Community Participatory Action Research (CPAR) Programme – SE England

-Health Awareness: Attitudes towards Cancer Screening
Romanian Community

1. Introduction - Background to the research

The Scottish Community Development Centre (SCDC) on its website presents the aim of the programme as follows: [1]‘The programme focuses on developing understanding of community health; understanding and application of community action research approaches; and building the capacity of participants (primarily from the BAME community) to undertake community action research’.

Included in this programme is Sussex Interpreting Services (SIS), as part of a successful [2]partnership bid in for Community Participatory Action Research (CPAR) to tackle health issues related to COVID-19. Sussex Interpreting Services is a Sussex based charity that [3]‘exists to enable full access, for people with language needs, to publicly funded services in order to improve health, education and quality of life’. The partnership is sponsored by NHS Sussex Health Care partnership with Trust for Developing Communities, Hangelton and Knoll Project, Crawley Citizen’s Advice Bureau, and Hastings Voluntary Action who were all involved in the research we contributed to in June 2020 about BAMER experience of Covid 19.

1.a. Background to issues from the NHS Cancer Screening Perspective

There are three NHS Cancer screening programmes – breast, bowel and cervical.

Cancer screening programmes are designed to detect pre-cancerous conditions and provide treatment before cancer develops (e.g. cervical) or to detect cancer in early stages where it is more easily treatable (e.g. breast screening) and thus people are more likely to survive.
Some groups of people are less likely to take up cancer screening, and we would like to understand more about the reasons behind this, in order to overcome barriers and ensure equality of uptake.

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[1] Community Participatory Action Research (CPAR) Programme – SE England
https://www.scdc.org.uk/cpar

[2] The Nhs, Covid–19 & Lockdown: The Black, Asian, Minoritised Ethnic And Refugee Experience in Brighton & Hove
The NHS, COVID–19 & Lockdown: The Black, Asian, Minoritised Ethnic and Refugee Experience in Brighton & Hove - Sussex Interpreting Services

[3] Sussex Interpreting Services

1.b. Background to issues in Brighton and Hove

In most communities there can be a reluctance to openly discuss cancer conditions including sensible steps to reduce the risk of being faced with a cancer diagnosis. In people from culturally and ethnically diverse communities this reluctance can be increased due to factors that include poor access to information or perceptions of conscious and unconscious bias toward them.

Nevertheless, Health Awareness is a subject that has been identified by the Community Voices Group in Brighton and Hove as one that is of much interest to them. As a group they have already discussed a several health-related issues and within the Group appetite exists to explore other subjects on health and well-being.

The subject of cancer awareness and screening has been raised with the Community Voices Group, those who were present felt despite the sensitivities and difficulties in discussing cancer it was a subject that needed to be discussed. It was pointed out by more than one person in the group that most people know someone who has had a cancer diagnosis.

2. The research proposal

For the implementation stage, SIS has offered the opportunity to a number of community interpreters to express their interest in March 2021 on the topic ***Health Awareness: Attitudes towards Cancer Screening.*** This topic is of interest to the communities SIS are working with as well as a priority for the healthcare system.

Due to the complexity of the health matter in the pandemic context, the potential practical implications of the cancer screening term itself – bears a completely different translation into Romanian (Test Papa Nicolau-Papa Nicolau Test) and to my interest and professional and personal links into the Romanian community, I have expressed my interest and was glad to be accepted shortly afterwards.

3. Research process and methods

I have chosen to approach, for my research, Romanian individuals, both males and females, that I have a closer connection with, either through my work as a bilingual advocate or bilingual navigator and also personally, friends that live in the South of England and that have had an interest in cancer or have had investigations for cancer in their past.

I have opted to focus my research activity on the following areas:

- an overview of how much people know about cancer,
- where information about cancer screening comes from,

- what information people feel they would benefit from,
- awareness of screening processes for cancer,
- what people from culturally and ethnically diverse communities know about access to screening and cancer services in general,
- potential barriers in accessing cancer screening services,
- how to tailor the cancer screening service to be suitable for people from different ethnic and cultural groups.

For preparation purposes, I have researched the information available and provided by SIS and SCDC on cancer and cancer screening for males and females and the issues encountered by the healthcare professionals in dealing with migrant communities on cancer screening.

The research methods used have been a combination of qualitative and quantitative methods in order to establish how cancer screening is viewed by a wide range of Romanian individuals: written in-depth questionnaire, video and audio discussions, listening, observations, attended video discussions on cancer and cancer screening.

I have centred the conclusions of my research on three types of Romanian groups: non-focus group- informal conversations and/or listening to health related complaints of individuals during interviews (approx. 50), focus group: 18 individuals, individuals refusing to take part, approx. 10.

