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Women's views on cervical cancer screening. A qualitative study of barriers to screening and HPV self-sampling acceptability

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1. Introduction

We conducted a qualitative study to describe women's views and experiences of cervical cancer screening in Switzerland, in order to offer a better understanding of the different obstacles they encounter in performing this preventive measure. We also assessed whether HPV self-sampling could offer an acceptable alternative to Pap smear testing. This introduction sets the background in which the study was designed and its results analysed.

1.1 Cervical cancer screening in Switzerland

In the world, cervical cancer is the second most frequent cancer among women, however eighty-five percent of cervical cancer deaths occur in low- and middle-income countries (WHO 2013). In Switzerland, each year, about 5000 women are detected with precursory signs of cervical cancer; 240 women are diagnosed with cervical cancer, half of them are aged less than 50. About 85 deaths are recorded per year, 80% of them occurring among women aged over 50 (Ligue suisse contre le cancer 2012). In Geneva, 100 new cases of cervical cancer were discovered between 2003-2008; this represents 20 to 30 new invasive cancer cases per year¹.

Secondary prevention based on cytological examination of cervical cells (Pap smear) aims at identifying abnormal cells among asymptomatic women (WHO 2007). Effective screening programmes can prevent most of cervical cancer (up to 80%) (WHO 2007). The rather low incidence of cervical cancer observed today in high-income countries is attributed to these programmes. In Europe, important differences in screening programmes exist across countries. In organized programmes, women in the target group are regularly invited to screening whereas in opportunistic programmes, screening is left to the initiative of women and doctors (Antilla et al. 2004). Organized programmes are considered to be more effective (Antilla et al. 2004).

In Switzerland, screening has been introduced at the end of the 1960s. As a result, the incidence of cervical cancer has decreased importantly, first among 55 to 69 years old women (Petignat et al. 2006). Since 1995, the number of cases has been decreasing in all age groups (Ligue suisse contre le cancer 2012). Screening is opportunistic in our country and no national prevention campaign exists. Official recommendations (Arbeitsgruppe 'Guideline Zervixabstrich' 2004) suggest that after two consecutive negative tests, a Pap smear should be performed every three years, among women aged 18 to 69 years. Screening is reimbursed by health insurance along these recommendations (OFSP)².

¹ Unpublished data from Geneva Cancer Registry, Massimo Usel, cited in Petignat et al. 2011 'Essai randomisé évaluant le dépistage du cancer du col utérin par auto-prélèvement HPV chez les femmes qui ne se rendent pas au dépistage'.

² <http://www.bag.admin.ch/themen/medizin/00682/00684/03853/index.html?lang=fr>, visited on March 29th 2013.

1.2 Underscreening versus overscreening

The United Kingdom National Screening Committee defines screening as: « a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition » (cited in Armstrong and Eborall 2012, p. 2).

As screening became more systematic during the 1970s, cervical cancer turned into a public health issue. During the 1980s, considered as the golden years of screening, professionals started to favor "over-diagnosis" (Junod 2005). "More is better" illustrated the conviction that any probability of developing cancer had to be prevented. However, increasing the number of exams produced more false results (false-positives and false-negatives) leading to rising criticisms. Within the broader debate about the potential harm associated to medical procedures (Moynihan et al. 2012, Welch 2011), the benefits and harm of screening are nowadays discussed (Petignat et al. 2012, Zwahlen et al. 2010). While some women benefit from early detection, cervical cancer screening can wrongly: reassure some (when screening produces a false negative result) and induce anxiety, unnecessary investigation and possibly treatment among others (when screening produces a false positive result). Such emphasis on the limits of the screening calls for a balanced and transparent information to patients. However, obtaining informed consent for screening might stand in contradiction with optimal uptake (Braun & Gavey 1999, Jepson et al. 2007, Armstrong & Murphy 2008).

In Switzerland, 79% of the women interviewed in the Swiss Health Survey in 2007 (OFS 2010, pp. 58-59) reported having ever been screened for cervical cancer; 45% had done it in the past 12 months. Rates were lower in the French-speaking part of the country where only 61% of women reported ever having a Pap smear test. Screening rates regularly increased until the age of 50 and then decreased. Women with lower education reported less often having had a Pap smear test than those with higher education. Screening was also less frequent among migrant women in comparison to the Swiss population (Gabadinho et al. 2007). These variations along age and socioeconomic indicators are reported in other countries (Waller et al. 2011, McKinnon et al. 2011). A comparison of 15 European countries showed that the socioeconomic gradient in screening participation is observed in countries with opportunistic programmes, but does not exist in those with organised screening programmes (Walsh et al. 2011).

These self-reported data indicate that some groups of the population are underscreened. At the same time, the actual number of tests performed in Switzerland exceeds those that would be expected based on official recommendations. Indeed the number of performed tests is almost twice higher (1 to 1.2 million tests/year) than expected (520'000 tests)³. This suggests that a fair amount of women are screened too often. Overscreening generates undue costs; a better use of resources would allow both a reduction of total costs and a more equal coverage of the female population (Petignat et al. 2006).

³ OFSP (2008) Recommandations de vaccinations contre les papillomavirus humains (HPV). Available on : <http://www.bag.admin.ch/themen/medizin/00682/00684/02535/index.html?lang=fr>. Visited on March 29th, 2013.

1.3 HPV self-sampling and vaccination

Cervical cancer is caused by an infection to HPV (human papillomavirus), which is mainly sexually transmitted. A high proportion of women are infected by HPV, but in most cases, these infections will resolve and have no consequences. When they are persistent, precancerous cells might develop. When left untreated, these cause cervical cancer (WHO 2013).

HPV tests were developed recently; while Pap smear identifies cell modifications, HPV tests assess the presence of HPV. It is currently being assessed in different contexts whether this test might provide an alternative to Pap smear test, in particular through HPV self-sampling that women can perform themselves at home, without the help of health professionals (Barbee et al. 2010, Piana et al. 2011). HPV self-sampling might offer a less intrusive procedure improving screening attendance, especially among women who are reluctant to attend the regular Pap smear procedure. Social science studies have started to examine the acceptability of HPV self-sampling in different contexts, emphasizing advantages and limits of this method.

As a primary prevention strategy, HPV vaccination has been introduced during the first decade of the 21st century in many countries. In Switzerland, vaccination programmes started in 2007. The Swiss authorities recommend the vaccination of girls between the ages of 11 and 14 years old, with a catch-up phase for those aged 15 to 19. The vaccination cost is covered by vaccination programmes set up by cantons; for women aged 15 to 26, costs of vaccination are also covered until 2017 (OFSP).

1.4 A social science study designed to complement the DEPIST study

The study presented here has been set up to complement an on-going clinical project funded by the Swiss cancer league entitled “Self-sampling for HPV in Women Who Do Not Undergo Routine Cervical Cancer Screening: A Randomized Trial” (KFS 02691-08-2010, Main applicant: Patrick Petignat), referred here as the ‘DEPIST study’. This trial aims at identifying the characteristics of the “unscreened population” in the cantons of Geneva and Jura and to assess the acceptability of self-sampling as an alternative to the Pap test. Women participating to the DEPIST study were systematically offered to participate to the social science study examining barriers to screening more in-depth.

1.5 The social sciences contribution to the study of screening

This project has been designed to provide an understanding of barriers to cervical cancer screening from women’s points of view. Its results are expected to contribute to cancer prevention and more specifically to provide relevant insights for the organisation of cervical cancer screening in Switzerland. It can be situated within a tradition of research, with a strong applied component, analysing the obstacles to cervical cancer screening in different contexts. These barriers typically include limited knowledge, shyness and embarrassment generated by the procedure, practical issues such as cost, and access to healthcare services. The existing research has often focused on migrant or minority women with the intention to

identify the beliefs that impede participation to cervical cancer prevention (Forss et al. 2001).

This project also aims at contributing to a sociology of screening, as currently developing among British social sciences scholars (Armstrong & Eborall 2012). Moving beyond the issue of attendance versus non-attendance and at the light of the changing relationships between patients and health professionals, this research is also interested in analysing women's experiences in regards to: the tensions associated with the provision of information on screening, the different ways individuals handle risk and prevention, the relationships with health care providers around screening. While health professionals consider screening as a routine, safe and non problematic procedure, social sciences studies have documented women's ambivalence in regards to screening (Howson 1999, Howson 2001a).

1.6 Our study

We conducted a qualitative study to document the views and experiences of women regarding cervical cancer screening, with the intention to assess the role of different obstacles among contrasted social groups. Fieldwork was conducted in Geneva in 2012. We adopted a focus groups methodology which facilitates access to women's perceptions of obstacles, through the comparison and confrontation of opinions and experiences in guided discussions. This format also offered the possibility to examine the broader context of cervical cancer screening, including relationships with gynaecologists as main providers of Pap tests in Switzerland.

The objectives of this study are the following:

- To describe lay views on cervical cancer, screening recommendations and the screening procedure itself;
- To assess the role of different barriers to cervical cancer screening;
- To evaluate the acceptability of HPV self-screening as an alternative mode of detecting cervical cancer.

By contrast with a study based on a questionnaire which would provide a quantitative distribution of obstacles as predetermined by the researchers, a qualitative methodology offers an opportunity to analyse the difficulties and ambivalence associated with screening in the terms used by interviewees, with a focus on their preoccupations.

1.7 Structure of the report

This report has been written as a preliminary step to the publication of different articles in scientific journals. After a chapter dedicated to the presentation of the research method, results are presented in four thematic chapters. Each one of these starts with a brief review of the literature and then presents the main results of the focus groups. Chapter 3 is dedicated to women's knowledge about cervical cancer, their sources of information and demands in that regards. Chapter 4 describes the main barriers to cervical cancer screening that have been reported in the focus groups, including structural, social, and emotional barriers as well as representations of risks and prevention that are not conducive to

preventive behaviours. Chapter 5 presents accounts on relationships established with gynaecologist, an element playing a central role in women's motivation to get regularly screened or not. Finally Chapter 6 presents the advantages and disadvantages of the HPV self-sampling method as they have been discussed by participants. The conclusions of the report offer a synthesis of the main results, address the limits of the study and offer some recommendations on ways to improve screening attendance.

2. Methods

Between May and November 2012, twenty-four focus groups have been conducted, with a total of 125 participants. This chapter provides a rationale for the selection of this methodology, describes the organization and conduct of the focus groups, presents the characteristics of the respondents and finally provides indications on the data analysis procedure.

2.1 The focus group methodology

We adopted a focus group methodology to assess women's views and experiences of cervical cancer screening, with a special interest for the obstacles they encounter in performing cervical cancer screening. A focus group consists in a 'focused discussion' between a researcher and a small group of interviewees (Barbour 2008, Duchesne & Haegel 2005, Krueger & Casey 2000, Morgan 1998). The moderation of the focus group by the researcher aims at encouraging a spontaneous but guided conversation while ensuring a balanced participation of the different participants. It is usually recommended to include between 5 to 8 participants per focus group, this number ensuring the presence of a range of opinions, while offering a fair chance to interviewees to participate in the discussion. The duration of the focus group should remain limited to a maximum of 120 minutes.

This qualitative method allows collecting information from a large number of people in a rather limited time period. Participants' interactions during the focus group facilitate the comparison of experiences and emphasize shared meanings, but also ambivalence and contradiction among them. This method is considered particularly adapted to address feminine issues, since it limits the power relationship between the interviewer and the interviewee, which is typically observed in situations of face-to-face interviews (Barbour 2007, Duchesne & Haegel 2005). Its disadvantages include limitations in the possibility to discuss topics in depth, due to time constraints but also to the sensitivity of some issues that people might prefer not to address in front of an audience.

Some basic principles, considered central in the use of this method (Morgan 1998), have been applied in our research:

- Elaborate an interview guide with simple and precise questions that match the research questions ;
- Organize homogeneous groups of participants, to limit power imbalance during the discussion ;
- Avoid embarrassing situations for participants.

The focus group methodology has been used in several recent studies on obstacles to cervical cancer screening (Logan & Mcilpatrick 2011, Markovic et al. 2005, van Til et al. 2003, Waller et al. 2011) and HPV self-sampling acceptability (Howard et al. 2009, Richman et al. 2011, Szarewski et al. 2011).

2.2 Preparation of fieldwork

Recruitment of participants

We had initially planned to recruit women aged between 25 and 65, along criteria related to their screening status and their social characteristics:

- The screening status: with a distinction between women regularly screened, i.e. at least every 3 years and those who had not been screened for more than 3 years, along the distinction used in the DEPIST study;
- The use of the HPV self-sampling method : with a distinction, among participants recruited from the DEPIST study, between women having undergone a standard Pap test and those having performed HPV self-sampling;
- Age : women aged below 40 versus women aged 40 and over;
- Origin : Swiss participants versus migrant women;
- Social position: low, middle and high.

The definition of these criteria responded to two distinct preoccupations: (1) to ensure that recruited women would represent a range of screening and social situations, (2) to facilitate the organization of homogeneous focus groups, a criteria considered important in the dynamic of the discussion.

Non screened participants have been recruited through the DEPIST study. To diversify the selection other screened and non screened women have been recruited through different channels. Posters and flyers (see document in Appendix) have been posted and distributed in feminine associations, local community centers (*maisons de quartier*), education institutions (University, HES), community associations and churches. As often as possible, resource persons have been solicited to recruit women in specific settings. Personal and professional contacts have also been used for the recruitment of participants. In addition, a 'snow-ball' strategy has been used to diversify the recruitment channels. Concretely, women having participated to a focus group were asked to encourage women they know to participate and to contact the research team.

Women having indicated their interest in participating to the study were contacted by telephone by one of the researcher. This first contact provided the opportunity to describe the study objectives and the research procedure to the interested woman. This discussion often lasted up to 10 minutes in order to provide a maximum of information to potential participants and to explain they would have the opportunity to share their opinions and experiences during the focus group while not being pressurized to talk about embarrassing and intimate issues if they did not want to. The first telephone contact also allowed obtaining information on the potential participant which helped in the organization of homogeneous groups.

Once a woman accepted to participate, she was invited to a focus group scheduled along her announced availability. Drop-outs represent a well-known downside of the focus group methodology. In order to limit its impact, a larger number than the expected number of participants was recruited for each focus group.

Interview guide

The interview guide was elaborated around 5 main topics : (1) information on screening; (2) emotions associated with screening; (3) the procedure used to perform a Pap test; (4) the practical difficulties encountered, including access, cost, past experiences, interactions with gynaecologists ; (5) the acceptability of self-sampling. The interview guide (see Appendix) combines open-ended questions addressing opinions about cervical cancer screening and experiences related to the procedure. At the end of each focus group, the self-sampling method was presented to the group with the aid of a kit, and its acceptability was discussed. Some focus groups included participants having used it and who could report on their personal experience with it; in other groups, this was not the case and the discussion remained more general. A brief questionnaire with social characteristics was filled by each participant at the end of the focus group (see Appendix).

2.3 Ethics commission approval

Before starting fieldwork, the protocol of the study has been submitted to the central commission for ethics of the Geneva Hospitals. The recruitment posters, information document, consent form and interview guide have been approved in early May 2012. At a later stage of the study, we decided to recruit younger women and asked for the authorization to lower the age limit to age 20, an authorization granted in October 2012.

2.4 Conduct of the focus groups

Characteristics of the focus groups

Most of the focus groups (18 out of 24) took place in a building associated with the University of Geneva Faculty of social and economic sciences, one was organized in the premises of an association, three in those of a church, one in charitable organisation and one in a private home. The location did not have a noticeable impact on the focus groups dynamic. We considered important to conduct them in a non medical setting, in order to allow women to talk freely about their experiences and the barriers they had encountered in relationships with cervical cancer screening.

All discussions were tape-recorded, with the authorization of participants. The focus groups lasted between 90 and 120 minutes on average. Seventeen focus groups were conducted in French, five in Spanish and 2 in Portuguese. Most discussions (all those in French and three in Spanish) have been moderated by the research assistant hired in the project. A Master student in sociology moderated the two focus groups in Portuguese⁴, and a Bachelor student conducted two focus groups in Spanish⁵. The information document and consent form had been translated for these groups. The focus groups purposively included only

⁴ Isabela Vieira Bertho participated to the project as an intern from September to December 2012. In the continuation of this internship, she is conducting fieldwork on cervical cancer attendance in Brazil that will be used for her Master thesis in sociology.

⁵ Juliette Fioretta conducted these focus groups for her Bachelor thesis in sociology. These covered a wider range of issues but also provided important data on cervical cancer. She has kindly accepted that we include them in the analyses presented in this report.

women (participants and researchers), as a strategy to encourage women to share their experiences and views.

The focus groups included on average 5 participants. In two cases only two participants showed up (minimum) and in another case (organized in a church setting) eleven women participated (maximum). Across all groups, 36 women who had committed to participate did not show up for the focus group, 17 of them did not provide any explanation. In three quarters of the focus groups, participants did not know each other previously; in 6 focus groups, organized by resource persons in specific settings (associations, church) the participants knew each other.

Empirical constraints – including available time and resources, difficulties in recruitment, women’s limited availability, last minute drop-outs – have affected the possibility to systematically apply in the organization of the groups the recruitment criteria described above. Consequently, focus groups have more than expected mixed participants with contrasting characteristics. However, despite this heterogeneity, a minimum coherence could be maintained and in each focus group, participants shared at least one common characteristic. At the same time, their heterogeneity on other criteria enhanced the comparison of diverse experiences and preferences, across screened and non screened women or across different age categories.

In regards to the screening status of participants, eight focus groups included only regularly screened women; eight non screened women only⁶ and eight combined screened and non screened women. Number of participants per group and common characteristics of the participants, when available, are summarized in Table 1.

Focus groups process

At the beginning of each focus group, the information document and consent form were distributed to participants. The objectives of the study were reminded to them and guarantee of confidentiality was reiterated.

Following the interview guide, the moderator led the discussion in a rather directive manner, with participants being directed to the central issues instead of getting distracted in side-discussions. However, according to a qualitative methodological approach, the extension towards topics spontaneously brought up by participants was not discouraged as long as it related to cervical cancer screening. Participants were also encouraged to react to others’ opinions and experiences. Particular attention was paid to avoiding embarrassing situations and when they occurred, the discussion was moved to another topic by the moderator. Inevitably, some leaders – less inhibited women, those knowing more about cervical cancer – talked more easily and kept others from expressing their views, despite the efforts of the moderator to balance the discussion.

⁶ ‘non screened’ refers to women who have not been screened in the last three years. For women recruited through the DEPIST study, this refers to their status before their participation to the study.

Table 1: Characteristics of the focus groups

Focus group identification	Number of participants	Common characteristic, when available
Women screened regularly		
FG3	4	Young qualified women
FG4	4	Swiss women only
FG8	7	Qualified migrant women
FG9	6	
FG12	7	
FG16	4	
FG21	3	Brazilian migrants
FG23	5	Latin America migrants recently arrived from Spain
Women not screened regularly		
FG2	4	
FG5	2	
FG6	4	Latin America migrants
FG10	5	
FG11	9	
FG13	4	
FG15	2	Swiss women only
FG22	11	Latin America migrants
Mixed screening statuses		
FG1	4	
FG7	5	Young women
FG14	4	
FG17	6	
FG18	6	
FG19	5	Brazilian migrants
FG20	7	Latin America migrants
FG24	7	Nicarguan migrants

Over the course of the focus groups, some women reported intimate and sometimes distressing experiences. More generally, extensive sharing of information and experience occurred over the discussion dynamics. At the end of focus groups, participants often expressed their appreciation of having been able to exchange with other women on intimate issues. Such appreciation about the participation to a research on cervical cancer has been reported in other studies (Forss et al. 2001, Markovic et al. 2005), some participants seeing it as a way to gain information and then sharing it with other women. The capacity of focus groups to generate empowerment and reflexivity among respondents has been emphasized (Barbour 2008).

Despite efforts to clarify from the start the status of this research and the non medical affiliation of the moderators, participating women often thought that they could obtain information during the focus group. This suggests a potential bias in the participants: those who wanted information might have been keener to participate to a focus group than those who did not have this urge; this limitation is further discussed in the conclusions of the report. When faced with these demands, the researcher moderating the discussion systematically referred participants to specialized websites and health professionals.

As a standard practice, refreshments were proposed to participants during the focus groups, as a way to facilitate exchanges among participants. In acknowledgement of her participation and engagement in the study, each participant received a sheet of post stamps (value: 18.50 CHF) at the end of the focus group.

2.4 Characteristics of the participants

One hundred twenty-five women aged between 24 and 67 participated to the focus groups. 57 of them were regularly tested for cervical cancer, most of them every year, some every 2 years and a few every 3 years; 68 had not been screened over the past 3 years. Most of the non screened women (40 out of 68) have been recruited through the DEPIST study, 20 of them had used the HPV self-sampling and 20 had had a standard Pap test. The rest of the participants (82 women) contacted themselves the research team, among them 54 were regularly screened and 28 non screened. The participants characteristics are summarized in Table 2.

Table 2 : Characteristics of the participants

	Screened	Non screened	Total
Recruitment			
Non DEPIST	54	28	82
DEPIST	3 ⁷	40	43
Age			
Less than 40	29	18	47
40 and over	28	50	78
Origin⁸			
Swiss	21	10	31
Migrants	36	58	94
Education			
Professional education*	23	48	71
Higher education**	34	20	54
Children			
Yes	27	50	77
No	30	18	48
Total	57	68	125

*professional education includes compulsory schooling, apprenticeship, maturity, professional schools

**university diplomas

Confirming results from the Swiss Health Survey (OFS 2010, Gabadinho et al. 2007), non screened participants were older, less educated and more frequently migrant. Migrant women are overrepresented in the sample. However they had mixed backgrounds and some were highly educated. Slightly less than a half (58) of the participants originated from Europe (including Switzerland) and the other half from further (Latin America 54 participants, Africa 12 participants). We attempted to organize focus groups with Muslim women, Asian or

⁷ Three women who participated to the DEPIST study turned out to be regularly screened.

⁸ This distinction between Swiss and migrants is not straightforward, some women can have several nationalities, some have migrated at different stages in their life. Here, we separate women in these two categories along their own identification.

African migrants only, however despite repeated contacts with some associations, our efforts were not successful. To assess the social position, we use a binary variable of education, differentiating women with a professional education from those who have attended university⁹.

2.5 Data analysis

The discussions were fully transcribed and, for those conducted in Spanish and Portuguese, translated to French. The transcripts were then systematically coded, using the Atlas.ti CAQDAS. Coding aims at conducting a systematic analysis of the interviews (Miles & Huberman 1994). Based on a list of categories or codes, each focus group transcript is coded, i.e. segments of the discussion referring to a specific category are accordingly selected and labeled. Most categories were defined before the coding process started, along the main research questions. However further codes also emerged over the coding process itself.

Following a first list of general categories, such as for example 'screening', 'information', 'cervical cancer', 'hpv', more specific categories were then defined such as 'vaccination', 'sexuality', 'risk factors'. A segment of a discussion could be coded several times when it referred to several codes (co-occurrences). At first, rather large segments of the interviews were coded along more general categories, this could include exchanges among different participants. At a later stage, these long segments were divided into shorter passages along more specific codes.

The Atlas.ti software helps the coding process by ensuring the application of a systematic approach. However the definition of codes and the coding itself are conducted by researchers. The coding process allows extracting all the segments of discussion referring to one code across interviews; the systematic comparison of extracts emphasizes the similarities and differences across the focus groups. In the following chapters, results are systematically illustrated with verbatim quotes from the focus groups transcripts. Qualitative analysis aims at describing the variety of opinions among respondents, it is not suited to describe their relative importance. In the results presentation, we account for positions that were shared by several women across focus groups. Therefore even when a limited number of quotes are used as evidence, the presented views are not anecdotal, i.e. limited to one singular respondent.

Following this process of thematic coding, the results chapters presented below provide an analysis of the main topics relevant to describe the views and experiences with cervical screening of the women we interviewed. After each verbatim quote, we provide information on the participant, including her age category (< 40 years old versus ≥ 40 years old), origin, level of education, screening status; in the chapter dedicated to self-sampling (Chapter 6), we specify when the quoted woman has tested the self-sampling kit. We also indicate to which focus group the quoted interviewees participated (FG1 to FG24). Pseudonyms have been attributed to all the participants.

⁹ Since participants belong to different generations and come from different national contexts, the comparability of social position indicators is difficult to establish. This explains why we decided to use this binary variable related to education.

3. Knowledge about cervical cancer screening

Information is expected to improve screening attendance. Furthermore, the provision of information is considered central in changing relationships between health care providers and patients. The latter are expected to be fully informed in order to be able to make autonomous decisions in regards to their health. This includes decisions around screening, especially since its respective benefit and harms are nowadays being discussed (Petignat et al. 2012, Zwahlen et al. 2010). In an opportunistic cervical cancer screening system like it exists in Switzerland, it is particularly crucial to assess what women know about cervical cancer screening. This chapter is organized along the following questions: what did women who participated to the focus groups know about their cervical cancer screening status? What were their sources of information on cervical cancer? What were their demands in regards to information in that domain?

3.1 Literature review

Social science studies conducted in different contexts and using different methodologies (quantitative and qualitative methods) have assessed women's knowledge about cervical cancer and its prevention. This literature recurrently emphasizes gaps in women's information on cervical cancer and its screening. Empirical studies conducted over the last 30 years keep observing that they confirm previous research showing that women have only vague and partial knowledge in regards to the prevention of cervical cancer (Forss et al. 2001, Howson 2001a, Lee Mortesen et al. 2010).

While a large number of studies have been dedicated to minority women, the gaps in knowledge are observed in all the studies, including those conducted with samples of the general population. For example, a study conducted in Sweden emphasized that information limitations were important even among women compliant with screening and who considered themselves well informed. According to these quantitative results, one woman out of three did not know which cancer was screened and half of them were not aware of the risk factors for cervical cancer (Ideström et al. 2003). A British quantitative study assessing women's understandings reported that their knowledge of risk factors was variable and that they overestimated both the cervical cancer risk and the effectiveness of screening in terms of mortality reduction (Philips et al. 2005).

