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# Barriers and facilitators to cervical cancer screening among under- and never-screened women in Flanders, Belgium – a qualitative study on community and healthcare providers' perspectives

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## Abstract

**Background** Cervical cancer is detectable and preventable in premalignant stages. In 2013, a population-based cervical cancer screening (CCS) programme was set up in Flanders (Belgium) promoting screening by means of sending reminder letters. Yet, in 2021, only a CCS coverage of 63.6% has been reached, which is just a bare increase since the implementation of the programme (62.7% in 2013) (Jaarrapport 2022, Centrum voor Kankeropsporing (CvKO), 2022; Jaarrapport 2015, Centrum voor Kankeropsporing (CvKO), 2015).

**Objectives** To explore the characteristics of under- and never-screened women in Flanders and to gain a better understanding of the barriers that prevent these women from attending CCS as well as factors that may facilitate CCS uptake.

**Methods** Twelve in-depth interviews and six focus group discussions were conducted with gynaecologists, general practitioners, community health workers and stakeholders providing support to women belonging to potentially underscreened population groups. Reported barriers and facilitators were subsequently classified using the Socio-Ecological Model (SEM). Finally, a causal loop diagram was constructed to visualise the dynamic interrelations among the barriers and facilitators.

**Results** Stakeholders and healthcare professionals confirm the vulnerability for cervical cancer screening in women with a substance use disorder and women with a migration background. The participation in screening among female sex workers is contingent upon their specific work environment. The group of never- or underscreened women is very heterogeneous and includes many women who are either unaware of CCS or have other priorities. A lack of focus on prevention is the most commonly reported barrier at the healthcare system level. Increasing awareness about cervical cancer (screening) and creating more opportunities for healthcare workers to offer prevention services are the primary facilitators.

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**Conclusion** To improve screening participation in Flanders, different screening strategies tailored to a diversity of women are needed.

**Keywords** Cervical cancer screening, Community workers, Healthcare workers, Barriers and facilitators, Underscreened, Sexual health

## Introduction

Worldwide, cervical cancer was the fourth most prevalent cancer in women in 2020. Despite being one of the most preventable cancers, according to the World Health Organisation (WHO), more than 604,000 new cases were diagnosed worldwide and nearly 342,000 women died from cervical cancer in 2020 [1]. On the other hand, efforts in cervical cancer screening (CCS) have successfully reduced cervical cancer incidence and mortality, especially in high-income settings where effective population-based screening programmes have been put in place, e.g. Finland and the Netherlands [2, 3]. In Belgium, there is no national CCS programme, as health screening initiatives as well as all other preventive medicine policies, fall under the mandate of the country's regional authorities (Flemish Region, Brussels-Capital Region, Walloon Region). As a result, each regional authority developed its own approach to CCS. In the Flemish Region, a formal, population-based CCS programme based on a call-recall system was set up in 2013. The programme, coordinated by the Centre for Cancer Detection (Centrum voor Kankeropsporing - CvKO) in collaboration with the Belgian Cancer Registry (BCR), promotes taking a smear test every three years among women aged 25 to 64. Women who fail to do so receive a letter in Flemish inviting them to make an appointment for screening with a gynaecologist or a general practitioner (GP) [4]. In Flanders, the vast majority of women (85%) consult a gynaecologist for CCS, rather than going to their GP [5]. In the other two regions, there are no formal initiatives, and CCS remains rather opportunistic. Within both systems, CCS coverage stagnated at approximately 60–65% for the last decade, with a slight decrease in Brussels and Wallonia and a stabilisation for Flanders [4, 6–8]. Both the opportunistic screening in French-speaking Belgium, but also the population-based screening programme in Flanders is confronted by a suboptimal participation rate.

Literature has shown that in Belgium, socioeconomically disadvantaged women, women with a lower education attainment and older women are more likely to remain un(der)screened, with the former groups often being referred to as “vulnerable populations” or “vulnerable women” [4, 6, 9, 10]. In Western Europe, homeless individuals, women living in poverty and migrants from regions with high human papilloma virus (HPV) prevalence are recognized as vulnerable populations in

CCS programmes. However, the understanding of vulnerability varies, and the absence of consensus on subgroup identification poses a challenge in implementing strategies to enhance coverage [11]. To our knowledge, only two qualitative studies have been conducted in Flanders on CCS and (non)participation. One study in 2015 surveyed general practitioners' perspectives on CCS in general practice and searched for strategies at the healthcare system level to increase CCS participation [12]. The other study (2017) explored the motives for nonparticipation in women living in (extreme) poverty [13].

Based on studies in other European countries on vulnerable women, we expected to find underscreened women in (i) female sex workers (FSW), (ii) women with a substance use disorder (SUD) and (iii) women with a migration background [14–18]. The present study zooms in at these specific subgroups in Flanders to verify their vulnerability to CCS and to identify their specific needs and barriers.

In addition, literature increasingly shows that also nonvulnerable women are often underscreened. For example, there is a tendency to lean to a more ‘natural’ and ‘self-directed’ form of medicine, i.e. complementary and alternative medicine (CAM), which might result in a certain reluctance towards screening if this happens at the expense of trust and belief in conventional medicine [19]. According to Belgian data, in 2018, 12.8% of the female population used some form of CAM in the last 12 months [20]. As such, more insights are necessary to understand whether these women could indeed be part of the group of underscreened women.

Similarly, according to a study by Marlow et al. (2017), there are two main types of nonparticipants: either women who are not aware of CCS or women who would like to be screened but are unable to translate their intention into action [21]. Practical barriers such as ‘forgetting to make an appointment’ and ‘having no time’ are known reasons for nonattendance [22, 23]. Furthermore, women may view screening as inaccessible because of barriers at the healthcare system level such as inconvenient location of the clinic or limited appointment times [23]. Therefore, a proportion of the 40% unscreened women could also be represented by nonvulnerable women who for example have a busy

schedule (household, demanding job) and do not prioritise screening.

