# CBIG-SCREEN

***Working collaboratively with vulnerable women to identify the best implementation gains by screening cervical cancer more effectively in European countries***

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## Deliverable 3.4

***Co-created pathways to improving cervical cancer screening access for vulnerable women***

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Lead Beneficiary: LSHTM, *Martin McKee, Rachel Greenley*
Partners involved: UBB, UTARTU, HPRC

| **Dissemination level** | | |
|---|---|---|
| **PU** | Public | **x** |
| **PP** | Restricted to other programme participants (including Commission Services) | |
| **RE** | Restricted to a group specified by the consortium (including the Commission Services) | |
| **CO** | Confidential, only for members of the consortium (including the Commission Services) | |

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**Executive Summary**

CBIG-SCREEN aims to address inequalities contributing to poor uptake of cervical cancer screening in vulnerable and underserved groups across Europe. By developing a co-created knowledge framework around barriers to CCS, CBIG-SCREEN will build tailored interventions from strategic stakeholder insight, focusing mainly on those impacted the most. Through running three pilot interventions in Estonia, Romania, and Bulgaria the project aims to make screening more accessible and acceptable to vulnerable groups.

For this project to work, co-creation must be central to every decision.

Through participatory methods, this deliverable aims to co-create pathways to improve cervical screening access for vulnerable women. In simple terms, we aim to use a participatory approach to engaging with key stakeholders to determine feasible and appropriate ways to improve the chance of women being screened and treated for cervical cancer.

This work complements the barriers/facilitators and solutions derived during the Collaborative User Boards in Work Package 2 and the capacity development assessment in Work Package 6.

This report outlines (i) the background of cervical cancer screening in Europe and (ii) the main objectives of CBIG-SCREEN, and (iii) the methods undertaken in this work package to address the barriers and leverage the facilitators, the perceptions, and preferences, which are thought to prevent vulnerable women from accessing cervical cancer screening by using co-creation methods and finally (iv) a synopsis of the results.

This deliverable initially sought to outline women's experiences in all intervention countries. Still, given time and resource allocation limitations, the deliverable was adapted to focus on time points within the intervention development process as a focal point. A complete list of partners involved is included below.

The desired impact is to establish understanding through the views and preferences of women with lived experience of particular vulnerabilities, which put them at greater risk for experiencing known barriers to preventative cervical cancer screening and treatment.

**Working collaboratively with vulnerable women to identify the best implementation gains by screening cervical cancer more effectively in European countries: Romania, Estonia and Bulgaria**

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**Deliverable 3.4: Research Team**

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|---|---|---|
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Acronyms

Cervical Cancer Screening (CCS)

Cervical Cancer (CC)

Human Papillomavirus (HPV)

Self-Sampling Kit (SSK)

Community User Boards (CUBs)

Work Package 3 (WP3)

**Background: CBIG-SCREEN**

Cervical cancer remains the fourth most common cancer in women. Yet, it is preventable. Vaccination against human papillomavirus (HPV) and screening are the mainstays individuals can take to prevent cervical cancer. However, if we widen our focus, we see more generally the extent to which the position of cancer as a cause of premature death reflects barriers across micro, meso and macro levels through an inequitable distribution of risk factors. In recognition of this challenge for those who have not benefitted from HPV vaccination, the European Union have commissioned a Horizon 2020 project to increase the uptake of CCS among underserved women in Europe (CBIG-SCREEN). Effective delivery of this outcome requires understanding the micro, meso and macro level barriers and facilitators of CCS access amongst underserved groups and an understanding of the interventions used to respond to these barriers.

The main objective of C-BIG-SCREEN is to attract vulnerable women to CCS programmes and retain them from the initial test to treatment. To do this, we will work in collaboration with these women to identify and develop strategies to meet their varied and specific needs, convincing policymakers to adopt these strategies and ensuring that programmes reach out to promote these interventions to communities of underserved women. In addition, CBIG-SCREEN will quantify the extent to which tailored CCS can be generalized and assess specific barriers.

We will analyze population-based interventions designed to increase cancer screening (e.g., sending reminders, financial incentives, mass media and social media, group education and one-on-one education), interventions designed to reduce barriers to screening (e.g., lowering structural barriers, reducing out-of-pocket costs, home-based screening tests, or less invasive tests), and provider-directed interventions aimed at clinicians (e.g., provider assessment and feedback, provider incentives, clinical guidelines, use of triaging biomarkers, or integrated services).

To address the socioeconomic and contextual factors relevant to the targeted region and community, we will combine information across settings only if it is reasonable to compare intervention effects across contexts to determine if the effects are comparable. We will formally quantify the extent of generalizability of the aggregate results by comparing uncertainty within trials to uncertainty across trials to reveal the role contextual variables play in predicting efficacy at the country and intervention levels. The certainty of the evidence will be evaluated according to GRADE criteria and presented in evidence-to-decision tables. CBIG-SCREEN will develop models specific to different settings. The experience we gain in these exemplary countries will help us identify difficulties likely to arise in other countries and develop solutions as part of a multicomponent intervention which addresses several steps in the screening cascade before the project is introduced in other EU states.

### Aim of Deliverable 3.4

This deliverable aimed to establish methods for co-creating with vulnerable women as part of the CBIG- SCREEN while also seeking to improve intervention development for improving cervical cancer screening uptake and treatment adherence. We used participatory action research methods to engage women from our target population, as well as healthcare providers or other relevant stakeholders who assist women along the pathway of care for cervical cancer.

From this skeleton of intervention components that we know "work" (established as the gold standard based on systematic reviews and other highly established evidence sources), we will use focus groups of stakeholder networks previously established by the Community User Boards (see report associated with D 2.3) to complete the intervention, with careful consideration to unique country context.

To date, we have been engaged in desk-based literature reviews to establish a knowledge base of previously established interventions which provide evidence of facilitating factors for CCS uptake. Further, preliminary community user board meetings have been held as part of complementary deliverables to provide barriers and facilitators directly from stakeholders within C-BIG SCREEN countries.

### Co-creation within CBIG-SCREEN

In line with the collaborative and participatory nature of CBIG-SCREEN, prior stakeholder engagement from subsequent work packages has served to inform the participatory methods, as well as carefully considering country context, leading to establishing the CBIG-SCREEN think-aloud protocol (Romania), prioritization protocol (Estonia) and digital stories (Bulgaria). Thus, WP3 adapted the CUB format to a *CUB lite* wherein participatory

methods using think-aloud, and prioritization methodology will be employed alongside other key informant interviews already taking place at the country level.

### Consent and Confidentiality

In alignment with the UK Mental Capacity Act (2005), we take the view that people are presumed to have the mental capacity to consent unless there is reason to believe this is not the case. This is also in alignment with CBIG-SCREEN principles of Participation and co-creation. Should there be any reason to believe that a person is unable to provide free and informed consent (related to the ability to comprehend, retain, communicate or voluntarily act on information), then we will use a formal assessment of capacity concerning consenting to Participation in this study (see below)

Data collection methods ensured participants were given information about the aims of CBIG-SCREEN research, and hard copies of the informational letter in English or a local language as needed were provided. The participants were invited to ask any questions before providing consent. Consent ensured permission to audio-record the discussion. In addition, the presence of a researcher from LSHTM was confirmed and approved by all participants before the initiation of FGDs, where she was present. During the CBIG-SCREEN think-aloud and prioritization discussion, all members were warned of the potential lack of confidentiality under specific situations and asked to maintain the confidentiality of anything disclosed in the discussion.

### Ethical Approvals

Romania: the protocol was approved by the Scientific Council of the Babeș-Bolyai University of Cluj Napoca, number 17.091/12.12.2022

Estonia: the protocol was approved by the University of Tartu Research Ethics Committee (protocol number: 359/T-22) on February 21. 2023., 2022.

Bulgaria: The Bulgarian Sociological Association approved the full CBIG_Screen study on 19.04.2022. An amendment was approved on June 15th 2023, which covered the Digital Story study design, recruitment and methodology.

**Study Design: Romania**

### Overview

Think-aloud is a qualitative research method in which participants speak aloud any words in their minds as they complete a task (Charters, 2003). A literature review has shown that think-aloud research methods have a sound theoretical basis and provide a valid source of data about participant thinking, especially during language-based activities. This methodology treats participants as experts by experience and will act to inform the enhanced CBIG-SCREEN cervical cancer screening and uptake intervention. The benefits of the CBIG-SCREEN Think Aloud include providing insight into people's experiences as they interact with the self-sampling kit, which is affordable to carry out and does not require many participants. Considerations of potential drawbacks of this method will consider the fact it relies on people verbalizing thoughts and impressions rather than objective measures considering for bias of social desirability.

