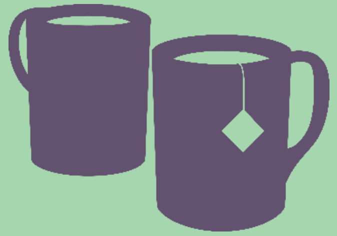
Health Awareness: Barriers to Cancer Screening in Crawley

Community Participatory Action Research

citizens advice in West Sussex
North South East

citizens advice in West Sussex
North South East



We are Citizens Advice

We can all face problems which seem complicated or intimidating. At Citizens Advice, we believe no one should face these problems without good quality independent advice and advocacy.

Our goal is to empower people and reduce inequalities so they can move forward and thrive.

We want every voice to be heard and to improve the policies and practices that affect people’s lives.

Citizens Advice in West Sussex (North, South, East) is an independent local charity, a member of the Citizens Advice Network.

Contents:

Background

What is CPAR?

Community members decide on the issue to be researched, design the methodology, carry out the research and make use of the results to influence policy and practice.

This is a very empowering methodology as it is ultimately the community members who achieve the real change.

Our Research Topic

During the Lung Cancer campaign, community members in Crawley acknowledged that there are various barriers when accessing primary care, which can be concerning for long term illnesses as it can be cancer.

Therefore they chose to research the topic of cancer screening, as they emphasised the fear around this in particular.

Who

The research was commissioned by Health Education England South East and developed in collaboration with the Office for Health Improvement and Disparities (previously PHE), the Scottish Community Development Centre and NHE England and Improvement.

Research Proposal

Throughout our previous research a common theme which occurred was that ethnically diverse communities face various barriers when accessing primary care.

Community members told us that sometimes they are unable to accurately express symptoms which is a major concern, especially when experiencing symptoms which could be a sign of a long term illness such as cancer.

Our advisory group, which consists of local community members from ethnically diverse backgrounds, highlighted that carrying out research which focuses on improving the access to cancer screening was essential.

Furthermore, with the increasing awareness work around Lung cancer alongside the new diagnosis hub opening up in Crawley, community members expressed the need to cover research around access to cancer screening.

Therefore, the focus of our project was to understand the attitudes and experiences to cancer screening in order to help us identify barriers to accessing screening, particularly for ethnically diverse communities in Crawley.

CPAR methodology is a community-centred methodology that allows gathering community-led recommendations that address specific barriers faced by members and achieve change.

Research Aims

① Understand the knowledge and attitudes on cancer, with a focus on cervical, bowel and breast cancer.

② Gather experiences of accessing cancer screening (and primary healthcare) in Crawley.

③ Identify barriers to accessing cancer screening services.

④ Identify community-led solutions to reduce barriers.

Gathering experiences of accessing cancer screening allowed participants to draw up the positives and the negatives of their experience, which allowed us to ask further questions regarding barriers.

For anyone who had not accessed screening directly, they were asked if they were aware of others. If not, we were able to ask them about direct barriers to accessing primary healthcare.

Our interview guide was led and reviewed by community members, and structured so we were able to talk about topics concerning systemic, cultural and lifestyle barriers.

The advantage of semi-structured interviews allowed us to be flexible and adapt our questions based on the interviewee's experience.

Promotion

Promotion

A wide range of channels were used to recruit participants, to ensure findings are representative of the diverse communities in Crawley. This included sharing flyers via social media, at places of worship in the local area, and reaching out to community and grassroots groups who took the lead by cascading the information to their networks.

Community Facebook groups

116,945 people were reached.

Information promoting the research was posted in over 24 groups.

Citizens Advice in West Sussex social media

The research was also promoted in the social media accounts of Citizens Advice in West Sussex (North, South, East).

1,519 people were reached.

Email

The project was promoted via email with key members of the diverse communities in Crawley, faith groups, grassroots movements, and voluntary sector organisations.

We were invited to faith group meetings, and our local Health Forum where representatives of the Local Authority and other partners were briefed in the project.