In order to be able to increase the coverage rate of CCS, we need to know which (sub)groups we are failing to reach in our CCS programme and why so. When considering programme coverage, the levels of attendance rely on individual women making the decision to attend CCS and translating that decision into action. A range of reasons for nonattendance has already been identified [13, 23]. Unfortunately, evidence for Belgium remains scarce. This lack of evidence makes it difficult for healthcare professionals to respond to the needs of their patients and facilitate when possible. In a recent study it is suggested that a shift in focus towards the settings or environments of the subgroups, such as sex work venues, communities with drug use, and homeless populations could serve as a more effective approach. Considering these settings as the defining factor of vulnerability, targeted interventions could be more easily implemented in order to address the specific barriers of these populations [11].

The aim of our study was threefold: (i) to identify and verify certain subgroups as underscreened in Flanders, (ii) to better understand the complexity of barriers that these women face in the process to/of cervical cancer screening and (iii) to determine what may facilitate their actions.

## Methods

### Study design & population

In this qualitative study we conducted in-depth interviews (IDIs) and focus group discussions (FGDs). The IDIs were conducted with professionals who provide health and social support to groups of the population who are known to underuse health services (i.e. migrant women, women with a substance use disorder (SUD), female sex workers, and women exclusively using CAM) in Flanders. During the IDIs the primary focus was on exploring whether these specific subgroups can be considered underscreened. Second, specific barriers and facilitators for CCS were discussed in depth.

After the exploration of potentially underscreened populations through the IDIs, FGDs were held with general practitioners (GPs), gynaecologists and community health workers (CHWs) to gain their insights into the perceptions of the current Flemish screening system and to further explore the barriers to and facilitators of CCS, both in general and for the specific subgroups. Reasons to choose these three groups include the following: (i) *gynaecologists* are confronted with CCS in their daily practice and can have valuable input regarding the perceptions on the current CCS landscape in Flanders; (ii) *general practitioners* in Flanders, can also be consulted for CCS, however, this occurs less frequently (15%) [5].

Just as the stakeholders, they come in contact with vulnerable women more frequently in their daily practice, including the underscreened women, and are believed to have more insights into the barriers for CCS; (iii) *community health workers* have valuable insights into the daily life and burdens of (vulnerable) women due to their trusting, one-on-one relationship with them.

### Participant recruitment

In the first phase, stakeholders were recruited for the IDIs using purposive sampling. We contacted associations, community organisations, healthcare centres and professionals who work with potentially underscreened women by telephone and email. All stakeholders were selected based on the fact that they work on a daily basis with women who belong to (one of) the target groups and are acquainted with their lifestyle and thinking.

In addition, in a second phase, we invited gynaecologists and GPs, who are currently active in Flanders, to participate in FGDs. To do so, we contacted representatives of LOK groups (Lokale kwaliteitsgroep, i.e. local quality group). These LOK groups are local groups of healthcare professionals that organise meetings to discuss their practices and to exchange experiences with peers to increase the quality of their work. Additional participants (GPs and CHWs) were recruited using snowball techniques based on the participants' network contacts.

Participants received information about the study and were asked to participate in an interview or an FGD. Recruitment continued until data saturation was reached [24].

### Data collection

All IDIs and FGDs were conducted in Flemish. A semi-structured guide was used containing open-ended questions followed by probing questions to explore several topics. Although not pilot tested, the guide was extensively discussed in the research team before data collection and no major issues arose during data collection. First, we tried to identify the hard-to-reach women in the context of CCS: which groups of women in Flanders, Belgium can we identify as never- or underscreened? We asked all participants, although more into depth during the IDIs, who they consider as hard-to-reach for CCS and why so. Second, opinions about the CCS programme in Flanders and perceptions about barriers to CCS were explored. We asked whether these barriers were specific to certain subgroups or for all women in general. Professionals were asked to share their perspectives and opinions on barriers women might face based on their experiences with these hard-to-reach groups. Finally, we gauged for suggestions on facilitators and strategies to

overcome the reported barriers. We asked if they could suggest changes to overcome those difficulties.

During the IDIs the focus was more on identifying the underscreened women by spending more time and asking more questions on this first topic. While, during the FGDs, more attention went to the exploration of the barriers to and facilitators of CCS.

Interviews and FGDs were conducted online as this research took place amidst the COVID-19 pandemic and resulting periods of lockdown. Data collection was recorded using the Zoom platform. A self-administered questionnaire was sent by email to all participants before each interview/FGD to collect information on their participants' professional background and experience with CCS and hard-to-reach groups.

Prior to the start of the interviews and the FGDs, the nature of the study was re-explained to the participants. The interviews and FGDs were facilitated by female moderators (JDV (BSc) and EDP (PhD), respectively). The reporting of this study was based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (see additional file 1) [25].

### Ethics

All participants were mailed an informed consent form that they had to sign and return before participation to show that they agreed to participate. Participation in the study was voluntary. The project was approved by the Ethics Committee of Ghent University Hospital (BC-06974, 24/4/2020).

### Data analysis

All interviews and FGDs were recorded, transcribed verbatim in Word, and anonymised. Transcripts were not shared with the participants. Data were analysed by two researchers (EDP and BV) using a content analysis approach [26]. A codebook with themes, subthemes, and main codes was constructed by the research team based on the interview and discussion guides (see additional file 3). Each transcript was analysed separately, and segments of the text were categorised into codes defined in the codebook using Nvivo software (Lumivero (2017) *Nvivo* (Version 12), [www.lumivero.com](http://www.lumivero.com)). The themes and codes were frequently discussed and checked by two of the authors (EDP, BV) to increase the reliability of the analysis. When new codes emerged during the codification process, they were added to the codebook. Illustrative quotes for each code were selected and translated into English. Throughout the analysis, the interpretation was compared with the verbatim data. The socioecological model was used to organise the multilevel barriers [27]. To visualise the complex interrelationship between the

different barriers a causal loop diagram was composed [28]. A causal loop diagram is a visual representation – generally referred to as a “mental map”- of dynamic complexity. It consists of causal linkages among elements of a system thought to generate a specific problem. Such a visual representation can help to see the nature of the dynamic complexities in the system and to better understand the policy implications [29] Fig. 1.