Qualitative studies further confirmed these gaps in knowledge (Howson 1998, 1999, 2001a, Jepson et al. 2007, Markovic et al. 2005, van Til et al. 2003). Women were often only vaguely aware of the purpose, the procedure and implications of screening, for example being uncertain about what was being 'checked out' during the exam (Howson 2001a, p. 171). Such poor knowledge was observed in different settings and across women of different sociodemographic backgrounds (Markovic et al. 2005).

Women interviewed in qualitative studies stated they wanted more information (Jespon et al. 2007, Markovic et al. 2005, van Til 2003). For example, they wanted to know more on cervical cancer itself, its incidence and symptoms, and on the benefits of screening (Jepson et al. 2007). This study comparing information related to breast cancer, prostate and cervical

cancer observed a general lack of knowledge about those diseases and their prevention, but emphasized that information was particularly missing in regards to cervical cancer screening.

Studies also showed that women usually have only limited knowledge of risk factors. One study reported that many women thought Pap smears were performed on women with reproductive problems only (Markovic et al. 2005), the association between cervical cancer and sexual activity was not well known (Braun & Gavey 1999). In several studies women thought that cervical cancer was hereditary (Blomberg et al. 2009, Fang et al. 2011, Philips et al. 2005) or related to their health conditions, psychosocial factors or lifestyles (Fang et al. 2011, Logan & Mcilpatrick 2011).

While these women were often in demand for further information, they felt that what was communicated by health professionals was inadequate, unclear or even inconsistent (Howson 1999, Jepson 2007, Martinez 2005, van Til et al. 2003). Some reported that their demands for further information were not necessarily met by health professionals who tended to minimize the meanings of abnormal results (Howson 2001a). An ethnographic study conducted in Venezuela showed that doctors justified providing limited information to their patients receiving abnormal results on the ground that they would not be able to absorb this information (Martinez 2005). Referring to the cultural background and low social status of patients, doctors considered that women provided with information would react irrationally, either by getting depressed and/or by refusing treatment. Similar assumptions about patients' limited ability to handle medical information have been reported in an ethnographic study conducted in a cancer ward in France (Fainzang 2006).

Qualitative studies on cervical cancer emphasized that women frequently felt anxiety in relationship with the prevention of cervical cancer: 'many participants in screening experience a sense of vulnerability associated with the process of screening and further investigation' (Howson 1998, p. 173). Attending screening did not necessarily alleviate uncertainty about cancer (Howson 1999, p. 209). Furthermore, these feelings of anxiety were often associated with the limited available knowledge (Lee Mortensten et al. 2010, Jepson et al. 2007). Different authors consider that the provision of information is likely to help women cope with the screening process and to reduce their anxiety (Jepson et al. 2007, Philips et al. 2005).

The provision of information on cervical cancer screening is however both complex and sensitive. Achieving individual autonomy and high screening attendance are potentially contradictory (Raffle 2001). On one hand, public health professionals worry that disclosing full information on risk factors associated with sexual activity might reduce screening attendance and, due to sexual behaviour risk factor, generate potential stigma towards women diagnosed with cervical cancer (Braun & Gavey 1999). On the other hand, promoting participation without providing full information is considered unethical (Armstrong & Murphy 2008, Jepson et al. 2007, Howson 2001a, Philips et al. 2005), especially since not fully informed women may have unrealistic expectations regarding screening, i.e. be falsely reassured by normal results (Philips et al. 2005).

Empirical studies concluded that patients did not consider they had given informed consent before cervical cancer screening (Jepson et al. 2007) or breast cancer screening (Osterlie et al. 2008). Some patients indeed did not consider screening being a choice, some women

reported feeling fairly pressurized to accept cervical cancer screening (Jepson et al. 2007). The study on breast cancer screening in Norway emphasized the fact that women felt information was not so crucial since they trusted their nonprofit health care system (organized screening) (Osterlie et al. 2008).

3.2 Results

Knowledge about cervical cancer and its screening

Across all focus groups, a striking and recurrent result was the limited knowledge women had on their own status in regard to cervical cancer screening. Indeed, while being regularly screened or not was a criteria for recruiting participants and organizing focus groups, we discovered during the interviews that many women were uncertain about their own status. This was also the case among women regularly attending a gynaecologist. Their lack of knowledge was related to different aspects, including : (1) whether they had actually been screened for cervical cancer, (2) what the procedure consisted of, (3) what did the results mean. The research format may have facilitated the emergence of their numerous reactions and questions, since participants realized during the focus groups that other women were often as little informed as they were themselves. In regard with risk factors, they were aware of the role of sexual behaviours in the risk of developing cervical cancer, but they also mentioned other explanations.

Does going to the doctor regularly mean I am screened for cervical cancer?

Many women reported that they did not know whether they were screened for cervical cancer, even though they were attending a gynaecologist:

"Just one question, when we go the gynaecologist: does she do it automatically or not ?" (Cassie, < 40 years old, Swiss, professional education, not screened, FG15).

"As I was telling you, as for myself during 30 years I didn't know that I was being screened for cervical cancer. I thought that something was being screened but I didn't know what" (Amélie, ≥ 40 years old, Swiss, higher education, not screened, FG2).

"I go to the gynaecologist once a year but I don't know exactly what he tests then" (Alison, < 40 years old, Swiss, higher education, screened, FG16).

"I have no clue how it works. But is a smear done in general when we go to the gynaecologist ?" (Christine, < 40 years old, French, higher education, screened, FG7).

Several women reported how in prevision of their participation to the focus group, they had called their gynaecologist office to ask for a Pap smear and were surprised when told that it had been done and that everything was fine (ex: Miriame, FG12).

Over the discussions taking place during the focus groups, many discovered that they must be tested since the procedure is performed routinely, without them being aware of it. This led Régine to state that it was performed without their explicit consent: « *Well, they've done it without my consent, I was a bit 'wouah'* » (Régine, ≥ 40 years old, Cameroonian, professional education, not screened, FG13).

Even among women who knew that screening was performed, doubts and questions were present regarding the meaning of the procedure:

"I've always asked to get the exam done without really knowing what's its use in fact. Then I just do it because I know one has to do a test, but I don't really know... what for..." (Maurane, < 40 years old, Swiss, higher education, screened, FG12).

Several commented on the fact that the doctor does not explain what is happening during the standard visit, as reported in their comments: *'I was not told', 'she does not explain', they don't say anything'*. This left them with 'not knowing' what is going on.

"I have no clue if I have been screened or not, in any case I was not told" (Elena, < 40 years old, Portuguese, higher education, not screened, FG18).

"She [the doctor] does not explain either ... really what it's for" (Maurane, < 40 years old, Swiss, higher education, screened, FG12).

"Maybe they do it to you and since everything is fine, they don't say anything, I don't know" (Biancha, < 40 years old, Polish, higher education, not screened, FG10).

One woman who knew screening was taking place during the visit stated that she had not gathered that information from her doctor:

"I'm not being told 'I test for cervical cancer', I'm being told 'I'm making sure everything is fine' (...). When he does as smear, then a smear of the cervix, I know it, maybe other women don't know, the gynaecologist doesn't pass on the information, but one knows that he's taking cells from the cervix to check that they're not... that they're ok, well normal as they say" (Mia, < 40 years old, Swiss, professional education, screened, FG4).

Carla's words are very illustrative of the ambiguity of the situation:

"Cervical cancer, I've not had time yet. I often go to the gynaecologist, they never told me to have the test, they often do the swab. I've never been told, maybe they've done it without telling me. They often do the swab ..." (Carla, ≥ 40 years old, Cameroonian, professional education, not screened, FG2).

Over the discussions, some women blamed themselves for their lack of knowledge, considering that they had not looked for the information properly, such as Cali:

"If you say it's part of the control, well of the screening that we do every year, well typically I've not informed myself, but I didn't know it (...) but maybe I've not looked further what was being checked with that" (Cali, < 40 years old, Swiss, higher education, screened, FG18).

The reactions that emerged during the focus groups reveal a general lack of awareness among women, of different ages and from different backgrounds, about the screening procedure. Even those regularly attending a gynaecologist were often not aware this was related to cervical cancer screening. Their accounts confirm the observation of Markovic et

al. (2005) that screening is performed during the gynaecological check-up without the provision of adequate information. It is likely that gynaecologists take the procedure some much for granted that they provide limited information about it. For them, screening is a routine they perform regularly without feeling the need to talk about it. Furthermore, they might prefer to avoid being too specific to limit worry among their patients. In a study related to prenatal screening, some gynaecologists we interviewed reported providing full information only when screening results were problematic, in order to limit undue anxiety (Burton-Jeangros et al. 2013).

What does the procedure consist of?

The procedure associated with cervical cancer screening remained vague for many of the women we interviewed. They had heard about it, but were not sure what it consisted of.

"I knew it was a screening for... let's say a test to see if there's something, but something that was... it was fairly vague in my head... what it was " (Ana, < 40 years old, Swiss, higher education, screened, FG12).

"We don't know what's happening during the smear" (Eline, < 40 years old, Swiss, higher education, not screened, FG7).

Some observed that the actual procedure is not visible, it can be performed by the doctor without them being aware of what is happening (by opposition to a breast examination or a mammogram for example).

"They do the swab, but we... sometimes we don't realize since we don't know, we are not aware, it's been done automatically" (Cloé, ≥ 40 years old, Portuguese, professional education, not screened, FG10).

"I just went to the gynaecologist, but I don't know whether he did the screening (laugh), I don't know. He's done a mammography and everything, but" (Dominique, < 40 years old, Spanish, higher education, screened, FG17).

On top of not knowing what is being done during the pelvic exam, Elena emphasized that it does not take much time:

"I went to the gynaecologist, I've done tests, I don't know what she has tested ! For me, it's a mystery! it doesn't take long the things ! I don't talk long with her, so I don't know anything" (Elena, < 40 years old, Portuguese, higher education, not screened, FG18).

Some believed screening was performed only when the doctor had identified a problem:

"I thought that screening was done only if the gynaecologist had found something wrong. But honestly I don't know if it's something that's done every time we go" (Valentine, ≥ 40 years old, Swiss, professional education, screened, FG16)

While the screening procedure is a priori part of the visit to the gynaecologist, their statements emphasized how the procedure was very vague for women. In the absence of an

explicit description of the test, some participants had difficulties to associate their visits to the gynaecologists with cervical cancer screening.

What do the results mean?

Participants to the focus groups also discussed the results of screening. Irina and Ema stated that screening aims at *,making sure everything is fine'*, but that formulation was not necessarily meaningful:

"As they say 'everything' is fine, but I don't know what it means exactly, well if 'everything' includes cervical cancer or not" (Irina, < 40 years old, Swiss, higher education, screened, FG12).

"It's to check if everything is fine, or not, the what exactly?" (Ema, < 40 years old, Brazilian, professional education, not screened, FG7).

Difficulties to grasp the procedure and its meaning also stem from the medical routine associated with informing patients about the results. Typically, the doctor performs the test and will get results a few days later from the laboratory. If the results are normal, the woman is not informed; if they are abnormal, then the woman will be contacted. A few women who had been in that case reported being told that they would need to be *,controlled'*, but without necessarily obtaining clear information on the results and their implications in terms of treatment. The procedure as it is set means that in most cases, women never get results themselves; they have to assume that not hearing back from the doctor after the visit means the screening is normal. This procedure was talked about in terms of *,no news is good news'*.

"And since everthing seemed ok, she did not provide any more results" (Maurane, < 40 years old, Swiss, higher education, screened, FG12).

"As they say ,no news is good news', and if you get news, it means you have to talk about it" (Mia, < 40 years old, Swiss, professional education, screened, FG4).

"The last time I went for a check-up, I was with a gynaecologist... who was... rather stressed, I could see she had lots of work, that she was overloaded... and then she told me 'Madam, no news is good news' I never had any news" (Heidi, ≥ 40 years old, Peruvian, higher education, not screened, FG11).

Several women said they did not like this procedure, as stated for example by Aïcha:

"That's also something: 'no news is good news', well wait, I don't find it cool" (Aïcha, ≥ 40 years old, Hungarian, higher education, screened, FG12).

The procedure related to disclosing results probably contributes to the low visibility of the whole procedure associated with cervical cancer screening. In the context of an opportunistic system, many women go routinely to the gynaecologist. However, if this routine is established, women are still often not well informed about the rationale for their annual check-up (see Chapter 5). Indeed, several thought that cervical cancer screening would require another visit, something to be asked specifically from the doctor. They also

often lacked a terminology to talk about screening. During the focus groups, they talked about ‚it‘ (,ça‘), the ‚smear‘ (frottis) or the ‚swab‘ (prélèvement), or showed their pelvic region to refer to the exam. Such imprecise knowledge on the screening is likely to contribute to the irregular attendance of some women, who do not seem aware of the purpose of a gynaecological visit. This absence of clear information probably reflects the relatively low visibility of cervical cancer screening in Switzerland in general.

Knowledge related to cervical cancer risk factors

When participants were asked what factors could trigger the disease, the sexual risk was the most often quoted, especially for women having multiple sexual partners and unprotected sexual relationships.

"I think people who have had venereal diseases, women who've had relationships with many men, they catch the disease and have so many infections that they have more probabilities to get get the disease" (Florence, ≥ 40 years old, Bolivian, higher education, not screened, FG6).

"If one has several partners. That's it, if one doesn't protect herself" (Cloé, ≥ 40 years old, Portuguese, professional education, not screened, FG10).

These statements sometimes included value judgements:

"In the case of my friend, it was really the immoral sexual life, it's been confirmed by doctors " (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

"For me, it's the people who always go to night clubs, who have 36'000 partners, who change all the time, or in the African countries" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

But other women considered that the sexual risk was relative.

"I think there is more than one factor, but I don't know... I think that if one has only one partner or several partners, it's not 100% sure... One can have only one partner over her lifetime and still get it" (Gertrude, ≥ 40 years old, Colombian, higher education, screened, FG8).

"Since the papillomavirus it's something that you get with a sexual relation, then people who have non protected sexual relations with several partners may have more chances to get be exposed... That's for sure. Now to know what percentage of cervical cancer start with a papillomavirus... to know whether it's not by chance... " (Mia, < 40 years old, Swiss, professional education, screened, FG4) who had a HPV positive result.

Rarely the allusion to prostitutes as a risk group came out during the focus groups. They seldom mentioned environmental factors such as pollution, quality of food or stressful lifestyle as risk factors. Some said that smoking or a poor hygiene could have an impact. A weak immune system was quoted, especially by women who have/had cancer and by those working with HIV patients. The hereditary factor was cited, for cancer in general but also in relationship with cervical cancer:

"Some [cancers] are hereditary because the doctor always asks whether the mother or a parent has had that disease" (Jane, ≥ 40 years old, Bolivian, professional education, not screened, FG6).

"Genetics I think, no? Genetic predisposition also... because there are people who did not have a lot of partners and who still have that" (Erica, ≥ 40 years old, Tunisian, professional education, not screened, FG13).

But the idea of genetic predisposition conflicts with the vaccination of teenagers against HPV, as stated by Maeva:

"Then if it's genetic then why do we... do we vaccinate?" (Maeva, ≥ 40 years old, Lebanese, higher education, screened, FG8).

These findings emphasize that among participants there was a dominant vision of a sexual risk associated to this cancer. However, reference to hereditary factors, observed in other studies on cervical cancer (Blomberg et al. 2009, Fang et al. 2011, Philips et al. 2005), were also present.

Sources of information on cervical cancer screening

During the focus groups, there was a strong emphasis on the perceived deficit in information on cervical cancer, in comparison to breast cancer. When prompted about their sources of information on cervical cancer, many mentioned knowing somebody affected by cancer or HPV. Next to this personal proximity with the disease, other answers mostly focused on the limits of general information on cervical cancer.

Professional and media information

Participants to the focus groups often commented on the fact that information on cervical cancer was limited in their encounters with their doctor:

"As for myself, very little, almost nothing, maybe I should keep myself informed, but in any case my gynaecologist never talked about it and I think that one hears much less about it than about breast cancer " (Alison, < 40 years old, Swiss, higher education, screened, FG16).

"Well, I was going really to get the pill and then I never heard the words cancer, nor uterus, well because I think I would have remembered" (Eline, < 40 years old, Swiss, higher education, not screened, FG7).

"I don't think the doctors communicate well on this. It's part of the package, it should be done, one does it, like many other things in fact and we don't know why we do it at the end. We know it's better to do it, but without questioning it more than that" (Christine, < 40 years old, French, higher education, screened, FG7).

Christine's comment could be interpreted as an implicit critic of the absence of informed consent, or at least the absence of full information on a series of medical procedures performed routinely by doctors.

Participants to the focus groups thought information on cervical cancer was more generally rare in the public environment, in terms of public health campaigns or in the media. Here the comparison with breast cancer was frequent, with an emphasis on the material often easily available in that case:

"I think there is a lack of information in regard to cervical cancer. I have the impression that there is still very little on that topic" (Alison, < 40 years old, Swiss, higher education, screened, FG16).

"In the mailbox, one finds for example breast cancer screening material, we are being warned. I receive this regularly" (Erica, ≥ 40 years old, Tunisian, professional education, not screened, FG13).

"Women's magazines do not talk much about cervical cancer. 'Cervical cancer at 30' is talked about, but it doesn't say what it's like, what are the treatments. We don't know anything. (...). Breast cancer is being talked about, tumor, but cervical cancer it's not talked at all the same" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

These statements about the limited access to cervical cancer information confirm the participants' experiences with gynaecological visits. While many know they should be (or think they should be) screened for cervical cancer, they consider that they do not have enough information about it.

Comparisons between countries

Some participants who had migrated to Switzerland commented on the fact that in their home country more information on cervical cancer was available, including regular public health campaigns. This was particularly the case for women originating from Latin America (Peru, Colombia, Bolivia, Brazil, Mexico). They talked about the presence of information in the media and also about the existence of free screening sessions.

"In latin America, there are campaigns. I'm not talking about one year ago, but about 12 years ago. Campaigns make people aware" (Carole, ≥ 40 years old, Bolivian, professional education, not screened, FG22).

"In our country, there are a lot of information. There are also times when they do it for free" (Féiëlle, ≥ 40 years old, Bolivian, professional education, not screened, FG22).

"And in Brazil too, it's good, there are campaigns on tv, I think it helps a lot. Then I think we're well informed" (Gladys, ≥ 40 years old, Brazilian, professional education, screened, FG21).

Several felt they knew more about cervical cancer than the Swiss women they were talking with, some reported having a vocabulary related to it that was not present here.

"In Switzerland, I heard less about it in the beginning, but now they are starting to wake up here. The other day, I was talking with a girlfriend, aged 35-40, and I was telling her that I'm going to do the Papanicolau test without thinking since in Latin

America, one says Papanicolau test. And I was told 'you said what ? the test of 'le petit papa Noël?'" I said : 'what ? you don't know it ?' I was really surprised to learn that women aged 35-40 had never heard about it" (Heidi, ≥ 40 years old, Peruvian, higher education, not screened, FG11).

A Canadian participant (Grace, < 40 years old, higher education, not screened, FG7) working in a medical environment thought, from her discussions with patients, that more health education was provided through school in her country than in Switzerland. By contrast a participant from Senegal (Filipa, < 40 years old, professional education, not screened, FG10) reflected, after being in Switzerland for a while, on the lack of information on cancer and screening in her own country.

The high prevalence of cervical cancer in low- and middle-income countries (WHO 2007) can contribute to explain the greater presence of prevention campaigns, including access to free screening, in those contexts. However, the contrast between these countries and Switzerland was not expected by many migrant participants. They were surprised by the relatively low level of screening here and by the absence of information. They perceived Swiss women as educated, more 'civilized' and insured therefore having no excuse not to participate in screening. In other words, they thought that if screening is available, people should take up the offer.

"We think that since these are developed countries, there is more instruction in all respects and people ignore almost nothing therefore they should be more informed about everything." (Monia, ≥ 40 years old, Bolivian, professional education, not screened, FG22).

"I think that Brazil is... I think that information on cancer works well. And I think that women over there know more about it than women here" (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

Patricia (Peruvian, ≥ 40 years old, higher education, screened, FG20) commented on the fact that due to the high mortality in her country, women are afraid of cervical cancer and therefore get screened. While cervical cancer is comparatively a low incidence cancer in Switzerland, the deficit of standard information in our country is still puzzling. The opportunistic nature of screening – in opposition to organized national programmes - probably contributes the 'taken-for-granted' status of cervical screening by health care professionals.

The role of the HPV vaccination campaign

Most participants were more knowledgeable about HPV than cervical cancer. They mentioned the recent focus on HPV in the media, in relationship with the launching of the HPV vaccination in Switzerland. In that context, some doctors had informed them about HPV, such as reported by Nathalie:

"There has been a time when doctors talked about it. My doctor, before retiring, talked about it at the time of the polemic around the vaccination, and he as a doctor was not necessarily supportive of this vaccine" (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

Participants also remembered finding leaflets in medical offices at that period.

"Information was supposed to be available to the whole public and in the waiting room of my doctor, my generalist, there were documents. Now they're not there anymore, but two years ago, when there has been that campaign, then yes they were everywhere" (Samantha, ≥ 40 years old, Italian, higher education, screened, FG9).

"I think it's fairly recent, it's two years, or something like that when they started talking about the papillomavirus. There were also posters in doctors' waiting rooms, even generalists, well not only gynaecologists. Let's say that the link between the papillomavirus and cervical cancer dates from that time" (Lea, < 40 years old, French, higher education, screened, FG9).

The media also participated to the diffusion of information on HPV.

"As for myself, I heard about it in the press, in the context of a vaccine for young adolescents, in cancer prevention. I've been fairly shocked by the way" (Louise, ≥ 40 years old, Swiss, higher education, screened, FG18).

"on the french channel, I think it was a campaign on French tv, advertisement either before or after a broadcast, but not in Switzerland. But not through my doctor. Yes, I live in Switzerland but my doctor never talked to me about it" (Cali, < 40 years old, Swiss, higher education, screened, FG18).

Proximity with the disease

Direct knowledge of cervical cancer was often related to having a family member who suffered from the disease, like mothers but also other relatives.

"I've had a personal experience since my mother had cervical cancer and she discovered it when she did the Pap smear" (Mathilde, < 40 years old, Greek, higher education, screened, FG8).

"I know it [cervical cancer] since I'm very little since my great aunt died of this cancer, and my mother had surgery for a cancerous tumor of cervical cancer" (Aurora, < 40 years old, French, higher education, screened, FG9).

"The mother of my boyfriend died of this cancer, she was about 40 years old, well she died about 12 years ago" (Samantha, ≥ 40 years old, Italian, higher education, screened, FG9).

This proximity with the disease provided them with direct information, but it had contrasting effects on their own screening attendance. Along a sense of personal vulnerability associated with their vicarious experience of cancer, some emphasized the importance of attending screening regularly.

"It's very important to do the Pap test ... and I think it's important to do it every year. Here in Switzerland, it's said that it's every two years... I think it's ... wait to for two

years ... [suggesting it is too long]" (Mathilde, < 40 years old, Greek, higher education, screened, FG8).

"Since I'm very young my mother takes me to the gynaecologist and I do the screening, every year. Between one and two years, it depends, but no more than two years" (Aurora, < 40 years old, French, higher education, screened, FG9).

"I have a friend in Peru who has cancer, not cervical cancer, and it's... my friends told me a few months ago, and I was scared ... and I say ... no, I have to go get screened, I will get screened this year" (Nikita, ≥ 40 years old, Peruvian, higher education, not screened, FG11).

However the proximity with the disease also generated some ambivalence regarding screening. Some women oscillated between the fear of testing and the hope that results would be reassuring:

"My mother had ... she had cancer and then... everything that's related... to cancer... scares me a lot and in fact I don't want to know. Then the last test I did with my gynaecologist... I was also going... for the pill, and I truly forced myself to ask, well now I have to do the test. But in fact, I didn't want to do it and I didn't want to know... event though I was hoping.... I was hoping to be reassured... I was scared ... I was scared of the result..." (Maurane, < 40 years old, Swiss, higher education, screened, FG12).

However some other women who had such proximity with the disease reported not being regularly screened.

"I think some people are reassured to know. Well, as for myself, I have sisters who have had worries, my mother, my grandmother died of cancer, then they are pretty careful in the family. The girls are careful. Then, they go to the gynaecologist and everything. And I've got sisters who are younger than me who have already had some problems, some things (trucs). Therefore sometimes people tell me [I should get screened] and I answer 'well I know'" (Cassie, < 40 years old, Swiss, professional education, not screened, FG15).

"My mother had cervical cancer at the age of 86, a cervical cancer, they removed everything, they say there's nothing left, that we were very lucky, no metastasis" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

These statements reveal that fear is potentially playing an important, but ambivalent role, in regard with decisions to attend screening. Fear as a barrier to prevention will be further developed in chapter 4.

Information through the family

Women reported that some information on cervical cancer screening was shared in the private sphere through a 'socialisation' across generations, between mothers and daughters. Some participants said that their mother had explained to them what are cervical cancer risks and ways to detect it.

"My mother, she would talk to us, since she was going for her control every year... she told me one doesn't know when one has cancer, but we knew that it was cervical cancer... I knew " (Joëlle, ≥ 40 years old, Peruvian, higher education, screened, FG8).

"I had heard very very little, but just the first time I went to the gynaecologist, my mother told me : 'don't be scared, maybe it will hurt, but it's to know if you could have cervical cancer'" (Daniela, < 40 years old, Hondurian, higher education, screened, FG16).

