This is the author's accepted manuscript for pages 329-351 in the following book: Human-Centered Service Design for Healthcare Transformation: Development, Innovation, Change. Editor: Mario A. Pfannstiel. © 2023 Springer Cham. https://link.springer.com/book/10.1007/978-3-031-20168-4

Chapter reference: Klonteig, S., Li, J., Halvorsrud, R. (2023). "My Heart Jumped. Do I Have Cancer?"—Results of a Co-design Study with Cervical Cancer Screening Participants. In: Pfannstiel, M.A. (eds) Human-Centered Service Design for Healthcare Transformation. Springer, Cham. https://doi.org/10.1007/978-3-031-20168-4_19

"My heart jumped. Do I have cancer?"- Results of a co-design study with cervical cancer screening participants

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Abstract

Cervical cancer can be prevented by routinely taking cell samples from the cervix (screening). The frequency of screening is a crucial factor, and there is great potential to utilize the registry data from the cervical screening program for the benefit of both the screening participants and their doctors. However, with the constant emergence of new types of tests and guidelines, not only screening participants but also their doctors may become uncertain about what the test results mean and what follow-up procedures should be in place. The goal of this study was to explore how to present test results to participants in a way that supports optimal screening frequency without causing unnecessary worry. This chapter presents the results of co-design workshops engaging women in the target group. Through the use of personas, trigger questions, and trigger material, we explored the group's current barriers and information needs. In all, 19 paper prototypes were produced during the workshops. Through a content analysis of the workshop material, we derived user requirements for a future digital tool intended to support optimal participation in the cervical screening program. We also report on lessons learned, threats to validity, and future research.

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1 Introduction

Cervical cancer screening involves mass examination of a population with no symptoms. The purpose is to detect early-stage cancer before the disease spreads and, in some cases, to detect and prevent precancer from developing. Cervical cancer is a type of cancer that occurs in the cells of the cervix—the lower part of the uterus that connects to the vagina. This type of cancer can be prevented by routinely checking cell samples from the cervix to detect precancerous changes. The incidence and mortality rates of cervical cancer have dropped substantially in the female population since the Nordic countries implemented screening (Vaccarella et al., 2014). The Norwegian Cervical Cancer Screening Programme (NCCSP, hereafter referred to as “the screening program”) (Cancer Registry of Norway, n.d.) is run by the Cancer Registry of Norway, targeting all women between the ages of 25 and 69. The NCCSP is responsible for managing and developing cervical cancer screening and has collected health data from almost two million women since 1992.

Historically, the screening interval for cervical cancer was every three years, following the principle of "one size fits all." However, the screening program has changed continuously in recent years due to new knowledge, technological advances, and improved methods. New and more targeted tests have been introduced, imposing changes in the recommended screening intervals. The screening program also provides personalized guidelines (algorithms) for how abnormal test results should be followed up. These guidelines are based on a combination of previous test results and a combination of different tests performed at the same time, collectively referred to as test history. With the constant emergence of new types of tests and guidelines, not only screening participants but also their primary care doctors may become uncertain as to what the test results mean and how they should be followed up. In addition, it is difficult to determine when it is time for a new test, even with normal test results.

Correct frequency of screening is a crucial factor in the prevention of cervical cancer. Every year, the screening program sends a reminder to about 450,000 women that their expected screening interval is overdue (Engesæter et al., 2020). A recent survey shows that there are approximately 200,000 women who have not taken a screening test within the past 10 years or longer, increasing their risk of undetected precancers (Anderssen, 2021). On the other hand, 1 in 10 women takes

screening tests too often (Klungsøyr et al., 2009), which may lead to overtreatment of insignificant precancers (Soper et al., 2020).

There is great potential to utilize the register data of the cervical screening program better and more efficiently for the benefit of both the individual participants and the healthcare system. To realize this potential, an innovation project for the public sector called “ShowMe” was initiated in 2021 with the overall goal of developing effective educational tools to support optimal participation in the cervical screening program.

1.1 Research challenge

The right to access own health data is a statuary right for Norwegian citizens. The health service is aware that many patients have problems understanding and using the information they receive from healthcare professionals (Nutbeam, 2000, pp. 259–267). Internet searches for participants in the screening program can be particularly demanding. Participants who search the internet without guidance are faced with a jungle of information, and potential challenges are misinformation due to highly variable quality of Web information. The screening program has historical data from many years back and may contain abnormal test results that have been resolved. Accordingly, it may be challenging to convey large amounts of available data to the screening participant without creating unnecessary worries.

The main research challenge is to present test results to screening participants in a way that supports optimal screening frequency without causing unnecessary worry. A further challenge is to offer decision support to screening participants and their primary care doctors for the proper follow-up of abnormal results.

In this chapter, we report the results from co-design workshops with end-users (screening participants). The focus has been on scenarios in which women have received normal test results, reflecting 90% of the screening test results per year (Engesæter et al., 2020, p.18). However, we have also explored a situation with mild cell changes that may create concerns, although it can be resolved without treatment.

2 Background

In the following chapter we will share some knowledge about cervical cancer, and how cervical cancer screening program is practiced in Norway. Then we will move on to the challenges in cervical cancer screening program that have been discovered in other literatures.

2.1 Cervical cancer and cervical cancer screening

Virtually all cervical cancers are caused by persistent infection of carcinogenic strains of the human papillomavirus (HPV). HPV infections are common in the population and are transferred by sexual contact. There are an estimated 197 subtypes of HPV, most of them harmless. However, some subtypes correlate with a higher risk of developing precancerous lesions that can develop into cervical cancer after many years. HPV subtypes 16 and 18 have historically been found in about 70% of cervical cancers and are considered the main carcinogenic subtypes. A persistent infection with HPV-16 or 18 (or another known carcinogenic HPV subtype) is therefore a risk factor for developing precancerous lesions in the cells of the cervix that can potentially develop into invasive cancer (Bzhalava et al., 2015, pp. 341–344).