## Results

### Sample characteristics

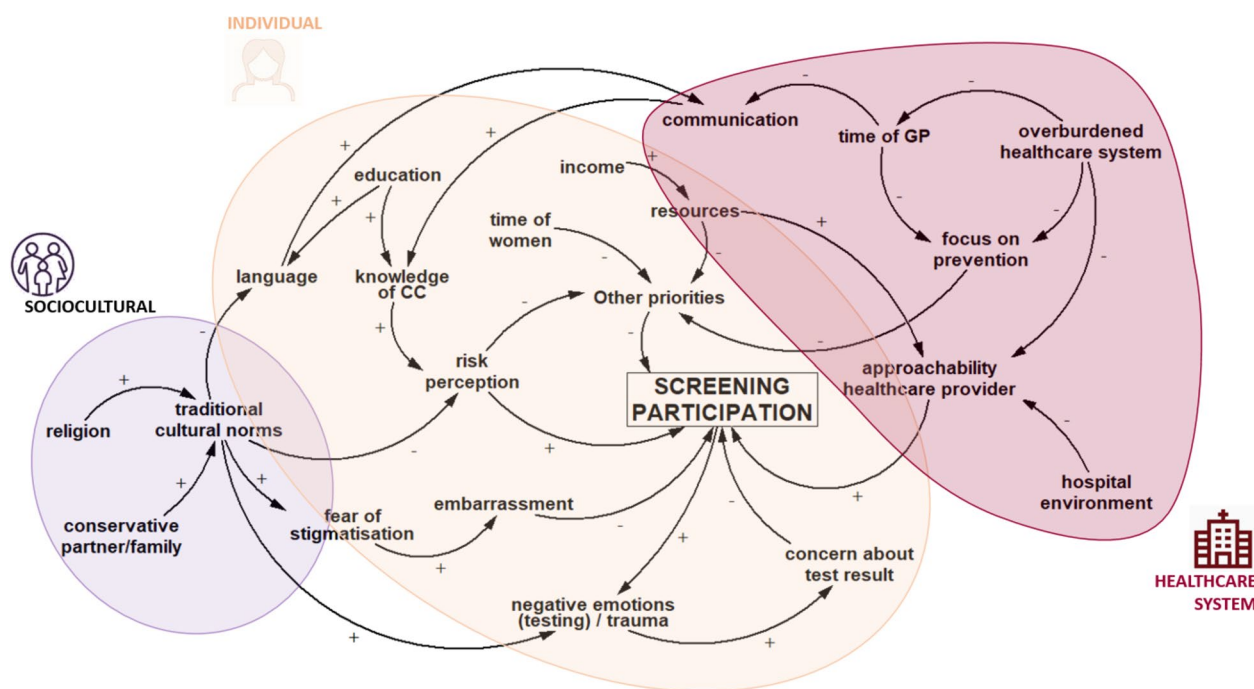
Overall, 58 organisations and 31 independent professionals were contacted. The majority of refusals to participate could be attributed to overburdening by the COVID-19 pandemic. In total, 12 interviews were conducted with 11 female participants and one male participant. Four participants were GPs working in a very specific setting: a drug rehabilitation centre (1), an outreach programme for female sex workers (2), and a community health centre with socioeconomically disadvantaged people as the main target group (1) (Wijkgezondheidscentrum (WGC)). Another two GPs are working as CAM practitioners, and three participants were active as social workers in nonprofit organisations (two working with women with SUD and one with migrants). The remaining three participants were a nurse working with women with SUD, a midwife (a CAM practitioner) and an interpreter who works in a nongovernmental organisation providing healthcare services. Overall, among the 12 participants, 3 worked closely with migrant women, 2 with FSWs, 4 with women with SUD and 3 with women who use CAM. (see Table 1 – and additional file 2)

We performed 6 online FGDs: 4 FGDs with healthcare professionals (2 with GPs, 1 with gynaecologists and 1 with a mix of gynaecologists and GPs) and 2 FGDs with CHWs. In total, there were 38 participants and each FGD consisted of three to twelve participants (see Table 2). Except for the 4 GPs working in a community health centre (WGC), the GPs and gynaecologists had no extensive experience with vulnerable groups. The 8 participating CHWs were working for or volunteering in 5 different organisations targeting vulnerable populations. Participants' characteristics are provided in Table 2.

More extensive information on profession, work experience and work environment collected through the questionnaires among all participants (IDIs and FGDs) and originating from the IDIs and FGDs can be found in the additional file 2.

Both the interviews and the FGDs lasted approximately 1 h. All IDIs were scheduled according to the availability of the participants and were conducted between May and October 2020. The FGDs were conducted between December 2020 and March 2021.





**Fig. 1** Causal loop diagram of the barriers for cervical cancer screening. The arrows in the diagram describe the directions of effect. A causal link from one barrier (A) to another barrier (B) is positive (+) when a change in A leads to change in B in the same direction; an increase in A leads to an increase in B and a decrease in A leads to a decrease in B. Conversely, a causal link from A to B is negative (-) when a change in A leads to a change in B in the opposite direction. Applied to the barriers, for instance, a woman with a lower education level will have less knowledge on cervical cancer (screening) and not perceive herself as ‘at risk’. Therefore, getting screened for cervical cancer will not be a priority and she will not participate

### Participation in national CC screening

#### Which groups are particularly under- and never screened for CC?

**Migrant women** - Women with a migration background were generally considered as being underscreened for cervical cancer and hard-to-reach for preventive care

in general. Participants assumed that women born in another country may have been less exposed to preventive messages throughout their life and therefore may be less aware of the importance of screening. Women may not be aware that they can also consult a gynaecologist, whom they consult for care during pregnancy,

