knew how my story would help others* and saw action taken." (emphasis added)

> “If the cancer centre had a small team that regularly visited the community and spoke our language, we would feel much safer and *more willing to open up* and participate in research or events.” (emphasis added)
>
> “Communities are happy to share their experiences, and they have been, but outcome and impact take time. No researcher, university or research institution seems to have the *long-term plan or capacity to follow through*.” (emphasis added)

According to participants, such one-sided and one-time data collection processes result in fatigue and disappointment at not seeing any effects. Such comments could motivate feedback loops that ensure outcomes are visible to participants.

D) Preferred Engagement Formats: There was overwhelmingly high desire for everyday and localised engagement. Participants sought research and outreach to be embedded in their daily lives. They favoured community-driven, accessible engagement, including local events, social media, and translated materials. Informal settings (e.g., workshops, peer groups) and digital platforms (e.g., TikTok, WhatsApp) were popular. Participants suggested that faith spaces (mosques, temples, churches), schools, social clubs, and community hubs are more effective sites for engagement. Older participants preferred in-person events, while younger ones leaned towards digital platforms. Expressing what such formats should look like and what some of the available facilities could be that would ensure their engagement, the participants noted,

> "Workshops feel daunting... A ‘chai and chat’ before afternoon prayer? As long as there is *food and childcare facilities and we can pray it can work*.” (emphasis added)
>
> “They should organise meetings and events for people with lived experience. It would be good to film videos of people with lived experience talking about their case so others could hear and see it first hand and see how it feels, *sometimes you can say more through expressions than words*.” (emphasis added)
>
> “People nowadays don’t read leaflets anymore. But a short video about the centre, posted on TikTok and Instagram, would get attention. Short videos are very effective at getting the message across, and *people are more likely to watch them*. That way, everyone will hear and see it—everyone can work together. It means you should share it with all your friends and everyone.” (emphasis added)
>
> “If Gujarati doctors host talks at the temple, crowds will come... They trust ‘their’ professionals.”

There was strong support for informal, dialogue-based approaches led by trusted figures, including community elders, youth ambassadors, and bilingual mediators. Furthermore, participants prioritised research addressing practical needs: early detection, mental health support, culturally competent care, and reduced delays. They wanted research to reflect lived experiences and yield visible outcomes.

E) **Cultural and Logistical Barriers to Research:** As previously highlighted in the sub-section on cancer services, research participation is generally limited by cultural stigma, language barriers, and logistical constraints (e.g., childcare, transport). Mistrust from lack of study follow-up or outcomes or perceived irrelevance also deters engagement.

> "I have been part of studies before but *never saw any outcomes*. That affects trust." (emphasis added)

Across reports, participants expressed feelings that research is "done to" communities rather than "done with" them and they are merely treated as "subjects" but that they are deeply interested in (effecting) change.

> "Marginalised communities are not interested in research; *they are interested in change*." (emphasis added)

These key findings form the core of the 47 interviews conducted by the 15 CRs in their own communities or the communities they work with. Across the reports, the CRs emphasised that it was primarily two factors that made it possible for the interviewees to have these conversations safely and with a sense of comfort:

1. The fact of researchers coming from the same communities and sharing a language.
2. Both the interviewers and the interviewees sharing some form of lived experience of cancer, making speaking with and between them relatively easier.

These findings reveal interrelated and intersectional set of challenges and opportunities in cancer care research and engagement. Gaining familiarity about the SCRC from the community researchers, the community members viewed this as a "unique opportunity to break away from the outdated ways of working" and opening pathways towards an alternate model of "inclusive, equitable, and community-led research and care." Such research and interventions that move care closer to communities and devolve power over decision-making to them, are fundamental to empowering communities to shape the outcomes of research and practice amid a nurturing environment of care and solidarity.

Recommendations

The following recommendations on cancer research and services are drawn from the cross-cutting themes from the fifteen reports by the community researchers and are based on direct participant experiences and suggestions.