The goal of the screening program is to discover precancerous changes that can be treated locally before they develop into cervical cancer. The screening program involves two different types of tests: (1) the Pap test, in which cervical cells are checked for abnormalities under a microscope (cervical cytology), and (2) the HPV test, a more automated test that detects the genetic footprint of the HPV virus. The Pap test is used for women under 34 years of age, while the HPV test is used for women over 34 years of age. Until now, the sampling procedure has been the same from the screening participant's point of view, both involving a gynecological examination. In addition, the screening program is piloting self-administered HPV testing.

A typical screening pathway in Norway involves a primary care doctor or a gynecologist performing the test and communicating the results to the screening participant. After a sample of cervical cells has been collected, it is sent to a laboratory for analysis. The results are returned to the requester and the registry of the screening program. Both

private and public laboratories analyze tests and communicate the results to doctors and the screening program. The screening program provides guidelines (algorithms) for how test results should be followed up. These guidelines are based on a combination of the age of the woman, previous test results, and a combination of different tests performed at the same time, collectively referred to as the test history.

What complicates the interpretation of the screening results is that there is no linear relationship between persistent HPV infection, cervical cell abnormalities, and invasive cervical cancer. HPV infection can go away spontaneously and indeed does so in most cases. Moreover, abnormal, precancerous cervical cells can revert to normal cells. The likelihood of this happening varies with age and other factors. With new types of tests and guidelines constantly emerging, not only screening participants but also their primary care doctors may become uncertain as to what the test results mean and how they should be followed up.

The public website concerning health services for Norwegian residents is known as Helsenorge.no. Here, personalized content from various healthcare providers is available (prescriptions, for example), a vaccination overview, and a summary care record with important health information. In the future, Helsenorge.no is expected to convey medical screening data to individuals. As of today, there is no integrated digital solution for communicating test results and history to screening participants.

2.2 Related work

A recent study focusing on screening participants' awareness and needs reveals a general lack of information about the screening program, procedures, HPV, and confusion about the interpretation of the test results (Siegel, 2022). Not only is the information itself important, but also the timing of the information.

Research has repeatedly found that increasing women´s knowledge of cervical cancer can relieve anxiety and stress and improve their willingness to participate in extra screening steps (Markovic-Denic et al., 2018; Papa et al., 2009). However, numerous research reports (Ciavattini et al., 2021; O'Connor et al., 2014; Szwarc et al., 2021; Verhoeven et al., 2010) have pointed out that getting adequate information from health care personnel remains a big problem for

women, leading them to look for answers online. For women who had a positive HPV test or abnormal Pap smear test, there was a large gap between the information they desired and the information they received. Specifically, they demanded more information concerning the explanation of results, the implications of results, the progression of the disease, disease management (follow-up steps and what patients can do personally to contribute to their recovery), the risks of cervical cancer, and sexual transmission of the disease. Similar findings were found in another survey with women from Spain, France, and Portugal: 80% of the participants wanted more information, especially on the consequences of the disease on emotions, family life, and partner relationships (Monsonego et al., 2011). Marlow et al. found that there are different information needs among women with positive HPV and those with negative HPV. Women with positive HPV were concerned about the casual and clinical aspects of cervical cancer, such as when they were infected, the cause of infection, and what they could do to treat current infection and prevent future infection. HPV-negative women often raised questions about the purpose and procedure of HPV testing, specifically the differences between HPV tests and Pap smear tests.

Other than the lack of information, Monsonego et al. found that around a quarter of the participants in their study had difficulty understanding the results. In a survey of 153 women who had abnormal test results, 71.4% of participants said that they felt confused over the HPV diagnosis and the different consequences caused by high-risk and low-risk HPV types (Daley et al., 2010, pp. 279–290). Many women reported that they were confused about the meaning of HPV and how they got it (McBride et al., 2021, pp. 395–429), and others did not know if positive meant good or bad. The main cause of this confusion was probably a lack of knowledge about HPV. While some participants were familiar with the term *normal* in the Pap test, they could not explain what the term meant, which reflects a lack of understanding of the results (Head et al., 2017, pp. 37–46).

3 Method and Approach

We used a co-design approach to gain insight into what current challenges the participating women experienced and how they envisioned the solution. Co-design, also called Participatory Design (‘Participatory

Design', 2022), emphasizes active involvement of all stakeholders in the design process, which includes "knowledge development, idea generation and concept development. " (Dahl et al., 2014, pp. 279–290) The designer will offer tools to help and support users in creating solutions. By involving users in creating solutions together with designers, it can generate more creative solutions (Mitchell et al., 2015, pp. 205–220; Trischler et al., 2018, pp. 75–100), and can promote user acceptance and satisfaction. Therefore, we decided to conduct co-design workshops in which users were given tasks and asked to create their own solutions. Personas were used to help users address their needs and promote user involvement (Nielsen, 2011).

3.1 Recruitment and workshop preparation

In this study, we used the convenience sampling (Leedy & Ormrod, 2019, p.272) method to recruit participants. We sent out invitations with a poster through the SINTEF[2] internal email list, through our personal LinkedIn channels, and through some Facebook groups[3]. The inclusion criteria were that women be between 25 and 69 years old and speak Norwegian. Both workshops were held physically inside a building belonging to SINTEF. Almost half of the participants were employees of SINTEF.