**Table 1** Sample characteristics of the interviewees

	Gender	Subgroup	Profession	Workplace
Int1	F	Migrants	Interpreter (Eritrean origin)	a healthcare NGO
Int2	F	Migrants	General practitioner	a WGC
Int3	F	Migrants	Social worker	a nonprofit organisation
Int4	F	Sex workers	General practitioner	a nonprofit organisation (outreach)
Int5	F	Sex workers	General practitioner	a nonprofit organisation (outreach)
Int6	F	SUD	Nurse	a medical centre
Int7	F	SUD	Social worker	a nonprofit organisation (outreach)
Int8	M	SUD	General practitioner	a medical centre
Int9	F	SUD	Social worker	a therapeutic programme
Int10	F	CAM	General and CAM practitioner	
Int11	F	CAM	General and CAM practitioner (focus on homeopathy)	
Int12	F	CAM	Midwife	self-employed

NGO Nongovernmental organisation, WGC Wijkgezondheidscentrum, community health centre, FSF Female sex workers, SUD Substance use disorder, CAM Complementary and alternative medicine

**Table 2** Sample characteristics of the FGD participants

	Participants	Gender	Subgroup	Profession
FGD1	2 gyn + 1 GP	F:3 / M:0	/	Gynaecologists: 2 General practitioner: 1
FGD2	10 gyn	F:6 / M:4	/	Gynaecologists: 10
FGD3	4 GP	F:3 / M:1	/	General practitioners: 4
FGD4	13 GP	F:7 / M:6	/	General practitioners in a WGC: 4 General practitioners: 9
FGD5	3 CHW	F:3 / M:0	Women living in poverty and/ or from socially excluded groups	Health promotor at WGC: 1 Social healthcare worker: 2
FGD6	5 CHW	F:4 / M:1	Women living in poverty and/ or from socially excluded groups	Social worker: 3 Social healthcare worker and nurse: 1 Volunteer: 1

Gyn Gynaecologist, GP General practitioner, CHW Community health worker, WGC Wijkgezondheidscentrum, community health centre

for preventive care. The invitation letter sent out by the screening programme in Flanders to create awareness and motivate women to get screened is often not understood because of the language barrier that migrant women might face.

*Int1, stakeholder: (...) they (women from Eritrea living in Belgium) do go to the gynaecologist when [they are] pregnant, but if you're not pregnant, you usually don't consult a gynaecologist (...).*

**Women with SUD** - Stakeholders working with women with SUD confirmed that in their opinion, most are underscreened for cervical cancer in Flanders and hard-to-reach for any kind of (medical) care. They are not motivated to take care of themselves, as one participant stated: ‘... someone who is truly using, for years and years, that's not [a priority], you will not get them motivated [for cervical screening]’ (Int9, stakeholder).

They were referred to as care avoiders, although it was mentioned within the group of women with SUD that there are still differences in accessibility: heroin users are typically reached by substitution programmes (methadone and needle exchange); speed users, on the other hand, often remain unreachable for care.

**Sex workers** – As for female sex workers, participants reported that screening uptake can differ among them: women who mainly work independently (at home, escorts) are most likely to be underscreened, while the sex workers working in clubs and bars are often more up to date with their screening. Some of them might even be overscreened since they are aware of their higher risk due to the nature of their work, and they have an easy access to healthcare services and therefore ask to get screened more often.

*Int5, health worker: Among the foreign girls for example, the Romanian girls, they are going back to their home country every once in a while, and are getting tested there. There they perform testing*

*more often, they are even testing too much for HPV [Human Papilloma Virus-causative agent of cervical cancer] (...).*

Girls and women working individually at home or as escorts are rather underscreened and hard-to-reach due to their hidden lifestyle. They cannot be reached by organisations providing medical and social care to sex workers. The healthcare workers stated that sex workers working in clubs, bars or window prostitution (the regular system) do have access to screening by several organisations with specific outreach programmes.

**Women in the oldest age group of the screening cohort, women without children** - GPs and gynaecologist who did not have specific contact with vulnerable and/or hard-to-reach women, mentioned women belonging to the older age groups of the screening cohort as being underscreened. They noticed that women no longer perceive themselves ‘at risk’ once they are in the menopause. Moreover, the GPs indicated that they often forget to offer it themselves to older women, as one of them stated: “Above 40 it tends to be forgotten more easily, both by the doctor and by the patient.” (FGD4, GP). In addition, women without children were identified as being less commonly screened as they had less familiarity with going to the gynaecologist.

**Women who use CAM** - Three of the CAM practitioners reported that their patients/clients as well as themselves are generally open to cervical cancer screening. Two of them even stated that their patients would be rather overscreened as they have a pro-active health attitude and can be considered as the ‘worried well’. In contrast, one CAM stakeholder reported not attending and even rejecting screening.

*Int10, GP: I actually think that we have a lot of people here (in our practice) who truly want that self-regulating system of ‘I just want to take care of my health by taking good care of myself’.*

### Perceptions about the Flemish CCS programme

In general, the opinions about the CCS practices in Flanders were rather negative, particularly among the GPs and CHWs. Gynaecologists expressed less strong opinions about the screening programme. The information about the screening programme was considered insufficient, and participants stated that thus far, there have been no sufficiently effective campaigns to create awareness, especially not focused on underscreened populations.

*FGD6, CHW: I also think that communication to people concerning such tests often takes place in writing or via all kinds of online media and that communication is often not accessible and does not reach the right people.*

A first remark participants made is that the majority of the underscreened populations is not aware of the existence of a CCS programme. Additionally, as some of the women in the migrant population and sex workers do not have legal status documents or have to move very often due to socioeconomic reasons, they lack an official address. This makes an invitation letter a weak medium to contact, inform and remind women.

Moreover, according to the participants, the invitation letter has several flaws. First, the letter is only provided in Flemish with no translation available. Second, the CHWs felt the content of the letter was unclear, seemingly intended for highly educated people and included much unnecessary language while lacking essential information.