### Study Setting

The CBIG-SCREEN Think Aloud was carried out in Cluj-Napoca and Cojocna (a small village near Cluj-Napoca).

These sites have been working to establish a core group of key stakeholders using community user boards to derive expertise, guidance and collaboration during our formative research.

### Eligibility Criteria:

- Micro-level stakeholders are defined as individuals who either have sought screening or treatment services in the past or women who have been underserved by traditional screening services.
- Meso-level stakeholders are defined as members of the healthcare sector who are directly employed with cancer screening or treatment initiatives.

Between December 14-17, we engaged with six women through the Think Aloud process. We intended to interview women in both Cluj and rural communities; however, due to the accessibility and availability of women, we were able to interview women in the rural community of Cojocna.

### Methods

Think Aloud verbal protocols are a data collection method where participants are asked to talk aloud while solving a problem, explaining what they think while performing the task at hand. The person is asked to speak out loud whatever thoughts come to mind, providing a concurrent account of thoughts and avoiding interpretation or explanation of what is being done (Van Someren et al., 1994). The verbal 'think aloud' protocol offers a way to gain information about an individual's cognitive processes by using verbal reports and raising thoughts into consciousness (Ericsson & Simon, 1998). Think Aloud verbal protocols provide rich verbal data about reasoning during a specific problem-solving or decision-making task (Fonteyn et al., 1993). Think Aloud verbal protocols have been used as data collection methods by researchers studying information seeking and information processing and can be useful for understanding decision-making more broadly.

Participants were given information on the CBIG-Screen project and engaged in interview questions about cervical cancer screening (CCS) experience and knowledge before the Think Aloud activity. At the start of the Think Aloud, the facilitator offered the self-sampling kit for CCS and briefly explained the objectives. During the Think Aloud, the participants were asked to focus on the clarity of the written instructions attached to the self-sampling kit and to tell their thoughts, reactions and emotions as they occurred while examining the self-sampling kit. Participants were reminded of this task's descriptive nature to better understand how self-sampling and cervical cancer screening, more broadly, worked for them. There was an emphasis that there were no incorrect responses and that any remarks regarding the kit were welcomed.

During the Think Aloud, women were provided with a replica of the self-sampling kits used in their area to look at, read the instructions and think through their experience as if they were using this kit at home. To aid the discussion, the facilitator was also provided with a set of open-ended questions to help the thought exploration when deemed necessary. Sessions lasted between 20-30 minutes, as we needed to consider the time feasibility of our participants. While the facilitator guided the Think Aloud in Romanian, the LSHTM researcher was making notes of stakeholder reactions, thoughts and questions. The workshop was audio recorded, and transcripts were transcribed and translated for analysis.

In order to create an inviting and open environment, considerations were made towards ensuring the use of open, semi-structured focused questions, which allowed participants to provide their thoughts and opinions without judgement or coercion. The use of broad interview questions first acted as a warmup exercise on the related but more general topic. There was also a careful consideration of the non-native researcher's "presence" in the room in which the guest researcher sat to the side of the participant to decrease distraction but could still make observations.

Results in the form of tables from both Romania and Estonia are discussed below in the results section while the Bulgarian findings are reported in narrative format, reflecting the different methodology.

**Study Design: Estonia**

### Overview

The results of the prioritization exercise and subsequent FGD with macro/meso stakeholders (described below) set the foundation for the FGDs held with women at the micro level. This exercise was established in order to explore interventions to support the completion of the cervical cancer screening cascade. This initial step of the exercise was completed in consultation with macro and meso Community User Board members.

### Study Setting

In order to develop successful interventions, it is essential to take into account the perspective of end-users, such as the target group of cervical cancer screening (micro), healthcare professionals (meso) and policymakers/payers (macro). The researchers worked in collaboration with these groups to gain a comprehensive understanding of their preferences. Without this multi-level stakeholder collaborative approach, interventions developed will not align with the needs, values, contexts and norms of the end-users, ultimately hindering their successful implementation in real-world settings.

Macro/Meso:

Based on CUBs (WP2), continuous collaborative events (e.g., workshops) with the active engagement of all key stakeholders

- Ministry of Social Affairs
- Health Insurance Fund
- Cancer screening registry
- Health practitioners

The CBIG-SCREEN Intervention Preference FGD were carried out in Tallinn[1] and Jõhvi[2]

The local WP3 researchers have been working to establish and maintain active communication (communication in which partners engage in a dialogue, providing ongoing input and responses to questions which arise in the intervention design process) with a core group of key stakeholders using community user boards to derive expertise, guidance and collaboration during our formative research. These stakeholders will be invited back to participate in this task[3] (Hinchcliff et al., 2014).

### Eligibility Criteria:

- Macro-level stakeholders are defined as individuals who are involved with healthcare decisions at an organizational level, such as government.
- Meso-level stakeholders are defined as members of the healthcare sector who are directly employed with cancer screening or treatment initiatives.
- Micro-level stakeholders are defined as individuals who either have sought screening or treatment services in the past or women who have been underserved by traditional screening services (in Estonia, vulnerability defined: WLWH, disability, region, drug injecting).

The members of the prioritization target group included:

- Macro level respondents (Ministry of Social Affairs n= 2; Health insurance fund n= 4)
- Meso level respondents (Gyn n= 4, GP= 1)
- Cancer Screening Registry (n= 4)

The members of the microfocus groups discussion (n=18)

All Participants aged 31 to 52 years

### Procedure

Macro/meso co-creation

The first step of the prioritization exercise was to establish interventions for prioritization which were selected based on CBIG-SCREEN Work Package 6 capacity assessment. Following this step, a web-based survey was sent to CUB members in which members were given a two-week timeframe of completion (March 1-13, 2023). The survey provided instruction for members to rate (assessment of the priority of each of the selected interventions) each of the 6 interventions proposed from WP6 using a five-item Likert scale (1 Not important – 5 Very Important) and with a final task to select one, the most important for implementation. The link to the survey can be found in Annex 2.

Following the completion of the survey, a focus group with meso and macro-CUB members to present and discuss the results of the web survey was completed by the UTARTU PI.

Timing:

March 21, 2023 – focus group with meso CUB

March 22, 2023 – focus group with macro-CUB

[1]Two focus group discussions were carried out in Tallinn. The first was in person by with the general public and the second over zoom with women who inject drugs (PWID).

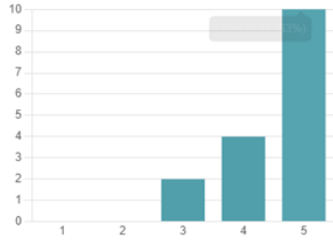
[2] Target group – general population women in the socio-economically challenged region

[3] This report highlights the benefits of engaging in **multi-stakeholder health services research collaborations**.

Results

1. **Complete follow-up: investigations, treatment after a positive screening test**

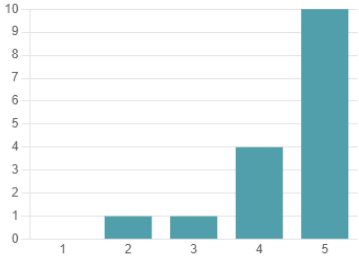
The % of women with the complete follow-up are an indicator of the quality of the work of the service provider who performed the screening (proportion of women who received the necessary examinations and treatment). **This was not deemed an intervention and will not be considered as such for the purposes of this deliverable.**




Average rating – 4.5

2. **Complete follow-up: an invitation to examination, treatment after a positive screening test, and reminder of missed the visit**

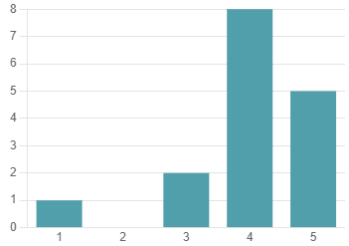
SMS reminder to the woman who participated in the screening (a) about the necessary and/or agreed examination and treatment; (b) reminder of missed the visit




Average rating – 4.4

3. **Participation in screening**

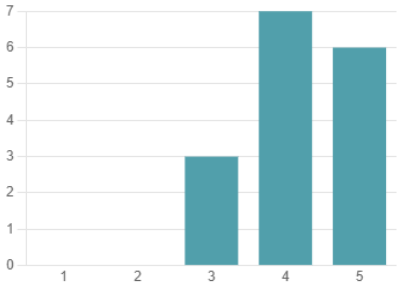
Multiple screenings at the same time --> possibility of HPV self-testing in the mobile mammography unit without pre-registration