- **Multilingual Outreach Campaign, Including Technology-based Innovative Tools:** Launch a campaign using translated leaflets, posters, and social media videos (e.g., TikTok, WhatsApp) in Arabic, Cantonese, Ukrainian, and other community languages to raise SCRC awareness. Place materials/QR codes in GP surgeries, pharmacies, and community hubs. Hold Cancer Education talks and awareness events in local schools and for young people to challenge stigma and silence surrounding it. Information should be given in 'punchy' and simple language, pointing out what people are entitled to and that services are free.

- **Peer Support Groups:** Establish peer-led groups for survivors and carers, focusing on mental health and shared experiences. Create focus groups for people from similar backgrounds who speak the same language or make them accessible by providing interpretation in different languages, so that people can talk about their past or current experiences for emotional support.
- **Bilingual Community Liaison Teams:** Recruit bilingual staff to conduct regular outreach in community spaces, building trust and sharing SCRC's work. Using community interpreters helps establish trust through cultural sensitivity and signposting. Advertise the option of being assisted by an interpreter. These community liaison ambassadors would accompany researchers during community outreach (e.g., workshops, community-led social events such as melas, barbeques), translate complex medical jargon into accessible terms, and co-design culturally relevant materials. Their trusted status would help dismantle scepticism, address misconceptions (e.g., fears about chemotherapy), and model respectful integration of biomedical and traditional practices. Compensate ambassadors equitably to formalise their role as bridges between institutions and communities.
- **Community Advisory Panels:** Create panels of survivors, carers, and advocates to co-design research priorities and materials. Compensate participants to value their expertise.
- **Culturally Safe Workshops:** Host workshops and awareness events in community hubs, mosques, temples, and churches, led by bilingual healthcare professionals and survivors. Provide childcare, food, and interpreters to ensure accessibility.
- **Social Media Engagement:** Develop short, multilingual videos featuring survivor stories and research updates, shared via Instagram, TikTok, and WhatsApp groups.
- **Early Detection Research:** Prioritise studies on improving screening access, particularly for over-60s and minoritised groups, including mobile units and pharmacy-led initiatives.
- **Mental Health Support:** Integrate psychological support into care pathways, with bilingual counsellors and post-treatment follow-ups to address emotional needs.
- **Faster Diagnostic Pathways:** Research strategies to reduce referral and treatment delays to address systemic bottlenecks, and how to integrate with alternative/complementary medicine and treatment.
- **Culturally Competent Care Models:** Study the integration of traditional remedies with biomedical treatments, addressing cultural preferences.

- **Accessible Research Participation:** Offer flexible engagement options (e.g., phone, drop-in sessions) with transport and childcare support to overcome logistical barriers.

- **Shift from consultation to collaboration with communities:** Foster partnerships with trusted figures, collaborate with GPs, pharmacists, and faith leaders to disseminate information and recruit for research, leveraging their credibility. Dedicate a specific month of the year to cancer when people can and access routine check-ups in local settings like GPs or pharmacies which are easily accessible to everyone.

- **Publicly report back** to communities on how their input shapes research and services.

- **More Funding:** Advocate for and shape policy towards funding to help local hospitals provide facilities and resources to support new research with communities.

- **Provide support and signpost** cancer survivors and their families to organisations that can help them, e.g. Macmillan, Cancer Research UK

Public and Community Involvement and Engagement Action Plan for the Sussex Cancer Research Centre (SCRC)

To operationalise the recommendations based on community insights and to build sustainable community engagement and inclusive cancer research pathways, the following action plan outlines practical and targeted steps for the Sussex Cancer Research Centre (SCRC).

