Health Awareness: Attitudes towards Cervical Cancer Screening among Polish women in Sussex

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sussexinterpretingservices

This project is a part of Community Participatory Action Research (CPAR). 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 NHS England and Improvement.

The project has been conducted in partnership with Sussex Interpreting Services, Trust for Developing Communities, Hangleton and Knoll Project, Crawley Citizen's Advice Bureau, and Hastings Voluntary Action, and sponsored by NHS Sussex Health Care Partnership.

Key findings

- All women were very serious about cervical cancer screening and made sure they
 test regularly. Some said that annual cervical screening, rather than every 3 years
 would be more desirable also available for individuals under 25 years old.
- 21% (n.8) of Polish women who completed the research do not attend cervical screening appointments in the UK. Having previously had a bad experience in the UK, feeling more confident in the private health care system in their home country were some of the reasons given.
- 24 % (n.9) the women surveyed who attended cervical screening in the UK also attend cervical screening in their own country primary at private gynaecological clinics. This bring the question how/ if tests taken in Poland (along with its results) are being recorded in the UK health system.
- All women highly valued to receive their English invitation letters/reminders
- The findings showed that there is still not sufficient knowledge about cervical cancer symptoms. There is a need for information in Polish and English
- There are doubts about quality of tests in UK as not carried out by a doctor

1. Introduction - background to the research.

The research subject I have chosen is 'Attitudes towards Cervical Cancer Screening among Polish women in Sussex'. This topic is of interest to the communities we are working with as well as a priority for the healthcare system.

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 several health-related issues and are interested in exploring other subjects on health and well-being.

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

Cervical cancer is largely a preventable disease, but the incidence in the UK has increased by 5% in the last decade. In addition, across Europe, the highest incidence of cervical cancer is reported in Central and Eastern European countries. Data from North West London found that migrant Eastern European women accounted for 28.2% of all new diagnoses of cervical cancer, and that significantly more Eastern European women had not previously been screened in the UK prior to their diagnosis, compared with UK-born women (90% vs. 52.6%).

According to the National Cancer Registry in Poland, 40% newly diagnosed cases of cervical cancer are very advanced and the chances of survival are low. In Poland, only 27% Polish women takes smear test. Poland has one of the highest incidences and mortality rates from cervical cancer in Europe.⁴

This study aimed to determine the cervical screening behaviours of Polish Women in Sussex, and explore their knowledge of and attitudes towards the National Health Service Cervical Screening Programme. This topic is a priority for the healthcare system, as they record low uptake on screening in this area.

2. Research process and methods

Due to the pandemic and challenges around face to face contacts the research was primary conducted via Survey Monkey and enriched by semi-structured interview. All questions were translated into Polish. Polish was also used during the interview to make individuals feel comfortable, not worrying about how to respond in English.

All promotion materials were also in Polish and everyone who took part in this project was offered an entry into prize draw for a £10 Amazon voucher. The biggest challenge was to convince larger numbers of individuals to take part in this research, especially in semi-structured interviews. It could be argued here that this was linked with individuals' busy lifestyles (three individuals initially agreed to the interview, but then found it difficult to find a time for it). Some also didn't believe that their feedback would make any difference, therefore chose not to engage.

Eventually, **37 individuals** responded to the survey and 1 semi-structured interview was conducted. To promote this, Polish Facebooks Groups, Polish Schools, Polish volunteer Mother & Toddler group 'Krokodyl' and connections with Polish Catholic Parish in Sussex were utilised.

¹ Cancer Research UK . Cervical cancer statistics. 2019, https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence

² Altobelli, E, Lattanzi, A. Cervical carcinoma in the European Union: an update on disease burden, screening program state of activation, and coverage as of March 2014. Int J Gynecol Cancer 2015; 25: 474–483, Google Scholar: https://tinyurl.com/mrtb4ep4

³ Anna Collins, HS, Esther, R, Panos, S. Impact of eastern European migration on cervical cancer characteristics in North London. In: BSCCP annual scientific meeting, Cardiff, 3-5 May 2017. Google Scholar: https://tinyurl.com/5n7kb6y3

⁴ National Cancer Registry in Poland: https://tinyurl.com/2p857cf4

The research was conducted with Polish women aged 25 to 64 years old, between 13 November to 20 December 2021.