Average rating – 4.0

4. **Home/self-sampling**

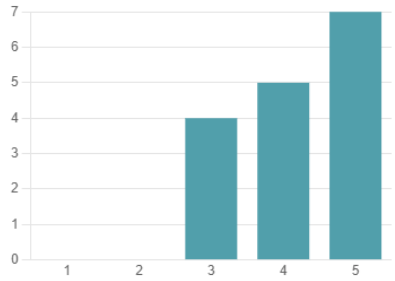
Making kits more available in health centres, pharmacies, harm reduction, including syringe exchange, substitution treatment centres and through the social assistance system




Average rating – 4.2

**5. Screening Test Result Notification (Content)**

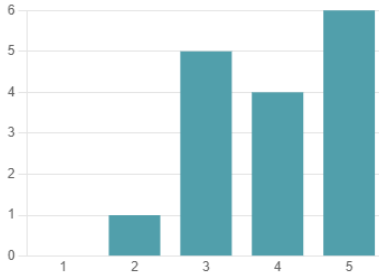
Improving both HPV negative and positive test result notification text based on stakeholder input (more user-friendly)




Average rating – 4.2

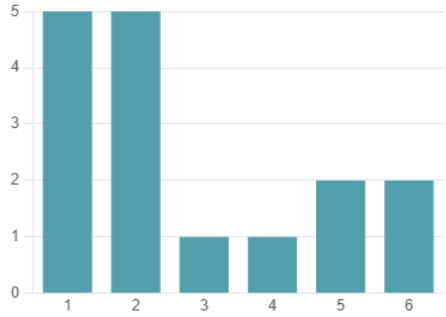
**6. Screening invitation**

Designing and personalizing screening invitations and reminders (including SMS) based on survey participants' inputs (more user-friendly)




Average rating – 3.9

**7. The most important of the mentioned interventions**




The most important intervention:

| Intervention | | Average rating | Ministry of Social Affairs | Health insurance Fund | Meso | Cancer Screening Registry |
|---|---|---|---|---|---|---|
| 1 | % of women with the complete follow-up as an indicator of the quality of the work of the service provider | 4.5 | 2 | | 2 | 1 |
| 2 | The reminder of a follow-up visits and missed FUP visit | 4.4 | | 2 | | 2 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 3 | Multiple screenings at the same time --> possibility of HPV self-testing in the mobile mammography unit without pre-registration | 4.0 | | | 1 | |
| 4 | Making kits more available in health centres, pharmacies, harm reduction, including syringe exchange, substitution treatment centres and through the social assistance system | 4.2 | | | 1 | |
| 5 | Improving both HPV negative and positive test result notification text based on stakeholder input (more user-friendly) | 4.2 | | 1 | | 1 |
| 6 | Designing and personalizing screening invitations and reminders (including SMS) based on survey participants' inputs (more user-friendly) | 3.9 | | 1 | 1 | |

Two focus groups (one with macro and one with meso) were held to triangulate the findings from the prioritization survey.

Micro level co-creation

Focus groups were conducted to gain insight into the underlying assumptions that contributed to the opinions and perspectives of vulnerable women. This approach was deemed appropriate as it fosters interaction between participants, enabling researchers to obtain a deeper understanding of the topic of interest. To facilitate meaningful discussions, the number of participants in each focus group was limited to a maximum of eight. In total, four focus groups were conducted. Ethical approval for the study was obtained from the ethics review board of the University of Tartu.

**Study Design in Bulgaria**

Overview

Cervical cancer is a highly preventable disease, which is caused by several strains of the HPV virus, which is sexually transmitted. Thus, its prevention and treatment are entwined with gendered discourses regarding appropriate sexual behaviour, promiscuity, blame and judgement particularly of women. Socio-cultural expectations of what it means to be a woman (and their intersection with other dimensions of inequality – minority status, poverty, access to care) are integrated into screening process. We locate this analysis in local context of Bulgaria a traditionally patriarchal (culturally specific) society with periods of intense scrutiny of women's reproductive and sexual behaviour.

We have been working on this topic since inequities among women in prevalence and mortality are clearly evident. These inequalities are avoidable since they are situated in socioeconomic inequities, systemic barriers to access to screening and early treatment, and gender hierarchies (Greenley et al., 2023). Bulgaria is among the European countries with the highest incidence and mortality rates from the cervical cancer, due to the lack of an organized screening program, an extensive list of barriers, and health inequalities between different groups of the population (Figure 1). Additionally, ethnic inequities in screening are evident in both countries. (Todorova et al., 2009).

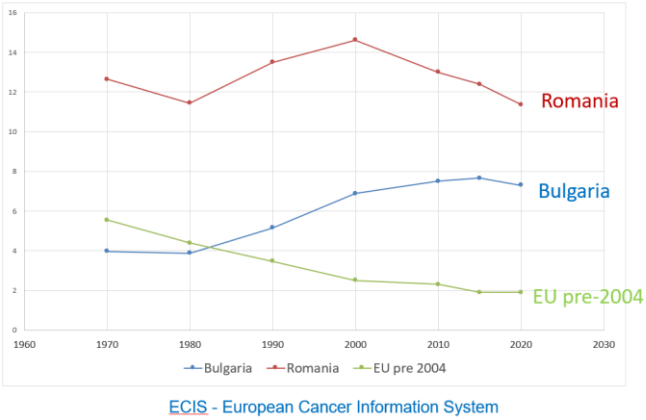



*Figure 1 Trends in cervical cancer mortality per 100,000 women, all ages*

As mentioned, central to the CBIG_Screen Project is an epistemology of knowledge co-creation, according to which community representatives are part of the research in all of its stages. Through the process of co-creation of research outcomes and action, we jointly identify the hierarchies, structural barriers and the inequities associated with this health issue. We use several qualitative approaches including collaborative user boards (3 focus groups), semi-structured in-depth interviews (N=27) and in WP3 – Digital Storytelling (DS) (N=16 participants).

The aim of the Digital Story Project is to generate knowledge around the barriers and lived experience of the cervical cancer prevention pathway as well as the co-creation of meaningful and contextually relevant cervical cancer health promotion messages by women for women, communities, and policymakers in Bulgaria. Through digital storytelling, women collaborate to co-create stories addressed to the community for health promotion, engaging participating underserved women as experts in their experience.

### Study setting

The CBIG-SCREEN co-creation study took place in a meeting room in central Sofia. Our team had already established communication and relationships with stakeholders at macro, meso and micro level, through multiple other components of the CBIG-SCREEN work packages. For this component of co-creation through Digital Storytelling, we invited women who had participated in the semi-structured in-depth interviews to also take part in Digital Storytelling.

Eligibility criteria

To participate in the Digital Story project, the women needed to have one of the identified vulnerabilities – ethnic minority status, low SES, or being unemployed. They needed to be from the city of Sofia for practical purposes (attending the workshops) and to have participated in the interviews (WP4).

### Methodology

The methodology recognizes underserved women as experts by experience and places them alongside more traditional evidence developed through experts by profession. Digital storytelling helps to create a shared understanding regarding the current best practices of cervical cancer screening through community engagement, and the identification of existing gaps and barriers in Bulgaria directly from those impacted most. This process asks stakeholders to participate in several workshops wherein they are encouraged to share their lived experience and expertise of cervical cancer screening. They are given flexibility and space to create Digital Stories and thus, impactful health promotions messaging. DS promotes active sense making among participants in a supportive story production process (Barcelos & Gubrium, 2018). Similarly to other participatory methods, it understands community members as experts on the topic, and centres the voices of those most impacted by intersecting systems of oppression and discrimination (in the healthcare system) (Fine et al., 2021),

These stories are short (3-4 minute), first person visual narratives that synthesize still and moving images, a voiceover recording of the participant telling her story, background music and text to document personal

experiences (Fish & Syed, 2021). In this methodology, research is seen as a process that positions traditionally silenced and objectified participants as active and legitimate knowers of themselves and their circumstances.

### Participants

The participants were N=16 women including 12 underserved women and 4 researchers. In tune with the co-creation philosophy, we were all learning the methodology together and we all (including the research team) created digital stories. With one exception, all the underserved women creating DS had also participated in the semi-structured interviews.