"When I was 9 and I had my periods, my mother took me to the gynaecologist. Then I think that for me it's fairly natural to know about cervical cancer. My mother on this aspect (...) I think she wanted to explain to me" (Giliane, < 40 years old, Brazilian, higher education, screened, FG21).

By contrast, some older participants (Gladys ≥ 40 years old, Jessica ≥ 40 years old) talked about the impossibility of addressing these issues at home when they were young. For them, information was received at school. A few other participants reported having been informed through school (Rihana, < 40 years old, Italian, screened, FG9), Grace (Canadian, < 40 years old, not screened, FG6). With the recent HPV vaccination campaign in Switzerland, some women reported getting information on it through their teenager daughters.

The participants statements on their knowledge gained through their proximity with the disease and the transmission of information through women in the family indicate that, around cervical cancer, informal sources of knowledge are important. In some cases, they seem to be more important than formal or professional information that is considered as insufficient.

Contrasting attitudes towards information

On this background of limited knowledge, the participants reported different expectations in regards to information about cervical cancer screening. Some clearly stated they would like to know more about it, but others stated that they were satisfied with the current situation. Their reports provide some relevant insights in regard to the issue of informed consent addressed in the literature review above.

Demands for information

Some participants clearly stated that they wanted detailed information ; a few women reported that their expectations in that regards had influenced the choice of their doctor.

"Me especially I would like to know everything, to know everything for example... when one is detected as positive and then... and then what happens ? Is it transmissible? except for this test to screen cervical cancer... I have no information... except what has been said here ... but if it's screened as positive then what happens ? What is it exactly ? How is it observed ? Technically I would like to know... and what are the consequences, what are the possibilities to get cured, to treat, to... I think that nobody knows " (Clotilde, ≥ 40 years old, Brazilian, professional education, screened, FG12).

"Then I changed gynaecologist, I went to see a male gynaecologist who was my mother's doctor and who, by contrast.... It went extremely well since he immediately understood that I wanted to know, I want to have information (...) I have a scientific mind, I like to understand, I like to know, I prefer to know what is wrong or what could go wrong rather than to imagine or remain in the unknown. Then that has been really, I was very happy with this gentleman" (Mia, < 40 years old, Swiss, professional education, screened, FG4).

"The doctors I choose are doctors who provide information" (Sarah, < 40 years old, Spanish, higher education, screened, FG1).

Some regretted their lack of information and wanted to know more. Often, they had hoped that the focus group would be a source of information to answer some of their numerous questions.

"Since like for every cancer, we have a risk, the disease we don't know how it will come. It's true you can prevent, but... for this cervical cancer, I've not done anything, I've not prevented anything. Well I can get the screening, that's all. But yes, really I miss information, it would be interesting to have more information to know..." (Dominique, < 40 years old, Spanish, higher education, screened, FG17).

"I really remember the information campaigns on tv and the radio, but not really to have had full information. It's the most important. To provide more information" (Yvonne, < 40 years old, Cuban, higher education, not screened, FG17).

During the focus groups, participants indicated that they were missing information on a wide range of aspects, including the development of the disease, the available treatments, and its incidence.

"Well, I didn't know that there was a vaccine, I did know at all that there was a cancer of the cervix precisely" (Eline, < 40 years old, Swiss, higher education, not screened, FG7).

"The cervical cancer, as for myself, I have no clue how it can develop. And how, what would be the progression of this cancer. How ? Does it go into the uterus ? I don't have a precise idea " (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

"It's true that we don't know the numbers for cervical cancer. How many women ? The percentage ? One knows, in Geneva, that for breast cancer, it's one woman out of nine?" (Gaia, ≥ 40 years old, Swiss, professional education, screened, FG18).

They also discussed about wanting to know more about the length and consequences of the treatment and worried about the impact it could have on their family. This kind of information, like data on incidence mentioned by Gaia, is probably more common in regards to breast cancer : due to its high incidence, it is more likely women will know someone who is being treated and will then be aware of the implications of the treatment.

Others commented on the fact that doctors should be more proactive and provide systematic information. These comments were associated with the observation that gynaecologists often did not have or did not take time to do it. This issue will be developed in Chapter 5. That chapter will also address the difficulties some women encountered in asking questions during the gynaecological visits, reporting the shame they felt about their own ignorance but also how the format of medical visits could make it difficult to raise questions.

Others appreciate not to know

Other participants reported they were not interested in having more information and that they preferred not to know all the details about cervical cancer, especially as long as there was nothing to worry about. This included women regularly attending a gynaecologist.

"She tells me what she does, but let's say, she doesn't go into details. Myself neither, it doesn't make me curious. Let's say the answer that my previous gynaecologist was providing, 'we are happy to tell you that everything is fine' I'm not going to ask for more. Now, if she tells me I have to come back, that there is a problem, I would like to know what is the problem. But as long as there is no problem, I have something else in my head, I'm sorry" (Emanuelle, ≥ 40 years old, Swiss, professional education, not screened, FG15).

"As long as they tell you that everything is fine, you don't ask that many questions" (Renée, ≥ 40 years old, Spanish, professional education, not screened, FG14).

For some women, having limited knowledge kept them from getting preoccupied by the screening procedure and its results.

"In fact I didn't know I was screened. I receive a small paper saying that everything is fine, then it's true she does not tell the specific exams, in case you would have cancer of this, in case you would have cancer of that ... it's very, it's done in a very sober way and at the end I've been controlled without knowing and without anxiety (...) As for myself, I lived it very well without knowing about it" (Madina, < 40 years old, Swiss, higher education, screened, FG4).

Other participants did not consider that knowing would help them with the treatment of the disease. To them, it would either happen or not, but could not be prevented.

"I do my routine control. I don't feel particularly at risk, I don't want to think about it, I don't want to think about it. In life, there are some fatalities, one can get controlled down and catch a cancer higher! It seems stupid, it's a fatality, I rather take things like that. Maybe I shouldn't " (Louise, ≥ 40 years old, Swiss, higher education, screened, FG18).

Information was not necessarily valued as a positive resource, some women emphasized rather that knowledge can generate undue anxiety or that it will not affect the turn of events, either they will get the disease or not.

Delegation to the doctor

Some considered that it was the doctor's job to proceed with screening and its results. They were happy not to get directly involved into the whole procedure. In their case, handling information was delegated to the doctor :

"I know it's a smear when they do a swab" Question: to know what? "If everything is fine or not, or I don't know, well I leave it to the judgement of the doctor ! I know she will check if there's not a virus, an infection... something that does not work properly, that's all. The details I don't know" (Cali, < 40 years old, Swiss, higher education, screened, FG18).

"Well I've been followed [screened] in Spain for many years. When I go, I do the control, I'm not informed, therefore I don't think that he does the test. Until now, I always left it to what the gynaecologist told me" (Sarah, < 40 years old, Spanish, higher education, screened, FG1).

"I never asked since it's true that ... I don't know, I trust her, I tell myself that if there was something to check, she will check it" (Irina, < 40 years old, Swiss, higher education, screened, FG12).

These diverse attitudes indicate that information is not valued by all women. While some would like to know more about the results and also about the available treatments, others who get screened prefer to remain fairly distant in this process. The different demands towards screening also suggest the co-existence of different types of relationships with doctors, some based on a trustful delegation to the gynaecologist, others emphasizing patient's increasing autonomy.

3.3 Conclusion

The extent of uncertainty about one own status regarding cervical cancer screening is an important finding. The dynamic of focus groups probably encouraged many women to express their doubts and questions once they realized that others had similar concerns and also reported lacks in their knowledge. These results suggest the absence a 'culture of screening' in the general population: cervical cancer screening is something that happens without women being fully aware and feeling properly informed about it. They usually know it exists and should be done, but many have only vague ideas about the procedure and its meanings. This lack of knowledge was reported in the study by women of different ages, origins and education levels; this means that limited information on cervical cancer screening is not typical of specific groups but rather can be found in the whole female population. Migrant women from Latin America even emphasized the contrast between Switzerland and their own countries, expressing some surprise at the low visibility of cervical cancer prevention in Switzerland.

Gaps in knowledge result from a combination of factors. Women's statements suggest that screening is a routine procedure for gynaecologists who apparently do not talk much about it. Furthermore, the opportunistic organization of screening in Switzerland implies that no standard information is provided to women expected to get screening, like it is the case in

countries having set organized programmes. On top of that, cervical cancer screening is a fairly elusive procedure: on one hand women do not see what is actually happening during the pelvic examination, on the other hand they often do not receive any feedback when results are normal. In that regards, a Canadian study reported that women would value receiving results systematically: 'Information sharing is important because it conveys a message that women are important enough to be told of their results' (van Til et al. 2003, p. 1128).

Participants reported some ambivalent attitudes towards information. Some women preferred not to know, as a protection against bad news, and avoided screening (Ménoret 2007). Others, willing to engage in screening, did not want to be fully informed and delegated screening and the management of its results to their doctor. However, a lot of women expressed an important demand for information. Getting information can fulfill different functions. It can allow women making informed decisions, with realistic expectations about screening (Philips et al. 2005). It can also play an important role in regard with the anxiety frequently associated to cancer. Being aware of the meanings of results and the management of abnormal cells could alleviate worries (Jepson et al. 2007). Accounts of informal transmission of knowledge among women of different generations, typically between mothers and daughters, can be related to a 'sense of obligation' towards significant others, as observed by Howson (1999): women consider, outside interactions with health professionals, that they should share what they know. This informal knowledge, reinforcing norms related to screening, can also participate to a higher attendance of women who are a priori reluctant but who may get motivated by their kins and friends.

These contrasting attitudes towards information imply that doctors are confronted with a range of demands that they have to take into consideration. Studies have revealed that patients' expectations in terms of information are not necessarily acknowledged by professionals (Martinez 2005, Raffle 2001). Arguments used to limit the provision of information include avoiding anxiety and improving attendance by limiting 'sensitive information' on sexual behaviours (Braun & Gavey 1999). However, Raffle (2001) suggests that not disclosing information can generate negative emotions such as anger and bitterness among patients.

Some argue today about the respective value of achieving a high screening attendance through limiting sensitive information on one hand, of providing full information to patients to allow them to provide informed consent on the other hand (Raffle 2001, Philips et al. 2005, Osterlie et al. 2008, Zwahlen et al. 2010). Our empirical findings on the experiences of cervical screening emphasize a diversity of expectations among the public and suggest that segments of the population would favour one position while others would probably prefer the other one.

4. Barriers to cervical cancer screening

We explore in this chapter the reasons expressed by women, "attendants" and "non-attendants", for not getting screened *regularly*. We also identify differences and similarities that exist between subgroups to better understand the actual coverage for cervical screening in Switzerland.

A recent review of the literature (Fang et al. 2011) states that structural barriers are the most often cited obstacles. However, among the barriers mentioned by the participants, no one seemed to be refraining screening attendance more than others. Therefore the order of their presentation in this chapter does not refer to a statement on their relative importance. Rather we show in the last section of the results how it is often a combination of barriers that keep women from getting screened regularly. Through these barriers, specific screening behaviours emerge and are considered via a typology differentiating women: who seem "overscreened", are "regularly screened", are "sporadically screened", who attend only because of a "specific event", who stopped after a "bad experience" and who are "unscreened". These categories are further detailed later in the chapter.

What are the obstacles preventing some women from getting screened? If cervical cancer is indeed the easiest cancer to screen for, what is the reason 40% of women are not screened in Switzerland?

4.1 Literature review

According to the medical and social sciences literature on barriers to cervical cancer screening, a variety of organizational, demographic and psychosocial factors contribute to the decision to get screened or not.

Structural barriers identified misinformation or limited knowledge (Braun and Gavey 1999, Armstrong and Murphy 2008, Philips et al. 2005), access to healthcare services (Fang et al. 2011), financial factors like low incomes (McKinnon et al. 2011), busy lifestyle, lack of childcare and full time work (Logan and Mcilpatrick 2011, Fang et al. 2011). Poorly educated women from a low socio-economical background have more negative attitudes towards screening and their attendance to screening is lower than that of women from a higher socio-educational level and with a higher income (Philips 2005, Szarewski et al. 2009).

Typical social barriers are negative emotional feelings (Logan and Mcilpatrick 2011), views on sexuality and lack of sexual education (Fang et al. 2011). The literature aiming at improving screening attendance has often focused on migrant women and on the cultural beliefs that impede participation to cervical cancer prevention (Forss et al. 2001, Lovell et al. 2007). Their illegal statuses, language barriers, difficulties in accessing health services and the absence of a relationship with a regular doctor exacerbate obstacles related to costs of screening. Studies comparing local and migrant women show a higher participation among the former ones (Azerkan et al. 2012).

Intimacy issues and embarrassment related to the pelvic examination represent an important psychological barrier (Piana et al. 2011). Age differences were found to play a role in the decision to get screened or not. Epidemiologically, cervical cancer risk starts to get high around the age of 30, therefore health professionals target young women to avoid a late diagnosis of cancer (Foley et al. 2011, Waller et al. 2011). Indeed, some authors worry about the decrease of screening attendance among young British women. Cohort effect (social disillusionment towards institutions in general (Lancuk et al. 2008) or structural and psychological barriers (access, time, embarrassment) explained the low participation of young women (Waller et al. 2011, Szarewski et al. 2009). Women over fifty also tend to be underscreened (Mubiyayi et al. 2002, Boulanger 2008), yet most cancers are diagnosed among older women. "Social age", combined to "biological age" tends to play a role in screening attendance, through the definition of expected periods of sexual activity, fertility and reproduction (Howson 1999).

Two models are used to explain the non-participation of women: 1) "the rational choice" model that points out dissuasive factors: fear, shame, pain, lack of information and 2) the "women centered" model that features barriers like the quality of information, not speaking the national language and not understanding the scientific terminology, inequalities in access to screening (Howson 1999, p.408).

The frequent association between fear and cancer can also exacerbate images of vulnerability (Clarke et al. 2006). Ménoret (2007) suggests that the decision not to get screened is made to avoid the bad news it could entail (2007, p. 147).). On the other hand, negative images of cancer can also fuel the belief that only an aggressive intervention can beat the potential cancer– the ablation of women's reproductive organs becoming the "normal" prophylactic treatment (Löwy 2011).

Lay views on health and disease also shape women's attitudes towards screening (Armstrong & Murphy 2008, Martinez 2005, van Til et al. 2003). The feeling that health is due to luck, or is a kind of 'genetic capital', observed especially in Asian cultures, can contribute to deter preventive behaviours (Fang et al. 2011).

4.2 Results

Women were generally supportive of cervical cancer screening as a way of preventing the disease. However their attitudes towards screening differed. Among the different reasons given by participants to not attend cervical cancer screening, we describe in this chapter the following categories: 1) structural barriers; 2) barriers related to the social environment; 3) embarrassment related to the pelvic exam; 4) lifestages influence; 5) fear of results and fear of cancer; 6) limited value of prevention. Information and relationship with the gynaecologist are also influencing screening in an important way; they are presented in separate chapters.

Structural barriers

Structural barriers most quoted by women were: the waiting time for getting an appointment with a doctor, the cost of the preventive act and the mobility of the gynaecologist necessitating to find a new doctor. A lot of women reported having been

discouraged by the difficulty in making an appointment for screening. This difficulty was reported by regularly screened women and by some who were not.

"The reason is to manage to make an appointment; it's very difficult to get an appointment! And people do not plan 6 months in advance; we don't already know what we'll be doing next week. They don't plan for 6 months" (Alberta, < 40 years old, French, higher education, not screened, FG17).

"In 5, 6 or 7 years that I didn't go, it occurred to me that I should go, so this time I called a gynaecologist, there was a spot available where my mother-in-law goes. But the fact that she told me, it was in January: 'yes it will be for the month of April', so I said, 'Listen, I will call back'. And if you call back, she'll put you again in four months, so that annoys me and then whatever! That's also a question of time, pfff! Yes, actually I would like it done as soon as I need it" (Emmanuelle, ≥ 40 years old, Swiss, professional education, not screened, FG15).

"I think what kept me from going to the gynaecologist is the long waiting time. When it hurts somewhere, we go to see the specialist, right? ... So I know that for me it's stupid, but telling myself that I must go to the gynaecologist and I don't have an appointment in 2 weeks, it annoys me! And for me it's an obstacle" (Elena, < 40 years old, Portuguese, higher education, not screened, FG18).

This was also reported by participants to focus groups in Canada (van Til et al. 2003). In that study, limited motivation to obtain screening was further deterred by the fact results would be obtained several months later only, due to the difficulty to get an appointment with a doctor.

The cost was a consideration for a lot of women facing financial difficulties, such as for example Renée:

"I used to go regularly. Now it's been just 3 years, but indeed for some reasons, I'm separated and unemployed at the same time, I have 2 girls, I have debts so eventually no time, no time, oh and moreover it will be some cost, so I limit. For me, there were several factors that came together all at the same time" (Renée, ≥ 40 years old, Spanish, professional education, not screened, FG14).

For Astrid, screening is a worthless expenditure:

"I have no problem with the terms of the test, it's only the time, I have to put time and money, that would be my only reluctance. I prefer to do something else (...). It's not that you don't have money, but you don't want to give it for this, you keep it for something else" (Astrid, ≥ 40 years old, Romanian, higher education, not screened, FG1).

The cost of screening was difficult to accept, especially among healthy women: due to their health insurance deductible, they have to pay for it while symptoms are absent:

"There's also money huh. To make an appointment with the gynaecologist when it's not a necessary expenditure, you must pay the deductible" (Valentine, ≥ 40 years old, Swiss, professional education, screened, FG16).

"Let's say I've had financially a tough period and then it's true that it's easily another 150 CHF to go. And apart from that, I have no health problems and I was on the deductible and suddenly I bypassed this check-up for financial reasons. Having said that there was no emergency on that side, (...). It's a check-up which, for the majority of the population who don't go to the doctor regularly, which is totally at the cost of the person... this check-up costs over 100 CHF. For a middle class budget, it's ok, in a lower budget, it does not fit. So it turns into a kind of secondary need, it's something that goes into a hierarchy, we put it aside, it's a question of priorities" (Madina, < 40 years old, Swiss, higher education, screened, FG4).

Illegal migrants in Switzerland faced further difficulties. In Geneva, a parallel health system for migrants - UMSCO¹⁰- exists. The system is organized so that a social worker first assesses whether an appointment with a doctor should be set. The process increases the waiting time for women who already have difficulties in taking time off work. Indeed they reported not daring to ask permission for leave from their employer:

"They give you a card and receive 30 persons. I went for my eye the other day. I went there at midday and left at 5 pm. Our bosses don't give us the permission and then to go see the doctor, still we need time. This is the problem right, we don't have time, we don't have bosses who say ok you can take two days off, impossible!" (Cheryl, ≥ 40 years old, Bolivian, professional education, not screened, FG20).

"Well it's 3 years now that I haven't been because it becomes more difficult for me to leave work to go to Hugo¹¹ and wait for the card " (Reymonde, ≥ 40 years old, Bolivian, professional education, screened, FG20).

The cost of screening represented the main barrier for migrants. As described by Florence and Cheryl, they came to Switzerland to earn money not to spend it; screening was therefore seen as a luxury they cannot afford:

"I'm illegal here in Switzerland; I don't have health insurance. I went once to the doctor because I wanted a mammography and a routine examination but he told me "it will cost you too much". And I have two children to take care of. Therefore for me as far as I can... but on the other hand, without health where will I go to work? For example, I wanted to do it because it's my responsibility but I didn't know where I should go and I told myself I wouldn't have enough money if it's expensive" (Florence, ≥ 40 years old, Bolivian, higher education, not screened, FG6).

¹⁰ Unité Mobile de Soins Communautaires (UMSCO). The Mobile Unite of Community Health is a mobile structure composed of a team of medico-social and psychological nurses that help people in precarious situations to access healthcare services.

¹¹ Nickname of UMSCO in reference to its location.

"Imagine how much it is? With my salary, do you think I can afford it, that I have the luxury to pay a private doctor? We migrate here because of an economic situation, for our children that we left, because we want them to study, to improve their lives no? So if paying the doctor takes our whole salary, then I better go back to my country!" (Cheryl, ≥ 40 years old, Bolivian, professional education, not screened, FG20).

The migrants we interviewed did not consider that national language was a major problem even when they went to a private gynaecologist. The lack of information and trust were more recurrent concerns. Therefore these women preferred being screened in their home country. Holidays back home were used to do all the checkups:

"I prefer to go once per year to check everything with the doctor, I prefer to do my checkup in Venezuela because the exam is different, it's more complete. I think we follow the methods of the United States that are more invasive, it's true, but I found that it is more detailed and I prefer someone who could observe more than just the smear. Here I didn't find a gynaecologist I could trust so I wait to go to Venezuela to get screened" (Stéphanie, < 40 years old, Venezuelan, higher education, not screened, FG14).

"I never went here. I've been here for 3 years. I do it in my home country and there I do it every year" (Férielle, ≥ 40 years old, Bolivian, professional education, not screened, FG22).

"Before I was checked in Portugal but then I said, ouf, every time I go on holiday I will bother to see a gynaecologist, I will find one here. I asked a colleague, she gave me the address, I went, I said no, never again! " (Claude, < 40 years old, Portuguese, professional education, not screened, FG11).

Some women reported difficulties to get screened after their gynaecologist retired or moved to another city. Finding a new doctor that matched the qualities of the previous one was sometimes difficult as reported by Caroline, Marguerite and Nathalie:

"The doctor I had for 25 years retired and the one who replaced him, I went to see him 4, 5 years ago, I think he was starting. It was horrible, only to insert the speculum and all the tralalala, I bled for a week! You bleed for a week then it's over, I didn't want to go back" (Caroline, ≥ 40 years old, Swiss, professional education, not screened, FG11).

"My gynaecologist was great, she left for Bulle and suddenly I found myself with no one, well I'm still looking for someone but I don't find someone with whom I have a connection, I feel really respected, well treated. Therefore it's been a long time I didn't go for screening, I'm a bit scared, I don't know where to go " (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

"I went to the same gynaecologist for 30 years. He retired and it's very difficult to change, to find someone with whom you feel at ease, you trust, it's more difficult therefore I space out my appointments" (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

Starting a new trustful relationship seemed difficult for some women, pointing out the importance of the relationship between women and gynaecologists (cf. chapter 5).

Barriers related to the social context

Women reported that some barriers related to the social context could limit their screening attendance. These included taboos related to sexuality, religion, partners' beliefs in regards to screening as well as a lack of "gynaecologist socialization". This last argument was more frequent among women over 50 and some migrant women.

In some focus groups, the barrier of religion was mentioned, usually in reference to Islam and relegating the issue of non-attendance to "Others", those who are culturally different.

"In some cultures, there's still the issue of hymen and that thing" (Pia, < 40 years old, Swiss, higher education, screened, FG3).

"In some cultures, it's very different. For example the Islamists and Africans, gynaecology is very difficult for women, more than for the Europeans" (Gabriela, ≥ 40 years old, Peruvian, professional education, not screened, FG6).

"These are the Arabs! Everyone from Maghreb, Egyptians, Saudis, all in my opinion, because they never get used to it. And then I see girls and young women here, and they say it's their mother who brought them to the gynaecologist. Here no, it is not the mother, it's the husband. It will never, ever, happen before the wedding. It's always after. I do not know how to say it. We are not free. We cannot talk about it with our mother, with our doctor. We cannot go to the gynaecologist before even if there's a problem" (Lucienne, < 40 years old, Egyptian, professional education, screened, FG16).

A focus group with Nicaraguan women highlighted that a husband or partner suspicion regarding visits to the gynaecologist constituted a huge barrier in their home country:

"And for me it was very serious, I was very scared, it was as if I had slept with another man. And I couldn't tell my husband, because he would have left me because of that " Question: You did not tell your husband that you went to the gynaecologist? "No (...) he said that if I put a intrauterine device or another device he would leave me because opening one's legs in front of the doctor that was for the "sinvergüenza" (women without shame) I couldn't even take the contraceptive pill, nothing" (Martine, ≥ 40 years old, Nicaraguan, professional education, not screened, FG24).

A study conducted in England (McKie 1995, p. 451) also mentioned the reluctant attitudes of male partners' in regards to gynaecological visits, especially when pelvic exams are performed by male practitioners. Women interviewed in that study interpreted these attitudes in terms of ownerships and control.

Many non-attenders explained that they did not get screened regularly because they had not "been used" to do it when they were young. This would reflect a generational problem, i.e. when these women were young, in the seventies, attending a gynaecologist was not a normative behaviour as it is today. The difficulty to talk about sexuality and contraception

with parents in those generations was also often mentioned (cf. chapter 3: "Information through the family" p. 29).

"This is a generational issue. We have not been accustomed. Me for example, I've never had a gynaecologist when I was young" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2).

"We did not grow up with the check-up, gynaecologist. Above all, since as long as you didn't have sex, you do not go to the gynaecologist and in our country, we have the first relationship when we get married otherwise not!" (Roberta, ≥ 40 years old, Colombian, higher education, screened, FG8).

"Because I have my mother who is 83 years old, I'm not raised in a way of going to the gynaecologist, we didn't talk about it (...). And women in the old days, wouldn't go to the gynaecologist, I have never heard my mother say that she had gone to see a gynaecologist. She had her children, that's it" (Jessica, ≥ 40 years old, Scottish, professional education, not screened, FG17).

Embarrassment related to the pelvic exam

One major barrier to screening is the pelvic examination with the insertion of the speculum, considered as a real hardship for some women.

"The external examination, I have no problem but I became totally hysterical for the internal examination. It's a feeling that doesn't last but I hate it honestly, I can't explain it, it's a feeling really.... When the speculum enters, this feeling of cold and pinching, it lasts only a fraction of a second but it makes me sick!" (Amélie, ≥ 40 years old, Swiss, higher education, not screened, FG2).