To facilitate the co-creation session, we created materials and two personas with sample histories (
Fig. **1** and Fig. 2). Since cervical screening is a sensitive topic, we created fictional personas so that participants could refer to them instead of themselves if they did not want to disclose their own experiences. We created personas to reflect typical use cases based on background studies and consultations with clinical experts. The persona called Karen is 35 years old. She has recently moved to another municipality and cannot remember when she took her previous test. Another persona, Maria (55 years old), had a recent test that revealed mild cell changes, which should not have caused a high degree of anxiety or worry, but did because of poor communication of the test results. In addition to personas and

[2] Sintef is a research institute with 2000 employees. https://www.sintef.no/en/
[3] https://www.facebook.com/groups/oslojobs/permalink/1885890831801179/

sample histories, we also prepared example sketches in various levels of fidelity to serve as inspiration (see *Fig. 3*).

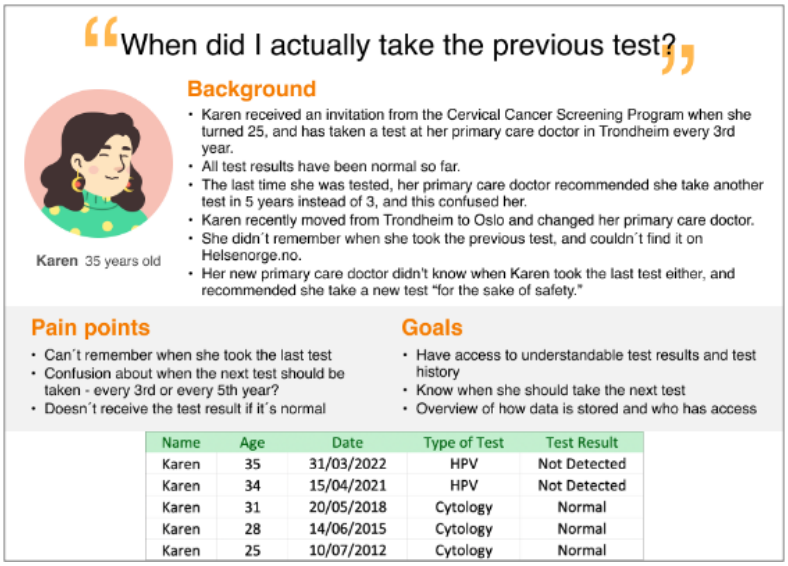

Fig. 1 Persona of Karen

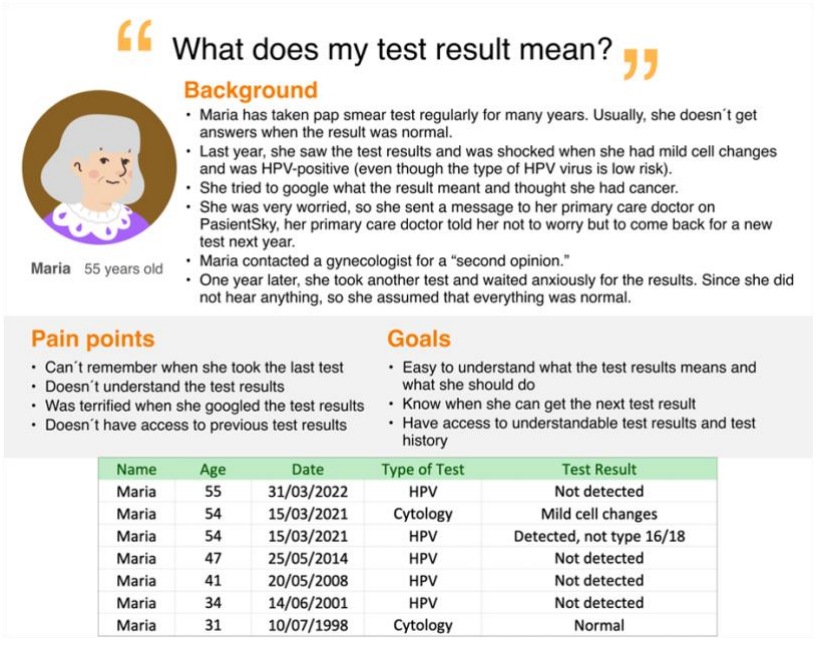

Fig. 2 Persona of Maria

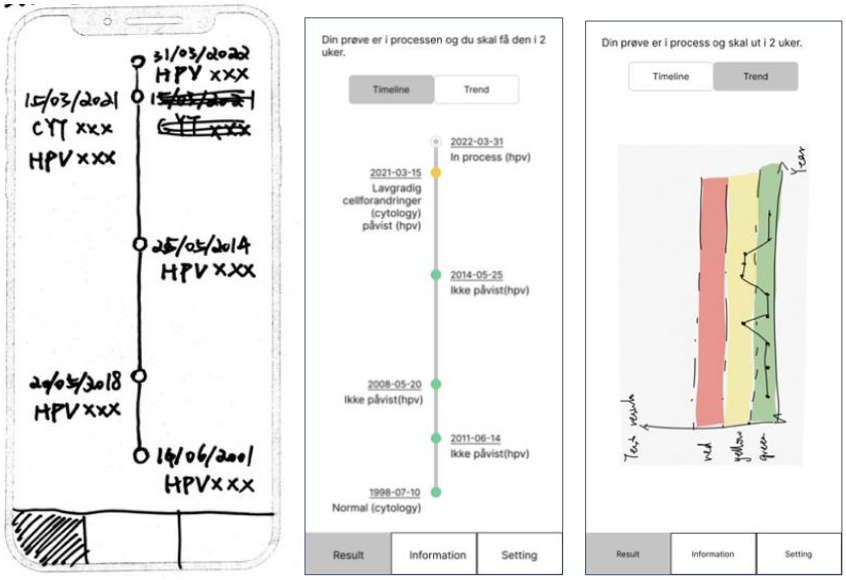

Fig. 3 Prompts and low-fidelity prototypes

3.2 Workshop procedure

The workshops were designed for a duration of two hours. Each workshop started with participants signing a consent form. The researchers then presented the screening program, the screening pathway, and current challenges. After the presentation, the researchers explained the ethical considerations of the study and set up some basic rules for the creative sessions. The participants were divided into two groups, each supported by a facilitator. The first several minutes were used to introduce the participants to each other and to discuss why they had signed up for the workshop.