### Procedure

We followed the Digital Story Methodology (Figure 2) and conducted 4 DS Workshops with vulnerable women (spring – fall 2023). Underserved women (12) and researchers (4) participated in four Workshops, held in Sofia. The underserved women had one of the identified vulnerabilities – ethnic minority status, low SES, or being unemployed. Their age ranged from 20 to 60 years, and they had different levels of education - from primary to high school. The process used a flexible approach, brainstorming and collaborative consultation with other women in subgroups


*Figure 2 Digital stories methodology*

**Workshop 1.** May 18th 2023: Initial workshop: introductions, discussion of purpose of project, examples and methodology.

**Workshop 2:** June 8th 2023: Discussing ideas for stories; preparing and sharing storyboards

**Workshop 3:** July 11th 2023: Completing story boards, collecting images, sharing ideas for finalizing, presenting publicly available resources for images and music.

**Work Package 3 Meeting:** August 28-30: Reviewed workshop pre-liminary findings, troubleshooting of issues, planning for completing of stories and dissemination.

**Workshop 4:** November 15th 2023: Story circles for presenting and feedback for draft DS. Mutual support and encouragement.

We continued communication, and completion of DS after these workshops. Publication of the DS on the free Wevideo platform and their discussion with the women is on-going. A total of 6 DS have been produced by the underserved women and 4 by the researchers.

**Data sources included in the ongoing analysis**

DS storyboards and images
the final 6 digital story videos

profiles of the authors and themes in their story
transcriptions from 4 workshops (in progress)
on-going reflections by the research team
ongoing conversations with participating women (in progress)

**Analytic approach**

All above materials were imported into the Atlas.ti qualitative data analysis platform (ongoing). We used the same analytic approach to all the materials, which is Reflective Thematic Analysis (Braun & Clarke, 2006; Braun & Clarke, 2022), supplemented with Visual-Textual Thematic Analysis (Trombeta & Cox, 2022).

## Summary of Analysis from Romania, Estonia and Bulgaria

Qualitative Analysis

In this report, we present data from WP 3.4 Participatory methods with stakeholders to support the development of tailored interventions in Estonia, Bulgaria, and Romania; the data is based on the Think Aloud and the prioritization exercise with associated FGDs as described above. Qualitative data was analyzed using techniques from the framework analysis approach (Lacey & Luff, 2001). Transcripts were translated into English and using thematic analysis: coding of themes and grouping in categories was adopted to develop a standardized coding frame that could be used across all countries to allow cross-country comparison of the results, using both deductive and inductive approaches.

**Results**

The following themes emerged:

| Romania (n=6) | | |
|---|---|---|
| Theme | Codes | Quotes |
| Barriers to screening | Limited awareness that screening options and screening are free. Fear of finding positive results. Negative emotions (and perceived inability to cope with these emotions). The stigma of poor hygiene during testing and fear of unsanitary healthcare practices. Feelings that they [women] are better off "not knowing". | "They're afraid. Because they feel that they might have that disease, and they're better off not knowing." |
| Barriers to self-sampling | Lack of knowledge about the kits (their contents and what each of the parts is) but also lack knowledge of how to use the kit. Fear of the pain (during use), language barriers of instruction, fear of waiting for a result. Fear of making an error in the procedure. Inability to ask questions in real-time. "First time fear" [completing the test for the first time]. Women are unfamiliar with this part of their anatomy. A further barrier was the desire to speak to a specialist, who are often very busy and difficult to access. | "I might not do it properly like the doctor does because we can't do it any better than the doctors." |

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| Barriers to treatment | The cost was the largest perceived barrier to the continuation of treatment. The cost of treatment and also the cost of transportation or time off work to get to appointments. A secondary barrier to cost was not having insurance which stopped women from wanting to determine if there was illness that would require treatment (and subsequently a cost). | "The problem is that you can't get an appointment. And people get discouraged. Some people will try to get a number, and some people stop doing it." |
| Barriers (general) | Competing interests and costs were not directly associated with the testing but came as a result of engaging with screening or treatment. Education was reported as a barrier for those in rural locations where the ability to understand medical terminology or literacy rates are reported to be lower. Fear of waiting for results or not knowing the next steps. Waiting times for the results, as well as for treatment. | "Thing that prevents you, I told you, is the money."<br>"I didn't understand any of the results. This formal Romanian language. What does all that mean? Negative, positive?" |
| Facilitators | | |
| Facilitators to self-sampling | Caravans attending rural locations were a largely held facilitator. This was also due to the fact women were greeted and introduced to a member of healthcare as well as had the opportunity to ask questions. Instructions were the other component that felt to be the most helpful in making self-sampling successful. | "But who wouldn't be willing to go at the caravan for free to go and get your test? Nah, it's good that you're paying for transportation and all." |
| Facilitators to treatment | Being provided with updates and having the ability to talk to a specialist provided a sense of courage and confidence. | "…talking to a specialist, like you. You feel differently when you talk to someone and especially when it's about this stuff, which most women have these problems. That cervical cancer problem. And when you come to talk to the specialist, he updates you about things. It gives you a little bit of courage." |
| Facilitators (general) | Having a sense of responsibility to remain healthy for others (mostly children but family in general). Further, support from family was also a large facilitator in overcoming fear. | "…once you haven't been through certain situations, there's no way to handle it. I don't know how I would react, but I know I would do my best to go for treatment. Because if you leave it like that, then... I have two kids and I wouldn't want anything to happen to me." |
| Impressions | | |

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| Positive | Despite the initial apprehension towards the participatory method, the majority of the women were able to visualize themselves going through using the kit with success. Their demeanour and willingness to engage became much stronger and positive as the discussion went forward. Women described moving through initial fear but with the instructions, they were able to cope with the fear and feel that the testing was positive. The use of clear instructions with pictures was a large contributing factor to a positive impression of the kit. | "It's really good that I'm doing this thing, that I can send it to the lab and see myself what I have." |
| Negative | One woman felt that the instrument used for self-sampling would hurt and was not in favour of the particular composition of the device (metal end). Another criticism was having to use the kit alone for the first time, as there would be fear of completing the test incorrectly or discomfort with the unfamiliarity of the whole process. | "The truth is a doctor knows best how to do it." |
| Neutral | One woman took a particularly neutral approach to the Think Aloud, wherein there was no fear towards the test. She approached the steps methodically and as a result she felt confident in her ability to read and follow the instructions. | [How do you figure out or what your difficulties are in figuring out how to use it.?] "I don't know, I would look first on the instructions. I would see what it says on the instructions." |
| Preferences | | |
| Awareness for testing | Preferences were to announce the arrival of the caravan in advance, and through different methods (Facebook, through the village store, over a speaker). | [How are we supposed to get the information out to everyone?]<br>"Well only like this, I said, if you do something here or come with the caravan, with the microphone, if you don't write, if you don't announce with a week before for free testing and so, either on Facebook or so, at the village store that everybody. Yes, and then they would be interested what day everyone who is available would come." |

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| Instruction | Many women preferred the instruction to be in their local language or to be explained by a healthcare provider who can take time to answer their questions. Unanimously, the use of pictures alongside written instruction was of benefit. | " Maybe if they explained it to us, it would be easier to have a specialist doctor explain how to do this. Perhaps we'd get comfortable with this stuff too. We'd understand that stuff too because there's a lot, for example, and with COVID test at one point, that you really must go to the doctor; after that, you could do it yourself at home." |
| Screening location | Many women were comfortable with self-sampling at their place of residency. One woman felt that having the caravan come to a closer proximity of her house was very helpful. | [And how do you feel about doing this test at home?]<br>"OK, it's not I don't know what. Wow, out of the ordinary. It's just normal. It seems normal to me. Us, the women to do it. It's okay." |
| Receipt of kit | Mail and through the Caravans were a preferred methods for kit acquirement for some. While for other women, it was felt that the kit should be provided by a healthcare provider (of any kind). | "From a doctor or from a nurse so everything related to the medical system." |
| Return of kit | One women felt that she would like to return the kit directly to the Caravan. Otherwise, mail was felt to be an appropriate method to return the kit as long as there was clear instruction to do so, or some women would return the kits to the labs after checking with their healthcare providers. | "well, no, I want to give it to the caravan. I talked to that lady, they introduced themselves, I gave her the test and if there's something I'll talk to her too, then at the post office who will give me explanations?"<br>"Send it back? I think I would go and take it to the doctor, so I can get from there what he needs (from the probe) to take it to the lab." |
| Delivery of results | By a person (health providers) were favoured by the majority of participants. This way, women could ask questions. It was felt that someone trained in healthcare was preferred as it offered a level of credibility in which lay people would not provide to the delivery of sensitive results. This could be done either face to face or via telephone. | "No, still a person, so if it's a problem and if it's ok had the person come and explain, tell you ma'am you're healthy, but you needed this, but you don't need this, You're ok. So then also the people is more based on medicine. But if you only send this to me, I look like a fool, because that's us without school, eight grades, what do I know? What did you say?" |

