Cancer Theme – Outreach Events January to April 2025

1. Introduction to Community Outreach Events

Three Community Outreach events were undertaken by the Cancer Theme of the Nuffield Department of Primary Care Health Sciences (NDPCHS) at Oxford University.

The aim of the events was to explore the views and experiences of the public about cancer testing in NHS General Practice and other community settings.

This report provides an overview of how the Community Outreach events were planned and delivered. It also outlines key findings and next steps.

2. Selection of Locations

Three locations were selected for the focus groups on the basis of meeting the criteria for inclusion within the NHS Core 20 Plus 5 strategy (NHS England, 2021)[1]. This strategy focuses upon improving health inequalities (including early diagnosis in cancer) for the 20 % most deprived areas in England and other groups which face additional, at times intersectional, barriers such as ethnic minority communities and coastal communities. Partnerships were developed at the local level to facilitate the focus groups.

Three locations were selected following planning and consultation within the Cancer Theme team. The three locations selected based on the above criteria were Leicester (East Midlands), Penzance (Cornwall) and Tower Hamlets (London).

2.1 Developing Relationships with Local Organisations

We developed mutually beneficial relationships with local community groups, health and research networks through the following ways:

- Promoting Community Consultation events via voluntary and community sector (VCS) communications, statutory and health services channels through digital and online media, in Leicester and Tower Hamlets (see table 1. below).
- Attending public focused events to promote Community Outreach events directly to public, (see table 1. below).
- Hosting regular planning meetings with health and VCS stakeholders in Cornwall including Whole Again Communities, NIHR Regional Research Delivery Network South West Peninsula (RRDN SWP,) Volunteer Cornwall and the Atlantic Medical Group.
- Identifying potential partners to assist with planning, hosting events and delivering health and wellbeing information at events. This resulted in the delivery of jointly planned events with Whole Again Communities in Penzance and the Carers Centre Tower Hamlets in London, whilst the event in Leicester

was planned directly by the Cancer Theme based on previously known local knowledge and contacts.

Table 1. Community Engagement Approaches by Locations

Location	Organisation	Methods of communication / engagement
Tower Hamlets	Carers Centre, Tower Hamlets (CCTH)	• Initial contact established via promotional article in Tower Hamlets Health and Wellbeing Forum. • Regular planning meetings between Community Liaison Manager and THCF. • Disseminated event flyer and partnered to host event.
Tower Hamlets	Bangladeshi Housing Association	• Initial contact established by Community Liaison Manager. • Attended summer fair to promote planned event and handout flyers.
Tower Hamlets	Tower Hamlets Health and Wellbeing Forum	• Published promotional advert, highlighting collaboration. • Attended online forum meeting. • Event flyer distributed to forum membership.
Tower Hamlets	Caribbean and African Health Network (CACATH)	• Contacted by Community Liaison Manager to participate at their inaugural event. • CACATH agreed to disseminate event flyer via email to their membership.
Tower Hamlets	Tower Hamlets Community Navigator	• Introduced to Community Liaison Manager by Tower Hamlets African – Caribbean Communities Association. • Event flyer disseminated to Community Navigator area-based contacts.
Tower Hamlets	Tower Hamlets Walking Groups	• Co-ordinators contacted and requested to forward.
Leicester	Voluntary Action Leicester	• Published event flyer in online newsletter disseminated to membership.
Leicester	Reaching People	• Disseminated event flyer online to membership.
Leicester	Leicester LGBT Centre	• Disseminated event flyer online to membership.
Leicester	Sue Young Cancer charity	• Disseminated event flyer online to membership and discussed participation at event.
Leicester	Wellbeing Champions online Forum meeting	• Participated in online forum members meeting to inform both statutory and VCS members of planned event. • Contact established with Sue Young charity and African Caribbean heritage network.
Leicester	City Retreat	• Initial contact made dropping flyers to display on notice board. • Attended Public fair to hand out event flyer to attendees and connected with organisations attending.
Leicester	Healthwatch Leicestershire	• Attended a health consultation, promoted event to attending participants.
Leicester	Jamila's Legacy	• Flyer disseminated to contacts and discussed participation.
Leicester	Apnapan	• Flyer disseminated to contacts and discussed participation.
Leicester	Together Against cancer	• Flyer disseminated to membership and volunteers.
Penzance	Whole Again Communities	• Promoted event to local people and organisations. • Partnered in planning, hosting of event.
Penzance	Volunteer Cornwall	• Promoted event to local organisations and partnered in planning, hosting.
Penzance	Atlantic Medical Group	• Provided health information, contributed to informal discussion and partnered in planning.
Penzance	RRDN SWP Agile Research Team	• Provided contacts, helped with planning, and delivered information on being involved in health research.
Penzance	Mobile Research Unit (NIHR)	• Showcasing facilities available on the mobile and providing information on research involvement.

