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EQUALITIES & INCLUSION

The Hangleton
& Knoll Project
Working for a better community

Community Participation Action Research

Cancer Screening

Contents

1. Executive Summary

The Trust for Developing Communities (TDC), a Brighton and Hove based charity, was commissioned to deliver a Community Participation Action Research (CPAR) project with ethnically diverse communities around themes of cancer awareness. TDC delivered this project in partnership with the Hangleton and Knoll Project (HKP).

Major determinants of cancer screening uptake in UK

Context

Ethnicity, social deprivation and gender have been cited as the major determinants of cancer screening uptake in UK cancer screening programmes[1]. Black, Asian and minority ethnic groups generally have a lower uptake of screening, with barriers identified as logistical, emotional, and cultural[2].

Brighton and Hove (B&H) sits within the top 10% of socially and economically deprived areas nationally. Statistics for 2019/20 show that B&H missed the 80% cervical and 70% breast screening targets, reaching 68.2% and 65.7% respectively[3].

Community Participation Action Research Project

The research was designed to understand views, experiences, and nuances from a localised Brighton & Hove specific sample of male and female residents from Black, Asian, and ethnically diverse backgrounds. The CPAR project used qualitative methodologies in the form of a focus group and twelve in-depth interviews. The Community Researchers were themselves from ethnically diverse backgrounds.

Qualitative methodologies used by the CPAR project

Key Findings

1. Trusted relationships in community groups are key

Health professionals presenting at cultural community groups was viewed by female respondents as an effective means for disseminating information on cancer:

'... we talk about health stuff all the time at our group'

Male respondents indicated that a group would provide a comfortable setting to talk more informally about cancer.

2. Cancer knowledge differed across genders

Knowledge of cancer symptoms amongst the male respondents in particular was limited. Male respondents were less comfortable discussing the subject of cancer. Some associated it with old age, others disliked talking about a subject they saw mainly as relating to death.

3. Barriers to accessing information

Some respondents cited the lack of English as the single most significant barrier to services:

'If your English is not very good, everything is difficult, you can't make yourself understood and most people don't have patience if you can't speak English'

‘Everything online…which do not know how to use…. If missed call, then have to restart again, it is stressful’

Digital literacy, and specific digital functionality, impacted the extent to which information could be accessed:

‘Everything online which do not know how to use…. If missed call, then have to restart again, it is stressful’

4. Logistics

Transportation, or the lack of, lead to occasional cancelling and rearranging of appointments to fit with the availability of friends and family with cars:

‘Have English barriers - few people who have cars help each other out and go with them’.

Recommendations

Literature reviews on the efficacy of cancer screening do not identify any one single approach to be more effective than another. In keeping with these findings, this CPAR project suggests multi-faceted and group learning approaches, that are logistically, culturally and linguistically tailored to the local context[4]. Specifically:

1. Accessible and culturally appropriate information

- Information material (images) to feature a broad range of cultural and ethnic identities
- More ‘accessible’ information on positive lifestyle changes – this includes both the material content and the mechanism used to share the messaging
- Tailored and translated printed information to accompany screening invitations

- Using simple text and clear visual content (e.g., leaflets) to ensure those who do not speak English well are still able to understand and follow instructions (e.g., when requesting a stool sample).
- ‘Spoken’ invitations
- Language and interpretation support available at screening appointments

2. Culturally welcoming environments

- Welcoming sessions – with interpreters and/or staff from ethnically diverse backgrounds
- Make sure people know where to go for help and support that feels accessible, open, inviting and culturally sensitive.
- Re-building of trust between health services and ethnically diverse communities post pandemic
- GPs to be more responsive if a patient has a cancer concern (e.g., lump in breast, or a genetic risk)
- Make services more patient-centred especially for those where English language is a barrier

3. Peer support combined with learning opportunities

- Delivery of group learning sessions in familiar, and supportive, environments
- General health/well-being groups for men in which cancer and other serious conditions can be discussed, but are not the sole focus for the group
- Specific education for women and adolescents of cancer risks and signs

- Coordinated opportunities for healthcare professionals to visit community groups and religious settings
- Community engagement campaigns must consider cultural sensitivities such as gender specific factors as well as faith/religious beliefs.
- Functional digital literacy education with a focus on skills required to navigate the healthcare system

4. Flexible transport options

- Provision of transport arrangements for screening appointments
- Further exploration into the barriers presented by public transport use and other viable transport methods

5. Commissioning focus

- Commissioners to focus on ‘quality outcomes’

2. Background

The Trust for Developing Communities (TDC), a Brighton and Hove based Charity, was commissioned by Health Education England to deliver a Community Participation Action Research project with ethnically diverse communities around themes of cancer awareness.