The main activity in the workshop was a sketching exercise. The participants were introduced to the persona Karen and her sample history. First, they were asked to elaborate on Karen's challenges. They were given blank paper templates imitating a mobile screen (see Fig.1 and Fig. 2**Fig.*1***) and instructed to individually draw a solution to present and visualize Karen´s sample history. When they had finished the drawings,

the participants presented their ideas to the rest of the group. Each facilitator presented the summary findings of her group to the other group. After the exercise with persona Karen, we repeated it with a different persona, Maria, who had a more complicated sample history. This sketching exercise was useful in revealing what information was needed in a sample history and how it should be visualized.

Adjustments to the Procedures

In the first workshop, both groups showed a certain reluctance to draw, so we provided them with some prompts (see Fig.3 **Error! Reference source not found.**). After seeing the prompts, one group started to draw while the other still hesitated. Therefore, we presented the hesitant group with some low-fidelity interfaces (see Fig. 3**Error! Reference source not found.**) and asked them to provide feedback on what they liked and disliked about them. We also asked whether the participants wanted to make changes to the interfaces.

After the first workshop, three facilitators reflected on why we had received fewer creative outputs than we had expected from the participants. One possible reason they identified was that the sample history printouts had too many design details, which may have limited the participants' creativity. The same reasoning was applied to the low-fidelity interfaces. The second reason the facilitators identified was that the task of visualizing the sample history was too difficult for the participants. To increase the outcomes from the second workshop, we agreed to make some small modifications, but we kept most of the procedures identical in the second workshop to ensure the consistency necessary to generalize findings across workshops.

In the second workshop, we presented a more simplified sample history printout and did not present prompts or low-fidelity interfaces. Since sample results are highly related to sample history, and the participants were more familiar with sample results than with sample history, we asked them to visualize the sample results before designing the sample history. We gave them time to reflect alone before drawing on the papers and gave them ample encouragement. With these small modifications, we noticed big changes in the second workshop compared to the first one; the participants were more willing to draw and share their ideas.

3.3 Data analysis

We used elements from rapid analysis, an approach that enables a time-efficient analysis compared to thematic content analysis (Gale et al., 2019). Transcript summaries of the workshop sessions were made using spreadsheets in MS Excel following the chronology of the workshop procedure. A matrix was prepared to identify and sort themes and to connect the transcripts with the visual descriptions. The themes used were “user needs/requirements” and “exemplary quotes.” Two researchers conducted the initial analysis.

In the second iteration, one researcher collated all the sorted material into a single spreadsheet. Here, material coded as “user needs/requirements” was then split into subthemes, namely, “current situation,” “information needs,” and “communication preferences.” The main themes and subthemes were discussed among the three researchers until we reached agreement. All the themes will be presented in detail in the following results chapter.

4 Results

We conducted two workshops in May 2022 with 7 and 10 active participants, respectively. Their ages ranged from 25 to 55 years; thus, all participants were in the target group of the screening program. All but one of the participants had experience with cervical screening, meaning they had had a Pap test taken one or more times. Three of the participants informed us, unsolicited, that they had experienced test results in which abnormal cells and/or HPV virus were detected.

The procedure described in Section 0 triggered the participants’ curiosity and many questions, which will be discussed in Sections 0 and 0. During the co-design sessions, the participants created a broad range of suggestions and solutions. A total of 19 paper sketches about the visualization of test results and sample history were produced during the workshops: 5 from the first workshop and 14 from the second. These sketches ranged from content with detailed wording (i.e., as shown in *Fig.1***Fig.*1*Fig.*1*) to modulars, such as the integrated applications shown in *Fig. 2***Fig. *2*Fig. *2*.

In the following two sections, we will elaborate on these results, which are structured in the following categories: current problems, information needs, and user-requirements.