The relationship building stage led to three events being arranged at local venues that were reviewed for accessibility and familiarity for local people to attend with ease.

2.2 Leicester Event – February 2025

Leicester is a city in the East Midlands where the majority resident population is of a minority ethnic background at 59.1%, with the largest minority ethnic community being South Asians (Office for National Statistics, ONS 2023)[2]. This event was hosted at Voluntary Action Leicestershire, which is a local charity that provides both direct services to local people and infrastructure support to community groups in Leicestershire. The event had participation from members of the public (19 people) as well as from health and wellbeing stakeholders. The health and wellbeing stall holders included:

- Apnapan – cancer support group
- Wellbeing Champions (Leicester City Public Health)
- Jamilas Legacy (mental health support)

The discussion was carried out in an informal manner in order to enable participants to contribute freely. Stories and experiences of accessing GP services were shared, along with experiences of living with and accessing support for cancer.

The public information video from Pancreatic Cancer UK was screened to assist with discussions. Research GP Brian Nicholson discussed early cancer detection research plans for primary care, including for pancreatic cancer and we showcased how non-invasive biomarker tests using blood, breath and urine would be used by displaying the actual tests and how they are used (blood vials, FIT test kits and breath testing equipment). A lively discussion occurred with cancer survivors sharing their experiences of cancer detection and treatment and the barriers and facilitators in their journey, including their engagements with their general practices.

Photo – Leicester Outreach Event at Voluntary Action Leicester (VAL)

The key issues identified by participants in Leicester:

- Siloed working in NHS, feeling of bouncing between services and lack of joined working/communications between health services. Participants felt they had to "chase services to get results of tests".
- Difficult to get face-to-face GP appointment, receptionists obstructing access. Digital exclusion and low levels of computer literacy meant that some participants perceived there were differences in opportunities available to access health services. There were strong perceptions that "some people get more help than others".
- Experiences of anxiety reported whilst people waited for results. How can they be supported? Potential role for primary care or cancer charities to provide psychological support whilst waiting for results.
- Terminology of tests can be confusing and needs explaining–positive and negative can be misinterpreted by patients, so need clearer explanations of what tests mean. Similarly, participants commented on challenges of understanding metastatic cancer and found it hard to understand, "why would breast cancer be in lungs?"
- Peer support accessed informally or via community organisations was helpful, whilst support from the NHS was seen as being absent, "where is the NHS?"
- Keen interest in which cancers could be detected by multi–cancer tests and the timeframe for when they could access multi–cancer tests as patients.
- Frustrating for patients when felt "fobbed off", with early symptoms which then go on to become cancer. Resulting in loss of confidence in health services as "one bad experience can affect others because 'people talk'."
- Infrastructure for translation support needed across NHS services, so that family members did not have to provide translation for their loved ones, whilst accessing health.
- Inadequate outcome of "all-clear" results if symptoms still persist. Frustrations expressed at lack of further investigations, "if not cancer then what is it?"
- Cancer "all clear" following treatment leads to fears of whether cancer will return and this impacts on ability to live actively "I'm fine, I'm happy, but I'm scared".

2.3 Penzance Event - March 2025

Penzance is a coastal town in Cornwall, which has some neighbourhoods with high levels of deprivation. Over 62.3% of households in Penzance Quay are deprived in at least one dimension of the Index of Multiple Deprivation, and Treneere in Penzance has one of the lowest income levels in England, (ONS, 2022)[3].

Initial contact was established between the Cancer Theme and the NIHR Regional Research Delivery Network South West Peninsula (RDN SWP), Volunteer Cornwall and Royal Cornwall Hospitals, NHS Trust. The Cancer theme was introduced to Whole Again Communities, a community organisation providing healthy eating and health information to local residents. Whole Again Communities, led on the promotions and organising of the event which was held at their venue, Trenerre Community hub. Additional promotions were undertaken by the Atlantic Medical Group (GP practice), and Volunteer Cornwall. Multiple online planning meetings were held with all partners.

The participants included 12 members of the public, men and women, with some health providers also sharing their experiences as patients. The impact of research trials was highlighted by RRDN SWP colleagues who discussed the benefits of being involved in health research and played a video of a local Cornwall based patient receiving cancer diagnosis as a result of being involved in a research trial. A patient also spoke about her experience of cancer treatment and importance of early diagnosis. Research GP Brian Nicholson spoke about early detection of cancer and research plans about how this may be achieved.