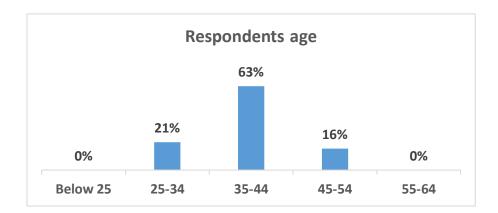
The main areas of focus were:

- 1. a broad overview of how much Polish women know about cervical cancer screening
- 2. where information about cancer screening comes from
- 3. potential barriers in accessing cervical cancer screening services
- 4. cultural attitudes towards the subject
- 5. recommendations to overcome this

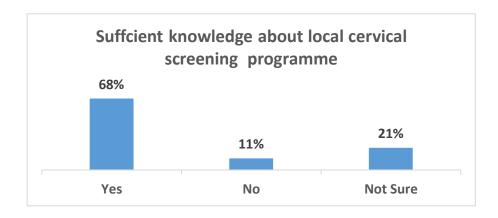
Wherever possible I'm focusing on action that can be taken from the research so that the community can see a change. For starter, I'm working on gathering all information available on cervical cancer in Polish/English on Padlet and planning to share this soon with Polish women. Also, where possible I've tried to respond to issues they raised during this research. For instance, raising awareness about local health services, support groups etc.

3. Research findings

Part one - background



All respondents were within the age when The NHS cervical screening programme was offered to women in the UK with majority of them 63% (n.24) being 35-44 years old. There were no respondents under 25 and in the age range 55-64.



Majority of respondents, 68% (n.26) felt that they have a sufficient knowledge about local cervical screening. One highlighted the importance of regular testing and monitoring of vaginal discharge.

21% (n.8) were not sure, and one said that they didn't really think about it and just will take the test when the letter arrives, others reported they will take the test even though they didn't know much about it.

11% (n.4) reported not having a sufficient knowledge about local cervical screening programme, but haven't provided any further information as to why.

When asked if they know what the cervical cancer symptoms are, the respondents felt less confident, with only 39% (n.15) saying 'Yes', 34% (n.13) not being sure and 26% (n.10) not knowing what they are. It could be argued here that there is a need to review what information is currently available and what could be done to make sure that more Polish women have access to it.

Among those who said that they know what the cervical cancer symptoms are:

- one was a doctor
- five reported using NHS website, four were using Polish medical websites e.g.
 Poradnikzdrowie.pl .
- one reported being well informed by own GP after having a baby (also being given publicity in English and Polish).
- one felt that the question wasn't asked correctly.

"My GP after a birth explained me all and gave me lots of resources in English and Polish"

Among those who said that they are not sure what symptoms are or didn't know them, five reported using NHS, same number was using Google, two were informed by GP and one picked up leaflets in surgery.

In both cases respondents reported searching for information in English and Polish.

Part two - system



Majority 55% (n. 21), of respondents reported taking a smear test locally. However, there were 21% (n.8) who take test just in Poland and 24% (n.9) who use both locations.

Among those who take test locally in Sussex, the main factor was a convenience, proximity to the place of living and reminders being sent by surgery, which were highly valued. One individual reported the whole experience being more pleasant in the UK than in Poland as procedure was done by a nurse who respected intimacy and did procedure on examination couch (different method of collecting sample in the UK: lying down, not seated position like in Poland) English way was more preferable. One individual reported having no alternatives, so taking test locally.

"It's more comfortable, I get reminders, the procedure is done by nurse, who respects intimacy and uses examination couch, not gynaecologist chair like in Poland, I prefer UK"

Among those who chose both locations:

- one reported having a very helpful GP
- one reported having regular tests in the UK plus additional ones when needed and where convenient
- two individuals reported taking regular tests in the UK, plus one each year during holidays in Poland to get a second opinion and double check everything is OK.
- One often takes test in Poland as a part of full check-up done by private gynaecologist, because appointment dates given in the UK often don't work for that individual

Among those who chose Poland:

- One reported that test is done straightaway when requested
- One felt that procedure is more trustworthy as is conducted by the gynaecologist and not a nurse. On their last visit, the individual was given also two home tests
- Two reported having a regular general health 'mot', including breast and cervical screening together in their home country with the same health specialist for years
- One reported whole procedure being less painful
- One reported that intimacy is better respected there. The individual reported seeing blood test being done in Poly clinic (Brighton and Hove) with open door. That experience put that individual off from having any procedures done in the UK.

- One reported test result being more accurate; in the UK always is ok even there is an infection. Examinations in Poland are more detailed
- One reported having a bad experience in the UK
- One said "I have time to go when I am on holiday in Poland"

Those who had tests done locally, in the Sussex prised the system for:

- Regular reminders, so they don't have to worry that missing it.
- Health professional conducting the procedure being highly professional, delicate, caring, and patient, as well as explaining well the whole procedure.
- Tests being done when needed even outside of regular appointments
- Whole procedure being painless

"All was explained very well, that's important so we can avoid any unpleasant surprises"

Women cited the following as barriers for attending cervical screening appointments in the Sussex:

- Fear of repeat experience
- No time to attend
- Doubts about quality of tests in UK as not carried out by a doctor

Missed appointments

95% (n.36) reported having a regular smear tests done, only two individuals were not sure. 97% (n.37) have never forgotten about the test.