"I'm stressed to know that there's an object that will enter inside my body. I'm always apprehensive about this moment, it's really the vaginal examination. Then when there is the breast palpation and the fact to be undressed does not bother me, but entering into such an intimacy, I need time and to feel at ease" (Ana, < 40 years old, Swiss, higher education, screened, FG12).

For some women like Lucienne, the "speculum bad feeling" and pain lasted several days:

"Every time that I do it, it hurts. I have the feeling that he used something in metal like this [speculum]. I hate this, I have the feeling that 2 days after it still hurts. And I don't want to touch, neither my husband to touch me, because it's always, I know it's in my head, but I don't know, it hurts. And I feel everything, even the big cotton to do the smear with, I feel it, as if it was still there. It's like this. It hurts too much for me. And he says : « you are a very sensitive person », I answer : « yes I know ». Two days later, I'm still completely closed" (Lucienne, < 40 years old, Egyptian, professional education, screened, FG16).

Issues related to shyness and embarrassments (body exposed) were often present in participants' reports. Comfort during the exam was considered essential, but as observed in different focus groups, this issue is in fact rarely discussed.

"It's an uncomfortable examination, well, you can be naked in other situations it's much nicer [laughs]. This examination is not pleasant and not every doctor makes you feel comfortable, there are some more, it depends a lot on the professional who is there. Therefore it's not comfortable. I don't know if these 30% of women don't get screened because of the embarrassment" (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

"I think the embarrassment also, because I don't know why but I have the feeling that gynaecologists, it's something a bit taboo in the society, there isn't too much talk about it, it's something too intimate" (Yvonne, < 40 years old, Cuban, higher education, not screened, FG17).

As expressed by Cassie, the intrusion of the doctor into the intimacy of the woman can be perceived as aggressive:

"We don't like to be naked, that someone unknown touches us. Even sometimes it's not only the palpation inside our body, it's the gaze inside, to put a finger inside, I think it is aggressive for a lot of people" (Cassie, < 40 years old, Swiss, professional education, not screened, FG15).

Women were particularly concerned by the examination when their relationship with the gynaecologist was poor or bad. When this relation was assessed in a positive manner, then the examination itself seemed more acceptable.

Influence of lifestages on attitudes towards screening

Menstruations, maternity and menopause portray *women* situations that are considered to necessitate medical surveillance in modern societies. As Valérie (FG13) and Véronique (FG3) argued, these phases are associated with different types of gynaecological visits that influence the chance a woman gets screened.

"Some of these women stages where we don't necessarily have options and must go to a gynaecologist" (Véronique, < 40 years old, Swiss, higher education, screened, FG3).

During the focus groups, we asked the participants to identify the moments in their life when their attitudes towards screening changed. They talked mainly about four factors - age, birth control, maternity and menopause – that affected their likelihood to attend a gynaecologist and as a result were related to their attitude and status towards screening.

Some women reported going to a gynaecologist for the first time around the age of 14 to 16, to the initiative of their mother. Situated in the context of the sexual majority, this visit was often associated with a sense of obligation for mothers:

"The first time I saw a gynaecologist, I must have been 15 years old. My mother, she said you have to go to the gynaecologist, and then let's go! It's cultural" (Samantha, ≥ 40 years old, Italian, higher education, screened, FG9).

"It was also with my mother, but I think it was maybe due to a social obligation" (Rihana, < 40 years old, Italian, higher education, screened, FG9).

At that age, visits to a gynaecologist were mostly related to menstrual pain or in relationship to some medical problems:

"I was almost 15 years old when I had my periods. But they came for example for one or two months and after that they stopped for a month or two ... my mom told me that it's better to go and see a gynaecologist to know why. That's it. He said that this is normal, there are women like that" (Claude, < 40 years old, Portuguese, not screened, FG11).

Others quoted that the necessity to consult a gynaecologist was related to the prescription of the pill in relationship with the onset of sexual activity (around their twenties). In those cases, it was more often a personal initiative (without one's mother).

"The first time I went to see a gynaecologist, I was 25 years old, I'd never been before. My relatives used to tell me; maybe it is worth to get screened. Well I went because I had to take the pill and that's it! But I could have waited some more years, I wasn't worried at all" (Aline, < 40 years old, Spanish, higher education, screened, FG3).

"Me, it was to take the birth-pill, this is the reason why I went to see her" (Véronique, < 40 years old, Swiss, higher education, screened, FG3).

The frequency of gynaecological visits was often related to the prescription of the birth control pill. Getting a new prescription was then seen as the major reason to go. Without this motive some admitted they would go less often. Therefore, the 12-month pill prescription acts as a regulator, giving the one-year habit:

"I think if I did not take the pill, I would go less often to the gynaecologist because you're bound to get the prescription. That's it and I think that's why I go, otherwise ... " (Michèle, < 40 years old, Swiss, higher education, screened, FG3).

"I think they also do that to push for the check-up, it was an obligation somewhere, when I had to take the contraceptive pill, I had to go. At the time this is true, as it's for one year, we have to go back and then I got into the habit" (Aline, < 40 years old, Spanish, screened, higher education, FG3).

This indicates that visits associated with birth control offer an opportunity for screening, but this is not the main motivation of younger women when they attend a gynaecologist. A few women reported using strategies to get a birth pill prescription without seeing a gynaecologist. One (Yannick, FG7) asked her generalist; others (ex. Emmanuelle, FG15) obtained it directly from their pharmacist.

Most participants stated that before the age of 30 they did not feel at risk for cervical cancer. By contrast, in their thirties, women reach the "age of reason", associated with a time of greater responsibility.

"When we are young, we don't think about cancer. Because we really start to control it, to do things like that, when really we are above thirty, it's bit like that, I think, in general" (Mathilde, < 40 years old, Greek, higher education, screened, FG8).

"I think that all the problems of cancer are for women who are older and therefore I tell myself that it's not important that I do check-up, it's not going to happen before a few decades. That's ridiculous, isn't it ! I am aware that this is ridiculous. But I really feel that if I do not have a precise reason to go there, why would I do a check-up ? " (Elena, < 40 years old, Portuguese, higher education, not screened, FG18).

"I think I started, I must have been between 25 and 30 years, because I had read somewhere that it was important to go after a certain age limit, I did not know what was that certain age limit, but I went to for that time" (Valentine, ≥ 40 years old, Swiss, professional education, screened, FG16).

This lifestyle often corresponds to the "motherhood phase", which is likely to reinforce women's sense of responsibility towards themselves and others. In some cases, getting married or pregnant represented the first screening opportunity, especially among migrants or women from previous generations.

"The first time I went, it was the first year of my wedding because it's expected that when we get married we have to get screened" (Patricia, ≥ 40 years old, Peruvian, higher education, screened, FG20).

In the focus groups, a common perception emerged about married women with children having more experience with health care services. Therefore having a child increases the chances of screening attendance, since women are then in need of expert advice. Indeed, among those who were not regularly screened, several participants associated their visits to a gynaecologist with pregnancy only:

"Just for my pregnancy, so two girls, aged 19 and 18. Afterwards no, I went perhaps once or twice in 19 years because I had a slight odour in my secretions" (Brigitte, ≥ 40 years old, Swiss, professional education, not screened, FG2).

"When we are pregnant, when I was pregnant I had to go. Every month I went to the gynaecologist" (Jessica, ≥ 40 years old, Scottish, professional education, not screened, FG17).

"I went there as soon as I was pregnant, otherwise never in my life" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2).

Their comments suggest that without the obligation associated to pregnancy, they did not consider necessary to visit a gynaecologist and therefore did not get screened. This was confirmed in statements reporting that being sterilized or having reached menopause signaled the end of birth control and as a result of screening:

"Pregnancies, we go yes. But once there is no pregnancy, it's true that the gynaecologist, it's no longer part of our lives" (Erica, ≥ 40 years old, Tunisian, higher education, not screened, FG13).

"I tell you frankly, me since I have been sterilized, I banished the gynaecologist" (Emmanuelle, ≥ 40 years old, Swiss, professional education, not screened, FG15).

The menopause phase was perceived either as a higher or a lower risk phase in regard to cervical cancer. For example, Rita, who had an image of the "vulnerable body" at menopause, associated this period with risks:

"I went there much later, when the menopause began, it started early enough at around 45. I went there because I was told to go there, it's like breast cancer, luckily they wrote to me every two years to tell me to go and do my screening otherwise I would not have gone. The fact of menopause is not clear, we begin to hear things from everywhere" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2).

In contrast, Roberta reported that the age of 50 meant the end of gynaecological exams for her:

"The gynaecologist, she told me: " From now on, it's every three years ... as you're 50" [Laughs]. And this is where I learnt that from 50 years old, the risk of breast cancer from 50 to 70 years old, it is higher, but on the other hand, the cervical cancer decreases with age and for me, ooh this is great news and now she told me it's every 3 years... Now, inside me ... I do not think to do that. I never had any problems" (Roberta, ≥ 40 years old, Colombian, higher education, screened, FG8).

Several participants stated that unmarried and sexually passive women were not or less in need of screening. Not wanting children, being faithful or homosexual were other reasons given by non-attenders:

"I didn't go to a gynaecologist because it was primarily for the pill and the contraception, which did not concern me because I thought to be a lesbian and in any case, didn't want to have kids" (Valentine, ≥ 40 years old, Swiss, professional education, screened, FG16).

"Me, it's over 3 years that I have not gone to the gynaecologist, but that's just because I did not really see any interest because I have had only one partner for 8 years and we protect us well and everything" (Yvonne, < 40 years old, Cuban, higher education, not screened, FG17).

"I said to myself well if I have no husband, if I don't have kids I don't need it" (Reymonde, ≥ 40 years old, Bolivian, professional education, screened, FG20).

Even for participants that were regularly screened, being sexually passive was a common argument given to not attend examination:

"When there's no more sexual relation or practically, in general this is what I hear around me: 'why will I go there? I have no more relationship'. This is what I hear. And for young people, it can also be the same, since I don't have, I will not go! " (Louise, ≥ 40 years old, Swiss, higher education, screened, FG18).

These results indicate how different stages in women's lives are associated with specific patterns of gynaecological visits (an issue further developed in Chapter 5). Diverse interpretations of risks were associated to these stages, such as the assumption that risks are lower after menopause or in the absence of sexual activity; the recent emphasis on HPV

and sexual behaviours as a risk factor for cervical cancer probably contributed to such assumptions. Such interpretations helped some women, especially those not being screened regularly, to justify their low attendance. References to these different stages in life show how social experiences, i.e. situations that unfold outside of any medical consideration, are important in both the interpretation and attendance of screening. Howson (1999) identified three forms of *compliance with screening* that mirror the lifestages identified in this section: i) a medical “*routine*” (ex: fertility control); ii) a “*responsibility of oneself*” (mature response) and iii) a “*sense of obligation*” to participate (1999: p.417).

Fear of results and fear of cancer

Fear was another feeling quoted in every focus group as a reason not to attend screening. The term was used 241 times during the focus groups (a minimum of 2 times in one focus group, and a minimum of 23 times in another focus group), which indicates the pervasiveness of fear. It was mainly related to the results of screening and cancer itself. In regards to the disease, women’s account included an image of cancer as dark in general and associated with a long suffering illness, painful treatment and death.

“It goes on and on in the head yeah. It’s a disease I think until now they didn’t find an efficient cure and this I think scares everybody” (Amanda, < 40 years old, Russian, higher education, not screened, FG17).

Some women reported being very afraid of cancer. In the case of Melody, this fear was associated with overscreening:

“Me, I want [to get screened more often], but my doctor doesn’t. But I always try and he tells me: “it’s checked already, it’s fine”. Okay but I am an hypochondriac, this is clear. I worked in a medical department, I became hypochondriac (laughs). Even earlier, my throat was a little sore and I told myself: “that’s it, I’m having a throat cancer”” (Melody, ≥ 40 years old, Burkina, professional education, not screened, FG1).

Some women reported a more generalized fear of cancer:

“I always fear to develop a cancer, whether it’s cervical, lungs or somewhere else, so, yeah I would always blame myself not to have done it, I wouldn’t live well if I don’t attend, to think...at least it’s done, that’s it, I don’t think about it anymore” (Miriam, < 40 years old, Swiss, professional education, screened, FG12).

“Me I admit I also fear cancer in general... I am afraid; it’s something I often think about. Sometimes I smoke a cigarette and then I think about this” (Ana, < 40 years old, Swiss, higher education, screened, FG12).

Fear of cancer had contrasting effects on screening. It made some reluctant to get screened, as commented on by Pia who interpreted unscreened women’s attitudes:

“The head-in-the sand policy, it’s less worrying, I don’t know. Somewhere you tell yourself I’d rather not know, I rather prefer not to worry, maybe a little bit like the HIV screening. I think that there are a lot of women today who fear this examination” (Pia, < 40 years old, Swiss, higher education, screened, FG3).

On the other hand, some women reported that having a member of the family suffering from cancer or a “personal alert” was conducive to regular screening for themselves:

"I had a huge fear, therefore I told myself yes I should go and do whatever needs to be done, yes. Without this big fear, I still wouldn't have gone " (Emanuelle, ≥ 40 years old, Swiss, professional education, not screened, FG15).

Maurane reported an ambivalent position, on one hand, the proximity with cancer through her mother was making her reluctant to be tested, and on the other hand, she was hoping that the results would provide reassurance (cf. chapter 3). The ambivalence between wanting to know and fear of abnormal results was clearly expressed by Amanda:

"Now it's a while I haven't been screened, following the operation I had, after the dysplasia. Today I tell myself that the screening is still a necessity to prevent... in case a new problem appears and at the same time it could reassure me. I did, I think it's more than 2 years that I haven't attended screening and I'm telling myself that I should really go back because it's important. But there is a part of me that doesn't want to know, still, in case of something goes wrong" (Amanda, < 40 years old, Russian, higher education, not screened, FG17).

For some participants, the fear of screening results was salient. As stated by Florence, the pelvic examination was not an issue, while the results were a preoccupation:

"Of course, the fear to have something. Me, I was afraid when I got screened, I can tell you, I spent three, four night, I couldn't sleep. I had to call the nurse to ask if she had received the results and she told me: "I told you I would phone you". Honestly, I couldn't sleep anymore, I wasn't feeling well" (Melody, ≥ 40 years old, Burkina, professional education, not screened).

"I'm not afraid of the examination, if it's a woman or a man it doesn't matter. I close my eyes, I don't see anything and it's done. But I fear the results of the screening. I start to build stories in my head: and if the result is positive, what will I do? And my sons still need me, I start to make a movie in my head" (Florence, ≥ 40 years old, Bolivian, higher education, not screened, FG6).

Fears are diverse and can relate to different aspects. They can either encourage women to get screened regularly, or keep them from doing it. Screening itself can be a source of anxiety, for different reasons, and the impact of fears on women should not be minimized.

Limited value of prevention

Some women considered that cancer could not be prevented, “we are all at risk” (Maria, ≥ 40 years old, Swiss, professional education, not screened, FG1).

"We don't know what provokes this disease. If we knew what provokes this cervical cancer, we could.... Suddenly the cancer is there and this is it" (Jane, ≥ 40 years old, Bolivian, professional education, not screened, FG6).

"In fact, everybody can be concerned" (Amanda, < 40 years old, Russian, higher education, not screened, FG17).

"I know that the cancer we all have it but it is asleep, it's not yet activated" (Cheryl, ≥ 40 years old, Bolivian, professional education, not screened, FG20).

Participants raised several arguments to put this risk into perspective and to keep it at a certain distance. No "visible" signals, in addition to being in "good health" (as a capital), provided the feeling that the illness would never appear, like Rita who said to have a "lucky star":

"I take my lucky star and carry on, I try to be optimistic, to see pretty things, I don't look too close at my health" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2).

These arguments were used to justify not attending screening and pushing away a medical preventive behaviour that is not seen as a priority. In fact, as Lucie mentioned, in order to feel concerned, one needs to feel at risk:

"You have to feel concerned too, like everything in the prevention area, to feel that we are "at risk"" (Lucie, ≥ 40 years old, Italian, higher education, not screened, FG17).

For women whose time is scarce, their general health was a good reason not to be worried about getting screening:

"I also have the feeling that if we are in good health in general, well, you still can catch something but, for me, if I'm feeling well, it bothers me and I'm taking a risk. I accepted it when I didn't go for three years" (Caroline, ≥ 40 years old, Swiss, professional education, not screened, FG11).

"I used to go every year, every year and a half and then, the time just flew by and without noticing it 3 years passed. I went without a problem to see my gynaecologist but up to now I didn't have any problem so" (Renée, ≥ 40 years old, Spanish, professional education, not screened, FG14).

A lot of participants explained that they *take care of themselves* by paying attention to their diet, practicing exercises and opting for natural medicine. This argument of control over one's own health has been promoted by health education over the last decades; it is also used as a reason to refuse vaccination (Burton-Jeangros et al. 2005).

The lack of symptoms was often mentioned by women as a reason not to pay attention to the screening. Not feeling any pain or sign of a possible disease deterred screening attendance.

"If my teeth don't hurt I don't go to the dentist, no? I must really be sick to go to see a doctor. I try to treat myself. Well here it's a bit difficult, if I don't feel any pain I don't go so, if I didn't have this problem I wouldn't have gone" (Emanuelle, ≥ 40 years old, Swiss, professional education, not screened, FG15).

"We never think that we will be sick, therefore we don't do it, as far as there are no signals. This is what's dangerous" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2).

The image of a "silent cancer" was mentioned by Kelly:

"So it's a silent disease, you realise it or you don't" (Kelly, < 40 years old, Bolivian, professional education, not screened, FG22).

And precisely because it is silent, "you don't wake up a sleeping dog" for Jessica:

"You know we say : "you don't wake up a sleeping dog ! You leave it quiet". So I had to go for a mycosis because it hurts, so I went. And I told myself it is luck if we have it or not. In my place, we say: "if everything is fine you don't go to see a doctor, you go to the doctor when you are sick". This is what I hear since I'm young" (Jessica, ≥ 40 years old, Scottish, professional education, not screened, FG17).

Another woman justified postponing the exam because she knew that the evolution of the cancer was slow:

"When you're told it is very slow, you don't have to worry so I told myself it's so slow, I still have some time, then we postpone, we postpone" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

For some women, going to the doctor was related to being sick not to being healthy (cf. Martinez 2005).

"I'm lucky not to be in need of seeing a gynaecologist in fact. I don't have this notion of prevention. For me the doctor you go when you are sick!" (Noémie, < 40 years old, Swiss, higher education, screened, FG9).

"You go to the doctor when something is wrong" (Erica, ≥ 40 years old, Tunisian, higher education, not screened, FG13).

Women, comparing their "good health" with that of their sick relatives or friends, were convinced that they would be spared:

"We say the others but not me, I, I won't catch it" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

As noted above, a lack of concern about health was also present among the younger age group, who did not feel at risk of cancer before the age of 30 (cf. *"Influence of lifestyles on attitudes towards screening"*). The lack of self-care, not taking time for oneself were reasons not to prioritize prevention.

"Me, I don't like it, I never go to the doctor, I never go to see anyone, I don't have this reflex to tell myself oh it's 10 years that I haven't seen a gynaecologist, but then I have nothing against" (Cassie, < 40 years old, Swiss, professional education, not screened, FG15).

"Frankly, for me, I tell you the obstacle is that I don't care, I tell you frankly"
 (Emanuelle, ≥ 40 years old, Swiss, professional education, not screened, FG15).

Barriers configurations and women's screening statuses

Women's account emphasized that, more than a single element explaining non-attendance, barriers often cumulated in their experience of screening. Factors related to the preventive exam itself – like embarrassment or fear of results for example - were often associated to social contexts such as: a divorce resulting in financial problem, an interruption in sexual activity, economical problems and time pressure with the children, which provided further justification for not attending screening.

Table 3 summarizes the six categories of barriers presented in this chapter, emphasizing the principal topics for each barrier with the main reasons expressed by participants not to get screened on one hand, to get screened on the other hand.

Table 3: synthesis of barriers

Barriers	Main topics	Reasons not to screen	Reasons to screen
Structural	Appointment, cost, access	Waiting time, expensive and worthless for a preventive act, financial difficulties, UMSCO, finding a new gynaecologist	Routine/socialization, screened in the home country (trust)
Social context	Sexuality, religion, partner, lack of socialization	Religion (only married and pregnant women attend), partner's suspicion, not used to it, age over 50	Pregnancy follow-up, marriage, sterilization, socialization: screening as a normative behaviour
Pelvic exam	Speculum intrusion, vaginal exam	Pain, embarrassment, shyness, intimacy, intrusion, bad experience	Acceptable if comfortable environment and respect from the gynaecologist
Lifestages	Age, birth control, maternity, menopause	No sexual activity, not married, not wanting children, end of childbearing, other way to get the pill, age under 30 or over 50, not heterosexual, faithful relationship, sterilization, menopause (decreased risk)	Specific problem, menstruation pain, birth-pill prescription, married, menopause (increased risk), age over 30
Fear	Results, cancer	Abnormal results, anxiety, family history	Avoid to miss "something", anxiety, to be reassured, family history, personal alert
Limited value of prevention	Fatalism, absence of visible signals	General good health (not feeling sick), lack of symptoms, care and concern, "slow" cancer, for "Others" not for me, natural medicine, age under 30	Feeling at risk, silent cancer

Along the different configurations of barriers observed among the participants, we could classify them on a *continuum* line according to their screening status. To one extreme of this line, one participant admitted wanting to increase the screening frequency, if she could, for fear that her gynaecologist missed a tumor, tending to have an *overscreening* behaviour. *Regularly screened* women are those who get "used to it" and do not question the screening process, they are trustful in the system. Some women who attend screening because of a *specific event in their life*, mostly their pregnancies, appear to be less socialized to visiting regularly a gynaecologist. They mentioned that they would appreciate a "reminding letter" from their doctor, without guaranteeing they would attend. Other women quit "the medical routine" because of a *disturbing event* such as financial problems, a divorce or because they lost their assigned gynaecologist who retired. Participants who were not regularly tested but still kept in mind that "it's good to get screened" tended to attend *sporadically*. As they had never experienced any problem in the past and were in a "safe" relationship, they tended to comfort themselves that they were less in need of screening than other "risk" groups such as prostitutes or young women.

The last three groups - *specific event*, *disturbing event*, *sporadic attendance* - were especially sensitive to the gratuity of the screening and were mainly participants from the DEPIST recruitment. For them, a personal or external "alert" such as "a tumor", the "visibility" of a screening campaign like DEPIST, a "pressure" from their daughters to get screened could represent key factors encouraging them to "get back" to screening. Indeed women who never get screened are rare. In our sample only one woman specified that she attended only once due to her *homosexual orientation*. She did not consider screening necessary since she assigned cervical cancer to heterosexual women. *Migrant women* that we interviewed expressed a desire to get screened and were particularly in favor of the HPV vaccination for their daughters. They failed to attend regularly for financial and time reasons, in particular due to their specific health track that increases the time process and interlocutors before getting to a specialist. For some of them, opportunities for screening are related to their home country visits when they take the opportunity to perform checkups. This "habit" reveals their limited trust in and understanding of the Swiss medical system, and the difficulties they encounter in accessing this system.

4.3 Conclusion

Participants generally agreed that screening as a prevention method is "good, necessary, and important"; however these statements can result from a desirability bias related to the invitation to participate in a research dedicated to cervical cancer screening. Our study is consistent with findings from previous researches. Common barriers identified in the focus groups are determined by external factors (social context, access to healthcare) and by internal factors (individual health, fears, embarrassment).

We noticed that access to gynaecologist represents an important barrier, often quoted by women: three months constitutes a too long waiting period for an appointment; they also tended to question the (lack of) availability from the gynaecologist, especially since the examination itself is completed too quickly. The role of cost is considerable, but not necessarily the most important barrier. It is surely the easiest to talk about. The preference of migrants for attending screening in their home country is worth emphasizing; their

screening status is then dependent upon the frequency of their trips back home. Not having been socialized to gynaecological visit was highlighted by women from a certain age, appearing as a generational issue. Partner and religion barriers were quoted linked to issues of intimacy and sexual taboos. The speculum intrusion being a «hardship» for some women dissuaded them to get screened.

We also noticed different concerns at different phases of life. Though some young women expressed being too young to feel concerned by screening and cervical cancer, others explained having been "socialized" to screening during their adolescence – as "part of what a woman has to do" - comforting the observation that women are encouraged to conform to the screening (Bush 2000, Howson 1999). Women having had repeated cervical cancer screening tests since their adolescence seem to continue attending screening regularly at later stages in their life. Access to contraception often played a central role in this routine. Some women tended to naturalize risk, considering that getting older *naturally* implied being at higher risk. However, this interpretation of increasing risk over age was not necessarily associated with increased screening as sexuality and pregnancy – related to their social experiences and considered to be main reasons to get screened – were absent. Fearing the results or to be diagnosed with a cancer could result into either a demand for screening or to an avoidance. Screening is indeed a situation not so easy to deal with for women, they are not "being" and/or "feeling" sick and "the absence of symptom" constitutes a sign of health; therefore the procedure can easily be considered as too expensive. In her "rational choice", not every woman sees the benefits of the examination.

Women's diverse behaviours reveal their ambivalence towards screening. The results presented in this chapter show that not one particular barrier but a cumulative range of factors and events, affect screening attendance. There is not a "specific unscreened woman" since a woman who used to be regularly screened could later and because of an event in her life, postpone, stop temporarily or definitely cervical cancer screening. Therefore the boundary between attendance and non-attendance is porous and flexible. To understand screening attendance, it is important to take into consideration those diverse social situations and their interactions with obstacles related to the testing itself.