Methodology

8 semi-structured interviews

We spoke to **8** members of the diverse communities in Crawley.

Semi-structured interviews encouraged a two-way conversation meaning we were able to gain rich qualitative data. It allowed residents to open up about sensitive topics, whilst the researcher was able to tailor the interview to ask further questions.

Challenges

Recruiting participants was challenging due to a high number of research projects carried out in the area by different organisations, and the Covid-19 restrictions.

To overcome this, we took a flexible approach and adapted the main method to gather insight to the participants preference.

2 qualitative surveys

2 further members of the diverse communities provided insight as we adapted our methodology to suit their needs and preferences.

We asked for email addresses, so we could ask further questions based on responses. This allowed us to simulate the benefits of semi-structured interviews in a way that residents felt listened.

Analysis

Thematic analysis was used to analyse all forms of qualitative data.

Themes that occur in a third of the transcripts are considered recurrent, allowing for a greater interpretation of the phenomenon under investigation and to minimise any potential analytical bias.

Ethical Considerations

Informed consent - We provided participants with an information sheet and got signed consent as well verbal consent in the interview. People were also told that they had the right to withdraw their consent at any time.

Anonymity – In our research we have not disclosed personal data. Furthermore when saving transcripts and data about participants we labelled them as 'participant A' etc. Also, when using case studies we have anonymised identities.

Protection from harm – We understood that discussing the topic of cancer may be upsetting of triggering for some people.

Therefore, we made participants aware that they did not have to answer the question if they were not comfortable and that they had the right to withdraw their consent at any time.

Confidentiality – We ensured data was coded to protect identity and maintain anonymity. This will be stored in line with GDPR.

Executive Summary

in West Sussex
North South East

1. Understanding the knowledge and attitudes on cancer

- Residents from diverse communities were happy to talk about cancer. However, they felt that they have limited knowledge about the topic, including how to spot symptoms.

- Similarly, the majority of our participants explained that they were **not aware of screening services and how to access them**.

- Many of them mentioned that there is **fear about having cancer**. This fear and stigma can prevent people from visiting their GP or going for screening.

2. Experiences of accessing cancer screening:

- **Only half of our participants said they had accessed cancer screenings**. This could be due to a variety of factors, including gender, age and lack of awareness of screening services.
- Those who have first-hand experiences of cancer screening provided **positive feedback on text reminders sent by their GP**, and letters explaining what to expect at their appointment. However, they emphasised the **need to provide translations** to those residents whose first language is not English.
- Some participants expressed having **difficulties booking appointments**, including cancer screening, that fit their working schedules.
- **Some participants rely on friends or family to travel to the appointments** due to a lack of transport.

3. Identified barriers to accessing screening:

- **Lack of knowledge and awareness** about symptoms, what cancer screenings are and how to access them.
- **Work and other commitments clash with the time of GP appointments** and many in the community cannot afford to miss work for appointments.
- **Telephone system to book appointments creates various difficulties.**
- **Language barriers** particularly for the older generation.
- **Covid-19** has created a number of barriers and highlighted existing ones.
- **Accessibility of transport** and limited local services affects access to screenings.

4. Community-led solutions proposed by participants:

- Awareness campaign on cancer symptoms, cancer screenings services, and interpreting services. Materials should be translated to key languages and disseminated using existing networks.
- Extending opening hours and adjust the booking system to improve accessibility.
- Reduce online appointments, create awareness regarding interpreters, and produce resources in key languages.
- Promote affordable transport for those who are unable to afford it, and local services.

Full Report

citizens advice in West Sussex
North South East

1. **Understanding** the knowledge and attitudes about cancer

- Many participants were happy to talk about cancer, however felt that they have limited knowledge about the topic, including how to spot symptoms.
- Similarly, the majority of our participants explained that they were **not aware of screening services and how to access them**.
- Many of our participants mentioned that there is **fear about having cancer**. This fear and stigma can prevent people from visiting their GP or going for screening.