Community Participation Action Research (CPAR) is where 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. TDC delivered this project this project in partnership with the Hangleton and Knoll Project (HKP), and our friends at Citizens Advice West Sussex, with mentoring support provided by the Scottish Community Development Centre.

2.1 Context

Ethnicity, social deprivation and gender have been cited as the major determinants of cancer screening uptake in UK cancer screening programmes[5]. Black, Asian and minority ethnic groups generally have a lower uptake of screening, with barriers identified as logistical, emotional, and cultural[6].

Brighton and Hove (B&H) sits within the top 10% of socially and economically deprived areas nationally. Figures for cancer screening in Sussex have seen reduction in screening rates[7] across all communities, and statistics for 2019/20 show that B&H missed the 80% cervical and 70% breast screening targets, reaching 68.2% and 65.7% respectively[8].

Studies from the UK and Europe over the past 15 years have identified ethnic disparities in uptake and knowledge of cancer screening programmes. A Sage report in 2010[9], and a Danish study in 2020[10] found similarities in their findings regarding barriers to access, awareness and take up of cancer screening provisions amongst black, Asian and ethnically diverse communities.

Local community engagement findings reveal degrees of reluctance amongst people from ethnically and culturally diverse backgrounds to openly discuss cancer, whether the focus is prevention, diagnosis, or treatment. The reason for this reticence is varied and complex.

2.2 Research Aims

This Community Participation Action Research Project (CPAR) was designed to understand views, experiences, and nuances from a localised Brighton & Hove specific sample of male and female residents from Black, Asian, and ethnically diverse backgrounds. The CPAR project used qualitative methodologies in the form of a focus group and twelve in-depth interviews. The Community Researchers were themselves from ethnically diverse backgrounds, and respondents were recruited through existing community groups and networks.

The report does not proport to be a definitive or expansive account of the themes central to this issue. Rather, it is an authentic qualitative exploration of how members from culturally and ethnically diverse communities' approach the emotive and sensitive subject of cancer, its diagnosis and treatment.

3. Methodology & Respondents

Due to the limited resources and short timescales, respondents were recruited by the Trust for Developing Communities and the Hangleton and Knoll Project through existing relationships with local community groups, networks, and contacts.

In total there were 18 female and 6 male respondents to this survey.

Respondents were aged between 30 – 75 years of age.

Three Community Researchers were recruited, also from ethnically diverse communities, who had existing trusted relationships with some of the groups and individuals engaged in this research. The qualitative research was carried out via:

- 6 in-depth interviews: Females
- 6 in depth interviews: Males
- 1 Focus Group discussion: Females.

Interviews took place between November 11th – December 17th, 2021.

Participants to the research came from a range of different diverse ethnic and racial backgrounds. Countries and languages represented in the survey included:

- Turkish
- Bangladeshi
- Nigeria
- Jamaica
- India
- Kenya
- Sudan
- Uganda
- Iran
- Eretria

Most respondents were either naturalised British citizens who migrated to the United Kingdom in the 1960s - 80s or were born in the UK. A minority of respondents were people who had successfully sought asylum in the UK.

All respondents were registered with a GP practice. When asked, most spoke positively and appreciatively about the NHS in general, and broadly expressed satisfaction with their Primary Care service.

4. Findings

Most respondents were aware of the seriousness of cancer and associated a poor prognosis with the condition. With this in mind, the interviews took a sombre tone as the subject of cancer was further discussed.

Across all respondents there were wide differences in cancer awareness and knowledge. It is worth noting, overall, there appeared to be some correlation between proficiency in speaking, writing and reading English, with levels of cancer knowledge, particularly in relation to cancer screening services and procedures. Likewise, respondents who were born in the UK, or had migrated over 40 years ago, appeared to have better knowledge than those outside of these categories.

Most respondents were able to name the common types of cancers, including Breast, Bowel, Lung and Cervical. Most people had either direct or indirect knowledge of someone who had cancer, and in some case close relatives.

There were some notable differences between the male and female interviews. Male respondents had to be significantly prompted to speak in depth on the subject of cancers. There was a tendency amongst male respondents to acknowledge the seriousness of cancer, but to disassociate themselves from personally being at risk.

'Yeah, obviously it can be very bad if you get it... it wouldn't look good for you, there's not much they can do for you'

'I am pretty healthy and look after myself, keep doing that, I think I'll be okay'

'I don't know anyone in my family who has had it, maybe we are lucky'

A few male respondents displayed unease at discussing cancers associated with men. Some were initially dismissive or uninterested in exploring the subject in depth. One male respondent said he did not know much about cancer, but it scared him, as it usually kills those who have it. A few male respondents spoke of the importance of getting checked (for cancer) and following up GP/surgery requests for general health checks, especially as one aged.