Table II: PCIE Action Plan for SCRC

Short Term (0-12 months)		
Goal	**Key Actions**	**Measures of Success**
Increase SCRC visibility in communities across Sussex	• Launch awareness campaign via local radio, social media, and translated flyers prioritising areas served by VCSE partners • Attend community events with pop-up stalls • Offer accessible information sessions explaining how cancer research works, including the typical processes and timelines to develop new drugs/therapies or new diagnostic methods, and implementation into health care	• Increase in public awareness of SCRC (through event feedback, short polls, or partner VCSE feedback) • Number and reach of translated materials (leaflets, videos, QR codes) • Engagement analytics (video views, QR codes, WhatsApp/Instagram reach) • Attendance at, and reach of community events/pop-up stalls
Build internal cultural competence	• Deliver cultural humility and competency training for researchers • Co-deliver with lived experience trainers and community researchers	• Number of staff trained • Pre- and post-training reflection or short confidence assessment • Evidence that training has influenced practice (CR/VCSE feedback, improved communications)
Develop multilingual communication toolkit	• Translate core materials into the different languages identified in the project • Use plain language and visual formats	• Number of languages included (aligned with those most represented in interviews) • Dissemination reach via VCSE networks

	• Prepare a dissemination plan with VCSEs for sharing them effectively with communities	• Community feedback indicating improved clarity/understanding
Establish a community advisory group (CAG)	• Recruit 8-12 public members from diverse communities • Co-design engagement, research priorities and feedback loops with the group	• Diversity of CAG membership (languages, lived experience, geography) • Regularity of meetings and participation levels • Evidence that CAG input influenced decisions/materials
Medium Term (12-24 months)		
Launch Community Navigator Programme	• Recruit, train and support 5–8 community health champions • Pair them with SCRC researchers for outreach, signposting and study input	• Navigators recruited and trained • Number of outreach engagements delivered • Increase in participation from communities who do not speak English as a first language • Community trust indicators (short feedback forms or partner VCSE reflections)
Host participatory research workshops	• Run small workshops using inclusive methods (e.g., photovoice, mapping, theatre) in trusted community venues • Pilot engaging different age and language groups through tailored sessions and translated content and co-deliver with VCSE partners	• Number of workshops held in trusted venues • Diversity of participants (language, age, lived experience) • Evidence that outputs informed research priorities, materials, or study design
Develop and distribute 'cancer care & research' explainer packs	• Co-create illustrated explainers, short videos and myth-busting content with CRs and communities, with advice from CAG	• Number of explainer resources produced (print, video, visual) • Distribution reach via VCSEs, faith groups, and pharmacies • Engagement metrics (QR scans, views, event uptake)
Start storytelling pilot	• Record 5–10 participant stories with consent. • Share via podcasts, community screenings, social media and SCRC website.	• Number of stories recorded, translated (if needed), and shared • Use of stories in awareness events, training, or digital campaigns • Feedback from participants indicating reduced stigma or increased understanding

Biennial Evaluation	• Evaluate the pilot interventions of the first two years, involving CRs, VCSE partners and/or the CAG. This will be crucial for scaling up in the next long-term phase.	• Completion of evaluation report with CR and VCSE input • Number of recommendations implemented in next cycle • Evidence of changes made based on the evaluation
Long Term (beyond 24 Months)		
Build sustained partnerships with community organisations/VCSEs	• Co-fund and/or co-bid for joint initiatives that embed CRs in research	• Number of jointly designed or delivered initiatives • Evidence of ongoing collaboration (shared resources, joint funding bids) • VCSE feedback indicating strengthened partnership and reciprocity
Integrate community feedback into research funding decisions	• Involve CAG in research design, grant applications and review processes • Publish how community input and feedback shaped research decisions	• Clear examples of CAG and community input shaping funding applications, priorities, materials, or study protocols • Transparency: publication of community-shaped decisions on SCRC platforms
Scale storytelling and peer education model	• Train additional storytellers • Embed survivor and caregiver voices in all major SCRC initiatives and public outreach	• Number of trained storytellers/peer educators • Frequency of storytelling activities in community settings • Evidence of impact: increased engagement, reduced stigma, improved understanding
Monitor and evaluate inclusive engagement impact	• Track participation by ethnicity, language, gender, and region • Publish annual engagement-impact reports and learning summaries	• Annual data tracking participation by language, geography, community group, and lived experience type • Identifiable trends showing increased participation from underserved groups • Public annual engagement impact summaries shared with communities • Evidence of reduced barriers reported (language, awareness, access)