My aim was to reach Romanian individuals from the following backgrounds:

- English (6) and little or non-English speakers (12),
- various genders - males (4) and females (14) (no other gender identified within the research focus),
- aged between 30-68,
- various professional backgrounds: medically retired (4), retired because of age (1), accountants (1), interpreters (2), workers in various industries (5), non-working/carers (4), teacher (1),
- from various areas throughout the South of England: SE (1) and SW (2) London, Hastings (1), Newhaven (1), Brighton&Hove (8), Worthing (2), Littlehampton (1), Bognor Regis (2); and from an immigration perspective, all settled in the UK between 1-10 years.

The questionnaire, used as the main detailed research method, was answered in writing, corresponding via emails, listening and observations were done remotely via zoom or WhatsApp calls and in person. The discussions were conducted in Romanian and the questionnaire was provided in Romanian to the research subjects, and consent was obtained mainly verbally and the answers were provided under the protection of anonymity.

In order to analyse the data and form my conclusions, I have considered all the formal and informal information, including justification of refusing to take part in this research. Also, I have referred back to prior data available either by previous research, further information and discussions during the CPAR training sessions and other materials available.

4. Research findings

For research purposes I have studied the Cancer Deprivation and Screening Study (2021) which shows that the 'coastal strip in Hasting, Brighton&Hove and Littlehampton' has been identified as one of 'the most deprived areas in England' and this was reflected in some of the refusal to take part in those areas: over 10 individuals explained that despite the fact that they appreciated the research, they justified by lack of time, feeling overwhelmed with work commitments and numerous financial hardships faced.

Apart from the in-depth focused research on the aspects related to cancer screening and its implications on Romanian individuals, during over 200 interpreting sessions, I have had various informal talks or listened to numerous Romanians complaining about issues related to health and the implications of these aspects in the following areas: housing, finance, work, immigration and family life.

In the BREXIT context, for Romanians getting unwell often resulted in losing jobs with knock-on effect on housing and invariably, immigration residency applications for either themselves or their family (or both). This affected the trust and interest in considering undertaking cancer screening or even discussing this health aspect.

The answers showed the following:

1. *an overview of how much people know about cancer*:

females interviewed tended to know in more detail what the cancer screening is for prevention of early detection of cancer cells, some provided symptoms to look for, e.g., 'sudden weight loss, extreme fatigue, persistent fever, enlarged lumps, skin changes';

more complex details were provided by people who have had further investigations, e.g., 'screening is a test to establish whether the sampled tissue cells show abnormalities. If these cells exist and are not treated, they can generate cancer with time' ; at least 60% of the interviewed people had either someone close or knew someone who had either been diagnosed with cancer or died of cancer, e.g. 'some [people] died, those who discovered it too late and the doctors' efforts were not enough to defeat the disease, unfortunately, people close to me';

males are aware of the types of cancer;

of the interviewed people (focus group) only 12 clearly indicated that they did not know that the UK ‘Cancer screening’ is the equivalent of ‘Papa Nicolau’ test done in Romania; 3 have undergone cancer screening and further cancer investigations, 1 actually recovering from cervical cancer.

2. where information about cancer screening comes from:

majority preferred to use internet for information, some from friends (language barrier was an issue getting information); two individuals indicated Macmillan Cancer Support as appropriate source of information and listed their support contact number; 6 did not provide this information

3. what information people feel they would benefit from:

there have been two categories of answers: the first category expressed opinions on motivation to attend screening and the second, opinions on when diagnosed with cancer.

In the first category, 6 answered that personally contacted by the GP would be most efficient; however, the majority preferred increased advertising, free support, short distances to the testing centres: ‘leaflets should be everywhere, at every workplace, or public spaces (libraries, cinemas, shopping centres, sports halls, schools, universities) with useful information regarding testing, advantages and disadvantages in not undergoing screening (with clear examples). In large institutions there should be allocated clean appropriate areas for testing’; the second category preferred to awareness of screening processes for cancer.

The second category would prefer direct access to information from a specialist in case of a diagnose: ‘the specialist is the best choice to follow an appropriate route for this problem, clarification of diagnoses, and steps to follow’.

4. what people from culturally and ethnically diverse communities know about access to screening and cancer services in general:

only about a third would prefer a specific gender in a video or leaflet, however, all agree that the most important is the knowledge and experience of a specialist physician, 6 indicated that having a network or friends and family is important, however, over 70% indicated that they would benefit if information was in Romanian; 1 person, cancer survivor, specifically requested quality of interpreting as well;

when compared to the Romanian healthcare system, specifically the aspect of addressing and being concerned with upsetting the healthcare professionals, the majority, over 70%, seem to favour the British healthcare system: ‘here (the UK) everything is different from this point of view, and the NHS staff are far kinder and closer to the patient and the patient's family than in Romania. I have gone through this experience and I have got a very good opinion about the NHS staff both in London and Brighton'; 'No, I feel free to contact the GP whenever I have a problem'; 'in both countries there are warmer, kinder or tougher physicians'; one person indicated that 'the treatment seems to be more accessible in Italy than the UK.'