The participants talked enthusiastically about their experiences of accessing GP care and the challenges they faced, and those with a cancer diagnosis shared their experiences accessing care. They were interested in how a new range of biomarker and other non-invasive cancer testing may be implemented in general practice, when it is already struggling to keep up with patient need. We employed a visual artist to map discussion points, and he produced four pictographic accounts of the issues raised in the meeting.

On the day, health information was provided by:

- The Atlantic Medical Group (health, cancer awareness and access advice)
- The Mobile Research Unit (promoting involvement in clinical trials)
- RRDN SWP Agile Research Team (being involved in health research)

Photo – Dr Tanvi Rai initiating discussion in Penzance

Photo – Mobile Research Unit which travels around Cornwall promoting involvement in health research

The Mobile Research Unit is an innovative project established by a partnership between National Institute for Health and Care Research (NIHR), the UK Vaccination Innovation Pathway (VIP), Moderna and EMS healthcare.

Penzance is one of the locations in Cornwall where the Mobile Research Unit is used to help people in rural and coastal communities to participate in research more easily, without having to travel so far to provide samples in hospital clinics.

Photo – Lisa Trebath and Jack Tiffin from Royal Cornwall Hospitals Trust, who deliver the services of Mobile Research Unit around Cornwall

Highlight of the event for many people was the sketch artist Keith Sparrow and his visualisation of the key themes discussed:

Photo – Sketch Art Visualisation of Discussion

Key issues discussed by Penzance participants:

- Difficult to get testing for cancer at younger ages. Participants talked about not being taken seriously by GP if they were younger than average age of diagnosis for a specific cancer. One participant recalled being told by his GP that he was "too young for PSA test at 44 years of age", despite having ongoing symptoms (which later turned out to be prostate cancer).
- Struggles to be taken seriously by GPs cause people to lose trust and confidence in health professionals. A participant shared the challenges and

repeated dismissals she faced, until she finally received a referral for further testing, which did lead to a positive cancer diagnosis.

- Confidence in GPs could be increased to some extent by GPs and primary care explaining reasons to patients for not testing or referring to hospital, “tell us, even if it is to tell us the waiting lists are too long or if we do not meet the criteria for referral”.
- Having to travel to distant hospitals from home because of a lack of infrastructure in Cornwall. This adds to tiredness and is very uncomfortable for anyone with cancer, “its uncomfortable after chemotherapy, and also having to wait a long time to take a wee because the hospital is too far”.
- Participants perceptions that if GPs not taking current health concerns seriously, why would they undertake non-invasive cancer tests at patient request.
- Lack of communication and joined up treatment plans between GP and cancer specialists for patients with other chronic illnesses in addition to cancer. This makes it difficult and confusing for patients to know which service to seek help from, “who provides the support when you have other conditions and cancer?”
- Suggestion about developing ‘body literacy’ so patients can understand what is normal for themselves and can communicate this better with GPs when there are changes.
- Seeing different GPs each time erodes confidence, “oh my days, everyone knows my life–it’s not a newspaper, it’s private. It’s too much for some people, they stop going. I like going to see the same GP. I don’t want to see Tom, Dick and Harry, I want to see Tom, Dick or Harry.”
- Suggestion for patients to receive training on how to use specific language and words so that GPs take concerns for testing seriously.
- Some improvement in provision of health services identified across Cornwall over time and especially over 10 years.
- Interest in multi-cancer tests and which cancers they would focus on. Suggested that multi–cancer tests be implemented “automatically”, like screening, to be successful.
- Perceptions that patient will only get adequate treatment “if you kick up a fuss”.

2.4 Tower Hamlets Event - April 2025

Tower Hamlets is a very diverse borough of London, with high levels of socio-economic deprivation and a high Black, Minority Ethnic resident population. Based in close proximity to the affluent City of London, and despite improving deprivation levels, Tower Hamlets still remains highly deprived as the 50th most deprived area nationally (Tower Hamlets Council, 2020)[4.]

Promotions and networking were undertaken with local voluntary and statutory sector organisations to promote the event and for local organisations to co-host. Tower Hamlets Carers Centre initiated contact with the Cancer Theme Community Liaison Manager and discussions resulted in to co–hosting an event at the Tower Hamlets Carers centre in Stepney Green. The Carers Centre were responsible for promoting the event to their members, whilst the Cancer Theme Community Liaison Manager promoted the event more widely.

Tower Hamlets Carers Centre showed a video they had produced with North East London Cancer Alliance highlighting issues carers encountered when accessing cancer services. We screened the public information video from Pancreatic Cancer UK to assist with discussions. Research GP Brian Nicholson discussed early detection of cancer research plans in primary care, which opened up discussion about the particularly difficulties faced by carers to see a GP (due to their caring responsibilities). Malachi, the Community Navigator delivered a presentation on how the Navigators role worked in the local area to support local people to access health services.