4.1 Talking about Cancer

Most male respondents said cancer was not a subject that was openly and commonly discussed in their families, circle of friends or communities. A few male respondents added they rarely discussed any health-related issues. One added, health matters tended to be discussed usually when there was a close connection with the illness, and someone known to the family/group/community. COVID-19 was considered to be an exception to the tendency not to talk about health and illnesses. Most were generally comfortable with discussions on COVID-19, infection rates, vaccination, variants, symptoms etc. A few felt because of its seriousness, COVID-19 had dominated all health-related matters.

A few male respondents said they thought their wives' and partners where more likely to discuss health related matters including cancer amongst other females, than in a wider mixed gender group/setting.

Amongst female respondents there was a more of general openness to discussing cancer and other illnesses. In many cases these types of conversations happened amongst close family and friends, or because the women were part of a community group who have been meeting for some time. The community group settings also allowed for specialist meetings, and sessions with healthcare professionals to meet with group members to discuss health issues, including cancer screening. Overall, sessions focusing on health matters were welcomed by most of these respondents. A key factor in the extent to which female respondents were comfortable with discussing cancer and other illnesses was the element of trust they had with those they were having these types of discussions with.

'Having network support this is where I get my information from. Seeking advice in community and giving advice'

'… we talk about health stuff all the time at our group'

Also, many female respondents acknowledged the value in being able to speak to someone (usually a professional person) who was not personally know to them.

In addition, male respondents suggested they would engage in a conversation on cancer if their doctor instigated it.

'Could do with a trusted source of information centrally so not reliant on family and friends as there is so much out there'

Some female respondents expressed similar levels of reticence in discussing cancer as that expressed by the male respondents.

'Talk sometimes, my father has cancer, upsetting subject to talk'.

'[We] tried to keep in family, not comfortable talking in community, only when seriously ill…It is a taboo'.

Some respondents referenced their faith in relation to a cancer diagnosis. They said that within their communities there were some people with a view that if a person had cancer, it was a curse from God. Others thought that survival of cancer was mostly in the hands of God rather than doctors or medicine. It was felt those that held these views were heavily wedded to the belief in the supremacy of their God. Therefore, any treatment for cancer had to be given with acknowledgment and respect of their beliefs.

However, it was acknowledged that even those with strongly held beliefs would unlikely refuse or forego treatment and put their trust solely in their faith.

'Someone coming to talk in our community, maybe in our Friday prayer. The imam can do health related topics along with religious beliefs'

'We only talk about this if someone has cancer, and we go and visit them but do not have knowledge of types of cancer, how it effects and how it is linked to our lifestyle and what we can do to promote good health. We pray for the person.'

'Sharing experiences and promoting and the raising awareness of the importance of going and that we will be supported in a cultural/religious way and not be judged'

One male respondent suggested that if cancer were not such a frightening topic, people may be more willing to discuss and learn about it. Another said it never comes up as a subject of conversation, so levels of awareness are limited. In a similar comment one respondent said men overall did not tend to meet just to talk. On the rare occasions they did, they would typically discuss subjects less serious or scary, such as sport or politics. He added maybe if men met each other more they might find talking about a wider range of subjects, including health and cancer, easier.

'Who wants to talk about death and dying of cancer'

4.2 Awareness of Cancer symptoms

Overall, female respondents demonstrated good levels of awareness of cancer symptoms. Responses given by some female respondents clearly indicated they had acquired accurate and, in some case, high levels of cancer knowledge. Symptoms mentioned by female respondents included:

- Swollen breasts
- Irregular/unusual periods
- Pains below belly button
- Pain under the arm
- Stools irregular different from usual
- Blood in stools
- Cervical pain
- Weight loss
- Unusual/ new mole
- Skin discolouration

Knowledge of cancer symptoms appeared largely to be a result of information acquired over many years. Attending cancer screening services, and related conversation once there, also appeared to be significant sources of information. In some instances, information was cascaded via conversations with family members, friends, and from people within their community.

Knowledge of cancer symptoms amongst the male respondents was limited. Most mentioned a lump in the breast, blood in stools for bowel cancer, and unbearable pain in the head. Other symptoms mentioned were general and non-specific, e.g. lung pain, general poor physical health. Some of the male respondents could not mention many, if any, specific symptoms associated with testicular, bowel or colon cancer.

Lastly, it seemed to be those with more socially integrated lives, e.g. went to work, in education/training, mixed with other cultures, had marginally wider knowledge on cancer symptoms than those who did not. Those with less advanced English language gave comparatively less information on cancer symptoms.