5. The influence of relationships with gynaecologists on screening behaviours

In Switzerland, screening is opportunistic and relies on women's and doctors' initiative. Most of cervical cancer screening is performed by gynaecologists working in private practice. According to the results of the Swiss Health Survey 2007, half of the interviewed women had attended a gynaecologist in the past 12 months (OFS 2010). The consultation rate was the highest among the 25-34 years old and then declined with age. The peak over the age 25 to 34 is attributed to visits associated with pregnancy. Women with a lower education level were less often attending a gynaecologist (41%) than those with a higher education level (66%) (OFS 2010, p. 46). These results relating to gynaecological visits confirm self-reported data on screening (OFS 2010), according to which older women and women with a lower education background are underscreened.

This chapter aims at assessing to what degree the relationship women develop with a gynaecologist influences their screening behaviours. Results are organized along the following sections: the onset and frequency of visits to gynaecologists; their past experiences with gynaecologists, ranging between negative and positive assessments.

5.1 Literature review

From a medical point of view, screening represents a cost-effective procedure that reduces morbidity and mortality. Hence it is perceived as a beneficial exam that women should attend as a routine. The British leaflet inviting women to attend screening describes Pap tests as quick, simple and painless (Armstrong 2007). It is considered as a normal part of reproductive and antenatal care which women are expected to endorse (Howson 1999).

However studies examining women's experiences with screening showed that many of them did not consider it as trivial. Screening implies that a professional accesses to a part of the body that is considered as taboo, therefore screening challenges the boundary between the public and the private spheres (Armstrong 2007, p. 78). Some women interviewed in Sweden did see it as something beneficial and non problematic (Forss et al. 2001). Nevertheless qualitative studies reveal the large extent of embarrassment and discomfort that women typically associate with screening (Howson 1999). In a Canadian study, women talked about the 'exposition' of their body as unsettling, including references to the position of the body during the pelvic exam (van Til et al. 2003). Expressions used by respondents referred to a lack of dignity, and some women felt the exposition even more embarrassing with age because of their body changing appearance. Women interviewed in Serbia also commented on the intimate nature of the exam and related it to their expectations that gynaecologists or health care providers should be particularly sensitive about the situation (Markovic et al. 2005).

The literature on barriers to screening has often emphasized the role of embarrassment as a factor associated with lower attendance (cf. Chapter 3). These attitudes have been often examined among migrant or minority women, as stated by Fang et al. (2011): 'cultural beliefs about modesty are often negatively associated with screening, whereas women who

reported less concern about embarrassment were more likely to obtain screening' (p. 79). It has been demonstrated that the relationship between doctor and patient influences a woman's decision to get screened. While the importance of being attended by a male or a female gynaecologist has been debated, it is more the attitude and approach of the doctor that seems to have a real impact, including: care, communication, expertise, competency (Logan and Mcilpatrick 2011). Fiebig et al. (2009) stress that women who are more receptive to screening are those who have been advised and remembered by their doctor. In their accounts of screening, women sometimes referred to the clash between their interpretations of the situation and the doctor's appraisal of it. Some respondents in Canada commented on the fact that the gynaecologist attitude in regard to the pelvic exam was too 'cavalier' (van Til et al. 2003). While performing the exam is a routine for him or for her, women felt it was 'an invasion' of their body, as stated by one respondent: 'it's a routine thing to a doctor but to us it's very traumatic' (p. 1123). Furthermore, abnormal screening results often generated important distress among women while being minimized by their doctor (Lee Mortensten et al. 2010). Their lack of information on these results' implications generated anxiety that was not necessarily alleviated by the health care provider.

In interviews, women reported some prior negative experiences with gynaecologists. On top of considering that gynaecological procedures were emotionally difficult, some reported that negative past experiences could deter their later attendance (Forss et al. 2001). In a Canadian qualitative study, one woman reported being 'sexually assaulted' by her physician and others considered they had been 'molested' during the exam' (van Til et al. 2003). Within a range of contrasting experiences, discomfort and embarrassment were common. Such contrasting experiences with gynaecologists were also reported in the context of pregnancy surveillance, with women focusing on both the bedside manners (empathetic,...) of the doctor and his/her expertise (Burton-Jeangros 2010).

5.2 Results

As reported in Chapter 4, the first visit to a gynaecologist motivated by prevention corresponds for some women to a practice taught by their mothers in their adolescence. For others, it is related to their sexual activity: the role of "yearly pill prescription" and pregnancies follow-up has been presented in relation with women's lifestages. Some women who started at a later stage in their life, talked about their first visit as 'one of those things one has to do' or something that one has to get used to since it is expected to become a routine. They further discussed on the rationale of their visits frequency and reported on mixed experiences with gynaecologists.

Frequency of visits with gynaecologists

The norm for many women (whether screened or not screened) is to visit a gynaecologist once a year. When pressed to explain why, some, as quoted before, referred to the annual birth-pill prescription. However several could not explain precisely why and referred to a feeling of duty or obligation (Sarah, Cali and Patricia).

"I go once a year (...). My mother took me when I was 14 I think and after that I've been told to go every year, and I don't get worked up, I'm going that's all" (Sarah, < 40 years old, Spanish, higher education, screened, FG1).

"I have the feeling it's something that's being said, one should go to the gynaecologist once a year" (Cali, < 40 years old, Swiss, higher education, screened, FG18).

"Usually we women have to do a control, an annual screening, that's the control, there is no other solution" (Patricia, ≥ 40 years old, Peruvian, higher education, screened, FG20).

This norm was followed even though the exact content of the visit was not clear : *"as for myself, I go to the gynaecologist once a year, but I don't know exactly what's he tests when I go"* (Alison, < 40 years old, Swiss, higher education, screened, FG16). The obligation was turned into a routine by others, such as Samantha:

"There's also a question of routine. For me, it's correlated, I've gotten used to go every year to the gynaecologist when I was young (...) I got into the habit, then I don't think I could forget to go to the gynaecologist" (Samantha, ≥ 40 years old, Italian, higher education, screened, FG9).

Several mentioned that their doctor made it clear that they should come back after 12 months, sometimes in the form of a reminder sent by the doctor's office:

"Because the doctor says so. Every year. I've been told it's every year, then for me that's it" (Jessica, ≥ 40 years old, Scottish, professional education, not screened, FG17).

"He [her gynaecologist] told me one should have a test every year and in case I don't go or don't call, his assistant calls me to remind me that it's already over a year and that I have to make an appointment for the test" (Lucienne, < 40 years old, Egyptian, professional education, screened, FG16).

Others directly related their visit to screening, considering the annual control as important:

"It's one of the reasons of course, to get a prescription [for the pill], but otherwise it's because I've always heard that it's still once a year precisely to be able to detect if there's something, if there's the beginning of cancer or something else" (Alison, < 40 years old, Swiss, higher education, screened, FG16).

"Yeah it's to avoid the disease in time" (Lea, < 40 years old, French, higher education, screened, FG9).

"And I do it every year. A small drop, you don't pay attention to it and it turns into something serious. Therefore, for me now, it's very important to do it every year" (Férielle, ≥ 40 years old, professional education, not screened, FG22).

Most of the women reporting the one-year norm are regularly screened, they follow the medical (and social) recommendation and get regular pap tests.

A few women said they were going more often, i.e. every 6 months. It was reported to be the norm in some countries, like Brazil as explained by Marjorie and Esmeralda:

"I do it every 6 months. Well, since I live here, I've done it less often. But in Brazil I used to do it every 6 months, absolutely" (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

"Yes, the same for me. Here I do it less. In Brazil, I was doing it every 6 months and here I do it once a year. Here I'm going less often, I take more time" (Esmeralda, ≥ 40 years old, Brazilian, higher education, screened, FG19).

Some were going frequently as a personal demand resulting from fears associated with cancer, as in the case of Melody:

"As for myself I go to see my gynaecologist, I think he's fed up with me, twice a year" (Melody, ≥ 40 years old, Burkina, professional education, not screened, FG1).

In other cases, this higher frequency was associated with the need to control abnormal results :

"My gynaecologist is French since I live in France, but it's true that we see them every 6 months. Yes, since... well she saw some values which are not very good, then she checks fairly regularly. I'm under observation. Previously, it was once a year" (Riahna, < 40 years old, Italian, higher education, screened, FG9).

"And it's very tiresome, since one has to go every 6 months, and the reason I've been given is that it's not a story related to cancer, even though I'm at risk. It's a story of triglyceride, cholesterol, when you take the pill, you've got hormones... you have to be careful..." (Aurora, < 40 years old, French, higher education, screened, FG9).

"If there's anything I've got to back before 6 months, then 6 months is automatic. The funny thing is that I've learned that even if the next test is negative, for 2 years we will continue like this... only if there's something aggravating, I'll be called in. But if I have no news, I just have to make an appointment in 6 months" (Aïcha, ≥ 40 years old, Hungarian, higher education, screened, FG12).

This smaller group of women were also regularly screened.

Some women reported going less often, i.e. every 2 years, considering that it was sufficient, that they could handle that frequency.

"Yes, every 2 years. As for myself, I go every 2 years since I consider it's largely enough" (Morgane, ≥ 40 years old, Swiss, higher education, screened, FG14).

"He told me one should do it every year... and the other year, I didn't go ... The second year, I got a letter from my gynaecologist which said I should go ... Yeah. Yeah. Yeah you have to do it... then I went. But every time, in the beginning, it was very, very hard to do it... In the end, I managed to get used to do it and I do it every two years. Every two years, I do it. And now, he told me it's every three years..." (Roberta, ≥ 40 years old, Colombian, higher education, screened, FG8).

Some related it to the reimbursement of the test by the health insurance. This reimbursement was contested in an other focus group by one woman who considered it as insufficient.

Other women reported going less often to see a gynaecologist, Elena said that the cost was an issue and limiting her visits :

"I think I went to see the gynaecologist 4 times in 12 years, each time, it's for something specific, because it's very expensive" (Elena, < 40 years old, Portuguese, higher education, not screened, FG18).

Some participants reported waiting to do the test in their home country, like Stéphanie for example:

"In every country I've lived, I've done the same. I've not attended screening in Geneva, I also lived in Lausanne and there I had a gynaecologist, but here I've not found a gynaecologist I trust, therefore I'm waiting to go to Venezuela to get screened. It's been three years without doing it because I've not been able to go to Venezuela. I'm doing all my exams with my gynaecologist over there" (Stéphanie, < 40 years old, Venezuelan, higher education, not screened, FG14).

In regards to the normal frequency of visits to the gynaecologist, women often talked about the one year visit. This was the result of a medical norm but also of a social norm ('this is what is said'). This norm was strong enough to make them go even though the rationale of the regular visits remained often unclear. Other women were going less often, their reluctance to visit a gynaecologist means that they are not regularly screened.

Relationships with gynaecologists

The literature emphasizes that the relationship established with the health care provider in charge of screening plays a central role in attendance. During the focus groups, women talked about their experiences with gynecologists and their expectations in their regards.

Male or female gynaecologist : does it matter ?

Participants to the focus groups expressed contrasting views regarding the gender of their doctor. Some clearly stated they preferred attending a female gynaecologist. They motivated this preference by the physiological similarity between the doctor and themselves:

"I'm very happy to have a woman because in fact she feels what I feel as a woman and for me it's very important, she has the same problems that I do" (Morgane, ≥ 40 years old, Swiss, higher education, screened, FG14).

On top of the physiological similarity, some considered it was easier to talk with a woman than with a man and thought that a female doctor would understand them better:

"For me, it was not an issue of competencies or not, it was a question, an issue that I cannot with a man, he is not like me... for me it was a woman, she understands me"

better, she has the same anatomy, because she has the same ... we can talk, one can tell her you know I have this here... [Laughs]. She knows... then I trust women more" (Roberta, ≥ 40 years old, Colombian, higher education, screened, FG8).

Several women commented on the fact that the pelvic exam was less embarrassing when performed by a woman.

"I would say that even if I prefer a male gynaecologist, the act I find it less unpleasant with a woman, I must admit it. Even though I like him very much as a person and everything, it was still more difficult on the moment whereas with a woman, I feel less embarrassment. If I have some, it's less than with a man" (Pia, < 40 years old, Swiss, higher education, screened, FG3).

"I think it's ok if it's a man, but with a woman one is more at ease, but it's ok" (Ema, < 40 years old, Brazilian, professional education, not screened, FG7).

"If I'm told he is a man but really super and everything, maybe I will give it a try. But I think that I would be more at ease with a woman, I've always had women and it has happened that I tried one and felt so awkward that I never went back..." (Aurora, < 40 years old, French, higher education, screened, FG9).

Next to these moderate comments, other participants clearly stated that they simply could not have a pelvic exam performed by a male gynaecologist:

"There's also... the issue of the man, I'm personally very bothered by it in fact. [Silence]. Because it's already... well the moment of the exam it's not when I feel comfortable and even less with this... I don't understand... well, I cannot... well, it's a preconception I know it well, but I cannot stand, I don't want that... he does that ... and this completely freezes me and ... I don't understand why there are some many male gynaecologists" (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

"Anyway, I didn't find it comfortable. All that and she was a woman ! if it had been a man I think I would have fainted (...) Well a male doctor... I think I would never have managed to do it..." (Magy, < 40 years old, Brazilian, professional education, screened FG19).

Other women had a completely opposite view and placed a higher trust in male gynaecologists. They thought that men were more competent:

"I prefer men. I don't know, I think I trust a man more. I think it's because I've always dealt with male doctors, then I prefer" (Thérèse, ≥ 40 years old, Dominican Republic, professional education, not screened, FG22).

Others commented on the inadequate attitudes of female gynaecologists, considering them either too cold, too brutal or lacking empathy:

"I don't trust a woman, because if I need surgery, I want it to be done by a very very good surgeon ". Question: And women are not? "Not always, I don't manage to have the same trust, even though I'm very feminist, but I've not found a woman. Either they

are too tough, I don't like, or too bossy, too cold, too scientific, I feel like I'm still with my mother and have to obey" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

"I prefer men ! Women are rough" (Jessica, ≥ 40 years old, Scottish, professional education, not screened, FG17).

Female gynaecologists could also be too soft and not professional enough in comparison to male doctors:

"I think women are more... like this... more easy going... and to comment... Yeah, yeah, they do more jokes than men" (Lorraine, ≥ 40 years old, Brazilian, professional education, screened, FG19). "That's why I don't like it. I think that a femal doctor... I feel more... I feel less comfortable with a woman... since they make more comments" (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

Some expressed a preference for the anatomical difference with a male doctor, the difference in physiology expected to make them more attentive and more careful during the exam. However an older male doctor was preferred to a younger one:

"Well I prefer men. In fact, I consider that they do not have the body of woman, they do not know the feelings therefore... they are maybe softer, one can maybe more able to complain if it tingles or pinches" (Miriam, < 40 years old, Swiss, professional education, screened, FG12).

"I prefer a man... and old. Yes... because ... I prefer since... since he has seen some already... Imagine a young doctor... who watches... that's improper..." (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

These contrasting comments on their preference in terms of the gynaecologist gender more generally reveal that the pelvic exam is often considered as problematic. Some say they would refuse to have it performed by a man, others tolerate it with a woman but still comment on their uneasiness. Next to these positions, many participants considered that the gender of the gynaecologist did not really matter, emphasizing that his or her personality and expertise mattered more.

"For me, it does not make a difference if it's a man or a woman. For me the most important thing is that he or she is a good doctor, that's all" (Stéphanie, < 40 years old, Venezuelan, higher education, not screened, FG14).

Common criticisms towards gynaecologists

During the focus groups, women talked about the qualities they valued and also about what they considered as inadequate attitudes in their encounters with gynaecologists. The lack of empathy of the doctor was explicitly mentioned by some women:

"My gynaecologist moved and I did not follow here since she was rather cold for a gynaecologist " (Maria, ≥ 40 years old, Swiss, professional education, not screened, FG1).

"I find my gynaecologist unpleasant, maybe that's why I don't go see her" (Elena, < 40 years old, Portuguese, higher education, not screened, FG18).

The organization of the visit was sometimes considered inadequate. Women commented on the too limited time available for the visit, a time pressure incompatible with the ethos of the profession according to Rita:

"They are in a hurry" (Carla, ≥ 40 years old, Cameroonesse, professional education, not screened, FG2).

"There's also the fact that doctors should take some time for us. They want to have one patient after the other (...). Yes, we have the impression that in the past medicine, the doctor did not look at his/her income, but now doctors worry about their income. It's very annoying, because for me it's not compatible with the profession. I understand that they have to make a living but to see patients one after the other and set the clock that rings after 10 minutes and then 20 minutes, I find this horrible" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2).

"In fact, I've been blown away... really... it's been... really difficult and she did not listen to me at all, we, we talked about nothing and at the end of the day I realize this problem... with... many doctors and in particular gynaecologists that... after 10 minutes they tell you: 'do you still have questions?' (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

Comfort is felt when the examination is not rushed, when gynaecologists take time and provide a space for women's questions. The notion that this was a right related to the fact that patient are paying a provider for a service was expressed by Biancha:

"I've know gynaecologist who were a little... well... in a hurry, rushed, not time, go go, they were doing it a bit in a rush. Then I don't appreciate especially since when one goes to the private sector, if one pays, I'm sorry, but it's a service that one ...that's what one expects" (Biancha, < 40 years old, Polish, higher education, not screened, FG10).

This time pressure is equated with a limited possibility to ask questions, even though women often reported they would have liked to obtain more information. Several felt that the attitude of the doctor was clearly discouraging their attempts, by making them feel that they should already know, as reported by different interviewees:

"Personally I have the impression that I'm a person who, when I need to ask a question, I ask it fairly easily. But in that particular case, I'd say that the attitude of the gynaecologist, she makes me feel that ... she doesn't have much time and ... then, yes, that I could be in her way, but I feel... that I disturb her schedule and on top of that, what's adding up to it, is my own discomfort because... I don't know how to exactly phrase my question, I've never talked about it and it takes me a little more time than I give up" (Ana, < 40 years old, Swiss, higher education, screened, FG12).

"I have the impression to be... even though it's rather fine with my gynaecologist... there are ... I have the feeling that for her, there are things I should already know (Maurane, < 40 years old, Swiss, higher education, screened, FG12). " The same for

me" (Ana, < 40 years old, Swiss, higher education, screened, FG12). *"I don't know how I could know them without having been informed, but I feel that I should know them !"* (Maurane). *"That's true"* (Clotilde, ≥ 40 years old, Brazilian, professional education, screened, FG12).

These comments emphasize clearly the difficulties of communication. The reactions of the doctor make the patients feel bad about their own ignorance and then too embarrassed to ask further questions, generating a spiral of limited knowledge (Maurane's comment). They were expecting the gynaecologist to provide balanced and appropriate information:

"They are specialists and they have to be able to explain to us in our language. When we want to change pill or contraceptive method, what does it mean ? The advantages, the disadvantages, we expect from them to provide advice also, not to be there only, 'well that's it, that's it'" (Gaelle, ≥ 40 years old, French, higher education, not screened, FG10).

"And we did not find, there was nothing then I never went back since I was not really satisfied with his practice [laughs] Maybe I should go back now, whether he does not have options... I know there are options but he did not... there was not the right tone, a good communication on that" (Mafalda, ≥ 40 years old, Danish, higher education, not screened, FG13).

Next to the difficulty of obtaining information, some women reported that they felt the doctor was not listening to them and therefore that they were not considered as a person:

"I often have the feeling to not be heard, maybe that's why, understood yes but not heard" (Amélie, ≥ 40 years old, Swiss, higher education, not screened, FG2). *"Not heard. That's a bit what happened for me, I have not been heard at all!"* (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2). [...] *"I couldn't stand this aspect therefore it hurts, [] it gave me the feeling I was not a whole person"* (Amélie).

"The gynaecologist, it's a bit particular, it would be nice to be taken care of, considered as persons, sometimes you have doctors, you are a number, well 'next'" (Valérie, ≥ 40 years old, Kosovo, professional education, not screened, FG13).

"When I started looking for a gynaecologist, I've seen some, I've changed some more because I did not find him empathetic at all, some sort of machine to run exam after exam, without even asking your opinion, really no. And maybe that's a reason I don't go regularly !" (Lucie, ≥ 40 years old, Italian, higher education, not screened, FG17).

These criticisms are mostly made by non screened women, suggesting that not having found the right doctor contributes to their status.

Negative experiences

"Especially since the persons I know who don't go [get screened ?], it's always due to negative experiences, it's painful " (Aïcha, ≥ 40 years old, Hungarian, higher education, screened, FG12).

As already mentioned in some of the criticisms reported above (Elena, Mafalda, Lucie), some women decide to not go back to a doctor due to a bad experience. This can relate to disagreements over a proposed treatment, especially if the doctor insists in a inappropriate manner.

"At that time I was in the menopause period and he insisted so much that I should take some hormones, describing a ravaged landscape if I didn't take them it seemed almost too... suspect let's say. I was not ready at all, I was having lots of questions and my intention was not to take them, which I've done and still do" (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

"Because I had a male gynaecologist who was very nice and once I entered menopause I had some fibroids in the uterus and he told me, as soon as I had reached menopause, well now we are going to remove this uterus and I said : 'excuse me ?'. He said : 'well yes, now you have some fibroids' ... And I told him : 'listen, usually at menopause fibroids go away therefore it's out of question'. Then he made a biopsy and I almost reacted strongly ... well I go out very upset and I never went back []. Luckily, I've not done anything. But then, I must say it was violent" (Manuela, ≥ 40 years old, Swiss, higher education, screened, FG4).

A bad experience with the pelvic exam, in particular pain associated with the procedure can deter further visits. The comments further emphasized the sensitive nature of the exam and the fact that some women experienced strong negative feelings about the procedure ('violated intimacy' Eline, 'almost rape' Marguerite) :

"She knew it was the first time I was going and she hurt me a lot when she did the exam. It hurt for days, I was bleeding, I called since I thought she had done something wrong. Then I did not go back. She told me it was normal since she had done a swab and maybe it was a little bit too much and since it was the first time, maybe my body was overreacting. And then that it was totally normal. It was not massive bleeding. But I was scared. And she told me it was completely normal, that one had to let time pass, that it would heal, that it was a very small wound, that it would heal., I was 25 or 26" (Daniela, < 40 years old, Honduras, higher education, screened, FG16).

"And then a person there who was rough, I believe it was at the maternity. Not hyper rough, but let's say who was not soft at all, and who did not warn me, who did that like at the factory. Then one does not necessarily feel well afterwards, even though, well, well I did not feel pain. But it's rather, yes, as if my intimacy had been violated. One doesn't feel very well with that" (Eline, < 40 years old, Swiss, higher education, not screened, FG7).

"Well the last person it's been for me almost a rape what she did to me, this woman to introduce this frozen thing and I told her it was hurting? and... she laughed a bit saying that I had had two pregnancies then I should know what it was like ! Well, I felt really bad and everything... yeah it was violent, it was nasty, it was... and then it's been a long time I did not go back" (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

The peculiarity of the gynaecological exam was often emphasized, Ana commented on the need to increase awareness about this peculiar situation instead of taking it for granted that women simply accept it.

"But I tell myself that maybe it reflects also... a certain reality that for many it's not... it's something that... not only is uncomfortable but maybe that it's really difficult to get to it, that it would be important that there is some sensitivity towards it... not only towards cancer prevention but also a sensitivity to... have another type of relationship when we go to the gynaecologist... to be able to... that the discussion be an integral part of the visit and that it should not be just a gift that ... one finds by chance a good gynaecologist " (Ana, < 40 years old, Swiss, higher education, screened, FG12).

Marguerite further commented on the inadequacy, from her point of view, of the setting of the 'traditional' pelvic exam and the position of protagonists in the procedure. She implicitly expressed the violence of the gynaecological exam, as she had experienced it, including the difficulty to obtain information due to the format of the visit:

"And that's why that now I know what I don't want, I've not found yet what I wanted... yeah this thing about the setting with the legs bend like that when there is no need for that, not at all, one can be lying on the side. Well there are lots of things where... I understood that if I was uncomfortable, it was because there was a very oppressing situation, for the comfort of the doctor, which was not adequate at all for the patient at the end of the day. And it was not my fault if I was feeling bad... and then also it was not my fault if I didn't think about asking that question because there was no possibility to ask that question in fact..." (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

These criticisms highlight that gynaecological visits are often problematic from women's point of view. On top of the poor communication and the absence of empathy, they often insisted on the fact that they felt uneasy and uncomfortable with the pelvic exam.

What is expected from a gynaecologist

Some women had good experiences with gynaecologist and were happy to report on what they appreciated. The doctor's capacity to listen and taking time to talk with the patient were valued.

"For me it's always the same, it takes at least one hour, we talk, it's very cool. He's a very good doctor, very well-known. In terms of contact, it's great" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

"For me, she takes all her time, it's first the upper part, then the lower part. I'm never all naked and that's when she talks to me" (Véronique, < 40 years old, Swiss, higher education, screened, FG3).

"He often was late in his appointments. The reason he was doing it was that he showed a human attitude, he was discreet, he was doing the exam and afterwards if one wished one could always, he was always open to something, then one did not have to

confide in him but he was open and that was fantastic” (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

Some reported that the doctor had a proper attitude towards the procedure: he or she acknowledged the particular nature of the pelvic exam and that the exam could be intrusive. These doctors would warn them before performing the exam or would talk to them in order to make them relax:

“The gynaecologist, he often excuses himself and tells us before : ‘you’re going to feel some things which are not very pleasant’. He tells us, he does not force it on us” (Joëlle, ≥ 40 years old, Peruvian, higher education, screened, FG8).

“Somebody who knows what that in fact is... that for us, it’s not a nice moment and who takes that into account and understands it” (Maurane, < 40 years old, Swiss, higher education, screened, FG12).

Comparing different experiences, Renée appreciated not feeling anything after the exam was performed (in opposition to previous painful exams):

“When I left the gynaecologist’s office, the few years I’ve done with her, it hurt, I was walking my legs apart. Whereas for me, well it’s personal, I’ve changed, I went to a man and I found it was much softer, it didn’t hurt. For me, that was the best criteria, to tell myself, it doesn’t hurt when he does it and it doesn’t hurt afterwards. It’s just great as if nothing had happened” (Renée, ≥ 40 years old, Spanish, professional education, not screened, FG14).