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| Support | Many of the women felt it would be beneficial to have the option to speak with a healthcare provider when necessary. One women stated that she would need the support of her husband during the process. | "The support of someone like you [interviewer] are that you explain, you tell us how I can do and send to (the lab), to get the written results to know what (diagnosis) I have."<br><br>"The husband's, of course. He's been by my side for a long time. He has supported me in all my difficult situations and of course I would ask for him too. But yes, my husband's. I would like to ask my husband." |

| Estonia (n=18) | |
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| Intervention | Themes |
| 1). Complete follow-up: invitation to examination, treatment after a positive screening test and reminder of missed the visit: SMS, reminders for post positive screening test care/follow-up | Themes which emerged under this intervention were preference for an all-encompassing pathway of care which was directed by primary healthcare providers. Themes which emerged on preference for test result notification included: test results delivered directly by primary healthcare provider. |
| | Notes<br><br>Gen Pop. Tallin<br><br>It was not clear if women would like "somebody "just look at their health data (one women). It was felt that doctors are too busy to do this work. It could be a case manager. A barrier is that it is complicated to get time for an appointment. It was felt that women themselves should be responsible for their own health, but that health awareness needs to be increased. Once suggestion was that a GP could be the person to check on the patient data and take contact if needed (one women).<br><br>Gen Pop. Johvi<br><br>That there was some discrepancy between the younger women versus older women during exchange of ideas for this particular intervention option. However, upon debrief with presenter (AT) following FGD, it appears that reminders were felt to be the most important intervention (which can be developed) due to factors of:<br><br>• competing interests<br>• forgetfulness<br><br>Women agreed that reminders are very important and needed, but also other routes of reminders (GP or other specialist) who can during other visits remind about active referrals in the patient portal.<br><br>One woman said that she forgot about her screening appointment and if not our FG meeting, then not sure how and when it would come up next time. |

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| | Women agreed that life is busy, and they forget about active referrals and the reminders should be done regarding it and also a day before the appointment.<br><br>Also, women do not know what to do if they have missed their appointment, the reminders could be also regarding missed and rebooking options.<br><br>SMS should contain not only reminders but also motivating language.<br><br>Cancer word is frightening, women do not know the cascade and that there are precancerous stages that are treatable.<br><br>Men's involvement is essential, women are not sharing their CCS and CC stories and experiences with men as it is a women's issue. Women do not know how to explain, what language to use and it is embarrassing.<br><br>PWID FGD: Tallinn<br><br>The overall feedback was positive, and they agreed that all kind of reminders are needed. Women discussed that PWID usually lose or change their phones and also, they do not have smartphones and SMS reminders would not be effective for this population. GPs or ID specialists' reminders would be more useful.<br><br>Several reminders would be great and those should be on both languages. Overall, they agreed that the awareness regarding screening and CC is low and even if SMS will be sent women still are not motivated or aware what it is for. |
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| 2). Participation in screening: CC screening combined with mobile breast screening radiology buses | Akin to the above intervention, from the perspective of the women, there was a large positive response at components of healthcare delivery which saved time and were more considered efficient. |
| | Notes<br><br>Gen Pop. Tallin<br><br>• monetary incentive would work<br>• women might be scared to undertake self-sampling (one women)<br>• sending self-sampling kit, a head of time, so women can take it with her when going to mammography bus<br>• media/social media/influencers need to be used more<br><br>Overall, women liked this intervention. Economical in terms of time.<br><br>Gen Pop. Johvi<br><br>This discussion was met with unanimous head nods and few questions.<br><br>Hesitation, one woman said that not all women will agree to do CC screening If offered on the bus. Not enough buses and going around at working hours. People do not know the schedule of those buses.<br><br>Women agreed that the more information and easy access to the testing the better.<br><br>PWID FGD: Tallin<br><br>Mammography bus option was not met with enthusiasm.<br><br>Women suggested to add self-sampling kits and screening option to the Convictus syringe exchange bus. Women suggested to add self-sampling option to the harm reduction organizations (Convictus nurses), centers working with sex workers (Atoll) and ID center in Merimetsa. |

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| 3).Home/self-sampling<br>(self-sampling/kits at the harm reduction / drug treatment / homeless shelters / pharmacies) | For this intervention, themes of preference for home/self-sampling emerged, often with a resounding positive response. Further, women discussed the location where they wish to access the self-sampling kits which often was extended to allied health professionals for ease of access. |
| | Notes<br>Gen Pop. Tallin<br>• Women like this idea Pharmacist looking at women age in the health data – this is OK<br>• At the harm reduction / drug Rx sites, personnel need special education on how to manage women with + screening tests.<br>Gen Pop. Johvi<br>During this discussion, having kits available at different locations was met with favor. Here, women endorsed the kits being given in places where women are more accepting and open (a joke was made for the kits to be given to them while they are dropping their children off at schools). But in all seriousness, the options available at pharmacies were well received.<br>One woman recalled having this experience this year and that she got the self-sampling kit in the pharmacy. She recalls that it was not that convenient because a pharmacist was explaining the procedure while there was a long line behind a woman and everyone could hear what to do, lack of privacy.<br>Long lines and if women are working it is hard to find a day off for a gynecological appointment. The system can be more in favor of more flexible appointments for example after working hours etc.<br>Hesitation regarding self-sampling kits, women would prefer a sample taken by a doctor. The awareness of self-sampling is low. Women are worried that there is a risk of taking it in the wrong way or most importantly that if will affect the result and the golden standard is a sample taken by a doctor.<br>Self-sampling kits should be accompanied by personal explanation and guidance. The self-sampling kit instruction is not enough. Instruction should be made on both languages, and the video (as in the airplane emergency video) with QR code could be sent with the self-sampling kit.<br>Overall pharmacy option was met with enthusiasm, and they agreed that it is a popular destination.<br>PWID FGD: Tallin<br>Women supported this idea. One woman suggested to consider reaching out to the sex workers and that she can provide more details of the group we can invite. Recuro and Convictus would be the best places for distribution of the self-sampling kits but highlighted that the explanation and guidance from the nurse at the center are critical. The pharmacy option seemed attractive. Women need more information (leaflets, posters, ads on bus and FB. Women in this FGD felt their population is stigmatized and that some healthcare providers treat them with poor attitudes which impact the further intend to engage with healthcare providers. |

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| 4). Screening Test Result Notification (Content): positive and negative screening test interpretations in the Patient portal | Themes for content of screening test result called for easier interpretation of results located on e-health databases. |
| | Notes<br>Gen Pop. Tallinn<br>one woman has accessed her data – test result was hard to find while the other women did not seem to have an opinion. They are used to have the result form their "own gynaecologist".<br>Gen Pop. Johvi<br>This was the midpoint in the FGD and the engagement of women in the discussion declined. The level of discussion and questions were limited compared to the other interventions.<br>The explanation could be in both languages.<br>Older women not really using a patient portal and those who are usually asking help from their siblings.<br>Results can be sent by SMS or the remainder of available result in patient portal with a link.<br>Regarding not informing about the HPV neg is not right, it makes women to worry so the Neg should be informed with the message "not to worry etc." and further explanation is available in-patient portal.<br>PWID FGD: Tallin<br>The overall impression was that PWID women do not use the patient portal very often. They would rather prefer a personal explanation. Women explained her story after she had HPV related surgery, that there was not enough information about what should be done next withing the screening program (to participate or not if offered). Limited access to the internet and patient portal within PWUD. |
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| 5). Screening invitation letter | Here, themes which emerged were the preference for information on the screening invitation, which was approachable and easy to understand, in native language, words which were inviting and welcoming. Mode of message delivery was influenced by age with younger women more interested in receiving information via social media influencers or celebrities and on their cell phones whereas older women preferred to have messaging through traditionally trusted channels. |
| | Notes<br>Gen Pop. Tallin<br>There was limited previous experience with invitations from women in this group. One woman remembers having an invitation email, bus as she has just seen her "own" gynaecologist – she deleted the email without reading<br>There was unanimous decision that the letter should be short, to the point and wild "pictures".<br>Gen Pop. Johvi<br>Discussion centred around the need for a more engaging and illustrative invitation on the online health. An example of a current banner highlighting organ donation was provided which demonstrated the use of rich colours, simple texts, nice pictures, was easy to see |