4.3 Personal experiences of Cancer

Many respondents were able to give accounts of people in their extended family or community who had cancer. Although not probed extensively, many of the examples given had poor outcomes. Some respondents spoke of people who had been diagnosed with cancer during the pandemic. These were seen as the most tragic examples as there was a perception that the lockdown prevented people from getting the treatment required that would have prolonged their lives:

'She couldn't get appointments, take her serious… but found cervical cancer and was at last stages of cancer. She passed away 2 months ago'.

'Brain tumour found in lockdown. He died from lack of support getting heard with headaches etc all the time, during lockdown'.

Amongst a few male respondents' cancer was primarily associated with old age, defined as 60+. This age-related association prompted a perception amongst these (younger) respondents that cancer was not something they had to worry greatly about at their age.

'I am 37, people who have it [cancer] are older'

'You get it more when you are old'

Apart from heavy smoking, minimal connection was made by male respondents between cancer and lifestyle. When prompted to identify lifestyles factors that have been associated with cancer, some male respondents mentioned diet but could not provide further detail on what specifically were the correlations between cancer and diet. Only one male respondent identified genetic association as a factor in some types of cancers.

4.4 Cancer Information

Overall, there are mixed views on the availability of information on cancer. Female respondents expressed more positive views on the extent to which there was effective public information on cancer.

When asked if they considered there was sufficient public information on cancer awareness and services, a majority of female respondents felt there were a good number of information leaflets.

'Yeah, there are quite a few on breast screening and that…my wife had a few. 'I've seen some in the surgery but haven't read any yet'

However, a minority said there should be more, specifically, and accessible for those who are not likely to read lengthy flyers. One respondent said whilst he would pick up and read a general health leaflet in his GP surgery, he had not picked up any that dealt specifically with cancer. When asked why he did not pick up cancer related information leaflets, he replied he was unsure, but considered it may be related to fear; fear whilst waiting to receive the results, believing the results would confirm the fear.

'I sort of think that if I read the symptoms in a leaflet, and I have definitely got it [cancer] and would be so scared to go to the doctor to find out for sure'.

Male respondents offered a range of views on the barriers and their impact on cancer screening awareness and knowledge of services. Most respondents felt there was sufficient information made available in GP surgeries, enabling an awareness of cancer. However, some added, because of its seriousness, a leaflet was not often something one would spontaneously pick up and read when in the surgery; not least because typically when in the surgery they would be preoccupied with the purpose of their non-cancer related GP visit.

'You see them [leaflets] but you're not really going to read them, because you don't have time, or want to read them there'.

One respondent said if someone in the surgery gave him a leaflet and recommended he read it, he would be more likely to read it. This is because he would see this as a direct and personal recommendation.

Levels of English language was cited by respondents (both female and male) as the single most significant barrier to services like cancer screening. Some respondents described community members who had to rely on others to get information and build knowledge on a range of social, health, educational, employment, and housing issues. 'Others' included family members, friends, acquaintances, and interpretation services.

'If your English is not very good, everything is difficult, you can't make yourself understood and most people don't have patience if you can't speak English'

'There's no point in a leaflet if you can't read it'

Overall, female and male respondents gave examples of people they knew in their communities who did not speak English well. It was felt others in the community did as much as possible to support those with poor English, however support and assistance was still required, and expected, from service providers. The role of interpreter services was mentioned by many male and female respondents as vital in these cases.

'Having an interpreter - the interpreter is like a social worker. Slowly explaining to people what health professionals said to them'.

One respondent named 'fear' as a reason people avoided learning more about cancer and cancer screening; because they are scared. He noted the common perception that cancer is associated with premature death, and people believed it was better not knowing about it.
He said information is available on cancer screening and treatment, but nobody talks about overcoming the fear associated with receiving a cancer diagnosis.

'They tell you what they will do if you get it [cancer] but they don't tell you how to stop being scared'.

4.5 Cancer screening awareness

Most male respondents said that they had attended a cancer screening appointment. Two respondents believed their routine health check, where blood was taken, was a test for cancer.

One respondent said pre-pandemic he was having respiratory problems. Screening for cancer was included as part of the clinical investigation. One respondent said when he was 60 he received a request for a stool sample. He added that many months passed before he sent it back.

There was low awareness of bowel cancer screening services amongst male respondents. Although most males were familiar that a bowel cancer test existed, few had undergone it or knew what it entailed. Most believed that cancer was mainly detected through blood tests. Some male respondents seemed to have better awareness of breast and cervical cancer screening, than of bowel or testicular cancer.

Most of the female respondents had experiences of cancer screening. Typically mentioned were smear tests (by most) and mammograms. However, it was noted that a minority of female respondents made no mention at all of attending a cancer screening.