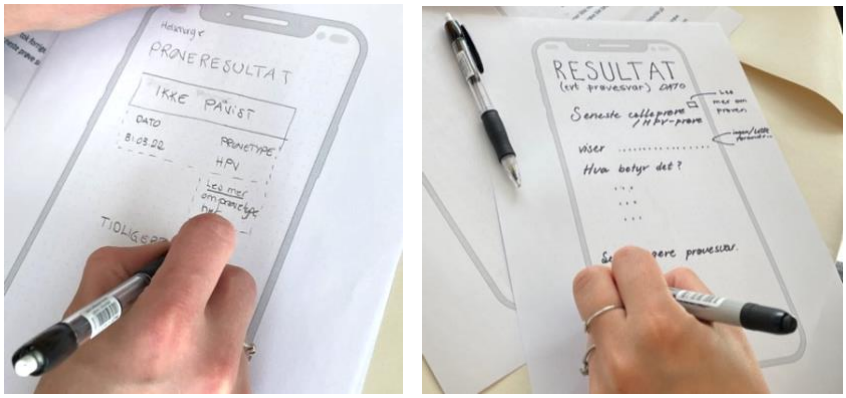

Fig.1 Simple drawings of test results sketched by participants

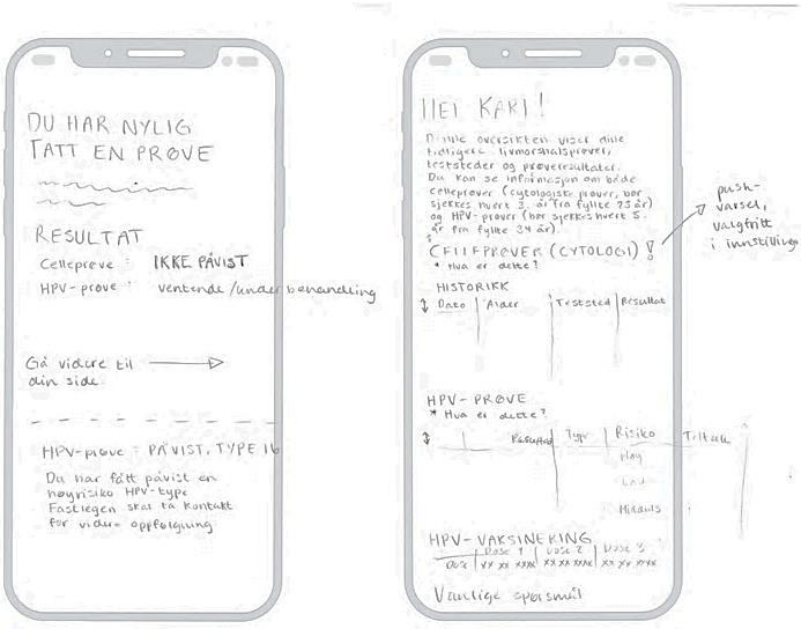

Fig. 2 An integrated solution sketched by a participant

4.1 Current problems

Knowledge about screening tests (cytology and HPV), algorithm, and program

Most participants were familiar with the practice of pap smear sampling. However, several had low awareness of being part of a cervical screening program. One participant said she had not heard about screening tests before. Another said, *"I am uncertain whether I have ever taken a screening test. I guess I have, but I have never been notified about it. I guess my primary care doctor has this under control.*"

Several of the participants were not familiar with the two different types of primary screening methods, namely HPV testing and cytology. Furthermore, they were not aware of abnormal cells, the various degrees of cell changes, or the causes of these changes. One participant said, *"I would never have known that cell changes potentially could disappear by themselves "*. For HPV specifically, knowledge varied among the participants. During conversations, we noticed that some participants were not familiar with different HPV types and risks, or how these were involved in cervical cancer, but a few had more knowledge. We are uncertain as to why some participants had more knowledge than others; however, we saw a trend that those participants who had experienced positive HPV results had more knowledge. Additionally, some participants were familiar with the HPV virus through vaccination programs.

In general, the participants showed low awareness of the recommended screening intervals. Some of them thought they should take the test on a yearly basis; others had no knowledge of this at all. One participant said, *"I think I have taken way too many tests. I took a test through my primary care doctor in [town], and he told me I should take the test yearly. When I came back the following year, he suddenly told me I should come back in three years. I did not understand anything."* Another reported, *"I have no idea when I should take the test, or that I have switched from a three- to five-year interval [participant is older than 34 years]. I thought one could check this through Helsenorge."* Only a minority of the participants knew the correct recommended interval to take the next test.

Reminders sent out from the screening program were also discussed. Some participants remembered that they had received a reminder, while others did not. One participant questioned the reminder system: *"Let's say I do not receive a reminder. How do I know if it is not time yet or if there has been a technical mistake?"*

Test Histories and Test Results

As described in the Background, there is currently no integrated digital solution available to access test histories. The following strategies can be used to access piecewise information related to the screening test: (1) reminders from the screening program, available from the public messaging service (DigiPost); (2) logs of previous appointments with primary care doctors, available for doctors in electronic patient journals; (3) communication logs with doctors offered through eHelath system or text messaging dialogs; (4) patient portals offered by private laboratories containing the date of screening test analysis (but not the results).

In addition to challenges related to accessing a test history, many participants reported that they did not receive test results from their doctor, and they assumed that it meant there had been nothing to worry about. However, such a passive way of receiving a normal test result, or "silent OK," often involves worries over time. Besides, maintaining consistency in result delivery is also important, as one participant said: *"The gynecologist took the test and said she would not contact me if the result was normal. She might have picked up that I was of the more nervous type. [later] I received a text message starting with, 'I have received your test results.' My heart jumped. Do I have cancer? The test results were actually normal, and I bet my gynecologist meant to be nice, but…"* When they did get results, several participants experienced difficulties interpreting them, often leading to anxiety after googling the test results.

Another significant challenge mentioned by the participants was the wait time for test results. They are not sure how much time it takes to get test results, and since they don't always receive the results, it can be challenging to know when they can relax. One participant said, *"Now I have taken the test, but when will I receive the answer? We need to help the patient ´put it away´by informing about WHEN the patient can expect to receive answers."* As a solution to these types of challenges,

participants suggested live updates of the screening status, similar to the tracking of packages, or simply showing the expected time for the result to be delivered.

4.2 Information needs

During the two workshops, the need for information was a recurring topic. The amount and type of information needed varied based on the test results and individual preferences. If the test results were abnormal (as compared to normal), participants reported that their need for information would be greater. This includes explanations of the different types of tests taken (HPV and cytology), specific HPV type, what they should do next, how dangerous it is, and so on. A few participants even wanted access to the raw data. For normal results, some participants said it would be sufficient to know whether the result was normal or not and the time for the next test, while other participants wanted to have explanations for the results and general knowledge about cervical cancer screening.

