Abnormal Cervical Screening and Follow-up Care among Women in Romania: A Qualitative Study

Appendix 1. Participant Information Sheet

We would like to invite you to take part in our research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask if you would like more information. Please also feel free to discuss this with anyone you wish.

What is the purpose of the study?

This study aims to explore the different experiences of women with cervical cancer screening and follow up, mainly women living in communities from remote areas in Romania.

The study will focus on women who participated in CEDICROM 1 and 2, experiences with follow-up care after an abnormal HPV or Pap test result from a cervical cancer screening among women who participated in CEDICROM 1 & 2. All adult women should undergo periodic cervical cancer screening. Screening aims to detect precancerous lesions, that is, abnormalities in the cells of the cervix, which, if left untreated, can develop into cervical cancer. When found, precancerous lesions must be followed–up and treated.

Why have I been chosen to take part?

You have been asked to take part because you participated in CEDICROM 1 and 2, and had a cervical cancer screening. Your insight and experience on cervical screening and follow-up of care after the screening will be highly appreciated , which will be used to inform and improve the national cancer screening programme policy in Romania

Do I have to take part?

It is completely up to you to take part. If you do decide to take part, you asked to sign a consent form. If you decide to take part but then change your mind, you are free to do so at any time without giving a reason.

What will happen if I take part?

You will take part in an interview with a researcher, Adriana Melnic, to share your experiences and knowledge about your cervical cancer screening and follow-up care. The interview will last approximately 40 - 60minutes, or as long as you would like to talk about your experience. With your permission, the interview will be audio recorded. You can stop the interview at any time, and you do not have to answer a particular question if you do not want to.

Where will the interview take place?

The interview will be carried out in person in Romania.

Are there any risks in taking part?

We do not expect there to be any risks or discomfort associated in this research study. However, if you feel uncomfortable then you can stop the interview at any time, without giving a reason.

Are there any benefits in taking part?

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You will be helping inform a national programme in Romania aimed to improve cervical cancer prevention and treatment.

Will my participation be kept confidential?

All the information that you give us will be kept strictly confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998.

This means that only the researchers will see what you have said. The audio-recording of your interview will be identified by a code number only. These audio-recordings will be transcribed, and identifying details such as place names and people's names removed from the transcripts. We will use quotes from the interviews in the write-up of the study but will ensure no one can be identified from these.

At the end of the study the research data, including consent forms, anonymised interview transcripts, field notes and your contact details, will be kept (in locked filling cabinets and/ or password protected at the Cancer Registry of Norway) for up to ten years.

What will happen to the results of the study?

After the study has finished, the results will be submitted for publication in an academic journal and presented at conferences. It will also help provide recommendations for cervical cancer screening programmes in Romania.

If you would like to receive a copy of the findings please let us know by using the contact information provided and we will happily provide you with one.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can withdraw without giving a reason. You can also ask for your data to be removed from the study and destroyed.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting, Andreea Itu at Email: itu.andreea@yahoo.com, Tel: +40 756 601 901, or Linda Nyanchoka, Tel : +33 75 34 29 417 Email: lnyanchoka@gmail.com who will try to help or put you in touch with someone who can.

Who is funding the research?

This research is funded by EEA/Norway Grants

Who is doing this research?

The research and interviews will be conducted by Adriana Melnic, adrianamelnic@yahoo.com

How can I find out more?

Just get in touch with Andreea Itu from The Oncology Institute "Prof. Dr. Ion, Chiricuta" Cluj-Napoca Email: itu.andreea@yahoo.com, Tel: +40 756 601 901, who will be happy to answer any questions you might have.

Appendix 2. Participant consent form

Title of the research project: **Abnormal Cervical Screening and Follow-up Care among Women in Romania: A qualitative study**

Abnormal Cervical Screening and Follow-up Care among Women in Romania: A Qualitative Study

Researcher: Linda Nyanchoka

Please initial box

1. I confirm that I have read and have understood the information sheet dated [ ] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without affecting your rights. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that, under the Data Protection Act 1998, I can ask for access to the information I provide and request the destruction of that information if I wish. ☐
4. I agree for the data that I provided to be archived at the Cancer Registry of Norway. I understand that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form. ☐
5. I agree to take part in the above study. ☐

_____	_____	_____
Participant name	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Researcher

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Appendix 3. Semi-structured interview guide

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Date: Interviewer:

Archival #: In person: Start Time: End Time:

Background (information about interview participant)

1) Tell me, a little about yourself?
   - ✓ (e.g. age, setting, ethnical group, education, living conditions, health insurance)

Cervical Screening

2) Cervical screening experience (knowledge on type of screening)
   - ✓ *Probe: e.g. HPV, Pap smear testing, both*
3) Cervical screening information provided after screening including results interpretation, and follow up instructions
   - ✓ *Probe:*
     - *Results provided*
     - *Interpretation of results*
     - *Type of follow-up required i.e. where and how to receive follow-up care*

Knowledge and experiences with follow-up services after abnormal cervical screening results

(Did interviewee receive follow-up if so talk about experience, if not talk about reasons that didn't permit follow- up)

4) Knowledge of follow-up services available?
5) Experiences with follow-up care after abnormal cervical screening?

or

6) Experiences with lack of follow-up care after abnormal cervical screening?
7) What are your perceived barrier to follow-up care after abnormal cervical screening?
8) What are your perceived needs to follow-up care after abnormal cervical screening?