Appendices

Appendix I: A Note on Methodology

I. Identification and Recruitment of Community Researchers

The project started with identification and recruitment of community researchers with lived experience of cancer screening, treatment, diagnosis, and/or caregiving. The identification was done at three levels: first through internal DRI networks, particularly the carer groups that it runs, second through the Sussex-based REN VCSE partners, and finally an open call for expressions of interest was circulated again in the DRI's internal networks and through the VCSE partners.

Following the identification, a selection panel was set up consisting of four members: the lived experience lead at SCRC, a Sussex Health & Care Research Partnership PCIE advisor-with specialist cancer knowledge and lived experience, and two members from the project team. For selection of the CR candidates, the panel considered four crucial factors: pan-Sussex representation, lived experience, gender diversity, and diverse forms and types of cancer. One of the primary considerations during the selection of community researchers was ensuring representation from diverse communities and places across Sussex, which in turn ensured that a diverse set of community members is engaged in this research. The idea was to focus on and reach out primarily to the members from minoritised and marginalised communities and ethnicities across Sussex as they have been found to be less represented in health and care research.

A total of eight candidates were selected as community researchers for this project. In addition to this, all the existing community researchers who had conducted research for the Phase One of REN were invited, among whom seven agreed to be part of this project leading to a total of 15 CRs involved. Most CRs who were a part of the research were bilingual or multilingual which played a crucial role in engaging participants who do not speak English as a first language and not needing to mediate conversations through interpreters.

II. Community Research Training

The newly selected candidates were provided bespoke training on core community research to develop basic research skills and knowledge required to carry out the project activities effectively. The training was devised by the Trust for Developing Communities (TDC) during the REN Phase One for the first cohort of the community researchers. DRI collaborated with TDC for delivering the training to new community researchers with minor adjustments specific to the cancer project. These adjustments were made in consultation with the SCRC lived experience lead, the PCIE advisor and DRI project lead. The training was delivered over three sessions and covered the following:

- Overview and objectives of the Cancer Research Engagement project
- Context and rationale for community research
- Principles of qualitative research
- Key principles and ethics for inclusive and effective community research
- Community research in practice
- The core principle for good qualitative interviewing
- How to use the discussion/interview guide during the interview
- Analysing qualitative interviews
- Coding and preparing qualitative analysis for report writing
- Summary report writing

Continuing the approach from REN Phase One, all the community researchers were hosted by VCSEs to provide necessary support in the research process particularly with respect to community engagement. The VCSEs involved in this project are:

- Diversity Resource International (DRI); lead VCSE: 4 Community Researchers
- Trust for Developing Communities (TDC): 1 CR
- Sussex Interpreting Services (SIS): 7 CRs
- Voluntary Action Arun and Chichester (VAAC): 1 CR
- Cancer United: 1 CR
- Crawley Community Action: 1 CR

III. Co-Creating Research Tools

a. The First Workshop: Co-creation

On April 01, 2025, all the community researchers, the project team and representatives from the SCRC and host VCSEs assembled for an online workshop. The session started with a statement affirming commitment to fostering a space that values diversity, equity, and inclusion and the celebration of unique perspectives and identities of individuals, ensuring respect and rejecting all forms of discrimination, including racism, ableism, homophobia, and transphobia. In the first half of the workshop, there were introductory presentations that included the overview, objectives, and methodology of the project as well as discussion of cancer research and the rationale for SCRC's engaging of communities and people with lived experience of cancer. In the second half, the community researchers co-created the first iteration of the interview guide through group exercises in the breakout rooms. The co-creation was moderated by the REN team, VCSE representatives, and the SCRC lived experience lead. For this exercise, collaborative platform Padlet was used by all the members during the group exercise for sharing their input in real time. The community researchers subsequently provided further feedback to this draft of the interview guide in a follow-up workshop meeting. The final Interview Guide is attached as appendix-I at the end of this Report.