Female respondents spoke more openly than their male counterparts, and with a greater level of cancer related knowledge. Most female respondents demonstrated good levels of knowledge about cancer screening services. There was specific mention of bowel, breast, and cervical screening. Many went on to state the importance of these services and the extent to which they play a vital role in preventative health care.

'Blessed with NHS service…ask a dumb question'

'Prevention, rather than cure…not just during crisis'

Some of the female respondents gave examples of their experiences of cancer screening services. There were mixed on whether the service was wholly positive or fully met their expectations.

Some female respondents spoke highly of the cancer screening service they had received.

'... a nice nurse, good technique, [we were] having conversation, nice and relaxed atmosphere'.

Whilst most female respondents were broadly satisfied with the screening service, there were a few respondents who felt more could have been done to improve their experience. Suggestions included,

- More information on lifestyle changes that impact on cancer
- Specific education for women and adolescents of cancer risks and signs
- Focused contact (face-to-face) when middle aged
- Adjustments in information sources (e.g., leaflets) to ensure those who do not speak English well are still able to understand and follow instructions (e.g., when requesting a stool sample).
- Make sure people know where to go for help and support that feels accessible, open, inviting and culturally sensitive.
- Try and make services even more patient-centric especially for those who do not speak English well.
- GPs to be more responsive if a patient has a cancer concern (e.g. lump in breast, or a genetic risk)

'I get nervous and anxious and if have option rather not go to the screenings its very personal, but I know how important it is'.

'... a nice nurse, good technique, [we were] having conversation, nice and relaxed atmosphere'

'I ask for mammogram but was not given one as not reached certain age. If have family history of cancer- test should be available even if not reached the age'

4.6 Cancer during the pandemic

All respondents said either they, close relatives, or friends, had experienced problems seeing or making appointments with their GPs during the pandemic; particularly during the periods of lockdown. One referred to a family member on more than one occasion having to attend an Accident and Emergency department to get medical assistance. Another was aware of a community member dying during the pandemic because they were not able to see a doctor over an extended period. Most felt it was appropriate that access to GPs was limited during lockdown, but some felt there had not been enough flexibility in the approach, which had resulted in people suffering unnecessarily.

'I get it, we have to take precautions, but what do you do when you're really in pain and you don't know what you do, when they say you can't see your GP?'

'With kids it really scary if they're sick, and you can't see a doctor'.

Amongst some respondents in their communities there is a perception that cancer services for screening, detection and treatment are not available due to resources and attention given to COVID-19. There are 'stories' circulating in some communities that people have cancer but are being ignored. Finally, when they do get appointments, their cancers have progressed to a point where their prognosis is very poor.

'[She had] Stomach pains for long time, just given, painkillers and not referred to examination'.

'Not close to me but hear in the community and we offer prayers at mosque but do not know the medical side'.

'Hear about late detections when they are at later stages and are under treatment'.

During lockdown one female respondent was concerned symptoms she was experiencing were associated with cancer. Unfortunately, during this time a family member died of cancer. The respondent's cancer screening was pushed back a year during lockdown. The delay caused the respondent anxiety and depression. She was unable to be tested, but also could not speak to a clinician about her concerns or symptoms.

Overall, amongst female and male respondents there was dissatisfaction with the GP/surgery appointment system during lockdown. Most spoke of their requests to see GPs being denied. The replacement phone system was not considered to be effective. Difficulties with GP phone services included,

- GP's and hospitals not speaking to each other. Patients having to do a lot of chasing/following up with their surgery and hospital
- Struggling to get the information they required from their surgery or hospital
- Difficulty explaining their medical need when not in person with a doctor; especially for those with a disability or limited English
- Perceptions of receptionists blocking/preventing direct communication between doctors and patients.
- Perception that doctors are not able to accurately assess and diagnose conditions over the telephone.

Many respondents' felt lessons should be learned from the pandemic and lockdown, regarding access to GPs and other medical personnel. It was felt the long-term impacts of the lockdown would be poor health outcomes for all serious conditions especially cancer.

Generally, respondents felt where people had a lower command of the English language, they were particularly disadvantaged when booking GP or hospital appointments. The level of information needed when requesting an appointment, such as describing symptoms, was seen as adding anxiety to an already stressful situation.

In addition, when they received letters or texts from the Surgery, in some instances, they did not fully understand what was being asked of them. Family, friends, or community support was vital for these patients; without which, they were not being able to fully access NHS support/care.

Further barriers related to the use of digital technology. Some respondents said they were not competent using the systems in place to book calls or follow/confirm information. In several cases these respondents always had to rely on other family members to ensure they confirmed or made appointments.