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| | as it was on the first page, was well received. Women discussed wanting scientific and medical jargon simplified and instruction easy to follow.<br><br>-the current invitation for screening is hidden amongst a lot of text and not appealing for the average women.<br><br>Language for older women should be different from those of younger.<br><br>The invitation is not captivating and has a lot of text. Not crucial, as the gynaecologist will remind, or it is their work. SMS reminder about the active invitation and the overall screening opportunity during the year.<br><br>The invitation should be brighter and more visible, like the donor organ ad that is currently available and memorable.<br><br>PWID FGD: Tallinn<br><br>Just one woman saw an invitation. They had no strong feelings about the SMS reminders. They mentioned again that the overall knowledge about this cancer screening is very low and that all invitations/posters/reminders are not user-friendly. |

The approach taken in Bulgaria differed in that it focused on story telling to inform the messages that would most effectively accompany the intervention. We kept in mind that the co-creation process shaped the purpose of the Digital Stories to be connecting with the community and sending empowering (public) messages to other women, which promote health through screening. The group dynamics are very important in co-creation work, however this analysis is still ongoing. We do not interpret the images and text/voices from the perspective of what was the intent of the authors, but rather from the perspective of what they might communicate to the potential audience; i.e. what worlds do the images and text bring forth. We present some of the themes below:

**Trusting Relationships**

Most Digital Stories were based on trusting relationships and dialogues. These included:

- Long friendships with women (often from childhood)
- Mother-daughter conversations or concerns
- Intergenerational memories, values, traditions and skills, in which grandmothers were mentioned in the stories, or were protagonists
- Responsibility to the community

Absences

In addition to the existing themes and topics, we believe that what was absent is important for the interpretation of the stories (Rogers et al., 1999). We identified absences based on what we expected from our previous research on personal experiences in healthcare, and the interviews conducted as part of WP4.

**Absence of explicit personal experiences** (first-person voice, personal pictures/faces are rarely included). This was true in the first drafts; after discussion in the group, some women re-did their audio recording in the first-person voice. There are several pictures in which women are with their backs toward the viewer. There are many ways to interpret this:

- as a form of resistance, stigma, or shame, considering that the topic is a sexually transmitted disease and the prevention is through a gynaecological exam; perhaps women would rather remain anonymous; though they did use their real names).

- and/or a way of speaking to/inviting many women into the conversation, through not using a specific individual? Women as a community?

**Absent providers.** This was also true for the first drafts of the DS, while later most stories included a photo of a provider as an afterthought. This could be a conscious or unconscious representation of mistrust or scepticism toward providers and healthcare in the country. It could also be an accurate representation of women's experience in which providers do not play a particular role in motivating for prevention. Explicit critique of providers is not heard, which contrasts with what was discussed in some of the interviews.

**An explicit screening message was often absent,** while they made a more general call to maintain ones health. This could reflect a hesitancy to talk about cancer and screening. Explicit screening messages were added in some DS after discussions in the workshops. One story does not talk about screening at all, but about cancer treatment

**Barriers in the health system** are rarely explicitly identified (health system, gender, age) which contrasts significantly with the interviews (WP4) and the CUBS (WP2) (Boje et al., 2024). The only barriers which was illustrated were financial ones, as some stories included finding solutions to financial limitations.

Presentation formats

- Metaphoric presentations of self-care healthcare – through flowers, ribbons, jewellery.
- Women's hands are represented in several of the stories - as active and creating (potting flowers, making ribbons and jewellery).
- Use of contrasts – between the two friends, personalities and decisions which could have serious health consequences
- Overall optimistic, cheery mood (flowers, happiness, healing) – creating a sense of empowerment and resilience
- Yet, threats were sometimes lurking in the background

Messages conveyed to the potential audience

Based on the above themes, we can summarize the messages which the potential audience might take away from the stories.

- It is important to show up for screening for cervical cancer since treatments are very effective if changes are identified early (at pre-cancerous stages)
- However, it is better to find a trusted friend with whom to share, consult and to travel with you on this path, rather than dealing with it alone
- Overall maintaining one's health is important and that value is grounded in friendships, family generations and community
- Providers are needed for the procedure (PAP, vaccine) but are not the first choice when it comes to advice and support

**Limitations**

While views reported were representatives of defined vulnerable groups from within Bulgaria, Romania, and Estonia and cannot be generalized to all across the CBIG-SCREEN consortium.

**Dissemination**

Discussed with Work Package 7, the plans are upon completion of the deliverable, videos will be made available to all participants and researchers Further, there is ongoing discussion of how to disseminate these videos to a wider audience, through conferences (planned workshop for the Conference of the European Health Psychology Society (https://2024.ehps.net/) showcasing digital story telling as an effective participatory action research method). Additionally, we have discussed a night where the story authors can present their work in an open forum, however these discussions are still ongoing.

## Conclusions across Romania, Estonia and Bulgaria

**The main findings from Romania**

The majority of women were accepting of the idea of self-sampling. However, a minority felt that healthcare services were best suited to be completed by trained professionals and would not feel comfortable using self-screening methods. The themes which emerged were predominately around barriers to participating in screening. These barriers included lacking reminders for screening, missed appointments, difficulty accessing appointment times with specialists due to busy provider schedules, negative attitudes of healthcare providers or previously negative experiences. In terms of the location of services, overall, the idea of a Caravan was considered a viable, all-encompassing option (providing the self-sampling kits while offering verbal explanations and reassurance, feasible point of kit collection, communication of results and the next steps). Women felt that using the mail system was an appropriate choice; however, there were conflicting views on the trustworthiness of the mail system, which could impact the return of the kit via the same method.

**Main findings from Estonia**

The FGD from the macro/meso level favored a complete follow-up: an invitation to examination, treatment after a positive screening test, and a reminder of missed visits. It was also agreed that one of the stakeholders could currently make it happen (to analyze the whole cascade). More simply, this would look like an SMS reminder to the woman who participated in the screening (a) about the necessary and/or agreed examination and treatment; (b) a reminder of missed the visit.

From the FGD with women, there were five discussion points which were considered most salient to the CBIG-SCREEN project:

1. reminding women to register for more tests or treatment after being HPV positive

2. distribution of home tests on buses, or a woman could come in without registering and get tested for HPV

3. availability of home tests at pharmacies, needle exchanges, and health centers

4. adding an explanation in e-health databases of what positive or negative HPV is, what those results mean, and what to do next.

5. send a reminder that you have an email invitation to e-health databases that the woman is eligible for screening. Again, there was a very strong signal regarding SMS reminders throughout the whole cascade: reminders regarding active invitations in Patient Portal, Participation in screening, test results, and active appointments.

**Main findings from Bulgaria**

The digital stories created in the workshops embody local (cultural) themes, (indirectly) personal experiences and relational processes. This methodology of co-creation has unique strengths and gives a different perspective on women's experiences compared to other qualitative and participatory methods. It is embraced by the women as a new, creative and innovative experience, which allows for reflections and sharing through conversations and arts-based activities. On the other hand, it is time-consuming, and uses technology which even though free, is not easily available to all. Thus, the research team both taught the method and also helped with the final video creations, creating imbalance in the group dynamics.

The absence of the first-person voice perhaps speaks to the difficulty of the topic and gendered meanings of prevention, shame, stigma. On the other hand, it also "speaks" of solidarity among women, mutual support and empowerment in conditions in which providers and the healthcare system are not prioritizing screening. The Digital story authors position themselves as partner/advocates in health promotion, speaking to other women seeking solutions to (indirectly portrayed) barriers in the health system. Resistance/critique of barriers is evident strongly in the interviews, and is more indirect in the Digital stories, which emphasize individual and relational empowerment. In conclusion, the findings from this component of the study indirectly illustrate existing barriers in the healthcare system, as well as solutions which women propose, having to do with mutually supporting each other.

**Prioritizing**

The general population of women in Estonia unanimously voted for **intervention 2**. For the FGD in Jõhvi, it appeared that reminders and clear and straightforward invitations were the dominating interventions when prioritizing options. Intervention 1, while all-encompassing was too *new* for women and it was difficult for them to conceptualize how this should work or works (even those women who had CIN treated). All in all, these topics were of interest, women were curious to find out and ask, but they were not engaged in prioritization. All discussions lead to general awareness.