- One individual did forget once, also ignored a reminder but that hasn't happened again.
- One felt that question wasn't appropriate. Some of them felt that testing should be more frequent, for instance one a year also available for individuals under 25 years old.
- One surveyed woman reported the need to undertake cervical cancer treatment in her early twenties and was passionate about raising the awareness about this disease among young girls.

Smear test during Pandemic

Five individuals reported difficulty in accessing planned cervical cancer screening appointment during the pandemic, with majority of them not being able to have one. One individual was offered a home test. One felt that question wasn't appropriate.

Smear test prior Pandemic

Just two respondents reported having problems with accessing planned cervical cancer screening appointment prior to the pandemic with one of them reported having 2 smear tests in a row was done incorrectly. Therefore, didn't go to the third appointment and decided to have the whole procedure done in Poland during regular check up with the private gynaecologist.

Part three - lifestyle

100% women surveyed were registered with their local GP in the Sussex and reported having their up to date contact details saved with them.

Part four - cultural

71% (n.27) felt that the gender or ethnicity of the GP or nurse who undertakes the cervical screening doesn't matter to them. Those who felt opposite preferred a woman, ethnicity didn't matter to anyone.

Respondents felt quite comfortable to talk about the cancer. Just three individuals felt that if they had cancer/ were suspecting they may have one, they would need some support in telling that to their friends/family. Other felt ok doing this themselves.

Other comments made by surveyed women

- "Those kinds of procedures safe lives. Myself, I'm after breast cancer treatmentsmall lump has changed my life. Because of fast diagnosis I could have treatment. Thank you"
- "Please don't be afraid, that doesn't hurt and last just few seconds but can really safe a life."
- "The procedure is fast, regular because of reminders, done by woman with respect and intimacy on examination couch"
- "Girls you need to test regularly, early diagnosis gives big chance for victory"
- "We have only one health, so please care of yourself"

6. Actions/ Recommendations

- The sample is too small to draw overreaching conclusions. More research is needed.
- To review how information on conducted smear tests /its results are being recorded,
 if the procedures are conducted outside of the country are recorded in patients' file.
 Make sure that invitation letters include information on the need to report to local
 surgery that smear tests was conducted somewhere else
- There is a need to review what information is currently available and what could be done to make sure more Polish women have access to it. Note that they still look for information in Polish.
- To provide the reinsurance that smear test conducted by nurse is as good as one done by gynaecologists, and that there is no need for a doctor to be there. More information on what procedure looks like and the level of training/qualification hold by the nurse who carries out the procedure.
- To explore the possibility of offering home smear tests for those who struggle to attend planned check ups
- To introduce more frequent testing, also for woman under 25yrs old. Raise awareness about cervical cancer symptoms among them as younger women get also sick.

7. Actions already taken

- Shared information about cancer support groups like: <u>WOLO Foundation</u>, <u>Macmillan</u>
 Cancer Support
- Shared information on what smear test procedure look like, explaining that it makes no difference whether the procedure is conducted by a nurse or gynaecologist.
- Managing expectations by explaining that majority of procedures Poles undertake in their county of origin are done there by private health professionals, who has lots of resource/ are able see patients quickly, but they charge for their services, in the UK we rely on national health services which deals with various challenges
- Shared information on alternative to GP health services where individual can receive help
- Provided reinsures that potential cancer symptoms are taken seriously by health professionals, shared personal experiences that took place prior and during the pandemic
- Shared <u>Cervical Screening Helping You Decide</u> document translated into Polish which is part of Cervical Screening Awareness Campaign
- Started to collect information on cervical cancer in Polish/English on Padlet with the aim to be shared with Polish women
- Shared information on where to look for volunteering opportunity e.g. <u>Volunteer</u>
 Centre

8. Acknowledgements

I would like to thank all 37 individuals who gave their time to complete the survey and 1 individual who took part in semi structured interview. I would also like to thank you all who helped me to promote this project among Polish community in Sussex, that includes Polish schools, Polish volunteer Mother & Toddler group 'Krokodyl', Polish church and admins of all local Polish Facebook Groups as well as thank to Sussex Interpreting Service and Scottish Community Development Centre for workshops and an ongoing support during the project.