*FGD3, GP: The leaflets that we have in the waiting room are only in Flemish, the invitation letter is in Flemish, you will not reach a large part of Belgium.*

*Int4, CHW: The letters that are sent are perhaps too noncommittal in some places. And also the language, there is also a problem. People receive that letter at home, but if they do not speak Flemish, then they do not know at all what is in that letter. And so, we (at our organisation) also have a 'welcome moment', where people can come by with a question, a problem, with something they want to talk about. (...) we don't really have many clients who come by with that letter. So I think that's something that in some families disappears or is thrown in the trash pretty quickly. Because they don't understand the information that is in it, so they can't act appropriately.*

*FGD5, CHW: That (letter) is really aimed at highly educated people, a lot of unnecessary language, too little information, ....*

A final point of criticism is the ineffective method of inviting people; the letter is very noncommittal and has little persuasiveness. This is in contrast to the letter sent for breast cancer screening, which provides an appointment that you can either attend or change yourself. This method was seen as more effective by several GPs and CHWs.

*FGD4, GP: I have never seen a patient saying 'I received a letter, I visit you because of my PAP smear' if you ask about [the invitation letter] sometimes they respond 'yeah I have seen something passing by' but it has no big effect.*

Another weak point of the programme, pointed out by the GPs, is that many women are unaware of the fact that they can get screened by their GP.

*FGD3, GP: When I say: 'You can just as well do that [the cervical cancer screening] here.' ... (The patient answers: ) 'Oooh, okay.' ... They really are unaware.*

*FGD5, CHW: I also think that the GP can play an important role in this because it is actually very little known that the GP can also perform the cervical screening (...) people often think that they have to go to the specialist [gynaecologist] for this [screening].*

### Barriers

All barriers were considered in relation to an adapted version of the Socio-Ecological Model (see Table 3). They were mapped against three of the five constructs of the model as defined by McLeroy et al. [27]: (i) individual (or intrapersonal) level considers characteristics of the individual such as knowledge, attitudes and behaviour, (ii) sociocultural (or interpersonal) level looks at formal and informal social networks and (iii) health system (or institutional) level focuses on access to screening services and continuum of care.

**Table 3** Reported barriers for CCS classified on different levels based on the Socio-Ecological Model

INDIVIDUAL	SOCIOCULTURAL	HEALTHCARE SYSTEM
Lack of knowledge	Traditional cultural norms	Overburdened GPs & lack of focus on prevention
Low risk perception	Religion	Communication
Other priorities	Family/partner	Accessibility
Low income/resources		
Language difficulties		
Emotional hindrance		
Fear of stigmatisation		

## Individual

### Lack of knowledge

The majority of participants reported a lack of knowledge as a major barrier in the target group of vulnerable women. Women often have low health literacy and many women even lack knowledge about their own body and anatomy: *“If you don’t know you have a cervix, how can you possibly know cervical cancer exists?” (FGD6, CHW).*

Even if they are aware of cervical cancer screening, it was reported that women often don’t know that they could also get screened by their GP. Therefore they won’t actively ask for screening when they happen to be at the GP.

### Low risk perception

As a consequence of a lack of knowledge regarding cervical cancer, women were reported to have a low perceived risk. Both GPs and gynaecologists stated that many women feel like CCS does not concern them. It was mentioned that many women only visit a gynaecologist when they are pregnant and do not see any reason to visit them afterwards if they don’t have any symptoms such as abnormal, irregular bleeding or other complaints in the genital area.

### Other priorities

In general, prioritising other problems or activities above participating in CCS was another major barrier. Specifically for women with SUD, it was clear that ‘having other priorities’ is their most important barrier.

*Int8, stakeholder, GP: if there are already three [letters] of the bailiffs there that they do not answer. Then that one screening will also be able to wait for a while....*

Furthermore, difficulty in finding time to attend screening was mentioned several times. It was reported that many women postpone their appointment or forget about it because they are too busy or lack the energy because of a busy household: *“Many women are single mothers or very busy with their jobs.” (FGD6, CHW).*

### Low income

Financial barriers, including both the cost of the healthcare service and the cost of the transport to get to a hospital, were mostly discussed by the CHWs: *“They won’t spend their last €25 on a doctor’s visit.” (FGD6, CHW)* The CHWs working with women living in poverty also mentioned that women are mainly concerned about the cost of further care if this is needed. This was also mentioned by stakeholders working with migrants and sex workers. In the case of women with SUD, it was reported that they would rather spend their money on drugs.

*Int9, stakeholder, social worker: If it [CCS] comes at a cost, then that’s certainly a barrier. Then they will certainly not be open to it.*

### Language difficulties

Participants who discussed barriers of migrant women reported that language forms a significant barrier in several ways. Their poor language skills hamper their understanding of the invitation letter. All interviewees working with migrant populations also mentioned that women struggle during health visits. Not only are they embarrassed to talk about these intimate subjects, they are also often ashamed over the fact that they don’t master the language. Therefore, they only consult a health professional for urgent medical issues. One of the stakeholders (who works as a translator) also mentioned that these women often (have to) bring a family member or friend as a translator. In that case, they do not feel comfortable to talk about intimate subjects like CCS.

*Int1, stakeholder: They cannot explain enough, they are ashamed anyway, (...) on top of that comes the language barrier, not easy. That means, you have to bring someone else. (...) Like I usually go with the women [to the doctor], okay, I am a trusted person to them. But I see, on their faces, that it is not easy.*

### Emotional hindrance

Different emotions were discussed by the participants as barriers in context of CCS. Embarrassment about gynaecological examinations was reported frequently. Especially among migrant women this appeared to be a major barrier.

