

Knowledge and awareness regarding cervical cancer prevention.

A cross sectional study in Kronoberg region.

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Background

Cervical cancer is the 4th most common cancer in women globally (1, 21). More than 85% of the cervical cancer cases occur in countries that have limited resources for screening, early diagnosis, and effective treatment (4). In Sweden over 8000 women are treated annually for cervical dysplasia, 550 women develop cervical cancer and about 150 dies from the disease (1). Cervical cancer development is dependent on persistent infection with oncogenic types of the very common sexually transmitted Human papilloma virus, HPV (4, 20, 22). Secondary prevention of cervical cancer includes population screening for HPV (Human papilloma virus) and cervical dysplasia via Pap-smear testing (Papanicolaou test). Primary prevention of cervical cancer includes HPV-vaccination and prevention of infection by condom use (4). WHO (World health organization) initiated in 2020 the “Cervical cancer elimination initiative”, stating targets regarding prevention of cervical cancer that must be met by 2030 to be on the path towards elimination of the disease (18).

In Sweden women are regularly summoned to participate in the national cervical cancer screening program known as GCK (gynekologisk cellprovskontroll). The screening organization, summoning and testing, is attributed to the region where the woman is registered (folkbokförd) at the time of sampling. The testing includes free of charge HPV-testing and cytological Pap-smears, in agreement with the constitution from The National Board of Health and Welfare (Socialstyrelsen) and the Swedish national guidelines for cervical cancer screening (3, 4, 5, 24).

According to the current screening program (November 2022) (4, 24), invitations to the screening begin at the age of 23 +/- 3 months. Invitations are later sent out considering when the last test was taken. Women aged 23-49 years are summoned for primary HPV-testing with a 5-year interval, and women over the age of 50 with 7-year interval. The test is followed by reflex analysis with cytology in case of HPV positivity. Extended HPV genotyping should be implemented. Invitation is terminated only after a negative HPV screening test after age of 64. Age at the last screening test can vary between 64 to 70 years since the invitation is based on the most recent test. The women who have been treated for cervical dysplasia receive invitations lifelong. Women who have not taken a Pap smear within the recommended time interval should receive new summons annually. Also, women who have not participated in screening in a screening interval after +4 years should receive an offer of self-sampling for HPV sent home. Women who have not participated for a long time (screening interval + 3-5 years), despite annual reminders and sent home an offer of self-sampling, should be contacted by phone. The guidelines also recommend the regions to offer HPV

self-sampling tests as an alternative sampling method to improve participation. National invitations and national information material should be used for good and equal information and care.

In Kronoberg region, the summoning system is, in the early spring of 2024, still based on the older version of recommendations and do not comply with the current national screening program. This is due to organizational and IT- problems. Also, extended HPV genotyping is not yet available in the laboratory. Women in Kronoberg are invited to the screening from 23 years of age and Pap-test is taken every third year between ages 23-50, and every five years until 64 years of age. HPV-self testing is not yet available as a screening alternative for all women, but during the autumn of 2023 HPV-self tests are offered to women in Kronoberg who have not participated in the screening for >7 years.

A high degree of women attending the screening is necessary to further prevent cervical cancer. Sweden's national cancer strategy (SOU 2009:11) has stated the goal of at least 85% coverage rate for gynecological pap smears (3).

In Kronoberg the degree of attendance to GCK, among women aged 23-70 years, was 68% in 2022. This is much lower than the national average of 82%. In more detail the screening attendance in 2022 in Kronoberg was 70% in the age group 23-50 years, and 64% in the age group 51-70 years. These are the lowest attendance results out of all Swedish regions (2). Data from previous years has been similar (6, 7).

In total the number of tests (cytology and/or HPV) taken in Kronoberg, in the screening ages 23- 70 years, in 2022 was 20028. Only 44% of these tests were performed in the organized screening, meaning that more than half of the women were not in fact summoned to do the test (2) and did not receive the informative national invitation letter.

Data from 2022 shows that Kronoberg region was one of the regions with the highest proportion of women aged 24–50 years that were *not* summoned and tested within the recommended follow up period. In this age group 7,6% of the women were missed, compared to the national average 3,0%. For women aged 51–70 11.5% were missed compared to 5.6% nationally (2). Though, Kronoberg region have not yet raised the recommended upper age limit for summons to GCK (from 64 to 70 years of age).