General information on HPV

Several participants requested more general information about HPV infections, different types of HPV and their associated risks of developing pre-cancer, the difference between HPV and cytology tests, and when/why these two types of testing are combined in the screening program. One participant reflected, in hindsight, on a positive HPV result: *"If I had just known what HPV was when I received the answer [positive HPV test], I would not have been so afraid. Now that I have educated myself, I do not think it is that scary anymore."* Some participants preferred information about the detected HPV type in relation to the test result/screening history. As one participant pointed out, *"I want to know specifically which HPV type it is so I can educate myself on that particular type. I do not want to know it was not type 16/18."* One group also suggested integrating HPV vaccination status into the digital solution. Because these topics are related, it would be beneficial to have "everything in one place."

Medical codes and terms in the test results

The participants required more information on the reliability/sensitivity of the sampling method, explanations of the results (especially when medical terms were used), rationale behind the recommended follow-up, and so on. Many discussions focused on medical codes and terms. The participants preferred non-medical terms whenever possible; for instance, one participant suggested the use of "cell test" instead of "cytology." However, some participants still preferred to have the medical term and the raw data available in a deeper information layer, for instance, to ease communication with health personnel. If any medical terms were used, participants felt explanations of these terms should be provided: *"All difficult words should have a link to something explaining the meaning of that word."* For instance, why the medical code "not detected" is interpreted as a normal test result should be explained to the participants. Another example is another medical code called "invalid test." Participants requested an easy explanation of this code, especially when the invalid result was not caused by the screening participants. Participants also discussed whether it was possible to use common terms, such as "detected" and "not-detected," for both cytology and HPV results, and whether they could receive additional specification on HPV type or cell changes.

Decision support

Several of the participants wanted decision support, both for normal results (to follow the recommended screening interval) and for abnormal results. For normal results, participants wanted to know when the previous test was taken and when to take the nest text (i.e., "Your next test is in 2026").

For abnormal results, one participant commented, "*I need to know what is happening next, be informed whether the doctor will contact me, or other things that should happen. For us [screening participants], this is not obvious*." Another participant said, "*If the test result is not normal it has to be clearly communicated in a message what*

they have found, and that it requires × follow – up." Several participants stressed that this information should also be available and accessible in the test results and test histories. One group suggested including a schedule of when future tests should be taken; the schedule could be dynamic in such a way that it could be updated if case results indicate a different time interval or changes in follow-up.

To aid decision support, participants stressed the need to know why the particular test(s) was taken, and the reasoning behind the suggested action. One participant said, "If you are going to report what [test] has been done, it is also important to inform you about *why* this has been done." Another said, *"If I was told to wait 12 months to take a new test, I would need to know if it was because [the health institution] does not have capacity, or if it is because it is really no rush."* Another participant said, *"I would never wait 12 months if I was told to wait 12 months with no explanation as to why. I would have booked an appointment at a private clinic immediately."*

4.3 User requirements

In general, participants agreed that they should have the right to access their test results and test history. As one participant said, *"The solution must be available so that everyone can get the test results."* Most participants were in favor of having this information available on an existing platform, which is an online portal for conveying health information (Helsenorge.no), instead of a separate application. However, one participant suggested having a separate application. This section will present further requirements for digital solutions that present test results and history.

Information Architecture

Many of the participants provided suggestions for how the information architecture of the digital solution should be designed, emphasizing that the front page should be clear and easy to understand, while more detailed information could be hidden further behind. As one person said, *"I do not want to click through several layers of information;, I just want*

to see the test results immediately." Another person said, "*The most important thing is to see the most recent test results, not the test history."*

As to how to easily access additional information in the deeper layers, the participants suggested the use of information boxes, hyperlinks, notes, and FAQs. For instance, one suggested, "*We can have a symbol right next to the test results, so you can click to read more about the different degrees of abnormal cells or HPV types."* This readily available information could reduce the participants´ needs to Google. In sum, information should be structured, accessible, reliable, and readily available.

Visualizations of test history

This section will examine some of the suggested visual elements in relation to the test history, see *Fig. 3*. In general, many participants preferred tables over timelines. Some reasons reported were that timelines could be difficult to orient (especially when using a phone), and that the scaling of time could be confusing. In general, the participants commented that the table could provide a better overview.

Participants also suggested alternative versions, some including everything on one site, while others included menus or tabs. Some suggested having everything on one screen with the possibility of scrolling. Furthermore, they suggested the possibility of hiding the history when having many test results and the opportunity to sort according to age or date. Another discussion was whether to include one table for all screening tests or to alternatively have one each for HPV and cytology. Here, the preferences also varied.