Limited knowledge of cancer symptoms and screening services

- **We identified a lack of awareness about symptoms and cancer screenings,** unless participants had previous experiences of cancer or worked for the NHS.
- Participants who could identify symptoms, were **more likely to know only about breast cancer symptoms**. This may be due to the success of awareness campaigns on this type of cancer.

To the question of what is cancer screening and what are the main symptoms of breast, cervical and bowel cancer:

“I think from understanding it’s essentially a sort of test, like a test beforehand and check people who are undiagnosed with cancer to see if they have any symptoms or any kind of diagnosis.”

“I don’t know that much. If I notice something unusual I would go to the doctor after a while and I guess they would do the referral. So I guess they take a sample and test it.”

“I know for breast cancer: lumps, different sizing of breast… But I am not sure of the other ones, Maybe swelling for bowel? “

“If the GP didn’t inform me there is no way I would have known about it.”

“Cervical cancer is so common in women but we don’t get educated on it. When we got the jab they didn’t tell us what it was, they just told us why we need to have it. It should have been taught to us in PSHCE.”

“I don’t know that much. If I notice something unusual I would go to the doctor after a while and I guess they would do the referral.”

“The thing is you would probably wait a couple months thinking its not that serious and it would probably go away on its own so you wouldn’t call the GP right away.”

Being unaware of the symptoms of cancer and the fact that some cancers may have hidden symptoms can prevent people from accessing life-saving screening.

Lack of knowledge around the cancer services available and the importance of early screenings, could prevent people from accessing such services.

Creating awareness around both cancer symptoms and screening services will allow people to understand why they should attend regular screening services, even if they are not experiencing any symptoms; and to visit their GP if they experience any.

Having limited knowledge of cancer symptoms and a lack of awareness of cancer services can be a significant barrier to accessing life-saving screening and early treatment.

Some participants expressed that they would not visit their GP unless they thought it was serious. Hence, not knowing the symptoms may delay access to screening, which could lead to a late diagnosis and a worse prognosis.

This can have a substantial impact on those who have English as a second language, as they may not be familiar with the words. This could add another difficulty as they may struggle to express they have symptoms of cancer to healthcare professionals.

Additionally, people whose first language is not English may rely on family members or friends to translate GP appointments, and if they are unaware of symptoms, cancer symptoms may be dismissed.

"I don't think they would go to the doctors unless they were in serious pain or something was very wrong. They wouldn't go for any minor pains, because they wouldn't know symptoms." (interviewee talking about parents who experience language barriers).

"Even me myself am not aware of symptoms they should make it available in local languages."

Limited knowledge of cancer symptoms and screening services

The NHS remains the most trusted source to learn about symptoms.

All our participants mentioned that they would use the NHS website if they wanted to learn more about cancer or any other symptoms.

However, all participants were digitally capable and confident in using the internet and that this response would not be the same for those who are digitally excluded.

Therefore, when making resources to raise awareness, it is important to take this into account.

"I would go online and check for any abnormal symptoms. Normal I would search on google. NHS website is the most trustworthy.

"NHS website and I would call the GP after experiencing symptoms. The thing is you would probably wait a couple months thinking it's not that serious and it would probably go away on its own so you wouldn't call the GP right away but if you call the GP then that appointment would take another few months."

In our research, it was also emphasised that some people may not be registered with the GP. Therefore, they will not receive letters or appointments to be aware of available cancer screening services.

Moreover, some residents may be reluctant to register to the GP and access screenings due to the healthcare costs attached to their immigration status.

Additionally, individuals who newly come to the country may not be aware of the services available to them regardless of concerns around costs.

"People are not registered with a GP. They don't know that they are entitle to it or where it is."

Olga

Olga is a volunteer who offers practical and emotional support and information to members of her community.

She has helped people to book appointments with primary healthcare providers in the past and she is aware of the importance of cancer screening.

Most women in her community were getting their breast screening in a mobile unit based in the K2 Leisure Centre. However, this seems to be temporarily closed and women do not longer know where to go.

Olga has found it difficult to get an update on the situation and feels frustrated that she can no longer support her community to access their screenings.