b. The Ethics Panel

As a simultaneous process, DRI set up an ethics panel comprising of two DRI directors who are both academics, a community researcher/member who is not part of REN, and a professor of Social Work from University of Sussex. It was ensured that none of the panel members were involved in the project at any level. Following ethical review, and incorporation of modifications request by the ethics panel, the project was approved. An ethics guideline document for community researchers was produced to ensure compliance with the ethical requirements of the project while carrying out the research. All the CRs signed the ethics guideline document.

c. The Community Research Pack

Based on the co-creation workshop and the ethics panel recommendations, the community researchers were given a total of four documents for conducting their interviews. These included:

- The interview script (Appendix-I)
- Participant information sheet and consent form (Appendix-II)
- Ethical guidelines document (Appendix-III)
- SCRC Introduction Note (Appendix- IV)

IV. Community Member Interviews

With the help of their host VCSEs, the community researchers identified participants within communities they are members of or work with and interviewed 3-4 community members each. The criteria of inclusion for interviewees were lived experience of cancer screening, diagnosis, treatment, or caregiving. Preference was given to people from minoritised backgrounds with English not as their first language. Most of the interviews were conducted in-person in a range of settings as per the feasibility and convenience of the research participants. The community researchers explained the objectives and purpose of the interviews along with ethical issues like confidentiality, anonymity and the interviews were carried out following all protocols including signing of the participant information sheet and consent forms. All interviews were audio recorded for the purpose of subsequent generation of transcripts and thematic analysis. Participants were provided with a participant honorarium gift voucher.

- **The Second Workshop: Preliminary Findings and Thematic Mapping**

On April 22, 2025, the second project workshop was convened online where community researchers presented their initial impressions and preliminary findings from their interviews. The Workshop started with a refresher session on data analysis and report writing delivered by TDC. The CRs were divided into breakout rooms with four CRs and a facilitator in each room. All CRs presented their initial impressions focusing on the interview process, common themes that emerged, and two recommendations that they could make at this preliminary stage. Padlet was again used collaboratively, particularly for collecting common themes.

Based on the discussions and the themes that emerged in the workshop, a guidance document for writing the summary findings was shared with the community researchers.

V. Analysis and Report Writing by Community Researchers

The CRs transcribed the recorded interviews (in most cases) first in the languages they were conducted and then in English. Subsequently the CRs carried out a thematic analysis of their interviews, and each produced a 3–4-page summary report, each of which was reviewed by host VCSEs and submitted to DRI for the final Report. The summary findings in the brief reports are comprised of five common themes along with a few other insights specific to each report. The most commonly identified and recurring were:

- Awareness and perception of SCRC and local cancer research initiatives
- Willingness and preferences for sharing lived experiences
- Engaging communities in SCRC's work
- Community challenges
- Research priorities

- **The Third Workshop: Stakeholder Workshop**

On May 21, 2025, for the third and final workshop, representatives from SCRC, partnering VCSEs and cancer care organisations joined the community researchers to discuss the findings and the next steps, particularly the co-creation of the PCIE plan for the SCRC. The workshop started with a detailed presentation by a DRI team member on the key findings and recommendations of the project. These findings were based on and informed by the reports and summary findings prepared by community researchers. In three breakout rooms, CRs and other participants discussed these findings and recommendations and provided feedback using Padlet. It was followed by a short presentation by a REN team member explaining what an engagement plan looked like and how the findings and recommendations of this project could be consolidated into an engagement plan for the SCRC. This was followed by another group exercise in breakout rooms where CRs and other participants brainstormed on the specifics of the PCIE plan.

After the workshop, the report summaries and the collaborative work from the workshops was analysed and consolidated into this project report. In total, the cohort of 15 community researchers conducted 47 interviews between April and May 2025. During the interviews, CRs were able to gather demographic information about the participants which when collated and analysed offered insights into the range of communities that became part of this engagement exercise. Such demographic information will be informative for designing future outreach efforts for the SCRC.