Photo - Associate Professor Dr Brian Nicholson outlining background to introduction of non–invasive cancer tests at the Carers Centre

Partner organisations that participated by sharing health and services information and their resources included:

- Tower Hamlets Healthy Workplaces – providing blood pressure and BMI tests
- North East London Cancer Alliance
- QuitRight (Smoking cessation)
- Tower Hamlets Carers Centre – carers and cancer leaflet
- Community Navigator – signposting to health service

Photo - Tony Collins - Moore from Tower Hamlets Carers Centre highlighting challenges in accessing cancer services for carers and cared for

Discussions identified the following key issues:

- Participants strongly felt that services not joined up, e.g. between primary and secondary care –referrals can get lost, people with multiple diseases/disabilities particularly struggle to navigate system.
- Difficulties getting appointments to see GP or undergo tests (e.g. blood tests, scans) may face waiting lists for non-invasive cancer tests.
- Carers face difficulty when accessing health services for themselves as they often need to arrange someone else to care for their “cared for”, whilst attending appointments. It was felt that some level of flexibility was needed within health systems for carers.
- Carers not always identified on health records of the person they care for, which leads to difficulties in being able to access help for the person they care for. “They should join up records of carers and the person they care for, otherwise I have to explain things from the beginning all the time.”
- Ongoing frustrations regarding having to repeat information to healthcare services, even to own local GP whom is seen more frequently than other health professionals, “my son is non-verbal”.
- Tests may not be accessible to everyone and reasonable adjustments/alternatives are not always offered, “some people can’t stand to have mammogram done or told they won’t tolerate endoscopy.”
- Flexibility within health systems was suggested so that the carer and the person cared for could be seen at the same appointment, as making arrangements for separate appointments was challenging and meant carers put their own health needs aside.

Photo - Tower Hamlets Community Navigator Malachi Howe's Information Resources

Community Navigator, Malachi, is responsible for guiding and signposting local individuals who wanted to improve health and wellbeing to appropriate services.

Photo - QuitRight Smoking Cessation Services

3. Lessons Learned on Implementing Delivery of Non-Invasive Cancer Tests

The three Community Consultation events indicated that participants would welcome the introduction of new cancer tests into General Practice and the community, as they valued the early detection and early treatment of cancer.

Participants highlighted key issues that they thought should be addressed prior to the introduction of new tests into General Practice and the community. Key issues included difficulties in access to primary care, poor communication of test results, a lack of recognition of different needs of diverse patient groups, and poor continuity of care both within primary care but also between primary and secondary care. They suggested that prior to the introduction of new cancer tests in General Practice there was an urgent need to improve these issues so that care was easier to access and more consistent for all patients and their carers.

Some participants found experience of booking appointments with a trusted GP stressful and complex. Participants also described their difficulties in being able to

communicate the seriousness of their illness to GPs. Some participants highlighted a need for patients to learn about the types of terminology and language that GPs would consider serious enough to make further referrals and to conduct specific tests.

Outreach group discussions demonstrated that participants felt strongly that improving basic primary care processes and the relationship between GPs and patients would benefit efforts to improve cancer testing.

4. Next Steps

By reviewing the feed-back we gathered from the outreach events as part of our internal review we have identified some practical outputs to address gaps and communication shortfalls related to navigating health services pathways, clarifying health and research terminology and empowering both patients and primary care professionals.

We are committed to:

- Producing a video explaining what cancer is, what metastases is and why cancer spreads from original site and what cancer test results mean. Content will cover role of primary care in cancer research and empower patients to contact GP if no follow up has been arranged after a test.

- Engaging with local GPs to attend consultation events and be part of the local conversation, outline terminology patients can use to navigate pathways and communicate effectively with health professionals, improving access for all, including groups perceived to be too young for specific cancers.

- Producing a glossary of commonly used terminology in areas such as tests i.e. positive and negative tests and health body literacy.

- Arranging follow up information events in each location to promote ongoing research studies, such as the ARMADILO study which will be the first evaluation of multi-cancer tests in primary care. These follow up events will take place between October 2025 – March 2026

- Delivering a GP led information session for local carers to improve knowledge of mechanisms within health services to link data, information of people being cared for, with their carers.

- Producing and forwarding a lay summary of this report by end of July 2025 to delivery partners, so they can provide copy to participants of focus groups.

- Delivering a carer education session to Nuffield Primary Care Health Sciences department, led by Tower Hamlets Carers Centre to address carers concerns accessing primary care.

- Including community participants as co-authors in our research and in our upcoming and future published writing.

- Enable GPs and local peer support groups to identify opportunities for local support groups and charities to fill NHS gaps in supporting patients waiting for test results and those who have received “all clear”, but still require wellbeing support.

References

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