Several women reported their doctor’s efforts in regards to the atmosphere of the exam:

“Well the next one, he was trying to put a special atmosphere. It’s a bit like when you go to a massage place, with a very dimmed light, then it’s a light where even if our body is exposed, it’s not so exposed [...] when the light is dimmed, everybody looks nice, without wrinkles, and then we are less anxious to show our body somehow, since we have to show it all, that’s for sure” (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

“Then I get ready for the exam, there’s a small room, a very small room where I can put my pareo, which are always very nice, very colorful, it’s very cute. Then she puts me... I sit down. And then I get undressed and she’s waiting for me afterwards [...] I need to be comfortable to do it, and then, it’s my femininity, it’s my inside body, therefore I have to be able to do it with someone I feel comfortable with” (Samantha, ≥ 40 years old, Italian, higher education, screened, FG9).

“And then she didn’t have a table with the stirrups, it was a table when one was lying down... with a small towel... well it was a completely different atmosphere... she was working without... without a desk” (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

Some doctors were praised for their efforts to make the exam more comfortable through warming the lotion (‘gel’) that is used for ultrasound (*‘this small detail is a fantastic detail’*

according to Nathalie FG5) or warm the speculum, or use plastic speculum that are more comfortable than metal ones :

"My gynaecologist, she warms up the speculum, it looks like it's nothing, but it's super comfortable" (Samantha, ≥ 40 years old, Italian, higher education, screened, FG9).

"In fact my super gynaecologist who was there, she ... during... the exam...to do the exam, she had... she didn't have... the metal speculums, she had those in plastic even if it requires more maintenance, and she was offering me to put it myself and to open it. And then she was showing me how to do it and we were taking time to do that and ... well... it was completely different from the other one" (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

Women praised the capacity of their doctor to explain and communicate with them, offering them time after the pelvic exam itself:

"Afterwards, once I was dressed again, we would make another appointment and, possibly, his way to open the conversation was : 'do you need something else ?' and it was very very discreet, then if we needed anything, the door was open, we did not have to use that opening, but it was fantastic. That's why I've had a hard time to replace him" (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

"I like her way to proceed, she is clear in everything she says, for me it's important to hear things, and the fact that she says them is reassuring for me" (Manuela, ≥ 40 years old, Swiss, higher education, screened, FG4).

Others commented on their doctor's understanding, his or her capacity to preserve the woman's dignity, to consider the patient as a person, in other words they felt respected:

"She was doing her work with a human attitude, that's to say, not like 'sit down, open your legs'! The human side. Not the condescending side either... For me, it's something... I've got a personality that fights for that, if I'm told 'do this, do that', if I'm told like that, it's over... I need some contact... things where I feel like I'm a human being, without judgement, and then that he's there to do his job" (Aurora, < 40 years old, French, higher education, screened, FG9).

"For me it's the same, what I like in that doctor is that she has a human attitude" (Michèle, < 40 years old, Swiss, higher education, screened, FG3).

"Somebody who takes care of the person in fact" (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

Several commented that they were appreciating a whole configuration of qualities in their doctor: empathy, professionalism, capacity to listen and to provide information, taking time for the patient:

"Because she's great, she is... on top of being soft and everything it's someone who... I find very professional and very listening, very... well I'm there ouff [relief sigh], nice what" (Clotilde, ≥ 40 years old, Brazilian, professional education, screened, FG12).

"She is very gentle, I've got a very good relationship with her, we have some good explanations, I can ask questions. And yes, I like her as a person, I trust her. The professionalism, the kindness, it's fairly subtle in fact" (Morgane, ≥ 40 years old, Swiss, higher education, screened, FG14).

"Somebody who does not measure his time, where we don't have the feeling that he has to hurry, quick quick and to the contrary, he talks with you, he enjoys listening to you and talking with you, very scientific, competent in his domain" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14).

In those positive experiences, women reported being very satisfied with their doctor. They appreciated the familiarity they had established with him or her, they needed to feel as being 'special', as being a person to be heard and taken care of.

These focus groups results show that the criticisms and the praise of doctors mirror each other, that is to say that aspects considered as inadequate by women having had bad experiences are emphasized as positive qualities by women who are satisfied with their doctor. The qualities that are discussed relate to the bedside manners of the doctors, their expertise and their ability to perform the pelvic exam in an appropriate manner.

The specificity of the gynaecological examinations

The peculiar nature of the gynaecological examinations has been discussed in different ways by participants. Some women commented on the fact that the gynaecological visit is in no way similar to other medical visits, this was in particular emphasized by women who were not screened:

"For me responsiveness is important, all doctors... yes, it's true that it's something personal, but I think that the gynaecologist is more personal than others. You have to talk about more personal things, then, in one's life, it's important to find somebody who likes his profession" (Dominique, < 40 years old, Spanish, higher education, not screened, FG17).

"Especially since in gynaecology, it's even more important to know that we are being considered in regard to what we feel, where it hurts, our individuality of things as we live them " (Valérie, ≥ 40 years old, Kosovo, professional education, not screened, FG13).

In different focus groups, participants talking about the pelvic exam used the expression 'open your legs' for the doctor. This reference was most negative, as what a gynaecological exam should definitely not be equated with. These comments reveal the ambivalence associated with the pelvic exam and hint towards its sexual connotations. McKie (1995) also observed in women's accounts references to the 'potentially sexual nature of encounters with male doctors' (p. 452). The women's emphasis on the need to talk about what was happening, the need to be acknowledged as a person - in particular for those reporting bad experiences - shows the need to establish an appropriate rapport in regard of the peculiar nature of the gynaecologist-patient interaction. Aurora makes explicit this necessity to strike a balance between a completely 'distant' provider and a too intimate encounter:

“It’s rather difficult to talk about that intimacy, one doesn’t want to be judged, one doesn’t want to feel assaulted by someone who is too... or someone who does not care enough also” (Aurora, < 40 years old, French, higher education, screened, FG9).

5.3 Conclusions

These results emphasize the importance of the relationships established with the gynaecologist. First we showed how women were ‘socialized’ into attending regularly a gynaecologist, without being clearly aware of the motivations of this ‘obligation’. Nevertheless those who were aware of the recommendations were more often screened for cervical cancer screening. A second section of the chapter emphasized the specific nature of the encounter between a woman and a gynaecologist. Criticisms and bad experiences were obvious motives for not attending screening. The focus group discussion turned out to be a format that helped some women to express their dissatisfaction with the ‘classical’ setting of the gynaecological examination. Listening to each other difficulties with different aspects of the visit made the participants aware of their shared uneasiness, an issue that is usually little discussed, either with professionals or in private discussions. It is important to highlight that positive experiences with gynaecologists were also common.

These results show the extent of the emotional consequences of screening and the pelvic exam. While embarrassment is often reported for migrant women (Fang et al. 2011), as part of their specific culture, our results and previous qualitative studies in western countries (Howson 2001a, Forss et al. 2001, van Til et al. 2003) suggest that embarrassment and discomfort are indeed present among most women during gynaecological examinations. Doctors tend to take for granted the willingness of women to accept a pelvic exam. However, due to the medical setting and the perceived norms (sense of duty, responsibility), women have often limited capacity to report on their feelings and experiences about it.

6. The acceptability of HPV self-sampling

It is thought that the human papillomavirus (HPV) self-sampling procedure might reduce some of the obstacles identified in previous chapters, in particular the organizational issues and barriers related to embarrassment. It is therefore regarded as an alternative to be especially promoted among women who do not get screened *regularly*. The key argument in favour of this test is that it can be done by the woman herself at home, thus avoiding a gynaecological examination.

In this chapter, we describe the benefits and disadvantages of HPV self-sampling as reported by participants to the focus groups and then compare their attitudes to HPV self-sampling with attitudes towards the Pap smear screening. Analyses are guided by the following questions:

Could HPV self-sampling increase the screening attendance and become an “embedded” practice such as the Pap smear test? Is it perceived by women as offering them a possibility of empowerment in regard to cervical cancer prevention? Which women consider it as an acceptable approach? Alternatively, what would be the reasons given for not adopting this method?

Most studies on cervical cancer screening focus on women who get regularly screened. Those that do not are rarely studied or are selected among specific migrants groups. In our study, the self-sampling method was presented in all focus groups. In a few groups¹² some women had actually tested it (n=20). Therefore, we report on a mix of opinions from *unscreened* women who tested the self-sampling method and from some who did not test it, as well as from women who are regularly screened and saw the self-sampling method for the first time during the focus group.

Participants who carried out the self-sampling test¹³ did it mostly unsupervised, using only detailed verbal instructions provided by a nurse over the phone and a written notice sent with the kit. A few women chose to use the test in the hospital fearing the consequences of testing it alone at home (especially women not speaking the national language). We had obtained from the DEPIST study some kits with their notice to be able to present the method to all focus groups participants.

6.1 Literature review

In the literature, HPV self-sampling is presented as an “innovative”, “new” method compared to the “traditional” Pap smear test. Self-sampling was promoted at the end of the 1970s and specifically conceived for unserved women without access to a healthcare system (Barbee et al. 2010). Various studies, mostly Anglo-Saxon, identified four factors in favour of this method: respect of privacy and intimacy, provision of comfort and absence of

¹² Focus groups: 2, 6, 7, 10, 11, 13, 14, 17.

¹³ Participants to the DEPIST study were randomized to receive either a self-sampling kit or an invitation to a Pap smear screening.

embarrassment (Piana et al. 2011, Dzuba et al. 2002, Igidbashian et al. 2011). Igidbashian et al. (2011) concluded that the “HPV test could be used as a primary screening test for cervical cancer”.

Common findings show that women from a higher socio-educational level are more in favour of self-sampling than those with a poor background or from migrants groups. Although these women noticed the benefits of the method, the fear of doing the test wrongly or/and getting wounded prevailed (Anhang et al. 2005, Howard et al. 2009). According to Wikström et al. (2007), regularly screened women tended to be in favour of the self-test.

Reasons for the use and preference of the self-sampling method are practical and emotional. Practically, the test can be done at home, at any chosen time; it is quick and the device is easy to use. Emotionally, the test appears more acceptable, more respectful, and more private than the Pap smear. Women expressed less shame and embarrassment compared to the Pap smear test (Dzuba et al. 2002, Igidbashian et al. 2011). Above all, it might signal the end of the pelvic examination (Howard et al. 2009), the main reason of non-participation according to Piana et al. (2011).

Reasons for refusing the test include: a lack of confidence in performing it correctly, fearing injury, a need to speak with a gynaecologist. The main concern for women is the efficacy of this method. As Waller et al. (2006) reported “the success of any self-sampling programme would depend on the method being feasible and acceptable to the target population” (p.208). This target population, often being “hard-to-reach groups”, is composed, mainly, of migrants. Indeed, a lot of studies are done on these specific populations. While the intention to improve the health of these groups prevails, the aim remains to evaluate the self-sampling acceptability. For example, Szarewski et al. (2009), who interviewed 28 Muslim women in London, reported a limited enthusiasm among this group. Women expressed difficulties using the test, especially for unmarried women who are not *supposed* to be sexually active (having sex out of wedlock is culturally forbidden). The self-sampling brought to the front issues related to trust and fidelity and was negatively perceived by women. For Waller et al. (2006), married women tend to be more in favour of self-sampling than single women. This has also been observed by Howard et al. (2009) highlighting the *belief* that women with children are more used to gynaecological exams, whereas women without children have less experience with this exam. Their study conducted in the UK concluded that Asian women are more negative towards the test than other ethnic women. The quantitative British study by Forrest et al. (2004) highlighted that, for Pakistani and Indian women, the willingness to try the test was related to their concerns about their ability to do it correctly. The study of Barbee et al. (2010) pointed out that for Haitian women, health is a personal and private matter, and that the self-sampling method respects this privacy wish. In this specific case, women often feared that exposing a *bad health condition* could put them at risk of deportation (being in good health is an entry condition to the USA) or socially marginalize them (cf. Pap smear in some communities tend to trigger husband suspicion on infidelity or lack of sexual desire after the examination). For all these reasons, this study concluded that self-sampling is a culturally acceptable method for cervical cancer screening.

Nearly all studies concluded that women’s attitudes towards self-sampling are mainly positive, HPV testing being “very favourable and accepted by women” (Igidbashian et al. 2011). More nuanced, Howard et al. (2009) noted that women who experienced both Pap

smear and self-sampling stated no preference, but if they had to choose, they would opt for self-sampling. However some authors trivialize this enthusiasm by concluding that even if women expressed favourable opinions to the self-sampling test, they still preferred the clinical examination (Anhang et al. 2005). The gynaecologist examination is seen as an opportunity to discuss other gynaecological issues or to obtain a more extensive check-up (and this even when they confessed the physical uncomfot of the examination). However this is not relevant in countries, such as the UK, where the Pap smear is not carried out by a gynaecologist (Waller et al. 2006).

6.2 Results

Participants who used the self-sampling kit were invited to share their experience with the group. During the focus groups, we were more concerned about the acceptability of the method, the willingness of women who had tested it to recommend the device to friends and to use it in the future, rather than about their evaluation of the ergonomics of the device. Among the 43 women who participated to the investigation DEPIST and to our focus groups, 20 had tried the self-sampling kit.

Our findings are consistent with previous studies. Arguments in favour of self-sampling are: it is practical and easy to use, time saving, it is less expensive, ensures autonomy, produces less shame and embarrassment, limits pain and is a good complementary method to the Pap smear. Indeed, some women found that self-sampling could allow spacing out gynaecologist visits (by alternating HPV self-sampling and Pap smears). On the contrary, arguments against self-sampling concerned the reliability of the test, the results, as well as the participant's ability to do the swab correctly. Some women found the device confusing and unsuitable especially for younger, older or disabled women - those who know little or nothing about their bodies. Women particularly resistant to the test feared that it could replace the gynaecologist whose role is considered essential.

Self-sampling advantages

Practical and easy to perform

Some participants, including some who have not used the self-sampling kit, said that the test had or appeared to be practical. Among those who had tested the self-sampling method (all able to carry out the test by themselves), the majority reported finding the test "easy to perform", "not painful" even "great".

"I found the act very trivial and quick to perform. Not at all unpleasant, it didn't hurt, it was very easy for me" (Heidi, ≥ 40 years old, Peruvian, higher education, not screened, FG11, Tested).

"It was really easy to do, I also find like you said before, that with the gynaecologist, it's much more stressful and painful. Whereas with that one doesn't feel anything. It's really very easy, very practical, well explained, very clear. It was great, I liked it a lot" (Stéphanie, < 40 years old, Venezuelan, higher education, not screened, FG14, Tested).

"There are things that make science progress or not, but in that case, it's really progress. It's something that doesn't require much time and one cannot say 'I don't do it because it hurts or because, I've got no time'. No difficulty with that. Nobody can say 'I cannot do it'" (Lucia, ≥ 40 years old, Bolivian, professional education, not screened, FG22).

Grace, who works in a hospital, said that she will adopt it in the future without hesitation if it is free of charge and can be sent through the post office (cf. "access, time saving") :

"I found it practical, for me it works, it's easy, practical, quick. For me personally, I find it very practical. I would use it" (Grace, < 40 years old, Canadian, higher education, not screened, FG7, Tested).

Rita was particularly enthusiastic:

"An extraordinary simplicity. I'm going to be simple, pragmatic, I think it's true for everybody, that it's great. I was very enthusiastic " (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2, Tested).

The kit was often compared to a "pregnancy test" and the procedure similar to introducing a "tampon" or a "vaginal suppository". The "easiness", "the rapidity" and the "comfort" of the method were also emphasized by unscreened participants who had not tested it.

"I think it's practical, you get it at home, you do it yourself instead of going to the doctor, if you don't have time to go to the doctor. And you mail it by post" (Madeleine, < 40 years old, Bolivian, professional education, not screened, FG6).

"I think it's nice, I tell myself, you're easy with it, you do it at night and put it in the post the next day. Rather than say well Tuesday at 9 am, I have to go there, I have to change the appointments. On the practical side, I think it's very good" (Emanuelle, ≥ 40 years old, Swiss, professional education, not screened, FG15).

Some screened women who were not in favour of the self-sampling test for themselves, still considered that it could be more acceptable for women who felt "ashamed and reserved", who "feared the examination" and who wanted to "save time":

"The practical aspect, one doesn't want to lose time, you do that at home in two minutes, whereas to make an appointment ..." (Aline, < 40 years old, Spanish, higher education, screened, FG3).

"I think it's more practical, quicker, more practical, more comfortable" (Estelle, ≥ 40 years old, Brazilian, professional education, screened, FG21).

Self-sampling could reduce the problems of accessing a gynaecologist. Christine said she might use it if she was in a remote place with no access to a specialist:

"Where it can be interesting, it's in the cases, when one is in a fairly remote place, where going to the gynaecologist is really complicated or where there are not many" (Christine, < 40 years old, French, high education, screened, FG7).

Stéphanie, who had migrated from Venezuela, said she could use it, but she would still prefer to get screened in her home country during holidays (cf. chapter 4).

"In case I'm in a situation like mine now, I'm abroad, my preferred doctor is not her, I think it's fine. Or if one is stressed, has not time, it's a good alternative" (Stéphanie, < 40 years old, Venezuelan, higher education, not screened, FG14, Tested).

Less embarrassment

As discussed in Chapter 4, a range of barriers are associated to the pelvic exam, including embarrassment, speculum intrusion, pain, lack of privacy and intimacy. Since these were affecting the motivation to obtain a Pap test, self-sampling seemed to offer an attractive alternative:

"If we could more easily access to this kind of screening, it's a good thing. It could avoid some drama later, because one doesn't dare to go see a doctor, to expose herself; for young women, for virgins, it doesn't distort a woman's image, it's important very early" (Brigitte, ≥ 40 years old, Swiss, professional education, not screened, FG2, Tested).

"It's practical, many persons, some girls are ashamed to go to the gynaecologist and even more if it's a man. They will not want to go, they will prefer this and they will do it. But one will never reach a 100% coverage" (Tania, ≥ 40 years old, Bolivian, professional education, not screened, FG22).

"Exactly, women who cannot stand to be looked at in those parts and then would stand better to do it themselves" (Mia, < 40 years old, Swiss, professional education, screened, FG4).

Claude, who had a prior negative experience with a gynaecologist whom she found too intrusive and suspicious, seemed particularly interested in this method:

"I would do that. No need to [imitates the medical act] and nobody will play with my..." (Claude, < 40 years old, Portuguese, professional education, not screened, FG11).

Support to the self-sampling method was expressed by women for whom the gynaecologist examination represented a hardship:

"It' so nice to be able to say I can do it at home" (Amélie). *"At home, exactly"* (Rita). *"It's simple, it's quick, I can choose my moment, I don't even need to undress"* (Amélie). *"It's so black and white, it's extraordinary"*(Rita). (Dialogue between Amélie, ≥ 40 years old, Swiss, higher education, not screened, FG2 and Rita, ≥ 40 years old, Italian, professional education, not screened, FG2, both tested).

"It's great to have had such an idea, to do it alone at home" (Lucienne, < 40 years old, Egyptian, professional education, screened, FG16), particularly « traumatised » by the speculum intrusion.

Heidi who had tested the self-sampling insisted on the fact that she had tested it “standing” and not “lying”, to signal a clear distinction with the gynaecological exam uncomfortable position:

"When I was about to do it, suddenly, I wondered, here they don't say what position to take. Do I do it standing, sitting, lying down, how do I do it? If I think as if I was in the gynaecologist's office, I should be lying down with legs opened. And I didn't want to be reminded of that, because when the gynaecologist, when you're lying down, he introduces a speculum, and he opens, it hurts, and then I did it standing. Bluntly, I'm inside, I turned it, I took it out, I put it in the container, in the liquid for transport, I broke it, I closed and hop, put it in the mail" (Heidi, ≥ 40 years old, Peruvian, higher education, not screened, FG11, Tested).

It is worth noting that women who tested the self-sampling and felt no pain during the swab worried about having done it inadequately. The absence of pain, in contrast to the pain usually felt during the pelvic exam with a gynaecologist, was then suspicious:

"It used to be very painful for me, he would go very deep and scrape with that thing, it was a moment that really was not a treat. And that's why I wonder if I've done the test right since I didn't feel anything. I thought that I must not have done it right, then I insisted a bit, but it was so small and thin compared with the gynaecologist. One cannot feel anything. I thought it was not possible, at the gynaecologist I feel it. It's worrisome because one wonders: 'did I do it right?' I've done it at home, I was expecting the pain, I was telling myself: 'it's because you don't dare go deep enough'. At the gynaecologist, it's really like a toothbrush that goes deep inside and scrapes, I would jump in the air and with this nothing! I almost felt nothing, I said ,but I have to go deeper, not too deep'. I've been told ,you go until where you can stand it'. Then I couldn't go deeper and I was standing it very well, it was painless, very little sensations" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14, Tested).

Cost

The self-sampling kit is not on the market today and therefore does not have a price attached to it. During the focus groups, it was supposed that it would be less expensive than the cervical exam. Rita and Nathalie considered that this could represent a potential problem for gynaecologists.

"The advantage is that we don't need to go to the doctor anymore. Well, what's up with the doctors' fees with their amount of... 10 minutes at 150 CHF, let's be honest. I don't think there's much interest to do this [self-sampling]! For my wallet and for insurance also (...) Then there are clearly some savings that can be made, I think that this kit is much cheaper than the doctor and his fees" (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

"One should also consider something else, this test is probably something that costs much less than going to the gynaecologist. Then it should be taken into account" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2, Tested).

The attractiveness of the “cheaper cost” or the “gratuity” of the kit was particularly acknowledged by migrants and women working with minority groups:

"Well, free, it increases the participation. When it's free for everybody, it's more practical" (Gabriela, ≥ 40 years old, Peruvian, professional education, not screened, FG6).

When we asked migrants if they thought this test would be accepted in their home country, they all answered affirmatively.

Access and time saving

In Chapter 4, we highlighted how the waiting list to get a gynaecologist appointment was annoying and discouraging many women. The time saving provided by self-sampling was very attractive as illustrated in the following quotations:

"It's the time, the practical aspect of this thing! I'm always running! You understand? If one could do the exam while walking, I would do it. The... I think, time! This thing is practical, you can do it yourself. As for myself, I don't have time to go to the gynaecologist" (Estelle, ≥ 40 years old, Brazilian, professional education, screened, FG21).

"It's all that to find, a doctor, an appointment, go to the appointment and all that. It was much easier like this [doing the self-sampling]" (Ema, < 40 years old, Brazilian, professional education, not screened, FG7, Tested).

"It's very practical it doesn't take time, one doesn't have to wait the appointment for one month and a half. Waiting lists are always very long" (Stéphanie, < 40 years old, Venezuelan, higher education, not screened, FG14, Tested).

Like Estelle, Ema and Stéphanie, some participants considered self-sampling as a good alternative for women who do not have time (do not want to lose time) to get screened traditionally. Following the idea of “saving time”, the possibility of receiving it at home was also valued.

"If they mail it and you sent it back like this, it's easier" (Grace, < 40 years old, Canadian, higher education, not screened, FG7, Tested).

Autonomy, do it yourself

The self-sampling test questioned the ability of women to do an act that was/is, up to now, an act only performed by professionals. It was also situated in their ability to self-diagnosis. Indeed women often explained that they perform breast self-examination to identify a tumour. Could the self-sampling be part of this “self-diagnosis gesture”?

"To be autonomous, to be able to control my own body" (Brigitte, ≥ 40 years old, Swiss, not screened, FG2, Tested).

"Well aside from the swab and to palpate breasts a bit, I don't see much interest in a visit, for me it was more for contraception that I was doing it. But if there's a way I can do it myself, I would do it fairly quickly" (Eline, < 40 years old, Swiss, higher education, not screened, FG7).

"If that method could be made available to women, it's a good thing. Absolutely because women can do it themselves, then you can send directly, you can know what's up, I think it's a good thing" (Nathalie, ≥ 40 years old, Spanish, professional education, not screened, FG5).

Who might use self-sampling and why?

When we asked participants: "Is the self-test adapted to every woman?", they frequently answered that it could be suitable for women whose visit to the gynaecologist was too embarrassing or the pelvic examination too painful. Indeed, the test received most support among women who avoided a screening because of the intrusiveness of the examination. In other words, a negative experience due to a pelvic examination and/or an inappropriate behaviour from the gynaecologist led women to prefer the HPV self-sampling (cf. section: "less embarrassment").

The question of "who" might be more susceptible to accept self-sampling" generated various answers. Some answered it is convenient for every woman and could make their life easier. For Manuela and Christine it could be particularly interesting for women who do not get screened for cultural reasons:

"There are also many women who cannot go to the gynaecologist for cultural or religious reasons, especially a male gynaecologist" (Manuela, ≥ 40 years old, Swiss, higher education, screened, FG4).

"In countries where incidence is really high, where there are not necessarily doctors, where on top of that there can be issues related to religion, where the gynaecological exam is more complicated. I know my father works at the hospital, then he regularly sees problems for example with people of Muslim religion who don't want to be examined by men, to be touched by men" (Christine, < 40 years old, French, higher education, screened, FG7).

Conflicting opinions arose around "young women", a population to target for Brigitte (to avoid shame), Melody (to save time), Gaia (to reduce cost) and Stéphanie (to not have to talk about it with the mother).

"For young women it can be nice because it doesn't cost anything" (Gaia, ≥ 40 years old, Swiss, professional education, screened, FG18).

"When I was young, I was doing things without telling my parents and I had been to the gynaecologist without telling anybody. I think for girls for who don't want to tell their parents that they are sexually active, it's a good tool" (Stéphanie, < 40 years old, Venezuelan, higher education, not screened, FG14, Tested).

Alternatively, the test could be unsuitable for teenagers or young women.