A CHW explained how the dimensions of embarrassment go much further than the sensitive nature of the gynaecological examination itself and include also the entire experience of not feeling at ease while attending healthcare services. She quoted a woman living in poverty who talked with her about her shame in front of the doctor:

*FGD5, CHW: I am quite embarrassed, my underwear... it is clean, however it is not nice and I don’t feel comfortable when getting undressed [CHW telling what a client/woman told her].*

A history of trauma, such as female genital mutilation or sexual abuse, also seemed to hinder women to go for CCS, according to both GPs and CHWs. The participants working with women with SUD mentioned that past sexual abuse is not uncommon in this population. As a consequence these women fear gynaecological examinations.

*FGD4, GP: ... victims of sexual abuse in the past, (...) they actually prefer to do this [CCS] under*



*anaesthetic, but they do not dare to ask or they are afraid when they go to the gynaecologist.*

In addition to the fear of the examination, the fear of (having) cancer was reported to be a barrier for women with a migration background. In many cultures you even cannot talk about ‘cancer’ as it would mean bad karma.

*Int1, stakeholder: ... they have the belief that if you say something with your mouth or with your words, it will happen to you. (...) So they don't try to talk about cancer (...) They give it a different name. (...) Say they have that 'bad disease'.*

### **Fear of stigmatisation**

A barrier for women with SUD and sex workers is the stigmatisation they sometimes feel when visiting a doctor or a clinic. Women with SUD were reported to experience discrimination by healthcare providers.

*Int8, stakeholder, GP: Many of our clients do not want their [medical] results (...) to be posted by us on the CoZo-platform [platform for health professionals to share medical information]. (...) They explicitly refuse (...) because of the social stigma.*

According to all stakeholders working with sex workers, they experience stigmatisation by society regarding their profession, leading them to live a hidden, double life. By consulting a doctor or a clinic they fear to lose their anonymity and reveal their true life and profession.

*Int4, stakeholder, GP: Among other things, there is a misconception that a gynaecologist, if he looks into the vagina, he can see how much sex you have, with how many different partners, ... So those women do not dare to go because they are ashamed of their profession.*

## **Sociocultural**

### **Traditional cultural norms**

The majority of the stakeholders working with migrant women reported that cervical cancer (screening) is not something that can be discussed openly. In many cultures it is taboo to talk about intimate subjects. If a woman is not married, there is no need for her to go and see a gynaecologist as she is not supposed to be sexually active. Women only consult the gynaecologist when they are pregnant. It is not common to go just for screening.

*Int1, stakeholder: ... it is like a machine [the uterus], that machine is working now, so we have to maintain [it], keep [it] clean and so on and so on. As soon as that work is done, so to say the pregnancy is finished, [there is] no need to go to the doctor.*

Stakeholders and healthcare providers mentioned that a male doctor performing the screening often is a barrier to migrant women or their husbands as this is not accepted in some cultures. However, one GP emphasised that we should be careful with this and definitely not assume it is true for all women with a different cultural background. Two GPs working in an area with a large Roma community described the Roma culture as matriarchal but not supporting preventive or gynaecological care.

### **Religion**

Religion as a barrier was only discussed in the context of women with a migrant background. The stakeholders were very clear that the lack of screening among the migrant population is unrelated to religion. According to them, it is much more a cultural issue. In contrary, religion was frequently suggested as a barrier by some GPs and gynaecologists, although their distinction between religion and cultural beliefs was not always clear.

*Int1, stakeholder: More than 98% of us (Eritrean women), we are all Christians (...) for us it is not about religion. It is more the culture that is heavy.*

### **Family/partner/gatekeepers**

The role of the family or husband in the decision process to go for screening differs in different communities. Some stakeholders mentioned that in north African cultures, gynaecological issues are seen as “the partner’s area”, and therefore visiting a gynaecologist is not allowed.

*FGD4, GP: ... sometimes the man is the only one speaking Dutch and the woman doesn't, yes, and then, I already noticed, it is like the man decides instead of the woman 'no we won't do that [cervical cancer screening].'*

Although not a real partner, a stakeholder mentioned that pimps sometimes prohibit their sex workers to see a doctor.

## **Healthcare system**

### **Overburdened GPs and the lack of focus on prevention**

First, an important barrier acknowledged by many GPs is that they are overburdened and have to set priorities during consultations. Therefore, many of them mentioned they lack time to give sufficient attention to prevention, including CCS. Furthermore, a GP reported that when vulnerable women visit with a specific request for help, they will start with helping them out with the more urgent problems. Besides that, some GPs admitted that sometimes they forget to bring it up during consultations, especially with postmenopausal women, because

the discussion about CCS is often linked to the prescription of contraceptives. This lack of time in consultations was not mentioned by the gynaecologists for whom it is one of their main activities.

*FGD3, GP: The GP's time itself is sometimes also a barrier in this respect, just because they cannot just take it all up in one consultation. If people already come up with two other problems, and if they are not stimulated enough to come back [for a PAP smear], yes then you miss it.*

Many GPs argued that prevention in general is undervalued in the healthcare system and that there is a lack of healthcare services focusing on prevention. As a result, GPs take up preventive activities but they have to slot them in into their already overbooked regular consultations.

Additionally, one stakeholder, declared not to perceive HPV as life-threatening as hepatitis and HIV among women with SUD, and is therefore prioritising hepatitis and HIV screening above CCS.

### Communication

The majority of the GPs also indicated that the language barrier faced by some patients makes it difficult for the healthcare provider to explain the importance of screening and to get the patient motivated. On top of that, GPs complained about the inefficient communication and lack of data sharing between gynaecologists and GPs. Several GPs mentioned that it is difficult and time-consuming for them to check whether or not the patient was screened by a gynaecologist, which makes it harder for them to systematically keep track of the patients that are not screened.

### Accessibility

In general, the participants mentioned that accessibility of gynaecologists is a barrier in Belgium. Although you can make an appointment with a gynaecologist without a referral from a GP, this seems to represent a bigger challenge compared to visiting a GP, according to healthcare professionals, CHWs and stakeholders. The clinical and formal setting of a hospital when visiting a gynaecologist was also mentioned by the CHWs as potentially overwhelming and negatively influencing the screening behaviour.