Overall, rating interventions as most effective was difficult, as women felt that all changes were relevant, and choosing just one intervention wasn't best suited for improved uptake. Access to information from primary healthcare providers at locations which fell outside typical clinical settings was also preferable. For example, this might include getting tests from nurses or exchange points, but these locations are still faced with a transient population with inconsistent healthcare follow-up behaviors. Some women favored more novel ideas on using public transit for increases and access to information. In contrast, other women preferred traditional routes of having their primary healthcare provider invite them for screening.

**Conclusion of findings across all countries**

Themes which emerged across all countries despite women engaging in different participatory activities:

Overall awareness of the screening concept and the cause of cervical cancer is low and the whole CCS cascade is not transparent (enough) for women. The overall opinion was that the information regarding CC and CCS is limited, in addition, that gynaecologists/healthcare provider will remind them of needed tests. The largest number of codes which emerged focused on gaining attention or information. This was further broken down into information relevant to age and appropriate information mediums where older women preferred to receive information by email or directly from their provider and younger women were more open to text messaging or e-health databases. Information on CCS is necessary moving forward as there was a substantial lack of awareness or appropriate information on services which are already available. This was one of the many barriers to CCS and treatment present by women, which was the largest category of codes overall. One factor contributing to the large number of barriers experiences is the limited prevention culture across both countries, with women having a complication relationship to the healthcare systems (generally this shows up as a lack of trust) however specifically for example in Estonia, there is a presence of anti-vaxxers in this area, many of whom are vocal in spreading their ideas around anti-vaccine campaigns.

A strength of these focus groups was that unanimously, women were very interested in self-sampling kits and said that would like to try it out once available. Most notably, self-sampling and follow up treatment need to consider the complexity of women experiences and capabilities in relation to the numerous barriers each individual faces. Due to stigmatization and neglect of this population, helpful tools or appropriate information is required to engage them in a screening and that clear guidance and increased effort should be made to communicate the importance of screening for women overall.

Based on the results of this activity, the analyzed data will serve to inform the development of the CBIG-SCREEN intervention in the Romanian and Estonian context, which will be further developed by WP6.

**Annex 1: Think Aloud Instruction**

" I'd like to play a game. We have the possibility, given that you said, for example, it's quite hard for the ladies to go and get their test or wait for the caravan that might not come or something. There is the possibility to do the test at home. The HPV test if you remember, the HPV test, it's that virus that has benign variants, variants that don't give cancer and variants forms of the virus that can give in the future for sure. Of course, the chance is quite small, but they can give and then this HPV test detects if the woman has those bad variants of the virus. Because if she has them, she can certainly get tested again after a certain period of time or the doctor decides what to do in that case. But an easy way is for the woman to test herself at home. To test herself and send the sample. And in that sense, we want to see how you perceive this possibility. If you would be willing to do that or if not, what would be the barriers, what would be the difficulties? What would be easy for you? Maybe it's easier than we think. And then this game is called thinking out loud, in the sense that I show you a kit, one of these self-sampling kits and you take it apart and out loud you say pretty much everything that comes into your head about it. About the instructions, what difficulties would you have, what fears, what would be ok, what did you understand, what didn't you understand? And I'll try to guide you with questions, because we're going to analyse everything you say and try to figure out how we can make this test easier to accept and do at home. Do you understand? So don't worry that, I don't know, there are things you don't want to say or don't know how to say. Say exactly what comes to mind. That's also called Thinking Aloud. Good? I'll give it to you and as you unpack it, you tell me out loud what you're thinking."

**Annex 2: Intervention Preference Exercise**

https://forms.office.com/Pages/ResponsePage.aspx?id=F2M1bQQNvEq2toyXc4hbsELxO6pHnu1HlGo2App6Jr1UMlQzSFdJTkM2TlIyRVBaM0Q4NUdWMUI5Ri4u

**Annex 3: Focus Group Discussion Education**

In Estonia every year 140 women are diagnosed with cervical cancer and every year 60 women die. cervical cancer is caused by a virus, and we can penetrate in different stages to cure or test and screen before it develops into an end stage. so, this is a unique cancer where we can do something. 99.8% of cancer is preventable in the early stages meaning we can cure it in the precancerous stages.

What are the methods of prevention? We have a vaccine against HPV and there is a state program in schools for girls 12-14 years old. In some countries they vaccinate boys as well and for example in England and there is a screening when women aged 30-65 years are invited every 5 years for a test. the invitation comes to patsinediportaal in digilugu, and the woman makes an appointment, comes, and has a smear by a gynecologist or obstetrician. Today we're going to talk about the 5 methods of determining cascade screening and we want to get your opinion on what you think about it. We will discuss each method one at a time. You have a cascade in front of you where you can see that after the test, if the result is negative, then you go back in the circle and then every 5 years you get invitations to get tested. If your HPV test is positive, then they will do additional tests to see if there are changes at the cellular level, if there is a precancerous condition and then they will prescribe treatment. We offer for discussion 5 things that we think can potentially be done in Estonia. You have to tell us if it would be effective in your opinion and which method of the 5 would be the most necessary in your group.

**Annex 4: Micro focus group support material**

See attached pdf

**Annex 5: Macro triangulation focus group support material**

See attached pdf

## References


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# Emakakaelavähk, Eestis

Juhtu aastas

Surma aastas

Elulemus

On ennetatav …


Cases


New cases of cervical cancer each year, 2016-2018 average, UK.

Deaths

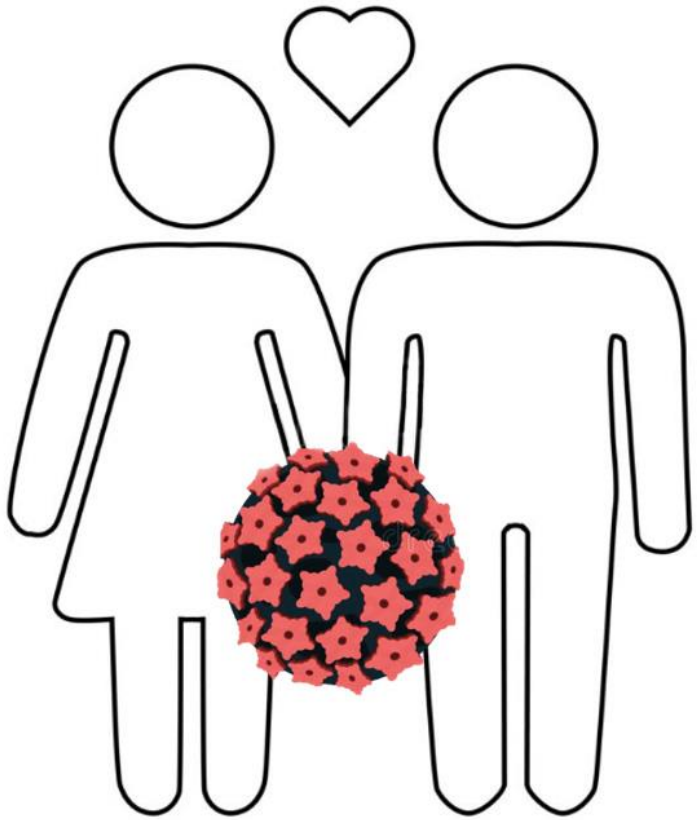

Deaths from cervical cancer, 2017-2019, UK.

Survival


Survive cervical cancer for 10 or more years, 2013-2017, England

Preventable cases


Cervical cancer cases are preventable, UK, 2015



Koolivaktsiin
12-14 a tüdrukud ja poisid

**Vaktsiin**

**Sõeluuring**

30-65 aastased naised
HPV test

# 1.sekkumine

Sõeluuringus osalenud naisele SMS meeldetuletus (a) vajalikust ja/või kokkulepitud uuringust, ravist; (b) kui naine kokkulepitud ajal ei pöördunud

# 2.sekkumine

Mitu sõeluuringut korraga --> mammograafia mobiilses üksuses
võimalus HPV isetestimiseks ilma eelregistreerimata

# 3.sekkumine

Komplektide kättesaadavamaks tegemine tervisekeskustes, apteekides, kahjude vähendamise sh süstlavahetuse, asendusravi keskustes ja sotsiaalabi süsteemi vahendusel

# 4.sekkumine

Nii HPV suhtes negatiivse kui ka positiivse testitulemuse teavituse teksti täiendamine sidusrühmade sisendite põhjal (kasutajasõbralikum)

# 5.sekkumine

Sõeluuringu kutsete ja meenutuste (sh SMS-ide) kujundamine ja personaliseerimine uuringus osalejate sisendite põhjal (kasutajasõbralikum)