Appendix II: Interview Script (REN Cancer Project)

STEP 1: WELCOME AND INTRODUCTIONS

- Thank them for giving up their time to speak with you (make them feel welcomed and valued)
- Introduce yourself
- Explain how the interview will work
    - Length and format (1 hour-1-5 hours)
    - How it will be recorded (on mobile/recorder) [It is advisable that participants are asked in advance about their consent for recording]
    - Reassure them that you can repeat or clarify questions
    - Reassure them there are no right or wrong answers
    - You can take a break or stop at any time
    - About anonymity: Their responses/quotes in the report will be used anonymously
- Allow for any questions before you provide a brief overview of your research

- Please note down the name, gender, age group, first language, self-described ethnicity, location of the participant and any lived experience/association with cancer.

[You might not need to ask this as a question as you would know most of these details already when you identified the participant for this research but please make sure that you do note down all these details]

STEP 2: OVERVIEW OF YOUR RESEARCH

- Provide a very brief description of your research (you will have provided a pre-read in advance for them to read or discussed on phone so this should be a recap and any additional information):

The project aims to:

1. Develop a community engagement plan for the Sussex Cancer Research Centre (SCRC).
2. Ensure people with lived experience of cancer are at the heart of research at the SCRC.
3. Understand how the community members across Sussex would like to engage with cancer research happening locally.

[Note: Please use the brief SCRC intro to share more information about the Centre]

- Explain why you are involving community members and how you will use their insights

The insights from this research will be used to develop a community engagement plan for the SCRC. We can use this to help the Centre to include people with different kinds of lived experience to be actively involved in the Centre. This could be hearing about research, helping set research priorities, designing studies or much more.

- Explain what stage of your research you are in and what is next

I have completed my core community research training and now I along with other community researchers affiliated with this project are conducting interviews with community members in our own communities/networks.

- Allow for any questions before you ask your interview questions

STEP 3: GUIDING INTERVIEW QUESTIONS

[***IMPORTANT** These are mere suggestions; community researchers are free to modify/change/add questions so long as the main objective of project is being taken care of i.e. getting concrete examples of how people would like to engage with the SCRC. You do not have to ask all of them]

Warm-up Questions

1. To get started, could you tell me a bit about yourself, what you enjoy doing, what keeps you busy these days, or anything you would like to share?

2. Have you ever been part of a conversation or project about cancer research or community health before? If so, what was that like for you?

Main Questions

3. Before this conversation with me today, had you heard of the Sussex Cancer Research Centre or any cancer research happening locally? If yes, what had you heard, what did you think of the information?

4. SCRC is keen to learn from people's lived experiences with cancer. What would make you feel comfortable sharing your own story or thoughts with their researchers—it could also be about someone you know, or even general opinions?

5. What do you think SCRC could do to get you or people in your community curious and interested in the SCRC's work?

[IF THEY NEED SOME EXAMPLES ADD] This could be through community events, running workshops, providing information, having a website, distributing short films or anything else you can think of. [Probe for details of what these might look like e.g. when, where, when, how?]

6. The SCRC wants to find ways of getting input and feedback from communities on existing or new research projects. What kinds of activities or approaches would encourage you or members of the community to provide input and feedback?

[Examples of what SCRC might want input/feedback on are: asking individuals to attend a focus group and them saying what they think about how a research study has been designed. It could be about an individual reading the 'patient' information sheet for a research study and feedbacking on how it could be improved. Filling out a survey about what they think is important to study in cancer research.

7. The SCRC also wants to involve communities at all stages of the research process like shaping research questions then looking at the study findings together. Is this something that you would be interested in?

[Examples of involvement: being on a project advisory group, contributing to the research agenda, advising on recruitment and data collection, co-producing research materials, participating in interpreting the findings and dissemination]

8. The research that is conducted at SCRC should be based on real world problems that are important for communities. From what you have seen or heard, what are some of the biggest hurdles people in your community face when it comes to things like cancer screening, diagnosis, and treatment?