'I have to rely on husband and children to make phone call to speak for me when they are home'

'Everything online which do not know how to use…. If missed call, then have to restart again, it is stressful'

4.7 Cultural Factors

Initially most male respondents said they had no preference on the gender of the doctor/GP they typically saw. However, on further prompting some did express a preference for a male doctor, particularly if the appointment might involve removal of clothing. Further, some said although it had not yet become necessary, they would request a male doctor if they considered the reason for their visit warranted it. Again, after prompting, some added that with testicular and bowel cancer tests, they would feel more comfortable with a male doctor.

'I don't mind who I see, but sometimes it might be better to see a man doctor'

The female respondents had a range of views on access to gender specific doctors/GPs. Many did not feel they needed to have a GP of a particular gender. The perceived competence of the GP, and levels of access to them, were seen as equally (in some case more) important as the GP's gender. Naturally, building and developing a long-term relationship with the GP was the basis of their satisfaction.

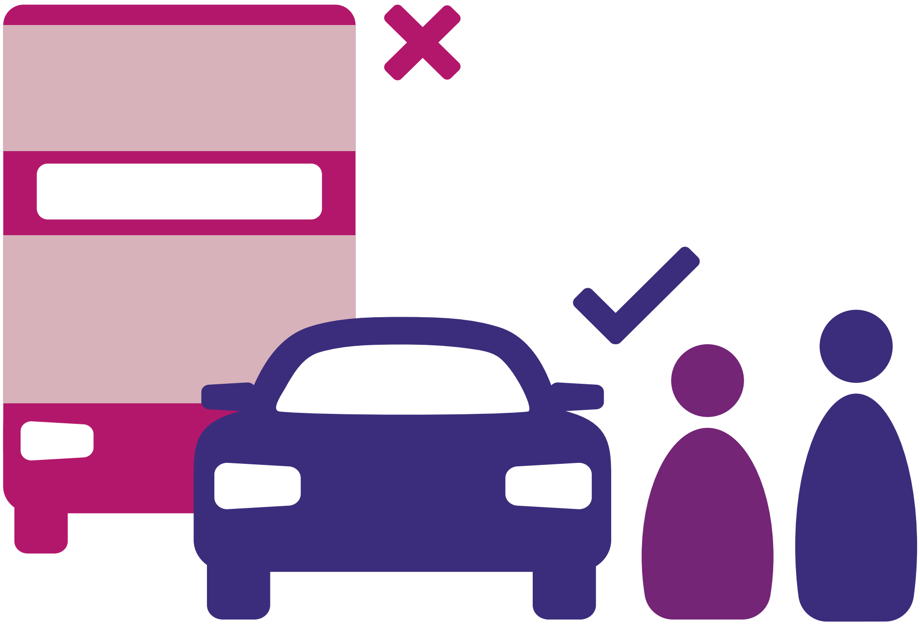
'No female doctor at my surgery… I have no problem, but it would be good to have female doctor at surgery too'.

Some female respondents said they would always prefer to see a female GP. However, for some, the lack of female GPs attached to their surgeries meant at times they had to wait longer to get their appointment.

4.8 Transport to appointments

Most male respondents did not feel transport presented a barrier to attending cancer screening appointments or services. In most cased these respondents had no other significant transport issues; most were car owners. Others said they had access to family and friends who would typically offer support with transport needs.

For some female respondents, transport to GP or hospital appointments required a degree of planning because they did not have regular access to private transport.



Mentioned by several respondents was the availability of taxis, when issues arose with car availability from family and friends. Hardly any respondents without their own transport mentioned using buses as an alternative. There was a perception that buses could not be relied on to get to appointments on time.

Most male respondents said it was not often they would be forced to cancel a medical appointment because of no access to transport. However, it was accepted that there would be instances when appointments would have to be arranged to accommodate the availability of support with transport.

Some female respondents said problems with transportation had occasionally forced them to cancel or change appointments.

'In the community, if you need help to get somewhere, someone with a car can usually help'.

'I don't drive, sometimes we would be really stuck without my brother, he's a taxi driver'.

'Taxi everywhere. Only one bus. Should have more bus services that take you to the hospital. Nearly 40mins between buses'.

'I have mobility issues - so taxi everywhere'.

'Have English barriers - few people who have cars help each other out and go with them'.

5. Reflections

Awareness of cancer screening, and services to support those with cancer, is perceived as relatively good. However, there are pockets within culturally and ethnically diverse communities which require a more targeted approach.

There is evidence from this limited qualitative community research to suggest most people from culturally and ethnically diverse communities are aware of the seriousness of cancer and the need/importance to access services to identity early symptoms of the condition.

However, there is also some evidenced to suggest that people who do not have high competence in English or who have relatively recent British status/citizenship (i.e. less than 20 years) may have lower levels of awareness and knowledge of cancer services. Moreover, competence in English is a significant factor in relation to the extent people from culturally and ethnically diverse background possess the confidence to engage with health and care professionals/services on health matters such as cancer.