“How can I promote it when I don’t know where it is? We need another central unit for cancer screenings in Crawley.”

Fear and Stigma

Fear of having cancer could act as a barrier to accessing cancer screenings because people feel shy or scared to take themselves to screenings.

Many participants expressed that there is a need to normalise the topic of cancer within local communities in order to reduce the fear and stigma around it and encourage people to visit their GP.

“Stigma around cancer - within yourself you don’t want to accept or you don’t want to think that it could affect you. I think it needs to be normalised more.”

“People might shy away talking about symptoms because they think they’ve done something wrong to get cancer so they might not be open.”

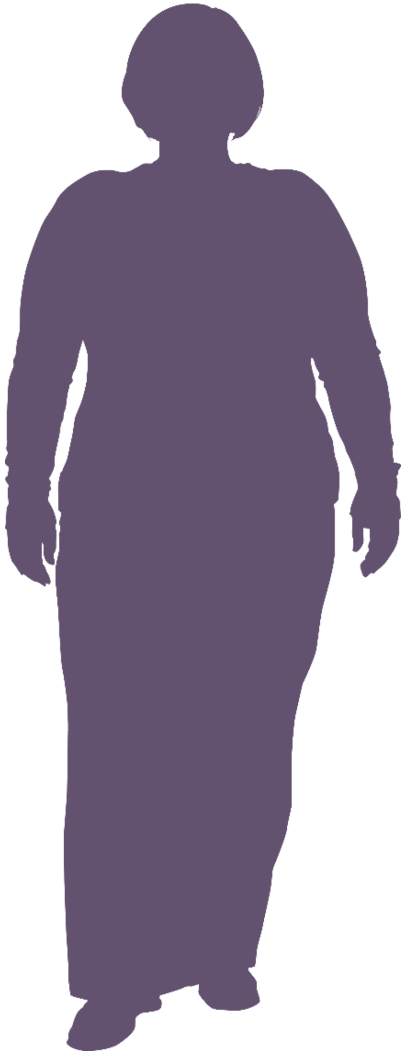
“Everyone has fears around the word cancer. The fear of coming forward and what it might find... This is exacerbated when you don’t know what the test is and why it is being done.”

Maria

“Within the African community, there is an assumption that cancer is contagious or that instantly they are going to die.

This is a barrier because without the support of people around you and the fear of death, those in the community may be reluctant to go for screenings as they do not want to hear bad news and scare those around them.

It needs to be stressed that the screenings are ‘not looking for something to kill you but to cure you’, they are attempting to look for things before things are really bad.”



2. Experiences of accessing cancer screening

- **Only half of the community members said they had accessed cancer screening**. This could be due to a variety of factors, including gender, age and lack of awareness of screening services.
- Those who have first-hand experiences of cancer screening provided **positive feedback on text reminders sent by their GP**, and letters explaining what to expect at their appointment. However, they emphasised the **need to provide translations** to those residents whose first language is not English.
- Some expressed having **difficulties booking appointments**, including cancer screening, that fit their working schedules.
- **Some rely on friends or family to travel to the appointments** due to a lack of transport.

Work and Time of the appointments

- Many people emphasised that **work plays a significant role in them accessing appointments**, including cancer screening, as they cannot get time off and surgeries are not open out of business hours. This includes after 6 pm and weekends.
- Others also emphasised that **some people in their community cannot afford to take time off work to go to an appointment**.
- The first step to accessing GPs in Crawley is to call at 8 am. Many **participants said they were unable to call at this time due to work or childcare commitments.**

"People cannot afford to take time off work if they have to pay bills and they don't have the time to wait around in A&E."

"I am unable to attend GP appointments or cancer screenings as they usually end at 6 pm in my local area and that is when I finish work."

"Most of the time when you call you are unable to get an appointment until two weeks later. If I'm not working local to the GP won't be able to go."

Barriers within the system to make appointments plays a substantial role in accessing cancer screening for residents.