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.



The contents of this report are fully informed by my community engagement and other relevant stakeholders.

If there is any aspect of this report which you feel is inaccurate or if you would like to be kept informed of any future engagement activities, please contact me.

Magda Pasiut

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9. Appendices

Appendix 1: Semi Structured Interview Template

Part one - background

Q1 - Age: What is your age?

Q2 – As you know I'm carrying out this research about cervical cancer screening, can you tell me what do you know about cervical screening (a smear test)?

Q3 – Do you know what are the cervical cancer symptoms? Where would you go to find this information?

Prompts: in what language would you look for this information

Part two - system

Q1 Where do you do smear test?

Prompts: Locally, in Sussex; in Poland, locally in Sussex and in Poland; in London; nowhere; in different place

- Q2 Have you ever missed any of your cervical cancer screening appointment? If yes, please tell us why and let us know what could help you to prevent this from happening
- Q3 During Covid have you had any difficulty is accessing your cervical cancer screening appointments (if you were due one)? How? What could be done differently?
- Q4 Have had any positive experiences in accessing cervical cancer screening? (follow up with questions, based on response)

Part three - lifestyle

Q1 - Are you registered with a GP surgery? If not, why not?

Q2- Is your GP having your up to date contact details?

Part four - culture

Q1 -How does the gender or ethnicity of the GP or nurse undertaking the cervical screening matter to you? How important is it to be getting the screening done by women, someone who can speak your first language? OR how important do you think these things are for your community?

If another barrier is mentioned then explore it.

Q2 - If you have had cancer/ was suspecting you may have one, did you tell your friends/family? Why, why not?

What could be done to encourage you to tell your friends and family?

Part five - improvements/conclusion

Q1 - Is there anything else that can be done to improve the access to cervical cancer screenings or to overcome the barriers that we spoke about earlier? Do you have any further improvements suggestions?

Prompt: for example, hearing stories of people who have recovered, being reassured you can choose the practitioner etc.

Thank you so much for your time today. The information you've shared is really valuable.

Appendix 2: Survey Template

Part one - background

- 1. Age: What is your age?
 - Under 25 years old
 - 25-34 years old
 - 35-44 years old
 - 45-54 years old
 - 55-64 years old
- 2. Do you feel you have a sufficient knowledge about local cervical screening (a smear test)?
- 3. Do you know what are the cervical cancer symptoms?
 - Yes
 - No
 - Not sure
- 4. Where would you go to find information about cervical cancer screening/ and cervical cancer symptoms? Please name few resources and state in which language you will be accessing this information

Part two - system

1. Where do you do smear test?

- Locally, in Sussex
- In Poland
- Locally in Sussex and in Poland
- In London
- Nowhere
- In different place

Tell us why

- 2. Do you attend regularly your cervical cancer screening appointments?
 - Yes
 - No
- 3. Have you ever missed any of your cervical cancer screening appointment? Please note that The NHS cervical screening programme invites women from age 25 to 64 for cervical screening. You get an invite every 3 years if you are aged 25 to 49. After that, you get an invite every 5 years until the age of 64.
 - Yes
 - No

If yes, please tell us why and let us know what could help you to prevent this from happening

- 4. During Covid have you had any difficulty is accessing your planned cervical cancer screening appointments?
 - Yes
 - No

If yes, please tell us what they were and would could be done by local services to overcome them?

- 5. Prior Covid have you had any difficulty is accessing your planned cervical cancer screening appointments?
 - Yes,
 - No

If yes, please tell us what they were and would could be done by local services to overcome them?

- 6. Have had any positive experiences in accessing cervical cancer screening?
 - Yes
 - No

Part three - lifestyle

- 1. Are you registered with a GP surgery?
 - Yes
 - No

If not, why not?

- 2. Is your GP having your up to date contact details?
 - Yes
 - No
 - I don't know

Part four - cultural

- 1. How does the gender or ethnicity of the GP or nurse undertake the cervical screening matter to you?
 - Matters a lot
 - Not Matter at all
- 2. If you have had cancer/ was suspecting you may have one, did you tell your friends/family?
 - Yes
 - No

Why, why not? What could be done to support you with this?

Part five – improvements/conclusion

1. Is there anything else that can be done to improve the access to cervical cancer screenings or to overcome the barriers that you have mentioned earlier?

THANK YOU

The deadline for completing this survey is **20**th of **December 2020**

We are delighted to be offering a prize draw for a £10 Amazon voucher, which you can enter at the end of the survey.

If you require this survey in another format, or if you have any questions, get in touch with us on mpasiut@gmail.com