"For young girls, where the relationship with the body is not that obvious, because tampons can already be an issue, some women do not use them. When one is younger, when one never had a sexual relationship, one does not have much routine putting something in there" (Christine, < 40 years old, French, higher education, screened, FG7).

When they talked about young women, the need to be seen and informed first by a doctor often came up:

"I don't think for young girls. I think it's a little too, yeah, no knowledge of the body. One needs someone who is a bit present, it shouldn't be the parents. Then, I'm not sure I see the interest. For young girls, it's still better to go to the gynaecologist" (Yannick, < 40 years old, Swiss, higher education, not screened, FG7, Tested).

"No I don't let my daughter to do that alone, it doesn't reassure me at all. I prefer, if she has to do this, that she goes to a gynaecologist" (Maeva, ≥ 40 years old, Lebanese, higher education, screened, FG8).

"But it's mostly that girls lack information, they can lack information and this is just a test, at some point one has to be with a health professional, because there are many other things to explain" (Alberta, < 40 years old, French, higher education, not screened, FG17, Tested).

Some felt self-sampling was not appropriate for older women or for disabled women:

"Isn't that self test limiting with age ? For example, can an older woman do it alone ? I thought about my grandmother. She's 60, she's obese, she has some mobility difficulties...I think that test is a little limiting. Because one can think that it's easy, but age, age is maybe a factor that limits its use" (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

"I'm working with minority populations, either sick for as the result of a whole lot of reasons or handicapped persons. I wonder how much it's easy to unscrew, it's not necessarily easy to unscrew when one is old and one is weak. And depending on the mobility, I fear that the tube is too narrow ; I think larger system should be designed" (Valentine, ≥ 40 years old, Swiss, professional education, screened, FG16).

It was not considered appropriate for women who 'do not know their body', with a reference to easiness with anatomy:

"Frankly, I'm not sure that a woman who doesn't go to the gynaecologist, I doubt that ... this is really when one knows her body very well" (Pia, < 40 years old, Swiss, higher education, screened, FG3).

"For women who know their body a minimum" (Brigitte, ≥ 40 years old, Swiss, professional education, not screened, FG2, Tested).

While many women commented on the different advantages of the self-sampling method, over the course of the discussions, they also raised a series of preoccupations that, at the end, made them on the whole little favourable to this method.

Self-sampling disadvantages

Self-trust: the right gesture at the right place?

The self-sampling test aroused a lot of fears among both women who tested the kit and those who had not. These fears included to hurt oneself, to rub at the wrong place, not to collect enough cells, to bias the results, the absence of trust in oneself to perform the test properly. Sarah, who had not tested the kit, summarized well the issue:

"I wouldn't trust myself to put that, to do what's needed to get cells on this, then I tell myself that I don't mind going for a screening. Not necessarily with the doctor, it could be done by a nurse, I don't know somebody from the nurse staff. But I don't feel like doing this kind of things alone at home" (Sarah, < 40 years old, Spanish, higher education, screened, FG1).

The procedure itself was questioned by women who tested the kit, like Jane who reported being afraid of breaking the stick inside herself:

"And if it breaks ? I called my friend and she told me : 'take that thing out, do not touch it with anything'. Then first I washed myself. She told me to put it until where my finger could reach. I've put it till there. I remembered she [DEPIST nurse] had told me to turn around once. But I didn't turn around because I was afraid it would break and I took it out immediately. I was nervous, but I've done it. For me, it's not practical. I prefer to be seen by a doctor, because one is scared it will break inside, that the cotton stays inside" (Jane, ≥ 40 years old, Bolivian, professional education, not screened, FG6, Tested).

Some raised questions about the female anatomy: where does the cervix begin? Where does it end? They worried about not being able to find their cervix:

"When exactly, can one have the feeling at the it's time to stop, or not scrape too much ? Since the person, well the gynaecologist, he can see what he's doing" (Eline, < 40 years old, Swiss, higher education, not screened, FG7).

"It has to touch the cervix, but I don't know if one can, maybe do that in the whole vagina, I don't know. I imagine that if one doesn't do it right, I don't know, people not used to it, and then don't do it correctly, if it doesn't get to the cervix and one rubs all the uterus" (Cassie, < 40 years old, Swiss, professional education, not screened, FG15).

Women who had tested the kit were not sure how far to insert the swab and how strongly they had to rub to collect cells. Rita even involved her husband:

"I had a doubt, it's my husband. I asked him. I told him 'read with me since I'm not totally sure to understand'. He read and he told me: 'no you have to do it like that'" (Rita, ≥ 40 years old, Italian, professional education, not screened, FG2, Tested).

"Where is this cervix ? The swab, it's not my problem, we all manage to turn around clockwise or anticlockwise, but for me it was to tell myself: 'am I high enough or not ? ' and then if I go up too much, do I take cells at the wrong place ?" (Tamara, ≥ 40 years old, Swiss, professional education, not screened, FG11, Tested).

"Just a doubt about how to behave around my vagina, if I had to stay around or if I had to try to... Afterwards, I read again, I stayed outside, there was no indication to stay inside the cervix" (Brigitte, ≥ 40 years old, Swiss, professional education, not screened, FG2, Tested).

Having to mail the sample implied to trust the post system, however the fear of the « post office » losing their samples often came up in the interviews.

"It's your health, you can take time, no [to go to the doctor] ? On top of that, you mail it by post. Imagine you mail it and then there's a strike. Will your thing... prestamped envelope. But even if you send it by post, even if there's not strike, let's imagine it takes 2-3 days, do the cells live for 2-3 days ?" (Aurora, < 40 years old, French, higher education, screened, FG9).

"I trust the doctor, but I don't trust the post because they often lose my letters. Then I prefer to go to the gynaecologist" (Renée, ≥ 40 years old, Spanish, professional education, not screened, FG14).

Some women expressed the fear of doing it wrongly, and then getting wrong results (in all groups).

"If you make a mistake ? And then you think you're fine. And maybe it's because you made a mistake. You get sick and...? oh, no ! Because, for example, if it says that the result is negative and it's just because you've not collected enough!" (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

"You're not going to put it at the right place, you're not going to collect the right stuff, and for that what will you get ? a wrong result !" (Lorraine, ≥ 40 years old, Brazilian, professional education, not screened, FG19).

"I would be scared of my performance in fact, to do it wrong and then to base my judgement on a result that maybe will not be 100%, due to my performance not to go far enough, not to collect enough, well I prefer, I would be more reassured with a professional" (Miriame, < 40 years old, Swiss, professional education, screened, FG12).

Fear of pain or injury was frequent. Some of the women who had tested the device reported having hurt themselves, especially since they were worrying that they were not thorough enough (not going "far enough").

"I felt it was not practical at all in fact. That it hurt, maybe I did it wrong, in a bad position, I was scared in fact, it was small! Then I told myself, the last thing I want is to break it inside while doing a wrong move, because there's a place where it's already pre-cut. I did not trust myself, I told myself I had done it wrong" (Alberta, < 40 years old, French, higher education, not screened, FG17, Tested).

"I was a little surprised, I feel comfortable with my body, but there still am I doing it the wrong direction ? And then when one is more or less sure that it's touching the cervix, it hurts somehow " (Mafalda, ≥ 40 years old, Danish, higher education, not screened, FG13, Tested).

"I was afraid not to reach the right place, then I think I put it a lot, I've had colics afterwards, I think that I pushed a lot" (Ema, < 40 years old, Brazilian, professional education, not screened FG7, Tested).

Ema and Yannick, two young women were scared to use it and explained that they were not used to tampons.

"I was afraid to put something, I've never used a tampon then I don't know. I was afraid to do it wrong, not to manage, to hurt myself" (Ema, < 40 years old, Brazilian, professional education, not screened FG7, Tested).

"I largely preferred someone else to do it for me. Because I use very rarely tampons. And also by fear to do it wrong, fear that it would hurt and that the result be biased by my fault. And then afraid that it would hurt " (Yannick, < 40 years old, Swiss, higher education, not screened, FG7, Tested).

Even though the lack of embarrassment was seen as a benefit of the self-test, surprisingly some women who had tested the kit quoted that this method could be more awkward than the Pap smear.

"But truly, I think that many women will be embarrassed to do it, at any age " (Grace, < 40 years old, Canadian, higher education, not screened, FG7, Tested).

"I don't give details, but on oneself, it's a little weird. Not intimist towards the material, and not necessarily ready to selfcontrol in that place of the uterus, vulvas ok. I think that doing a swab on the tip of the tongue, I can do it, it's easy. But everything that's of gynaecological order, maybe it's more personal, but I couldn't see myself with a mirror, etc." (Tamara, ≥ 40 years old, Swiss, professional education, not screened, FG11, Tested).

As Howson (2001b) highlighted, the visualisation of the inside body is not necessarily "easy to watch" for every woman.

Some women, having tested the device or not, expressed the wish to do it for the first time with their gynaecologist or at least to receive his/her explanations with the guarantee that they would do it "correctly".

"If the first time, I do it with the gynaecologist, if she shows me how to do it, or if it's well done or not and then I do it on my own. That's it, that she shows me how I do it and if I do it right, if she agrees and tells me, 'yes you can do that', why not ? But there are still many questions left" (Maeva, ≥ 40 years old, Lebanese, higher education, screened, FG8).

"I might go to the a gynaecologist so he tells me how to do it well, how to position myself, to make sure it goes where it's supposed to go. To trust myself more" (Yvonne, < 40 years old, Cuban, higher education, not screened, FG17, Tested).

Elena considered she would only use it upon her/his doctor's request:

"If it's your generalist who advises it, myself I know that I trust authority, I would do it ! because, after all, we do urine tests, I think we can do exactly at the same place the same thing, if my generalist proposed to do it" (Elena, < 40 years old, Portuguese, higher education, not screened, FG18).

These comments emphasize the trust they placed in the ability of the doctor to perform the test properly, while not trusting their own ability to do it.

Does the test work?

The lack of confidence in the accuracy of the self-test was a common concern and was the reason Yannick, who used the self-sampling test, preferred the Pap smear.

"Reliability, and about what we were talking about earlier, because since we do the whole series of tests, one might as well do it whole in one go, and not one thing and then another one" (Yannick, < 40 years old, Swiss, higher education, not screened, FG7, Tested).

"I should do both. If I do this, you give me results and I go to the doctor and he gives me results, then we will know which... we will know whether it it's true or not. At the moment, I cannot say anything else, I'm not a doctor, I can't. I have to do both, to get both results in front of me" (Carla, ≥ 40 years old, Cameroonian, professional education, not screened, FG2).

Valérie said she would like the self-test to give an immediate confirmation that the collected cells were « appropriate » like a pregnancy test. Without instant results, she thought the test was useless:

"I don't see the usefulness of the thing if one cannot verify if it's a test that's done right or not. The fact of not being able to know immediately if it's right, not the result, just to know that we've done the test properly. I've done HIV screening, one gets a verification. I think it's a pity not to have that" (Valérie, ≥ 40 years old, Kosovar, professional education, not screened, FG13).

The second frequent question was: "Is it sterile?" Participants were concerned about whether the fluid and the device were aseptic and for those who tested the kit, if they had cleaned themselves enough like Mafalda:

"On top of that it's not explained if one has to be sterile, for example myself I've had lots of bladder infections and each time, one really has. It's more or less sterile to have a valid test, it bothered me because it's not well explained, there's not explanation on hygiene before or..." (Mafalda, ≥ 40 years old, Danish, higher education, not screened, FG13, Tested).

"When one goes to the doctor, everything is sterile, etc. Then I don't know if I would do it right just in terms of cleanliness. If some persons do it right regarding cleanliness, but I don't know to what extent it matters" (Noémie, < 40 years old, Swiss, higher education, screened, FG9).

"In my opinion, the risk is that the sample will be contaminated. Let's say I put the stick and everything and while I'm opening the small thing, the stick gets in contact with the wall or something. The sample is contaminated. That's what in fact, I thought about it afterwards, because as it's some liquid" (Daniela, < 40 years old, Hondurian, higher education, screened, FG16).

When comparing the two tests, a majority of the participants considered that the Pap smear is efficient while the HPV test is questionable. Nearly all participants were not aware that the two tests measure different things. One woman, knowing that they are two different tests, believed that the self-sampling method is more reliable than the Pap smear as it detects the presence of the specific HPV responsible for triggering cervical cancer.

"As I understood, it's that they don't go together, because the pap shows if you have cancerous cells already, and this one shows if you have a virus of the dangerous group. You make this self-sampling, you know whether you already have in your organism a virus that is from the group of viruses than can give cancer" (Astrid, ≥ 40 years old, Romanian, higher education, not screened, FG1).

Participants not attracted by the self-test were mainly women who regularly went to screening; they questioned the reliability of the test, its results and the procedure. They were further worried that this test could replace the interaction with the gynaecologist, whom they considered as an essential interlocutor and the only competent person for such an important check-up. Indeed the risk of missing cancer with self-sampling was very present in women's accounts, especially among *regularly* screened women. In fact, some participants reported that they felt safer after a gynaecologist examination like Véronique:

"Maybe it's wrong, but I almost have the impression that the annual check-up protects me. It's ok, she's seen me, she's palpated me everywhere, then if there's something..." (Véronique, < 40 years old, Swiss, professional education, screened, FG3).

For these women, gynaecologists are professional, competent and legitimate to screen women, an opinion shared by women who had tested the kit (Erica) and by some who had not.

"A gynaecologist knows, whereas we don't know, as for myself as says X, I wouldn't dare to introduce a thing and, I cannot. Whereas a doctor, a person who is there is his profession, in his work, it's more safe" (Cheryl, ≥ 40 years old, Bolivian, professional education, not screened, FG20).

"Go to a gynaecologist, it's his domain, everybody his job" (Erica, ≥ 40 years old, Tunisian, higher education, not screened, FG13, Tested).

"I don't think it can replace a visit with the gynaecologist. I prefer to spend 5 uncomfortable minutes, to feel it's not comfortable but to be reassured that he knows

what he does, that he knows how to do it, he knows how to collect the sample. And in fact I even think at the same time the exam is fairly soft, it's fairly quick"(Fabienne, < 40 years old, Brazilian, professional education, screened, FG19).

They also pointed out the importance of the contact, of having someone to answer their questions, a moment that is "irreplaceable" for Clotilde and Aïcha (screened) and Frederique (unscreened and who had tested the kit):

"The moment to do this exam, it's also the time we have to talk with the gynaecologist of other things that are not necessarily related. It's a little bit the excuse to have this time for that, for me that cannot be replaced" (Clotilde, ≥ 40 years old, Brazilian, professional education, screened, FG12).

"Nothing can replace the person who has learned all this well, to whom we can ask questions and whom we trust" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14, Tested).

"This medical visit once a year, it's ideally the time when one can ask questions adapted to our life situation before/after the delivery etc., well everything that goes with it. If I don't have this, then when do I ask my questions? Regardless of the fact that we can do this at home or not, I think that the medical visit could, should respond to a whole bunch of other issues" (Aïcha, ≥ 40 years old, Hungarian, higher education, screened, FG12).

They often mentioned that the gynaecologist examination represents « something more », it includes complementary exams and guarantees a proper follow-up. The gynaecological visits were seen as providing a more comprehensive check-up:

"I still find more comfortable to do it at the doctor, who will anyway do all sorts of other check-ups at the same time" (Dalida, ≥ 40 years old, Swiss, professional education, screened, FG4).

"On top of that, the gynaecologist doesn't only look at cervical cancer, we can have 10'000 others things" (Pia, < 40 years old, Swiss, higher education, screened, FG3).

"When one does a test like this, it's just for that. It's very specific for the papillomavirus. When you go to the gynaecologist, you have other things going on. There, if it's only for that, I would do it. But to go to the gynaecologist, we're still obliged to go for the other things, for more information, for our body in general, our woman's life which changes with time, and the moments of life. I think it will not keep me from going to the gynaecologist" (Heidi, ≥ 40 years old, Peruvian, higher education, not screened, FG11, Tested).

And since screening is a medical routine, "it runs well", "it's an evidence", they considered there is no need, for the « well checked women », to change what has been implemented for years.

"Maybe, I don't know, if I was 16 and I was told : 'take this, you can do it like this [i.e. use self-sampling]', maybe I would have another opinion, now it's been part of my life

to go to the gynaecologist once a year" (Pia, < 40 years old, Swiss, higher education, screened, FG3).

In a focus group including women who had tested the self-sampling method and some who had not, the latter asked systematically: "Did you manage to do it alone?". This was raised as an issue by Véronique for example: "*I'm happy not to have to do it by myself" (Véronique, FG3). Fabienne and Magy (Brazilian) wondered if they would be brave enough to do it alone:*

"I don't know if I would be brave enough to do it by myself. I think it's not comfortable. We have ovules we can insert when we have a leak and some cream. It happened to me that the doctor put it all, and it was a relief, it was done. And me to do it myself, I'm not ok" (Fabienne, < 40 years old, Brazilian, professional education, screened, FG19).

"I would never be brave enough to do it, to put it" (Magy, < 40 years old, Brazilian, professional education, screened, FG19).

In a more moderate way, some women saw an opportunity to alternate self-sampling with Pap smears. In that case, the self-test represents a good compromise to space out gynaecologist examinations.

"Every other time I could do it like that, and the second time, I would go to the gynaecologist to make sure it's still ok" (Manuela, ≥ 40 years old, Swiss, higher education, screened, FG4).

"I think every other year would be good, it's fine in-between two visits to the gynaecologist if we can check-up ourselves a bit" (Frédérique, ≥ 40 years old, Swiss, professional education, not screened, FG14, Tested).

"Since I go every other year to my gynaecologist, why not do that test in-between. That's a good idea, especially for people who don't have much time, then do it in-between this control and make an appointment with the gynaecologist the next time" (Morgane, ≥ 40 years old, Swiss, higher education, screened, FG14).

For Amanda who is unscreened, it is an opportunity to increase screening:

"For me, once a year is not sufficient, I should do it every 6 months and in that case, it can be a good thing to supplement, to go maybe once a year to the gynaecologist and then 6 months later to check. Not as an alternative, as a complement" (Amanda, < 40 years old, Russian, higher education, not screened, FG17).

Therefore, many participants were clearly not ready to challenge the traditional 'division of labor' between patient and doctor.

Risk of missing "something" by "kicking out" the specialist

This criticism was mostly made by screened women and those who had a family history of cancer like Aurora who had not tested the kit and rejected the idea of promoting it:

"I think that it's a scandal, the word is a bit too strong, that they have that in mind because it's hiding one problem. If there are people who have, we know that we have to

do the prevention of screening or something like that, and that there are obstacles and we should try to unblock people, to find another way. But with and that implies the specialist. Not that! It's more the fear of the drifting, because we're almost at the 'complete idiot's guide in obstetrics' (kit de l'obstétrique pour les nulles), you do it all at home, because the industries will say, ok but it's less expensive, it's great. And then later everybody will be sick!" (Aurora, < 40 years old, French, higher education, screened, FG9).

"I'm not sure it's such a great idea in terms of public health, because I think we still should go to the gynaecologist for other reasons than I don't really see the interest of, somehow, exonerate them. They [women] will think: oh bah, I've done, then I'm done, it's not worth going to the gynaecologist and it's a shame in a sense" (Christine, < 40 years old, French, higher education, screened, FG7).

Several participants pointed out that the self-test would not solve the problem of non-attendance due to a bad relationship between doctors and patients. They stated they would like more efforts to be done to improve these relationships, rather than solving the problems by reducing medical visits.

"I would prefer that there is some thinking at the gynaecologist to think about softer things, more pleasant, rather than that at home alone. Because if this is done, it's not to help us, it's to help the clumsiness of gynaecologists. It doesn't help us if gynaecologists must be taught how to behave with women, that's what can help us" (Marguerite, < 40 years old, Swiss, professional education, screened, FG12).

"For me, it's like with the speculum, ideally there should be an alternative, well I can very well imagine that this possibility can exist and that efforts are made so that trained gynaecologists be empathetic ideally" (Ana, < 40 years old, Swiss, higher education, screened, FG12).

For Véronique, self-sampling "dehumanized" a medical act:

"I find that there this is dehumanizing medical acts, we should not to lose the human relationship, at least in that domain!" (Véronique, < 40 years old, Swiss, higher education, screened, FG3).

They considered that the self-sample test should not replace gynaecologists' visits, especially since these are including other preventive acts:

"The Papanicolau, it can do many things, not only cervical cancer, but also for other things. The HPV, to see if there is a wound, something like that, that would be in that region, it's more to see if you have something in that region of the cervix " (Lorraine, ≥ 40 years old, Brazilian, professional education, not screened, FG19).

"My fear with this thing is that it starts replacing the gynaecological visit, and there are many other things that can be checked with the gynaecologist. This self-sampling is great, I found it a very good idea. But I don't think it can replace the visit. Because the problem with the cervical cancer, it's exactly in the initiative to go to the gynaecologist.

The initiative to do prevention. With this self-sampling this initiative goes to zero" (Marjorie, < 40 years old, Brazilian, higher education, screened, FG19).

Like Michèle and Mickaela said, "I will need to go anyway to check my breast" so the self-test would not replace the medical visits in their cases.

No guarantee that women will get screened

Some participants – screened and not screened – stated that the self-test would not guarantee that more women get screened. They thought that not regularly screened women were lacking information or lacking in self-care attitude.

"Not sure that people who are either poorly informed or not informed, somebody who is not informed who receives just this, it doesn't mean anything, there is no support. Somebody who doesn't go because she doesn't know, she will not understand anything. Somebody who does not do it because of embarrassment, I would be surprised if this would be useful" (Véronique, < 40 years old, Swiss, higher education, screened, FG3).

"If this self-sampling was in a pharmacy and if women keep not being informed on how to do the exam, which is important, it will not change anything. They have to be informed. Nobody will buy it, if they don't know they have to do the test" (Fabienne, < 40 years old, Brazilian, professional education, screened, FG19).

"If this [self-sampling] is given away, you don't care, you put it in your bag and it will stay there. If you want to use it, it's that you take care of yourself" (Monia, ≥ 40 years old, Bolivian, professional education, not screened, FG22).

Their comments suggest that the embarrassment related to the pelvic examination is not the only factor limiting screening.

6.3. Conclusion

While a number of advantages have been associated with self-sampling, disadvantages have also been often emphasized by participants to the focus groups. Opinions ranged from a total enthusiasm to a total rejection and, in the middle, some ambivalent attitudes. These attitudes included doubts about the results, the materiel, the ability to use the kit correctly, the fear of getting hurt, of missing "something". This suggests that the method could increase the participation of cervical screening, but among some specific women only, in particular those who were particularly interested in being offered an alternative to the gynaecological examination.

Consistent with other studies, there was a major concern – expressed by women who had tested and some who had not - over performing the test accurately. Preoccupations about doing the test "properly/right" prevailed, especially among women who undergo regular screenings. Most participants were more confident in their gynaecologist's ability than their own to collect cells samples and preferred the gynaecological visit even if the pelvic exam is uncomfortable and embarrassing. Women who had not tested it and who were *a priori* favourable to it when the procedure was explained to them during the focus group, finally

preferred over the course of the discussion the gynaecological examination, for safety reasons.

The literature suggested that screened women would be more willing to accept self-sampling, but our study does not confirm this observation. The most enthusiastic women were those unscreened for whom the speculum intrusion was so painful, “traumatising”, and time consuming that they would immediately adopt the self-screening test if they could. However, in the focus groups, not all unscreened women would have accepted it. Furthermore more, among the women who had tested the device, some said they would not use it again in the future, especially young women who were anxious to hurt themselves, not to use it accurately and uneasy with the device.

In the end, even though many women perceived the benefits of self-sampling, most participants indicated they would not use the HPV self-sampling method. Women who had not tested the method and just looked at it during the focus group turned out to be more negative towards it than those who had tried it. For them, the actual use of the test might have demystified the device. In line with the demands for information reported earlier (Chapter 3), most women could not differentiate the specific goals of the two methods. Only two women suggested that this device could represent a “financial threat” for gynaecologists.

Interestingly, self-sampling was considered as an acceptable method in addition to the Pap smear test, rather than as a replacement to it. Women saw it as a possibility to gain more information by collecting cells more regularly than their visits to the gynaecologist. This could paradoxically contribute to overscreening.

In the focus groups analysis, we did not notice major differences between migrants and Swiss women on this issue of self-sampling. Both groups expressed concerns regarding the test accuracy. While we could not identify differences across their origins, some women saw self-sampling as an opportunity to increase screening in their home country, especially in Africa (a continent often quoted). The Latin America women we interviewed tended to prefer a relationship with a doctor rather than self-sampling.

Some generational difference could be noticed: young women, who are used to visiting the gynaecologist, did not see the necessity to change this practice, whereas some older women, less used to going regularly to a gynaecologist, seemed more in favour of self-sampling, especially if they had a bad experience with pelvic exams in the past.

The self-sampling method, so far, does not seem likely to modify rapidly and thoroughly women’s behaviours in regards to screening. While some might find it more acceptable, many emphasized that the gynaecologist remains the expert and not the woman. Self-sampling replacing the gynaecologist would be unacceptable and dangerous for some women. Therefore, they often thought that the focus should not be on which test needs to be promoted to increase screening, but instead insisted on the importance to improve the gynaecological examination and relationship with the doctor on one hand, the diffusion of information on the other hand. This preference of women for encounters with gynaecologists can also result from the dependency on medical expertise, especially in

relationship with female body issues, described in the literature on medicalization (Conrad 2007, Martin 1987).

Finally, it is important to note that studies concluding that self-testing can increase the participation of women were conducted in countries (especially the UK, Canada, US, Australia, New Zealand) that adopted a systematic screening programme. In those contexts, women targeted for self-sampling were those who did not respond to the invitation for cervical smear collection. The situation is completely different in Switzerland which has an opportunistic screening system.