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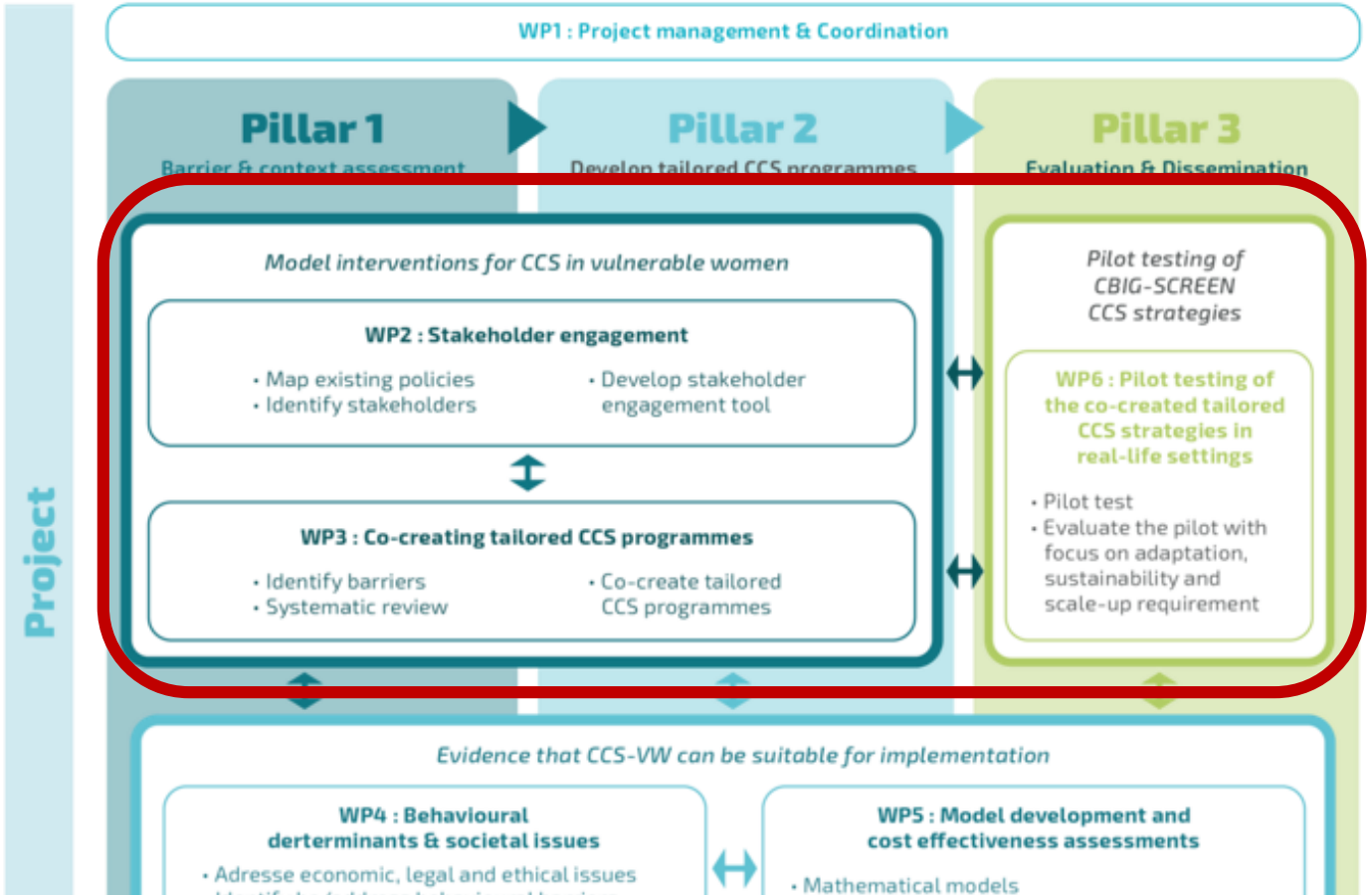
# Emakakaelavähi sõeluuringu tõhustamine Euroopa riikides

# CBIG-SCREEN

Projekti eesmärk vähendada ebavõrdsust emakakaelavähi sõeluuringutes

14 partnerit 10-st erinevast riigist ja projekt kestab 2021-2026

Rahastab Euroopa Komisjon programmist „Horisont 2020“




EESTI

MAKRO, MESO, MIKRO

*sõeluuringu tegevuste kaardistamine

*sõeluuringus osalemise barjääride ja lahenduste kirjeldamine

*sekkumiste hindamine ja kujundamine

# Sekkumised

I Terviklik raviteekond: uuringud, ravi positiivse sõeltesti järel

II Terviklik raviteekond: kutse uuringule, ravile positiivse sõeltesti järel

III Sõeluuringus osalemine (juurdepääs)

IV Kodu/isetestimine

V Sõeluuringu vastuse teavitus

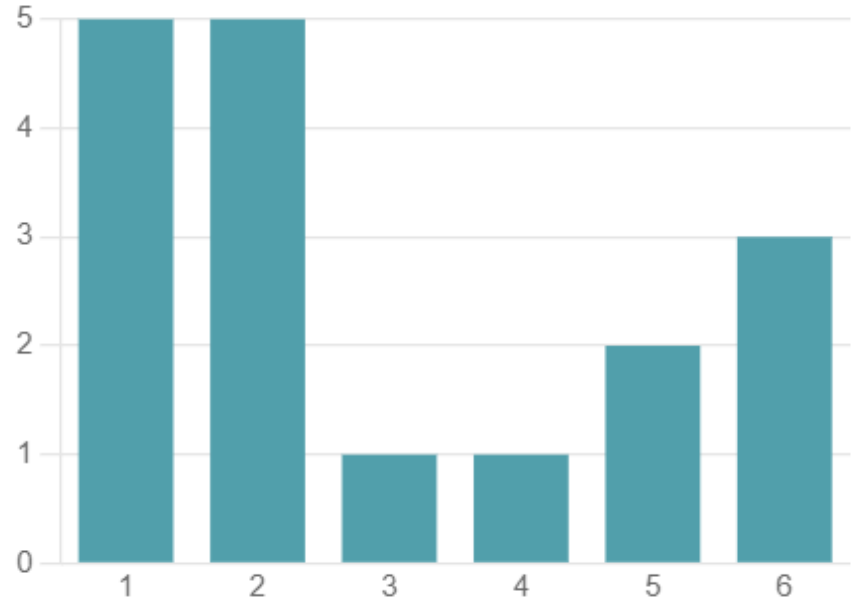
VI Sõeluuringu kutse

# Tulemused. Keskmised hinned

Macro level  Ministry of Social Affairs n= 2; Health insurance fund n= 4 Cancer Screening Registry (n= 4)

Meso level (Gyn n= 5, GP= 1)

| | |
|---|---|
| I Terviklik raviteekond: uuringud, ravi positiivse sõeltesti järel | **4.5** |
| II Terviklik raviteekond: kutse uuringule, ravile positiivse sõeltesti järel | **4.4** |
| III Sõeluuringus osalemine (juurdepääs) | **3.9** |
| IV Kodu/isetestimine | **4.2** |
| V Sõeluuringu vastuse teavitus | **4.2** |
| VI Sõeluuringu kutse | **4.0** |




Olulisim sekkumine

# CBIG-SCREEN võimalused

## I Terviklik raviteekond: uuringud, ravi positiivse sõeltesti järel

Markeerida sõeluuringu läbiviinud teenusepakkuja töö kvaliteedi indikaatorina tervikliku raviteekonna järgimus (naiste osakaal, kes vajalikud uuringud, ravi saanud)

# CBIG-SCREEN võimalused

**II Terviklik raviteekond: kutse uuringule, ravile positiivse sõeltesti järel**

Sõeluuringus osalenud naisele SMS meeldetuletus (a) vajalikust ja/või kokkulepitud uuringust, ravist; (b) kui naine kokkulepitud ajal ei pöördunud

**X haavatavale naisele SMS meeldetuletus võrreldes SMS-ita**

CBIG-SCREEN võimalused

## V Sõeluuringu vastuse teavitus

Nii HPV suhtes negatiivse kui ka positiivse testitulemuse teavituse teksti täiendamine sidusrühmade sisendite põhjal (kasutajasõbralikum)

## Patsiendiportaali HPV+/- vastuse teavituse kujundamine

# CBIG-SCREEN võimalused

## VI Sõeluuringu kutse

Sõeluuringu kutsete ja meenutuste (sh SMS-ide) kujundamine ja personaliseerimine uuringus osalejate sisendite põhjal (kasutajasõbralikum)

## Kutsed haavatavatele naistele