Overall, amongst most female respondents there is an open approach to discussing cancer and serious illness. These conversations occur within families, amongst close friends and are also facilitated specifically or informally at community groups they are associated with.

But once again, for a minority of female respondents' discussions on serious conditions such as cancer are limited. However, some said membership of culturally specific groups provide excellent opportunities for people who do not discuss health related issues such as cancer. The group format offers a collective, safe, equitable and supportive environment for matters of this nature.

Conversely, most males in the research were less comfortable discussing the subject of cancer. Whilst some felt it was less relevant to them because they associated it with old age, others disliked talking about a subject they saw mainly as related to discussing death.

From a broader cultural perspective, there were mixed opinions about the extent to which this influenced the reluctance to discuss cancer. Overall, responses suggest that culture has limited influence on the extent to which cancer is discussed in their communities. Albeit some acknowledged a minority in their communities who view cancer as a curse from God, and that for this minority, cultural factors relating to faith may influence their behaviours and the extent to which they might engage. When planning or considering engagement campaigns or activity, service providers should ensure that they have considered cultural sensitivities that may impact on successful or effective community engagement. These are likely to include gender specific factors as well as faith/religious beliefs.

The different gender attitudes to discussing cancer were also reflected in the levels of knowledge held. Female respondents gave good, and accurate information on cancer symptoms, the types and screening services. Male respondents were broadly accurate in the information they gave. However, it was not as extensive as that provided by the female respondents.

It should be recognised that there is amongst many males from ethnically and culturally diverse backgrounds a reluctance to discuss serious health related issues. Therefore, rather than supporting service and groups focusing solely on cancer, an approach could be to support general health/well-being groups for men in which cancer and other serious conditions are encouraged to be discussed.

Across both female and male respondents there were some examples of close family members or friends who had cancer. And many respondents (females in particular) had attended cancer screening services. In cases of cancer screening and treatment, respondents spoke positively of the services they received. Most were appreciative and very satisfied with NHS staff who they engaged with during screening procedures.

The disruption caused by the COVID-19 pandemic to routine primary health and hospital services were mentioned by most respondents as a source of frustration. Most understood the need to change the approach to seeing health professional in person during the pandemic. However, many felt the alternative arrangements did not provide the level of access and support patients wanted, especially for non-coronavirus related matters, including fears of having cancer.

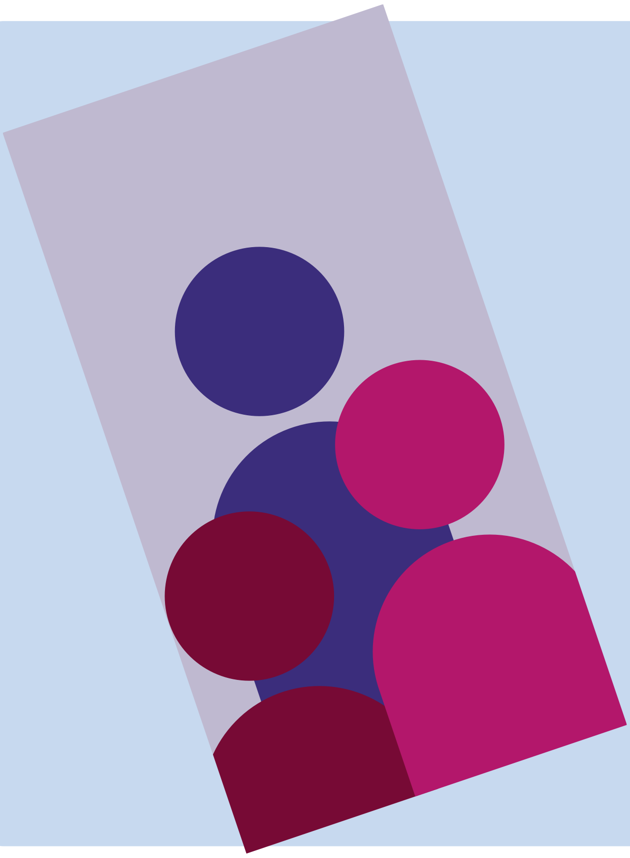
Despite the levels of cancer related knowledge that existed amongst the respondents, overall, there was a view that more information could be made available to increase awareness and understanding. Specifically mentioned was a need to ensure information be made available in the different languages commonly spoken in Brighton & Hove. In addition, it was felt important that information was accessible for example in 'plain English'.

The role of health professionals attending and giving presentations at cultural community groups was highlighted as effective; both in sharing information on cancer directly with group members, and enabling wider dissemination across different communities.

Male respondents indicated that an informal group setting could be an effective way of talking about cancer; providing a comfortable environment for men to open up and engage in the conversation and topic.