Conclusions

Main findings

This study has allowed to describe different barriers to cervical cancer screening reported by a sample of women living in Geneva. Results emphasize that difficulties to get screened arise in different respects. They suggest that rather than one single factor explaining non-attendance, a constellation of barriers contribute to deter women from attending screening. These factors relate to aspects of the Pap smear procedure, including gaps in information, the reluctance or difficulty to attend a gynaecologist, the uneasiness associated with the pelvic examination. They also include aspects related to the social life of these women. In particular the different life stages they go through are related to situations (pregnancy, absence of sexual activity,...) more or less conducive to attend a gynaecologist for preventive reasons. Social reactions defined by taboos related to women's bodies, influential in some cultures, and life events, such as a divorce or job loss, can also play a role in screening attendance. Results further suggest that, due to these diverse influences, women may have uneven trajectories in regards to cervical cancer screening, i.e. they might be regularly screened at some point in their life, then quit doing it and possibly get back to it later. These results, provided by qualitative data collected through focus groups, gave a voice to the women themselves, offering them a chance to address the obstacles they encountered around screening in a comprehensive way.

Cervical cancer screening is a complex medical and public health issue, associated with recent evolutions in medical knowledge and changes in practices through the introduction of HPV tests and HPV vaccination. While the medical community may take for granted that the population in Switzerland is well informed about cervical cancer and its screening, the focus groups we conducted emphasized that a fair number of women are lacking basic information about the disease, its treatment, its prevention and screening itself. These gaps contribute to their non-attendance (see Chapter 3). Gaps in knowledge were not specific to particular subgroups among the participants and were observed for Swiss and migrant women, for those with a professional education and those having attended university, among young and older participants. Doctors' limited communication about cervical cancer screening might aim at limiting undue anxiety. However, we observed that partial or limited knowledge is conducive to anxiety and dissatisfaction, confirming the results of previous studies (Philips et al. 2005, Jepson et al. 2007).

Women's accounts suggest that the term 'screening' is a polymorphic word, an umbrella term that embraces several things: it can refer to the screening tool used to collect the cell sample, to the cytological exam itself or to the campaign and associated to health information. Our findings reveal that these different meanings generate confusion in the population. This can contribute to explain why most women are not sure what the screening is for and what exactly is screened, therefore are not certain about its value. Partial knowledge can also influence reporting about attendance and our results emphasize the difficulty to measure screening coverage through self-reported quantitative data, like the Swiss Health Survey for example.

Demands for information and clarification match the opinion often expressed by participants that cervical cancer screening is useful. This means that women who are not regularly screened do not necessarily question the Pap test in itself. Rather they encounter different barriers that keep them from attending (see Chapter 4). These barriers are of diverse nature, some are practical and related to the organisation of the health care system, such as for example the waiting time before getting the procedure done, once one has set her mind on doing it. Comments in regard to costs indicate that despite a universal health insurance coverage in Switzerland, preventive care is not necessarily easily accessed. Social life can interfere in screening attendance as observed around social reactions, especially from men in some cultural communities and from partners or husbands who might not be supportive. Furthermore social lifestages also influence the likelihood to attend a gynaecologist and consequently to be screened.

Lay views on health and disease, fears associated with cancer and its prevention also affect screening behaviours. Participants accounts revealed how much talking about cervical cancer encompasses emotional and moral connotations. These views are interpreted by some as signs of insufficient information and promoting fatalistic attitudes. However, work on fatalistic attitudes suggest that these might fulfill specific functions for individuals, like relieving stress and managing uncertainty, especially when they consider that they lack control over their health (Keeley et al. 2009). From women's perspective, screening is not necessarily associated with increased control over future health as stated by Howson (1998): 'Indeed uncertainty is not necessarily alleviated in the case of cervical screening, but for some women, may be exacerbated' (p. 209). In regard to prenatal screening, we also described how pregnancy surveillance can exacerbate uncertainty for some women (Burton-Jeangros et al. 2013). Such lay views, associated with ambivalent feelings about the 'borderland' situation (Martinez 2005) between feeling healthy and receiving abnormal results, contribute to explain why some women, in the absence of any symptom, do not see the benefits of screening.

The focus groups offered a space where women could talk about the whole process of screening and their contrasting experiences in regard to gynaecological visits offer important insights on the obstacles that relationships with doctors can represent (see Chapter 5). While these aspects are often little discussed, their accounts suggest the existence of a variety of practices among doctors. In addition, recurrent references to the comfort or its absence, to the importance of communication around the procedure indicate the ambivalence associated with the gynaecological check-ups. Women emphasized their need to feel respected in their relationships with gynaecologists. Many participants were hoping that their preoccupations regarding the peculiar nature of gynaecological examinations could be made more visible.

In regards with the evaluation of the HPV self-sampling kits (see Chapter 6), some participants were a priori interested in the device and saw various advantages in comparison to the gynaecological visits. However, they often considered these advantages for other women, not for themselves. A few participants considered that the self-sampling kit could result in women's empowerment by making them able to perform an act traditionally performed by doctors only. However, many valued the regular visits with a gynaecologist, despite their contrasting experiences reported in Chapter 5. They preferred that a professional perform the smear since few women were confident in the 'do it yourself'

procedure, emphasizing risks of error due to their own lack of skills, but also problems attributed to the rest of the system, including preoccupations with the absence of a sterile environment at home, the loss of their sample in the post, the inversion of results by the laboratory. Interestingly, these risks of error were not considered when the doctor performed the swab. These reactions suggest that while patients often voice concerns today about the health care system, their dependence towards professionals and the quality of their relationships with doctors, the possibility to take over some of the tasks traditionally performed by doctors is not valued. This could explain why the idea that screening can be a 'choice', either made or not by a woman, was never raised in the focus groups (to one exception). Discussions about the disadvantages of self-sampling helped women to talk about what was important in their encounters with gynaecologists and confirmed that, despite their criticisms, they still considered important to attend a gynaecologist regularly.

This study was conducted with a sample of women representing different age groups, education levels, family situations and coming from different national contexts. The findings suggest that barriers to screening, including gaps in information, are not restricted to specific groups but are present across the whole population we interviewed. The notion of age refers to different elements. It is a biological notion that relates to stages having specific risks for the disease. It is also a social notion, in two respects. It refers to successive generations having grown up in contexts where screening and/or attending a gynaecologist was not necessarily taken for granted (as we described it for older women in Chapter 4). Age is also associated with social norms defining appropriate sexual behaviours in both younger and older ages, staging for pregnancies. These norms are influencing visits to the gynaecologists and consequently screening behaviours.

The study included a mix of migrant women coming from different contexts (Europe, Latin America and Africa), with different education levels and legal statuses. Migrants from Latin America considered that cervical cancer screening information was better in their home countries than in Switzerland; furthermore a fair number of them reported preferring to attend a gynaecologist back home, due to some difficulties to access the Swiss health care system, but also routines established back home seemed preferable and more trustable. While preoccupations towards migrant women screening behaviours and in particular the role of cultural influences on their attendance are frequent in the literature (Forss et al. 2001, Fang et al. 2011), this focus might not be justified. Issues of access and cost of care are important, especially for illegal migrants, furthermore they may have to cope with pressing demands that make screening seem irrelevant. Nevertheless, it is important to consider that the influence of culture is not limited to migrant women. All women think and act towards screening in relationship with some cultural conceptions, be they Swiss or Bolivian. Furthermore, shame and embarrassment related to the pelvic exam are typically associated with migrant communities (Fang et al. 2011). However our analyses show, and some other studies did also (van Til et al. 2003, Howson 2001a), that western women report similar concerns with the pelvic examination. It can be hypothesized that this embarrassment also relates to the uterus itself, an organ that is not visible (by contrast to breasts) and therefore difficult to grasp and feel comfortable with.

Screening attendance behaviours have been analysed by some social scientists in terms of expectations and norms related to gender roles (McKie 1995, Howson 1999, 2001a, 2001b). It is worth emphasizing in our findings that many women talked about the 'obligation' of

attending a gynaecologist, of attending screening as something that one has to do, as a responsible attitude towards health but also as a responsible behaviour expected from women who are supposed to take care of their own and their family's health (Howson 1999, Bush 2000). This feeling of duty was however not necessarily associated with relevant knowledge. This could explain the importance of informal knowledge shared through women in the family, from mothers to daughters but also from daughters to mothers in some cases. On the other hand the role of men around screening and cervical cancer often remains implicit. Women who participated indicated their ambivalence towards interactions with gynaecologists, with opposed points of views in terms of the gender of the doctor. Men are also sexual partners who either encourage or not screening behaviours of women (McKie 1995). In some cultures, men have an important say about access of women to preventive care, with husbands deciding when to take their wives to a gynaecologist.

Results from this study indicate that women may have uneven screening trajectories over their lifecourse. From a public health perspective this is approached in terms of over- versus underscreening. There was no consensus among the focus groups participants about the 'normal' interval for screening, reflecting the heterogeneity within the medical discourse. Our findings suggest that some women, a small proportion, might be particularly preoccupied by the disease and might, to be reassured, demand for more than recommended tests. Kavanagh et al. (1998) also reported on some women willing to ask for more Pap smears in order to reduce their own risk. For them, changing recommendations and the now longer interval (3 years) between screening is considered inadequate. Such demands for more screening might be particularly expressed by women having previously received abnormal results or having a close proximity to the disease in their family (Bush 2000). On the other hand, a constellation of factors can contribute to underscreening, associating factors related to the screening procedure and the social life of women. This means that there are contrasting attitudes among the public towards screening, with some women demanding more prevention and surveillance and others needing to be convinced that screening is a useful procedure.

Our findings revealed that screening, for some women, produces undesirable consequences, confirming the need to pay attention to the harms of screening (Zwahlen et al. 2010, Osterlie et al. 2008, Raffle 2001). These included in particular the psychological burden of the procedure, with ambivalent attitudes towards the benefits of being informed. Little attention is paid to fears and ambivalence. However the anxiety associated with screening can be quite important, as illustrated by the case of a few women among the participants. These, having been treated successfully for precancerous cervical cells, were subsequently refusing to attend screening, in order to avoid going through a process they thought was generating unacceptable anxiety, even though it had kept them from developing a serious disease.

Limits

The study presents different limits. Results indicated how much the women who participated to the focus groups reported gaps in their knowledge, including about their own screening status, and how they were demanding for more information. Their motivation to obtain such information might have encouraged them to participate to our study. This

means that the sample might be biased towards women who are particularly in need of information. The focus groups methodology may have hindered the possibility to discuss some intimate issues related to the screening procedure and some women probably felt shy to address some aspects. However the discussions reported in the results also indicate the openness and willingness to share their experiences of these women. It remains likely that they talked more about obstacles related to the system, to the encounter with the gynaecologist than to their more personal and intimate barriers, that might be more difficult to expose to others. Even though the sample was fairly diverse, we only partially reached some specific subgroups, in particular Asian, African and Muslim women, whose experiences would have enriched our findings. Furthermore, it proved difficult to recruit unscreened women (outside of the DEPIST study). Fieldwork was conducted exclusively in Geneva, with its specificities in regard to migrants proportion and characteristics. However we expect the findings to provide insights on the experiences and views on screening of women living in the French-speaking part of Switzerland.

How to improve screening attendance ?

Results describing factors affecting women's motivation to get screened are expected to offer some insights about improving screening attendance. Our results emphasize the importance of the context in which screening takes place, highlighting both the role of the social experience of women and of their past and present relationships with gynaecologists. The combination of barriers we presented above suggest that there is not a specific measure that can easily increase coverage. Furthermore, reserves expressed towards HPV self-sampling suggest that this is not likely to offer a simple alternative to Pap smear testing that would be adopted in the population.

However, findings strongly emphasize the need to offer comprehensive and detailed information about cervical cancer, risk factors, prevention measures and available treatments. While screening has been in place for several decades, it does not mean that women are knowledgeable about it, this includes younger highly educated Swiss women. The opportunistic nature of screening in Switzerland and the absence of a national prevention campaign means that there does not exist an easily identifiable source of regular information, including updates related to changing recommendations and scientific knowledge. In an opportunistic system, screening is a choice (not an obligation like in an organized system). This reinforces the need to provide full and detailed information, to the intention of the whole population, irrespective of age, origins and education levels. Furthermore, this communication should encompass both men and women, since the former are directly involved in HPV infections, and not be limited to heterosexual individuals.

Results also suggest that changes in the organisation of screening could improve screening attendance. Accounts related to the cost of screening and to the organisation of Pap smears (getting an appointment, obtaining results) should be taken into consideration by policy makers and health care providers. Illegal migrants might be particularly sensitive to these issues, however they have been more generally discussed by participants, with constraining social characteristics (Swiss or migrants, professional education or higher education). Due to

the peculiar nature of gynaecological examinations, efforts in offering comfortable and respectful examination conditions should be reinforced.

While screening for cervical cancer is routine and taken for granted from a professional perspective, women's accounts showed how much the value of screening was not obvious to them. Improving the gynaecological visits settings for all women and providing access to information is likely to help overcome fears associated both with cancer and with its prevention. Access to full information will also contribute to encourage women to attend screening because they understand it is important, rather than doing it only out of a sense of obligation.

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Appendices

Recruitment material

 <p>UNIVERSITÉ DE GENÈVE FACULTÉ DES SCIENCES ÉCONOMIQUES ET SOCIALES DÉPARTEMENT DE SOCIOLOGIE</p>	<p><i>Le point de vue des femmes sur le dépistage du cancer du col de l'utérus</i></p>
<p>Dépistage du cancer du col de l'utérus Votre avis et votre expérience nous intéressent</p>	
<ul style="list-style-type: none">• Que pensez-vous du dépistage comme méthode préventive du cancer du col de l'utérus ?• Quelles sont les raisons pour participer ou ne pas participer à un dépistage ?• Que pensez-vous de l'auto-prélèvement ?	
<p>Vous souhaitez participer à cette étude par entretiens collectifs (focus group) :</p>	
<p>Vous avez entre 20 et 65 ans et :</p>	
<ul style="list-style-type: none">• vous n'avez pas effectué de frottis de dépistage du col utérin depuis au moins trois ans• vous effectuez des dépistages réguliers• vous ne savez pas si vous êtes dépistée ou non	
<p><u>La confidentialité est garantie</u></p>	
<p>L'expérience personnelle de chaque femme est importante dans la perspective d'une réflexion sur le dépistage du cancer du col de l'utérus aujourd'hui. Cette étude est financée par la Recherche suisse contre le cancer.</p>	
<p>Durée de l'étude : d'avril à décembre 2012.</p>	
<p>Vous pouvez nous joindre :</p>	
Par téléphone :	Par e-mail : vanessa.fagniol@unige.ch
022 379 83 10 079 419 14 32	Par fax : 022 379 83 25
<p>Ou en renvoyant le bulletin ci-dessous par voie postale à :</p>	
<p>Vanessa Fagniol, Département de sociologie, Université de Genève, 40 bd du Pont-d'Arve, 1211 Genève 4</p>	
<p>Je suis intéressée à participer à l'étude « le point de vue des femmes sur le dépistage du cancer du col de l'utérus »</p>	
<p>Nom et prénom _____</p>	
<p>Numéro(s) de téléphone _____</p>	
<p>Adresse postale _____</p>	
<p>Adresse e-mail _____</p>	
<p>Sous la responsabilité de la Professeure Claudine Burton-Jeangros, Département de sociologie, Université de Genève, 40 bd du Pont-d'Arve, 1211 Genève 4</p>	

Information sheet



UNIVERSITÉ
DE GENÈVE

FACULTÉ DES SCIENCES
ÉCONOMIQUES ET SOCIALES
DÉPARTEMENT DE SOCIOLOGIE

Document d'information aux participantes

Etude « Le point de vue des femmes sur le dépistage du cancer du col de l'utérus »

Chère Madame,

En Suisse 30 à 40% de femmes ne participeraient pas au dépistage du cancer du col de l'utérus. Différentes barrières ont été identifiées pour expliquer cette absence de participation. Afin de mieux comprendre les attitudes des femmes face au dépistage de ce cancer, leurs sources d'information, les avantages et désavantages mis en avant, nous menons l'étude susnommée.

Nous nous intéressons au point de vue des femmes, à leurs expériences du dépistage et souhaitons aussi connaître leur avis sur l'auto-prélèvement comme méthode alternative au dépistage classique. Nous planifions de réaliser 20 entretiens de groupe dits focus group avec des femmes âgées entre 25 et 65 ans. A cet effet, nous sollicitons votre participation pour un entretien de groupe constitué par 5 à 6 femmes maximum. Cette discussion collective durera entre une heure trente et deux heures environ.

L'expérience personnelle de chaque femme est importante dans la perspective d'une réflexion sur le dépistage du cancer du col utérin et les moyens de l'améliorer. Cette étude sociologique vient compléter l'étude clinique en cours du Docteur Pétignat qui s'intitule « Essai randomisé évaluant le dépistage du cancer du col utérin par auto-prélèvement HPV chez les femmes qui ne se rendent pas au dépistage ».

Le protocole de cette étude a été approuvé par la Commission centrale d'éthique de la recherche sur l'être humain des HUG.

Le recrutement des participantes repose sur une base volontaire, et à tout moment, vous avez la possibilité de revenir sur votre accord et/ou de quitter l'entretien de groupe sans en donner de raison.

L'entretien de groupe sera enregistré sur cassette puis retranscrit et étudié par les auteurs de l'étude. Les enregistrements et leur retranscription sont traités de manière confidentielle et uniquement dans le cadre de cette recherche. Votre médecin n'y aura pas accès. Les éventuelles citations des entretiens seront anonymisées.

Les enregistrements seront détruits une fois l'étude terminée ; toutes les données de l'étude seront détruites au plus tard dix ans après la fin de cette étude.

Les résultats de cette enquête seront publiés, et vous seront communiqués sur simple demande.

Nous vous remercions d'avance vivement du temps que vous aurez la gentillesse de nous consacrer, et restons à votre disposition pour toute précision complémentaire.

Prof. Claudine Burton-Jeangros
responsable de l'étude

Claudine Burton-Jeangros, prof. associée
Docteure en sociologie
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Consent form



UNIVERSITÉ
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DÉPARTEMENT DE SOCIOLOGIE

Document de consentement

Etude « Le point de vue des femmes sur le dépistage du cancer du col de l'utérus »

La responsable de l'étude signataire, la Professeure Claudine Burton-Jeangros et/ou ses collaboratrices spécialistes m'ont informée oralement et par écrit des buts et du déroulement de l'étude portant sur « *le point de vue des femmes sur le dépistage du cancer du col de l'utérus* ».

J'ai lu et compris le document d'information destiné aux participantes à l'étude susnommée. J'ai reçu des réponses satisfaisantes aux questions concernant ma participation à cette étude. Je peux garder le document d'information destiné aux participantes et je reçois une copie de ma déclaration écrite de consentement.

J'ai eu suffisamment de temps pour réfléchir avant de prendre ma décision. J'accepte le fait que la responsable de l'étude et ses collaboratrices spécialistes, les représentants des autorités et des commissions d'éthique aient un droit de regard sur les données originales, ces informations restant toutefois strictement confidentielles.

Je participe volontairement à cette étude. Je peux à tout moment retirer mon accord de participation à cette étude sans avoir à donner de raisons. Aucun inconvénient pour mon suivi médical ultérieur ne doit découler de cette décision.

Je consens à participer.

Date et signature
de la participante :

Date et signature
de l'investigatrice :

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Interview guide

GUIDE D'ENTRETIEN

1. BARRIERES AU DEPISTAGE

Information, connaissances

Sur le dépistage :

- Que pensez-vous du dépistage comme méthode préventive du cancer du col de l'utérus ?
- Pourriez-vous me donner la/les raison(s) principale(s) pour laquelle/lesquelles vous n'avez pas fait de dépistage ?
- Est-ce qu'un événement particulier ou une personne de votre entourage a joué un rôle dans votre décision de ne pas effectuer un dépistage ?

Sur le cancer du col utérin, sur le VPH :

- Avez-vous entendu parler du cancer du col de l'utérus ? D'où viennent vos informations, vos connaissances sur ce cancer ? Quand en avez-vous entendu parler pour la première fois et par qui, quel canal et à quelle(s) occasion(s) ?
- Avez-vous entendu parler du Virus Papillome Humain ?

Expériences passées

- Pouvez-vous raconter comment se sont passés vos dépistages, vos expériences passées ?
- Comment s'est déroulé le dépistage en lui-même, l'examen médical ?
- Saviez-vous être dépistée ou pas ?
- Avez-vous eu facilement accès à un test de dépistage dans le passé (rendez-vous facile à obtenir, accès, lieu, trajet) ?
- Est-ce que vous vous faites accompagner ?
- Comment avez-vous vécu l'après dépistage ?

Réactions associées au dépistage

- Appréciez-vous de recevoir une information régulière sur le dépistage, ou non ? Si oui, sous quelle forme (rappel, ...) ?
- Concernant l'étude du Dr. Petignat : Comment avez-vous vécu le fait qu'on vous contacte par téléphone/poste pour un rappel de dépistage ? Qu'avez-vous ressenti ? Que pensez-vous de cette démarche ?
- Question supplémentaire pour le groupe de femmes « âgées » : Quand on vous dit être une population/groupe « à risque », qu'est-ce que cela signifie pour vous ?

Organisation

- Quel(s) est/sont le(s) problème(s) majeur(s)/l'/les inconvénient(s) que pose(nt) le dépistage pour vous ? (coût, rendez-vous, temps, peur, examen, praticien, culture, ...)

Interaction avec le/la professionnel-le de la santé en charge du dépistage

- Avez-vous un-e gynécologue attiré-e ? Si non, un généraliste ?
- Pensez-vous que c'est important d'aller consulter un gynécologue chaque année par exemple ?
- Avez-vous confiance en votre gynécologue actuel ? A quoi cela tient ?
- Etes-vous du genre à poser beaucoup de questions à votre gynécologue ? Diriez-vous que vous êtes exigeante, que vous suivez ses instructions, ses conseils ou vous arrive-t-il d'être en désaccord ou douter de lui/elle ?
- En général, comment qualifiez-vous votre relation avec votre médecin/gynécologue (confiance, bonne communication, disponible, ...)?
- Est-ce que le sexe de votre gynécologue influence votre décision pour un dépistage ou pas? Est-ce que votre médecin/gynécologue influence votre choix ou pas d'effectuer un dépistage ?
- A votre avis, qui devrait être en charge/responsable d'effectuer un dépistage ?
- Diriez-vous, qu'il/elle vous a bien informée sur le dépistage? Vous demande-t-il/elle de prendre des rendez-vous réguliers par exemple (ou autre(s) conseil(s) donné(s)) ?
- Auriez-vous des suggestions à adresser aux professionnel-le-s pour améliorer votre participation à un dépistage en général ?
- Si une campagne devait être réalisée, sur quoi mettriez-vous l'accent ?

2. AUTO-PRELEVEMENT HPV

Test

- Que pensez-vous de ce test ? Qu'est-ce que cela évoque chez vous ? En aviez-vous entendu parler ? (par qui, quel canal, ..)
- Si vous avez rencontré des difficultés à faire le test, pourriez-vous nous les faire partager ?
- Comment qualifiez-vous cette méthode ?
- A votre avis, est-elle fiable ?
- Avez-vous trouvé l'information/la lettre explicative adéquate, facile à comprendre? Est-ce que le vocabulaire est adapté, trop scientifique ou pas assez ? (Détails, techniques, simples ?) En général avez-vous reçu des explications appropriées pour effectuer le test ?
- A l'avenir, préféreriez-vous faire un auto-prélèvement chez vous ou au cabinet médical/dans un lieu médical (avec du personnel médical) ?

Comparaison avec le test PAP

- Qui préfère utiliser la méthode de dépistage par auto-prélèvement et pourquoi ? Quelles sont les raisons pour l'utiliser ?
- Si vous l'acceptez, est-ce dire que vous allez l'utiliser par la suite ou non? Si non, pourquoi ? Les résultats vous semblent-ils aussi fiables que le test PAP ?
- Pour celles qui préfèrent le dépistage classique, pourriez-vous nous donner les raisons qui motivent votre préférence ?
- Qui est plus susceptible d'utiliser l'auto-prélèvement et pourquoi ? Y a-t-il un profil particulier à votre avis ou est-ce adapté à toutes les femmes ?
- Pour les prochains dépistages (si vous effectuez un dépistage) : quelle méthode choisirez-vous ? Et pourquoi ?

Entourage

- En avez-vous parlé autour de vous ? Si oui, quelles ont été les réactions de votre entourage ?
- Le conseillerez-vous ou non ?
- A votre avis, ce test pourrait-il augmenter la participation des femmes au dépistage ?

Fin de discussion

- Finalement, que pensez-vous de la prévention en général?
- Enfin, souhaitez-vous ajouter quelque chose ?

Nous vous remercions pour votre collaboration.

Participants questionnaire

Merci de bien vouloir répondre aux questions suivantes :

Quel âge avez-vous ? _____ ans

Quel est votre état civil ?

- célibataire
- mariée ou en couple
- divorcée ou séparée
- veuve*

Avez-vous des enfants ?

- non
- oui,

Si oui, combien d'enfants avez-vous ? _____

Quel est votre pays d'origine _____

Actuellement, exercez-vous une activité professionnelle rémunérée?

- non
- oui, à plein temps
- oui, à temps partiel

Si oui, quelle activité exercez-vous? _____

Quel est le niveau de formation le plus élevé que vous avez atteint ?

- scolarité obligatoire
- apprentissage
- maturité
- formation professionnelle supérieure
- université, école polytechnique

Est-ce que vous fumez ?

- non
- oui

Si oui, combien de cigarettes fumez-vous par jour _____

Ex-fumeuse : quand avez-vous cessé de fumer (quelle année) ? _____

Remarques : _____

ENCORE UN GRAND MERCI POUR VOTRE PARTICIPATION !