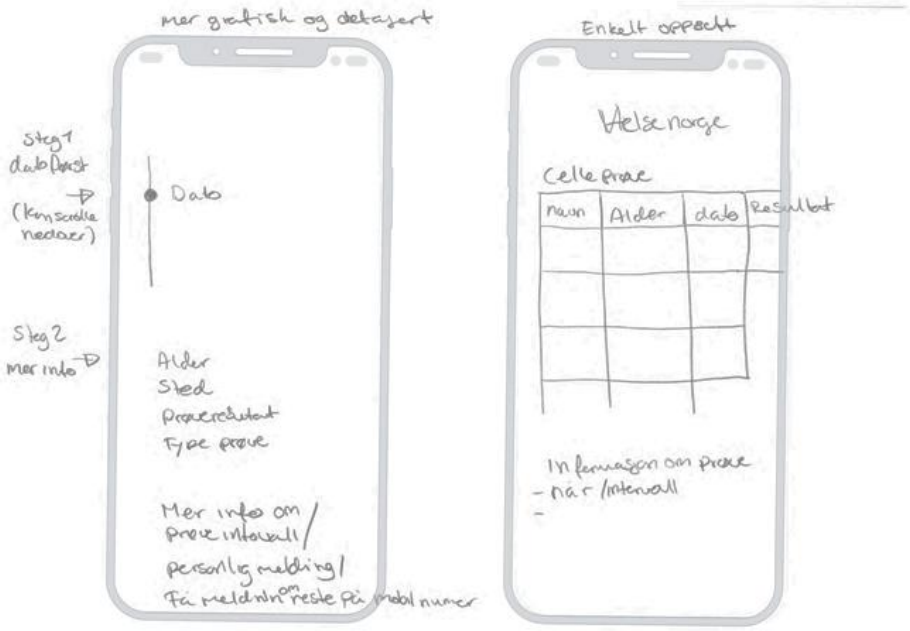

Fig. 3 Sketches by participants illustrating two different visualizations of test history

Communication preferences

A variety of communication preferences were reported during the workshops, ranging from how participants wanted to be notified about the results and time for the next test to the wording and tone of voice that should be used when communicating the results.

The participants mentioned that they wanted to have live chat communication with doctors and chatbots. For some purposes, they preferred to have direct consultation with humans (e.g., a doctor), while some simple, frequently asked questions could be taken care of by a non-human chatbot. If none of these were possible, several participants suggested that at least the doctors' contact information should be available in case there was a need for a call.

In addition, the participants would like to have notifications regarding test results or the time for the next test, with the flexibility to choose the preferred communication channel and an active (e.g., pull notification) or passive (e.g., push notification) communication style through personalized settings. Push notification means that the server

sends a notification to the user (‘Push technology,’ 2022), while pull notification means the user initiates the request for specific information (‘Pull technology,’ 2022). As mentioned previously, the time interval between two sample tests can be up to 5 years, which can be quite challenging for a human brain to remember. Although they might currently receive a physical or digital notification letter, some participants said they would prefer to receive a push notification (SMS or e-mail) to remind them that it is time for the next test. One participant wanted a table showing the schedule for all upcoming tests over the next 10 years.

As for how the test results should be delivered, preferences varied based on the situation. As one participant said, “*If the test result is very serious, I want someone to call me. If it does not require immediate action, i.e., minor cell changes, a well-formulated message could be sufficient.”* Despite the desire to receive test results quickly, some participants wanted an SMS notification informing them that the test results were *available* without revealing the results. However, for women who had difficulty accessing the digital portal to see the results, one participant suggested adding an option to “contact your primary care doctor.”

Regarding tone of voice, the majority of the participants preferred an informal, personal communication style (e.g., starting with “Hello [name]”) regardless of normal or abnormal results. One participant explained, “*Bad news also has to be communicated, and it would be best if bad news were delivered in a human way.*” Others commented that the wording should be carefully chosen and individually adjusted. When one participant saw “don’t worry, this should be ok, etc.” in the example sketches we provided, she seemed offended at being told how she should *feel*. Here is her quote: "*My test result doesn’t need to be so much ‘don’t worry, this should be ok, etc.’ I just need to know what the results are and what we should do about them. If I received a message [like the one with ‘don’t worry’ written in it] and something was actually wrong, I would be pretty annoyed*.”

Categorization of test results

There were heterogeneous opinions among the participants on how test results could be best categorized. Some preferred a simple binary “OK/not OK” or “detected/not detected,” while others preferred more nuanced categories, e.g., a triage system to indicate normal results

(green), a need for follow-up (yellow), and immediate follow-up (red). However, some reacted to the use of colors, claiming that a non-green color would be more frightening than clarifying. For HPV testing, some suggested indicating whether the HPV type was low, medium, or high risk. As one participant said, *"'Not type 16/18' means nothing to me."*

Transfer history from tests taken in other countries

Some participants had a non-Norwegian birth country and stressed the necessity of including test results from countries outside of Norway. For instance, one of them explained, "I moved to Norway and received a message saying I should take a screening test, but I had already taken the test a couple of months earlier in my home country." For these screening participants, it could be valuable to manually add history manually from tests taken in other countries to their records.

5 Discussion

The prevalence of cervical cancer in Nordic countries has declined and has become a rare disease as a result of high-quality screening programs.**Error! Bookmark not defined.** To support further development of the Norwegian screening program, the aim of this study was to explore the potential for improved screening experiences by giving participants access to screening data. This implies the design of a user-friendly, precise presentation of complex, longitudinal medical data and mapping preferences for decision support for end-users with various test results.

The current procedure for communicating the test results to the screening participant is highly variable. Given a normal result, many are not actively informed (silent ok) (Lindau et al., 2002). Participants in the workshop reported that this could cause unnecessary worry, and that they would prefer the opportunity to check the test results. In Britain, according to the NHSCSP guidelines, all women should receive an answer within 6 weeks after they take the test (Goldsmith et al., 2006). Abnormal test results are communicated through phone calls, in most cases, followed by letters. Sometimes the laboratory results are sent from the physician to the women, with some variations in different countries (Monsonego et al., 2011).