Many of the members that took part in the research said that the system to book appointments with local GPs makes it difficult for residents to book an appointment if they are worried about symptoms.

Community members highlighted that calling at 8 am is challenging due to work and childcare commitments. They emphasised that there are long waiting lists, and they often do not have the time to wait.

Some said that when they are able to access and get through the phone lines, appointments are unavailable.

"It is difficult to get an appointment initially. At 8 am it is very busy, by the time you get through the waiting list all appointments are gone. It's a long waiting time."

Samuel

"If you call them up in the morning they just don't pick up the phone. They say call in the morning, if you do they say we will call you back but they only give you one call back... If there is an issue they don't bother.

Then you've got two weeks and you have to give symptoms to receptionist and they tell you its not serious."

Language as a second language:

"My parents sometimes tell me to go to the doctors with them because they think they will be taken more seriously as there will be someone there to speak to them on a different level."

Since the pandemic, many appointments have moved online and this can be problematic for individuals who have English as a second language. They have said that **it is easier to express themselves face-to-face**, as they can show an area of pain rather than describing it.

Individuals who have English as a second language may have difficulty understanding health professionals due to the terminology they use. **This was highlighted both by community members and a professional we interviewed.**

Community members expressed that language barriers could be particularly problematic for the older generation.

Zara

"Language would be a big barrier. When my mum has appointments I have to go with her, if I'm not there she'll come back and say they did something but I don't know what it was then she will give me the letter.

Obviously she trusts the NHS and doctors but you do kind of have to know and have to consent for that too.

Its very difficult for her to explain her symptoms. Sometimes she will go rambling but not say the issue she has to say and this could lead to misdiagnosis."

Language barriers can have a significant impact on someone's health, as they may delay booking an appointment since they may rely on friends or family members to go with them.

Individuals who are competent in the English language can have limited knowledge of cancer and accessing services, meaning those who are dependent may have their symptoms dismissed.

Although there are interpreters available for patients, there is a lack of awareness around this amongst residents.

Travelling to the appointment:

- Community members highlighted that there are cancer screening appointments that take place outside Crawley.
- Those who cannot drive mentioned that they may **rely on friends or family or public transport**, which may be difficult in areas where some bus routes are no longer available.
- Community members highlighted that when there is public transport, the **cost may prevent people from attending their appointments**, especially if this is not taking place in the local area.
- People who work long hours may be **unable to take time off work to travel and attend cancer screening appointments.**

“The bus timetable is unreliable […] My sister was saying that two buses were cancelled recently.”

“I don’t drive so I had to get someone to drive me.”

“A lot of people are dependent and unable to make the journeys by themselves.”

“It used to be in Crawley hospital and it was more accessible, but when it is on the outskirts, many do not drive so it’s less accessible.”

Joey

"My Sister does not drive and would have to take 2 buses so she puts it off, she says 'I am not going' or 'she's not going to bother.'

I encouraged her with our history.

Transport is a big issue for the BAME community, having accessible routes to healthcare is important."

All community members mentioned transport would be a barrier to accessing cancer screening. **Those who had experience attending cancer screening highlighted that they were lucky they had access to transport**.

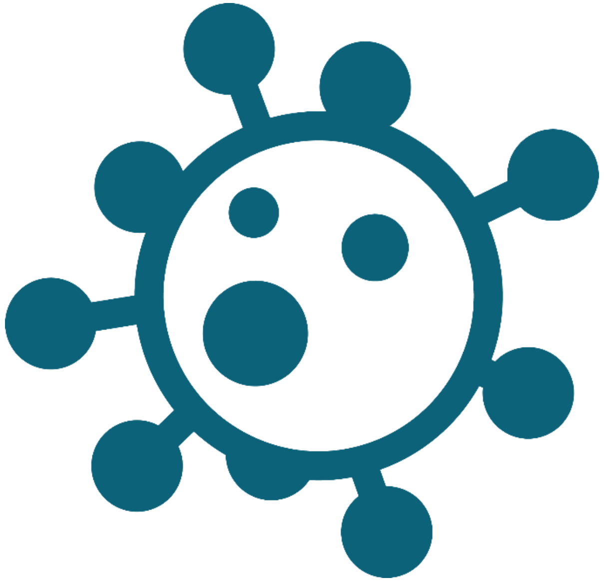
3. Identified barriers to accessing screening during the pandemic:

In the previous sections we have identified barriers that Crawley residents from a diverse background face when accessing cancer screening services. Some of these barriers have been highlighted by the Covid-19 pandemic, which has heightened worries for patients.