*FGD5, CHW: Even I feel acute stress when I am in a waiting room and think about whether or not they will forget me or if I have heard and read things correctly.*

GPs recognise additional barriers for women without a global medical file (=an electronic medical file that you keep with a specifically chosen general practitioner. It contains all your medical data and provides an overall picture of your health situation), which mean they are not registered with any GP and, thus, do not benefit from a higher reimbursement and a trust person who manages and centralises all their medical information. This aspect was also mentioned by the stakeholders of women with SUD. Lacking a residence permit or health insurance was confirmed to prevent some migrant women and sex workers from accessing healthcare.

### Facilitators

Considering the socio-ecological model, all facilitators mentioned, can be mapped under the healthcare system level.

### Awareness raising

The majority of the participants recommended to raise more awareness around CC and to sensitise all women aged between 25 and 64 years emphasising their potential risk, even though they have no symptoms. Mass media campaigns, including social media were suggested channels. Some stakeholders also proposed to organise theme months about CCS within the organisations and institutions working with the vulnerable groups. The CHWs stressed that the content of this information needs to be kept simple, with basic and plain language, preferably complemented by visuals: *"By communicating in a very clear and also safe manner a lot can be achieved."* (FGD5, CHW) In addition, some GPs are also asking for accessible and understandable information material in different languages.

### Trusted key person

Some of the stakeholders working with the specific sub-groups proposed to use trusted organisations or people experienced in contacting specific hard-to-reach groups as the entrance to get in touch with these women and to then give adapted information according to cultural beliefs and differences. It was mentioned that with clear information, a lot more is acceptable than we generally believe. For the majority of women, they believe the main facilitator will be a personal trust relationship with their care provider.

One of the stakeholders working with migrant women raised the idea to first inform the men in the community. In many contexts, in marriage the male partner will take the decisions so in order to have him on board we should inform them as well.

*Int1, stakeholder: I always think: first explain to the men because they have more power at home. (It is) better to always give the men the explanation (...) also about smears. If the men know about (it), I think they [the doctors] can work more preventively together with the wives.*

Many GPs stated that it was their task to take up a (more) proactive role and check for all their female patients if they are screened. This was confirmed both by CHWs and gynaecologists indicating that the GP remains the first contact person.

### **Personal motivator**

In order to do so, it was mentioned that it would be more effective and compelling if the invitation letters were coming from the general practices. However, some GPs already tried out an approach of systematically contacting women that are under- or never-screened, but experiences and outcomes were mixed. Regardless of who would send the letter, most agreed that the invitation letter should contain an already set appointment, similar to the breast cancer screening invitation, to make the invitation more effectual.

### **Structured organisation of preventive care**

The GPs also advocated for a more structured way of offering preventive care in order for patients to know what measures they have to take at what age and for this to become a well-established practice. That way, the responsibility would be borne by both the GP and the patient and the risk of forgetting it would be reduced. A reorganisation of the medical files software could also support a fluent process of indicating if a patient is screened correctly and potentially improve the collaboration with gynaecologists. Another suggestion to take some of the burden of the GPs is to have a nurse in charge of this kind of preventive consultations who could perform the PAP smears.

## **Discussion**

This exploratory qualitative work demonstrates that the group of under- and never-screened women in Flanders is very heterogeneous. The diversity within and especially the intersectionality between these groups reveal the complexity of defining the 'hard-to-reach population' in Flanders. There is a paucity of qualitative studies on the factors influencing the CCS participation among women in Flanders. To our knowledge it is the first time a qualitative study about CCS was conducted to identify particular underscreened groups of women in Flanders and specify the barriers they face. This study has provided novel insights and new knowledge and enhances our

understanding of what determines (non)participation in CCS among underscreened Flemish women. Ultimately, these findings can help policymakers and healthcare researchers to develop different evidence-based screening strategies tailored to a diversity of women to improve screening participation.

Asking stakeholders about the participation in CCS of the (vulnerable) populations they work with, confirms that most female sex workers, women with SUD and women with a migration background face strong barriers inhibiting them for participating in screening, confirming studies in other countries [11, 15–18]. For women using CAM, however, the stakeholders were not unanimous, making it difficult to confirm whether they tend to be underscreened. For that reason, no barriers specific for CAM were identified. The lower coverage in the older part of the screening cohort reported by the Centre for Cancer Detection (CCD) was confirmed by the perceptions of GPs [4, 9]. In addition, women without children were also identified as being less commonly screened [9].

In general, all participants had rather negative perceptions about the Flemish screening programme for cervical cancer. Despite a population-based programme being in place since 2013, the majority of women are considered to be unaware of its existence. According to the participants the invitation letter misses its target. A letter is a weak medium to inform vulnerable and socially disadvantaged people and it is perceived as very non-committal in comparison to the one for breast cancer screening [13]. For women speaking only a foreign language, the letter being in Flemish is an additional barrier. In Flanders, the exclusive use of Flemish in administrative communication, such as the invitation for the CCS programme, is mandatory by law. In the last year, translations of the invitation letter and additional information have been made available on the website of CCD in ten languages. However, a referral to these translations is not mentioned in the Flemish invitation letter. In addition, according to the discussions, the existence of these translations is not known among physicians either.

When discussing barriers, GPs and gynaecologists focused more on the organisation of healthcare services, while the stakeholders and CHWs highlighted more individual barriers specific for the population they work with. Since gynaecologists are hardly confronted with the underscreened women their input on perceived barriers was scarce and could possibly be more based on assumptions.