A general finding from the co-design workshops is the need for basic knowledge about cervical screening, the screening algorithm, and the HPV virus (see **Table *1***). These findings are in line with a number of other studies (Head et al., 2017; Monsonego et al., 2011). (i.e., Head et al., 2017**Error! Bookmark not defined.**, Monsonego et al., 2011**Error! Bookmark not defined.**). Furthermore, these findings show that the need for additional knowledge changes radically when the test results are not normal. For instance, when the result is normal, a simple "thumbs up" can be sufficient, but when it is abnormal, participants want to be informed about screening methods, algorithms, risks, and other matters. These findings are also prevalent in other studies (Marlow et al., 2020) (e.g., Marlow et al.).**Error! Bookmark not defined.** Previous studies have indicated that additional knowledge can reduce stress and anxiety among screening participants receiving abnormal test results (Markovic-Denic et al., 2018; Papa et al., 2009).

Table 1 Information needs identified in the workshops

Topic	Frequently asked questions
Primary screening methods	What is the difference between cytology and HPV tests?
	Why/when do you combine the tests?
Screening algorithm	How long should I wait before I take the next test?
	Why should I take a different test after I turn 34?
	I have usually waited 3 years. Why should I wait 5 years now?
	Someone told me you should take the test every year. Why 3/5?
HPV virus and genotypes	How is HPV related to cancer?
	What is type 16/18, and what does it mean?
	Can HPV infections pass?
	When did the enrollment of HPV as a primary screening method begin?
Cytology	What do you mean by "abnormal cells"?
Cervical cancer	How much time does it take to develop cancer?

Participants described the current situation for accessing previous test results as a fragmented service, where they must combine and integrate data from different sources to gain information about their previous results and their next due date. We identified several user requirements for a digital solution presenting test results and history from the cervical screening program (see **Table *2***).

Table 2 User requirements identified in the study

User requirements	Explanation
Access to data and accessible tools	Everyone should be able to access their test results and test history
	The digital solution should be available to everyone, preferably through HealthPortal.
Information architecture	Patients should be able to see the most recent test results first and also the estimated date for the next test.
	Ability to dig deeper and get more information, including information on screening history, HPV vaccinations, and raw data
Explanation of medical terms	Medical terms should be simplified when possible (i.e., use “cell test” instead of “cytology”)
	If a medical term is used, an explanation of that term should be available
Immediate access to information	Information must be immediately available, i.e., if cytology is mentioned, it should be easy to immediately find more information about cytology (for example, via a hyperlink in the word itself)
Reliable sources	Referral to trustworthy sources to avoid misinformation and random googling
Decision support	Information about “what is next” regardless of test results
	If the test results are abnormal, there is a need for more in-depth explanations and the ability to contact someone (i.e., a chatbot or the primary care doctor).
Overview of test status	The ability to see the status of the test to avoid worrying while waiting for the results (i.e., the test is currently being analyzed by the lab)
	Some type of reference points as to how long it takes to get results
Flexible settings for reminders and notifications	Some want a reminder of when to take the next text or when the test results will be available; others do not
	Communication channels vary; some prefer SMS, others prefer e-mail
Transfer history from tests taken in other countries	If you have taken a test in another country, it should be possible to add this test into the digital solution so the user can have an overview

5.1 Lessons learned

Involving users in the development of a digital solution for access to, and presentation of screening data led us to some valuable lessons that could be of use to researchers and designers. Using personas was a good strategy. Concrete stories helped focus the discussion and overcome the

"cold start" problem. The use of personas eased communication and collaboration, as participants did not need to share their own experiences. On the other hand, the personas addressed too many pain points and challenges, which could be overwhelming for the participants. Focusing on fewer challenges would probably reduce the cognitive load on the participants and give them more flexibility in the time schedule. Additionally, the proposed trigger questions for designing a solution to visualize the test history in the first workshop were too broad, which made it difficult to get started. Providing time for self-reflection before sharing in sub-groups was a success factor, as it fueled the group discussion and resulted in less dominance from the more talkative participants.

5.2 Limitations and threats to validity

We identified several limitations in this study. The sample in the current study was relatively small and biased toward women working at a research institute, which lacks representativeness of the general female population. Therefore, the user needs concerning improving information on test results and providing time for the next test—for the purpose of increasing their participation and adherence to the screening program—that we found in this group of women might not apply to women of other backgrounds. Another limitation is the priming of the participants. The researchers provided participants with knowledge about cervical screening in the introduction of the workshop, which may, for instance, have stimulated curiosity and elicited the need for more information. Specifically for the co-design, the participants may have been impacted by the researchers showing examples (test histories and prompts).

6 Conclusion and future work

We conducted two workshops with 17 female participants in total. Using a co-design method has given us rich data material, including knowledge of the current situation and user requirements for a digital solution. Our findings indicate a need for a digital solution to provide screening

participants with an overview and decision support related to their test results and history. Furthermore, our findings are in line with previous studies showing that screening participants need more basic knowledge about cervical cancer and cervical screening. A digital solution dedicated to the cervical screening program is needed and would probably support improved screening frequency, both to reduce unnecessary sampling and to prevent infrequent sampling. More research is in the pipeline to explore needs from screening participants and for doctors, including a survey to quantify and validate findings in this study, and interviews/workshops with doctors to understand their needs and challenges in communicating test results to women.

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Acknowledgments

We would like to express our gratitude to all the workshop participants. Special thanks also to Ameli Tropé, Linn Fenna Groeneveld, Kristin Hoel Brenden, and Jan F. Nygård at the Cancer Registry of Norway and Mona Stensrud and Ingvill Moe at the Norwegian Cancer Society for their comments on the manuscript and their fruitful collaboration throughout this project. Special thanks to Charlotte J. Haug for her contributions to the manuscript. The "ShowMe" project receives funding support from the Norwegian Research Council, grant 321081.

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