Fear of visiting local GPs in case of catching Covid-19. For example, one member stated "not making up the scare, it is happening" because their partner caught Covid-19 after visiting hospital.

Many community members felt that other illness were forgotten about if it was not Covid-19 related, therefore delayed going to the GP.

Community members felt that there were very limited number of appointments available or a delay in receiving appointments due to Covid-19. This includes face-to-face appointments.



“People are scared to go to the hospitals in fear of catching Covid there”

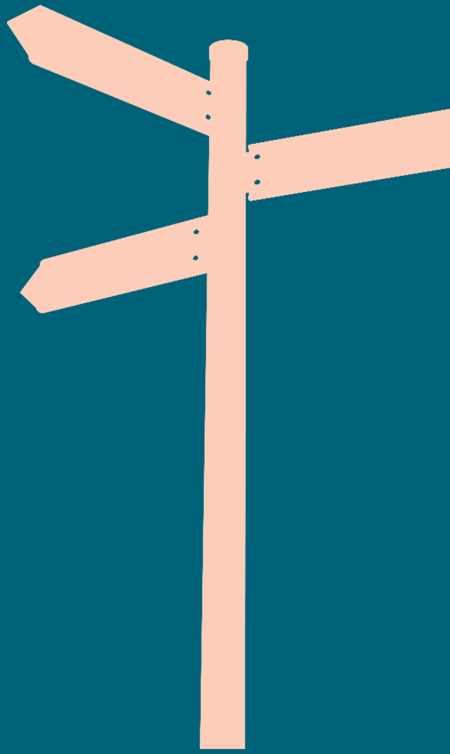
“During lockdown people were scared to leave the house. More hesitant, especially as numbers are rising.”

“My partner went to hospital for something else and caught Covid there. It is a valid scare, not making up the scare. It is happening, people are catching Covid.”

4. Community-led solutions

Participants were asked to provide solutions to the barriers they faced:

- Improve accessibility.
- Increase communications, including translated materials, to raise awareness of symptoms and screening services and reduce the fear and stigma around cancer.
- Promote affordable transport.



1. Improve accessibility for appointments

- **Opening hours to be extended.** Appointments for both GPs and screenings to be available after business hours, including after 6 pm and on Saturdays. This will allow those who work full time and have other commitments to attend appointments and get the treatment they need.
- **Flexibility around the system to book appointments.** Many felt this was a key barrier because there are long waits to get through the call and once they get there, the appointments are gone.

“8am appointments close even if you call before this the appointments go. Previously they had 2pm, that is no longer there.”

“I have work, most of the time when you call you are unable to get an appointment until two weeks later. If I’m not working local to the GP I won’t be able to go.”

“All evidence shows that offering out of hours appointments improve uptake significantly.”

“8am system makes it hard to access GP appointments, long queues as soon as you get through the appointments are all gone. Because of school/work, not everyone are able to stay on the phone and wait for the queues to end. It never used to be like this.”

Addressing these barriers within the system will improve accessibility for a large number of residents due to their circumstances and the difficulty in avoiding these.

2. Awareness campaign: increasing communications

All of our participants stated they had limited awareness of both cancer symptoms and screening services, which can be a key barrier to accessing services and can lead to crucial health outcomes.

Therefore, it is fundamental to increase communications through a variety of methods which are relevant for all residents in Crawley. Using a wide range of methods, and key languages can help to remove barriers and reach all members of the community.

The awareness campaign should target those who are digitally excluded, experience language barriers, older generations and younger generations to raise awareness of the importance of attending cancer screening.