5. potential barriers in accessing cancer screening services:

majority expressed no gender preference when undergoing cancer screening but expressed preference of having access to information and discussions in own language: 'it is much more relaxing to speak in your own language at a screening';

the impact of the current pandemic seems have created divided opinions: 'my relationship with health has not been impacted by Covid' and 'Covid has affected me directly, I am more motivated to check my health. I am concerned because I am aware that I do not have a healthy lifestyle'; on accessing screening the pandemic seems to have been identified as delaying the process; other potential barriers were appointment times: 'if when booked, it is hard to take time off to attend appointments. There should be slots available in the evening as well.'

6. how to tailor the cancer screening service to be suitable for people from different ethnic and cultural groups:

access to a better information and knowing cancer survivors seems to be prioritised: 'maybe a better information and if I knew more people that got cured'; 'yes, listening to life stories and knowing people explain their experience in surviving cancer',

majority, over 80% did not find travelling a problem needing tailoring; accessible booking times and use of appropriate Romanian interpreters has been prioritised. When asked what would motivate one to access cervical screening, all direct answers were vague, indicating that there is nothing that community or others can do, and it is all down to the individual.

5. Key findings - what I have learned

There are a few aspects that have prompted me to the conclusion below and it is based on all the Romanian individuals that I have presented the research topic to, focus-group or not, either discussing briefly about it or refusing to participate in:

1) overall, Romanian who live in the UK are interested in their health and the current pandemic has served as a wakeup call in looking into healthy life style, monitoring health overall;

2) Romanians do feel confident to contact the GP in need but would prefer easier access for further treatments or investigations; cervical screening in the evening would definitely increase interest;

3) more practical information on plus and minuses of considering a cervical screening, in more accessible format, available practically everywhere would increase interest;

4) emotional impact of potentially finding there might me abnormalities when taking the cervical screening by an individual would definitely be lowered by access to cancer survivors and their cancer journey stories;

5) what cancer survivors have taught me when listening to their story is that treatment and emotional impact does not end when they are surgically cured, there is need for counselling sessions, longer appropriate community support, which is not easily accessible and it is still not clearly understood, i.e., I have recently interpreted for a 2 part assessment for a counselling support and the outcome was transfer of case to another organisation, outcome was beneficial for patient but patient had difficulty understanding this process and the wide access system in the UK; which leads me into

6) although all respondents knew something about cancer and cancer screening, they knew very little of how the system works in the UK;

7) which is significant, because the Romanian community that I have discussed with repeatedly emphasised that they would prefer dealing with specialist advice and route for treatment and not much rely on family for information;

8) however, a network comprising of friends, family and especially cancer survivors from the Romanian community would be quite beneficial;

9) returning to point 7), i.e., access to professional information, none of the Romanian respondents were happy with information passed through family or friends but through professional interpreters, the above example of one cancer survivor from London relocated to East Sussex was explicitly reluctant on using untrained and unskilled interpreters due to past unhappy experience during cancer treatment; this was particularly relevant for this study, as the respective individual expressed 'especially now I have found a proper interpreter and there is the element of trust which is important to me as our discussions were only over the phone and I have never met you';

10) the pandemic has produced various impacts, from managing health remotely, to learning to look after oneself, however, it has produced significant financial loss and delays in healthcare which have been the main justification for those Romanian individuals declining to take part: 'I know cancer is important and I know people in my family who lost

the battle with cancer, however, I am sorry but I do not have time to answer your questionnaire, I am faced with eviction because of shielding.'

One final conclusion, as a professional linked to the Romanian community in SE England is that, there are key elements resurfacing from this study in what would need to improve in order to increase Romanian community access to cancer screening:

- Accurate information about cancer screening and the existing support system/network in SE England does not seem to be easily available
- Plenitude of information would increase interest
- Cancer survivors network in the community in the native language is needed
- Romanians are happy to access the GP, would prefer easier access to specialist support and treatment if needed
- Information is still preferred using a professional interpreter rather than a friend or family (only allowed present as support)
- More evening appointment slots are needed

6. Actions – Recommendations for SIS and recommendation/actions for other bodies – HEE/PHE/ICS and other relevant organisations in the SE England

I believe that this study might provide SIS with an evidence backed reasoning for going a step forward in ensuring the healthcare commissioners provide their patients with the professional linguistic support needed for information purposes, especially considering the extensive amount of years as the main professional language provider in Sussex.

Also, as quite a significant amount of Romanian respondents have indicated, developing and awareness partnership with relevant cancer outreach organisations within the community in which cancer survivors are invited to discuss their cancer journey in the native language.

Due to SIS' long social and community impact has progressively developed a wide variety of stakeholders and in turn, could also benefit from their input in continuing to support SIS in developing sustainable partnerships in the SE England.

Please see the questionnaire and CPAR consent form

Acknowledgements

The CPAR programme was initiated and funded 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.