9. From what you have seen or heard, what are some of the biggest hurdles people in your community face when it comes to finding out about research opportunities (related to cancer research)?

10. How do you think SCRC could help tackle these challenges and make a difference for people in Sussex (reflect on cancer screening, treatment, caring and research)?

[Examples could be organising cancer screening days with local doctors and pharmacies, starting research studies locally to test new treatments, and investigate how common cancer is in the area to spot trends and patterns]

11. Do you feel that things like your cultural background, gender, sexual orientation, ethnicity, race, education, where you live or other markers of your identity have shaped your experiences with cancer care, research, or the support available? If so, how?

Closing Question

12. Is there anything else want to share about how SCRC could connect with you or your community that we haven't talked about yet?

STEP 4: WRAP UP

- Explain what the next steps for you are and when they can expect an update on how you used their responses

We will transcribe these interviews, write our brief findings and share it with our project team who will convert it into a report/plan which should be available in the month of May on the website of SCRC, REN, DRI, and other partner VCSEs. I will share a copy of the report with you.

- How they claim their honorarium/thank you voucher

Thank you vouchers worth £25- £37 that can be used on all major supermarkets in the UK. Take their phone number/email on which the voucher will be sent out.

- Express Gratitude

IMPORTANT CONTACTS

For any logistical issues during/after the interview please contact : Tacye Turner at Tacye@driorg.com / 07586340592 & Mudasir Amin at admin@driorg.com / 07741754870
For any other issues regarding wellbeing/emotional issues during/after interviews please contact: Jane Woodhull at janewoodhull@outlook.com /07590495403 or Patrick

Appendix III: Participant Information Sheet and Consent Form

Project Title: Developing Public and Community Involvement and Engagement (PCIE) plan for Sussex CANCER Research Centre (SCRC)

Project Lead/ Research organisation: Sussex Research Engagement Network (REN)
Implementing Partner: Diversity Resource International (DRI)
Project Funded by: NHS England

Objectives of the Research:

- Develop a community engagement plan for the Sussex Cancer Research Centre (SCRC).
- Ensure people with lived experience of cancer are at the heart of research at the SCRC.
- Understand how the community members across Sussex would like to engage with cancer research happening locally

[Note: Please also see a brief overview of the Sussex Cancer Research Centre attached with this]

Declaration of Consent (Initial each box)

I have read the Overview, have asked questions about the study, and have received satisfactory answers to my questions.	
I understand that participation is voluntary and that I am free to withdraw myself or my data at any time, without giving any reason, and without any adverse consequences.	
I understand who will have access to personal data provided.	
I understand how personal data will be stored and what will happen to the data at the end of the project.	
I understand how the research will be written up and published.	
I understand how to raise concerns or make a complaint about aspects of the research	
I understand the potential risks and benefits associated with this project	
I understand that quotes from anonymised audio recordings/transcripts/notes may be used in research outputs.	
I agree to take part in the study.	

If you would like a copy of the report, please provide an email address:

Name of Participant:

Signature:	Date:
Name of Community Researcher:	
Signature:	Date:

The information you provide in this form is for the sole purpose of recording consent and will not be used in the report.
Should you have any concerns with this research, or you require further information, please contact Mudasir Amin at admin@driorg.com

Appendix IV: Ethical Guidelines Document

DRI Ethical Guidance for Community Researchers (CRs)
For use during data collection activities – April – May 2025

Why Ethics Matter
As a Community Researcher, you work closely with people in your community, which comes with responsibility. It is important that you treat people with respect, care, and professionalism. In addition as a researcher, you are guided by the essential principles of ensuring confidentiality and anonymity and seeking informed consent.

Ensure you have access to a Consent Form and a Participant Information Sheet to share with your participants.

This ethical guidance supports you, as a researcher, in always following good ethical practice while collecting stories, experiences, perspectives, and information.