Sofia

“Getting diagnosed is the biggest issue, especially when there are no symptoms. I went to a screening last year, I had no pain, no lumps.

When I got the letter to go for further tests, my cells were turning and had to have procedures. There are hidden symptoms.

People need to be encouraged to go to screening from GPs and nurses.”

Community-led ideas to raise awareness

1. Attend community events:

Community members emphasised that having an NHS professional attending local community events would be a good way to reach specific communities to share information.

"Having a health dedicated area at events and have people there with flyers/information, someone to have a presence at these events, it is accessible like that."

"If an event is made just for this people may not come. There are events happening and this can be part of the conversation within the event."

One community member suggested having someone who speaks fluently in the preferred language at awareness events, because **"the more they hear in the event the more it will be thought about in their minds."**

Community-led ideas to raise awareness

2. Teach in schools and have events at work:

Participants expressed that discussing cancer in these environments will enable residents to be more aware, normalise the topic of cancer, and enhance knowledge on the importance of screening and your health.

“Teach in schools, that’s when you first get taught things it’s your first time you get access. When your older you get stuck in your ways and you’re very like stuck with your mentality and the way you think. If you can teach children about sex education why not teach them about their health.”

“Raise awareness in work places, as you are more mature. Events should be done once a year so people are more open about health and create awareness.”

“You don’t have to be ill to see a doctor you can be proactive and catch it before it is serious. I think those kinds of conversation would be useful.”

Community-led ideas to raise awareness

3. Produce more leaflets and flyers and locate them in key areas.

Many participants emphasised that there is not enough awareness on symptoms of cancer and details of services available to them which is why they have limited knowledge. Interviewees suggested a number of key areas where leaflets should be displayed, which includes:

- Places of worship
- Work environments
- GP surgeries
- Local transport
- Public toilets
- Social Media

Participants who were aware of symptoms, only knew about breast cancer symptoms. This may be because there is symptoms around other cancers that are not shared as widely.

Community members also emphasised that it is important to ensure that any materials that are produced should also be **translated in local languages and shared widely** making use of existing networks.

They also highlighted that if there were **resources which are representative of the diverse community**, people are more likely to pay attention to it as they feel they can relate to the content. In turn this will allow them to understand the importance of screening.

Additionally, they suggested that GPs should place an emphasis on the need to get screened to help encourage patients.

Community-led ideas to raise awareness

4. Produce materials in a wide range of formats:

Many of our participants acknowledged that older generations within their community prefer some methods of communication over others. For example, using apps such as WhatsApp, YouTube and Facebook.

Therefore, they suggested the following ideas:

- Creating translated materials that can be shared on apps like WhatsApp and Facebook.
- Producing adverts or videos on YouTube.

"Translated videos popping up on YouTube next to other videos or as an add. If it was simple English they would ignore. This is helpful for the older generation."

"Relatable content is important. If it comes from their community it will be more helpful because they can connect to the content. That will give a sense that anyone can be affected by cancer and people will be more likely to talk to their friends and the GP and seek immediate help."

Furthermore, many of our participants spoke about the stigma around cancer in their community, which creates a barrier to accessing screening.

However if they saw content with people they can relate to and the positive outcomes of attending a screening, they may be more open to the topic.

3. Promoting affordable transport

"Transport is a key issue for the BAME community, long bus routes, often cancelled, finance issues, need more local screenings."

"Used to be in Crawley hospital – more accessible but when it's on the outskirts, many do not drive making it less accessible."

"Many in our communities do not drive, transport is a key issue, and there are a lack of bus stops."

Community members expressed that transport may be an issue for individuals from ethnic minorities as some do not drive or find themselves dependent on public transport or others.

Local screenings or mobile units would be beneficial for the community. Additionally, this will address barriers for those who are unable to travel far due to work or other commitments.

Moreover, many of our participants highlighted that **financial barriers can prevent patients from accessing transport** and they suggested that a free pass to travel to appointments for those who experience this, is necessary.

Acknowledgements:

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