6. Recommendations

Literature reviews on the efficacy of cancer screening do not identify any one single approach to be more effective than another. In keeping with these findings, the CPAR project suggests multi-faceted and group learning approaches, that are logistically, culturally, and linguistically tailored to the local context[11]. Specifically:



6.1 Accessible and culturally appropriate information

- Information material (images) to feature of a broad range of cultural and ethnic identities
- More 'accessible' information on positive lifestyle changes – this includes both the material content and the mechanism used to share the messaging
- Tailored and translated printed information to accompany screening invitations
- Using simple text and clear visual content (e.g., leaflets) to ensure those who do not speak English well are still able to understand and follow instructions (e.g., when requesting a stool sample).
- 'Spoken' invitations
- Language and interpretation support available at screening appointments

6.2 Culturally welcoming environments

- Welcoming sessions – with interpreters and/or staff from ethnically diverse backgrounds
- Make sure people know where to go for help and support that feels accessible, open, inviting and culturally sensitive.
- Re-building of trust between health services and ethnically diverse communities post pandemic
- GPs to be more responsive if a patient has a cancer

concern (e.g., lump in breast, or a genetic risk)

- Make services more patient-centred especially for those where English language is a barrier

6.3 Peer support combined with learning opportunities

- Delivery of group learning sessions in familiar, and supportive, environments
- General health/well-being groups for men in which cancer and other serious conditions can be discussed, but are not the sole focus for the group
- Specific education for women and adolescents of cancer risks and signs
- Coordinated opportunities for healthcare professionals to visit community groups and religious settings
- Community engagement campaigns must consider cultural sensitivities such as gender specific factors as well as faith/religious beliefs
- Functional digital literacy education with a focus on skills required to navigate the healthcare system

6.4 Flexible transport options

- Provision of transport arrangements for screening appointments
- Further exploration into the barriers presented by public transport use and other viable transport methods

6.5 Commissioning focus

- Commissioners to focus on ‘quality outcomes’

7. Acknowledgements

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NHS
Health Education England

scdc
scottish
community
development
centre

NHS

NHS England and NHS Improvement

tdc
EQUALITIES & INCLUSION

The Hangleton
& Knoll Project
Working for a better community

7.1 Footnotes

[1] Weller, D. and Campbell, C 'Discussion Paper: Uptake in cancer screening programmes: a priority in cancer control' in *British Journal of Cancer* (2009) 101, pp. 55 – 59. doi: 10.1038/sj.bjc.6605391

[2] Kelly, C et al., 'Interventions to improve the uptake of screening across a range of conditions in Ethnic Minority Groups: a systematic review' in *The International Journey of Clinical Practice* (2018) Vol. 72 (8) doi: 10.1111/ijcp.13202

[3] NHS Cancer Screening Program (via Open Exeter) https://fingertips.phe.org.uk/ 19/20 data updated in Dec-20 Caveats: This data is based on 19/20 data and is the most up-to-date published and therefore will not reflect any recent changes to performance

[4] Eilbert, K. et al. (2009) 'Approaches to improving breast screening uptake: evidence and experience from Tower Hamlets' in *Br J Cancer* 101(Suppl 2): pp. 64 – 67 DOI: 10.1038/sj.bjc.6605393

[5] Weller, D. and Campbell, C 'Discussion Paper: Uptake in cancer screening programmes: a priority in cancer control' in *British Journal of Cancer* (2009) 101, pp. 55 – 59. doi: 10.1038/sj.bjc.6605391

[6] Kelly, C et al., 'Interventions to improve the uptake of screening across a range of conditions in Ethnic Minority Groups: a systematic review' in *The International Journey of Clinical Practice* (2018) Vol. 72 (8) doi: 10.1111/ijcp.13202

[7] www. England.nhs.uk /south-east/2018/01/22/brighton-and-hove-cervical-screening-rates-lowest-in-south-east/

[8] NHS Cancer Screening Program (via Open Exeter) https://fingertips.phe.org.uk/ 19/20 data updated in Dec-20 Caveats: This data is based on 19/20 data and is the most up-to-date published and therefore will not reflect any recent changes to performance

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[10] Tatari, C.R., Andersen, B., Brogaard, T. et al. Perceptions about cancer and barriers towards cancer screening among ethnic minority women in a deprived area in Denmark – a qualitative study. *BMC Public Health* 20, 921 (2020). https://doi.org/10.1186/s12889-020-09037-1

[11] Eilbert , K. et al. (2009) 'Approaches to improving breast screening uptake: evidence and experience from Tower Hamlets' in *Br J Cancer* 101(Suppl 2): pp. 64 – 67 DOI: 10.1038/sj.bjc.6605393