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1. Informed Consent

Before carrying out any research, you must:

- Clearly explain verbally who you are and what the project is about.
- Ensure that the research participant has read, understood, and signed the Participant Information Sheet, which provides information about the research and its process.
- Let the participant know their participation is voluntary (they can say no or stop at any time during or ask for their information to be deleted for a defined time after the research intervention).
- Get clear permission, as stated on the Consent Form, to take notes, record, or use their words as part of the research.
- Clearly explain verbally how the information they share will be used.
- Ensure that they understand and sign a Consent Form and have the contact details of those managing the research.

Tip: Use simple language when explaining the project, its purpose, and how the research will be carried out, and always check that the participant understands.

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2. Confidentiality and Privacy

- In all of your write-up or recorded material, take great care not to share personal information (e.g. names, addresses, anything that could identify the participant)
- Store any notes or recordings safely and securely (use a password if digital or lockable cupboards if paper) and clearly state that all information gained will be deleted at a specific time.
- Make it clear to the participants that everything shared will be kept confidential unless they share something that makes you concerned that they or someone else is at risk of harm. This will be shared with the project lead.
- We recognise this is a community project, and people may know each other. However, information shared in interviews should not be shared outside the project.
- Important: If someone says something that suggests they are at risk of harm, speak to your DRI contact immediately.

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3. Respect and Cultural Sensitivity

- Be kind, non-judgmental, and open-minded
- Let people speak in their way and ensure that they can take breaks if needed
- Be aware of cultural or personal differences that might affect how people talk or share
- Avoid pressure or persuasion - listen with respect and sensitivity.
- Where there have been language barriers, explore what is available to address them.

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4. Minimising Harm

- Avoid topics that might be upsetting and beyond your trained expertise as a community researcher.
- If someone becomes distressed, stop the interview or focus group and support them.
- Offer signposting to help on the Participant Information Sheet (e.g. support organisations or services).
- Let participants know they do not have to answer anything they are uncomfortable with.

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5. Your Responsibility

Before starting fieldwork:
Have a good understanding of the purpose, remit and limitations of this research

☑ Read and understand this guidance
☑ Ask questions if anything is unclear
☑ Sign to confirm you agree to follow these principles

And remember the importance of sensitivity and confidentiality

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Signed: ___________________________
Name: ____________________________
Date: _____________________________

Please include this signed form in your final report. This shows that your research followed ethical practices.

If you have concerns or questions, don't hesitate to get in touch with your DRI lead.

Appendix V: Sussex Cancer Research Centre (SCRC) Introduction Note

The Sussex Cancer Research Centre (SCRC) is a pioneering initiative in Sussex, England, dedicated to improving cancer treatment and outcomes. It was Launched in June 2024. It brings together world-class researchers, clinicians, and people with lived experience from Brighton and Sussex Medical School, the University of Brighton, the University of Sussex, and local NHS trusts, including University Hospitals Sussex. The SCRC's work spans from laboratory research to clinical applications, focusing on translating scientific discoveries into real-world benefits for people affected by cancer.

SCRC conducts cutting-edge cancer research, supports innovative projects, and fosters collaboration across institutions. It also engages the community through creative initiatives, such as art and writing workshops, to connect people with lived experience of cancer to the research process. The Centre provides funding for PhD studentships, early-career researchers, and community engagement projects, ensuring Sussex remains a hub for cancer research excellence.

Aims and Objectives of SCRC

- Enhance cancer care by bridging the gap between lab research and bedside treatment, ensuring all people with cancer benefit from Sussex-based advancements.
- Put people with lived experience and their stories at the heart of research, encouraging their input to shape studies and priorities.
- Foster collaboration among researchers, clinicians, and the community to share knowledge, resources, and expertise for greater impact.
- Fund groundbreaking research and nurture the next generation of cancer researchers to drive long-term progress.
- Engage the Community by building meaningful connections with diverse Sussex communities, ensuring research reflects their needs and experiences.