A wide range of barriers to screening were discussed by the participants, mostly similar to those described in other studies [23, 30]. The two main barriers on individual level that were mentioned in our study were a lack of knowledge, more specific health literacy, and having

other priorities or problems that require their attention. The lack of knowledge, in turn, leads to a low risk perception, another barrier frequently reported by the participants. For migrant women, foreign sex workers and women with a low health literacy the language barrier is a causative or contributing factor to their lack of knowledge. The stakeholders of migrant women did not perceive religion as a barrier. This is in contrast to earlier findings [31–33] and the perceptions of some of the healthcare providers in our study, though confirming a recent Finnish study [34]. The second main barrier, having other priorities, comes along with the more socio-economically disadvantaged status of the women in the subgroups: having financial issues, irregular status, housing problems,... These other priorities together with the fact that CCS is prevention and not an urgent matter, makes women postponing or ignoring it.

Prevention not being a priority is not only seen at the individual level, but also at the healthcare level. Medical doctors in Flanders are overburdened and have to prioritise as well. There is no time for a GP to bring up the topic of CCS, give information and offer the extra guidance vulnerable women need in their decision-making process. In addition, the healthcare system in Flanders lacks healthcare services that are merely focusing on prevention.

During the discussions it became clear that it is never one single barrier that prevents women from participating in CCS. On the contrary, it is a complex tangle of factors on different levels influencing each other. For example, a typical scenario for a woman with a migration background: her language barrier prevents her from understanding the information offered through the invitation letter resulting in a lack of knowledge on cervical cancer screening. In addition, she does not receive information from family or friends as it is not customary in her culture to get screened, nor to talk about cancer as they assume it might lead to getting cancer. Finally, due to her lack of knowledge she does not perceive herself 'at risk'. The causal loop diagram gives a clearer and visual overview of the complexity and the interrelationships between all the barriers (see Fig. 1).

The causal loop diagram enables exploration of the potential impacts of changing system elements on screening participation. It identifies multiple leverage points for improving population level impact of cervical cancer screening services. These leverage points include increasing the awareness around the subject of cervical cancer as a prerequisite for all services to succeed in significantly enhancing the screening coverage. To that end, decent structures that offer preventive healthcare measures and tools to support the decision-making process, tailored to these women's needs and capacities, need to be established to enable health professionals to

offer (information on) screening. For example, financial support for GPs to have a nurse in their practice whose focus is solely on preventive care, the development of shared decision-making tools with a specific focus on vulnerable populations that can support efficient service provision [35]. In addition, a better alignment between (the software of) digital medical files and screening registries could increase the efficiency in the daily practices. Remarkably, when asking for facilitators the GPs did not seek for solutions within themselves or their practices. Instead, they suggested action points for external parties or on different levels rather than engaging in self-reflection to consider personal changes. This, could be a result of the majority of them being overburdened.

Taken together, the causal loop diagram emphasises that the whole of the system must be taken into consideration when making investment decisions. Future research should further explain and refine the relationships depicted in this causal loop diagram. These relationships could serve as a foundation for the development of tools and strategies that effectively assist both healthcare providers and vulnerable populations in the process towards screening.

This study has some limitations. Firstly, recruiting participants and keeping their adherence for this study was challenging as the focus of healthcare professionals and the entire healthcare system at time of conduction was concentrated on the COVID-19 pandemic. Secondly, the COVID measures resulted in having to conduct the FGDs online causing a derogation of the sharing atmosphere and making it easier for the participants to hide and keep silent. On the other hand, the online setting made it possible to have these group conversations during the pandemic and to have more participants engaged in this study as they would not lose time commuting. Finally, to not overcharge the participants during these challenging times, we decided to not imply the member checking technique as this can be very time-consuming and demanding. Despite not conducting member checking, the repetition of the same items in the various interviews and FGDs (i.e., data saturation) enhances the reliability and validity of our results.

This study's key strength is that, to our best knowledge, it is the first to provide in-depth insights into the motivators and barriers for specific subgroups related to cervical cancer screening in Flanders (Belgium) according to different healthcare professionals' perspectives. In this way, our study is a valuable addition to the study of Piessens et al. [12] that explored strategies on healthcare system level to increase CCS participation, but mainly focused on the perspective of general practitioners. The added value of our study concerns not only the difference in perspectives but also the inclusion of stakeholders from a variety of groups within the population.

## Conclusion

The wide variety of barriers to screening identified confirms that the under- and never-screened women are a very heterogeneous group. It is impossible to define 'the' underscreened Flemish women. As a consequence, it is highly unlikely that there is such a thing as 'the' strategy to address underscreened women. Ultimately, policymakers need to develop different screening strategies tailored to a diversity of women to improve screening participation. More tailored screening intervention programmes and an improvement of healthcare professionals' resources for preventive care are also needed.

## Abbreviations

CCS	Cervical cancer screening
CvKO/CCD	Centrum voor Kankeropsporing - Centre for Cancer Detection
BCR	Belgian Cancer Registry
GP	General practitioner
FSW	Female sex worker
SUD	Substance use disorder
CAM	Complementary and alternative medicine
IDI	In-depth interview
FGD	Focus group discussion
CHW	Community health worker
WGC	Wijkgezondheidscentrum
NGO	Non-governmental organisation
HPV	Human papilloma virus

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-024-20166-9>.

Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

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## Authors' contributions

H.V. and I.K. were responsible for the conceptualization and the methodology of the study. J.D.V. performed the data collection and transcription of the interviews and E.D.P. of the focus group discussions. The formal data analysis and interpretation and the preparation of the figure were performed by E.D.P. and B.V. B.V. wrote the main manuscript. Supervision was carried out by H.V., I.K. and O.D. All authors reviewed and edited the manuscript and agreed on the published version.

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## Availability of data and materials

The data underlying this article cannot be shared publicly due to the privacy of individuals that participated in this study. The data will be shared on reasonable request to the corresponding author.

## Declarations

### Ethics approval and consent to participate

This study was approved by the the Ethics Committee of Ghent University Hospital (BC-06974, 24/4/2020). Informed consent was taken from all participants. Informed consent forms were sent to all participants via email. Participants had to return a signed version to show that they agreed to participate. Participation in the study was voluntary. All methods were carried out in accordance with relevant guidelines and regulations.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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