By participating in the screening, it is estimated that the risk of cervical cancer is reduced by 90% (4). An age-period-cohort study from 2014 describes a projected “no-screening scenario” based on

cervical cancer incidence data from the Nordic countries over a 50-year period, showing that over 60.000 cases, or 41-49% of the expected cases, of cervical cancer may have been prevented by introduction of pap-smear screening in the late 60's - early 70's (8). Statistics from The National Board of Health and Welfare shows there were 325 women who died of cervical cancer in Sweden 1960, and 130 in 2019 (24).

Women not participating in the screening are also missing out on the health education that the screening entails. A Swedish cross-sectional study from 2019 concluded that the awareness of HPV as a STI (sexually transmitted infection) was low among women who had abnormal Pap-smears (9). Of the 122 included women in the study, only 50% were aware of the HPV infection, and only 40,2% that HPV is a sexually transmitted infection. Further, large Scandinavian population-based surveys, have been performed in 2004-2005 and 2011-2012 to investigate pre- respectively post HPV-vaccination awareness of HPV (10, 11). The post-vaccination study showed that 24-38% of Scandinavian women had never heard of HPV, even after the introduction of HPV-vaccination program(s). HPV awareness pre-vaccination among the Swedish women were 67,5%, compared to post-vaccination awareness 74,8%. Studies on populations in Great Britain, USA and Australia, have similarly shown generally low awareness about HPV (16, 17, 23).

Since August 2020 both girls and boys in Swedish primary schools (year 5) are offered vaccination against HPV within the national childhood vaccination program. From 2012 until 2020 only girls received the vaccine in school (1, 4). In 2012, there were also a so called "catch-up vaccination" of girls born in 1993–1998. The current childhood vaccination program target children between 9-14 years of age and since autumn 2019 the 9-valent vaccine Gardasil 9 is used (4, 15). Further, women born 1994–1999 are offered free HPV vaccination (Gardasil 9) with subsequent HPV testing as part of a study-campaign called "Utrotningsprojektet" (Eradication project), in purpose to eradicate cervical cancer. All Swedish regions participate in the campaign which launched in May 2021 (1, 12, 13).

Statistical data from the Public Health Agency of Sweden (Folh lsomyndigheten) shows that HPV- vaccination coverage for vaccinations given in child health care 2022 in Kronoberg region were: 84,8% coverage for 12-year-old girls who have received 2 doses, compared to 87,6% nationally, and a coverage of 79,1% for 12-year-old boys who have received 2 doses, compared to 82,7% nationally (14). The vaccine coverage for women born 1994-1999 was almost 45% in Kronoberg in February 2024, which was the second-best coverage-rate out of all Swedish regions (12).

The level of knowledge and awareness about GCK, HPV and HPV-vaccination among women in Kronoberg-region is unknown. Since the women in Kronoberg are not summoned in time, women over 64 years of age are not included in the screening, and the coverage of screening is generally low in the region, it is suspected that the knowledge and awareness among women in Kronoberg could be low. The knowledge and awareness are further suspected to be lower in women born after 1999 who haven't had children in school, since they have not been invited or asked about HPV-vaccination within any organization (eradication campaign or school vaccination program).

The purpose of this study is to assess the knowledge and awareness about cervical cancer prevention among women who attend to the Women's health clinics in Växjö and Ljungby, Kronoberg Region. The two primary questions are: Do the women know why the Pap-smear is done and are the women aware of HPV? Further aims are to compare awareness and knowledge between women of different ages, demographics, their earlier Pap-smear history, and vaccination status. Additional aims are to obtain information about how the women experience and feel about GCK, how and where they seek information and how they want to be informed about GCK and HPV.

Material and method

Study design

A cross sectional survey including women in Kronoberg region. Women included in the study population are invited to answer a completely anonymous paper form questionnaire during their visit to the Växjö and Ljungby gynecological clinics. Attached to the questionnaire is written information about the survey.

The study is designed to be a pilot-project of a larger study including a larger population of women.

In this study and text, the word "woman/women" is used in general for persons who have, or have had, female reproductive organs.

Study population

The women included in the study are women visiting women's health regional clinics in Växjö and Ljungby, Kronoberg region. Women of all ages and ethnicities, with all kinds of gynecological problems, including early pregnancy and postpartum health issues, visit the regional clinics every day. The selected population are thought to be a good representation of women of varying

sociodemographic characteristics. In this study it is assumed that random samples by self-inclusion would be representative for the target screening population of women aged 23-70. It is also assumed that it will be possible to analyze any differences found in level of knowledge and awareness in relation to age and level of education by this method of data collection.

Excluded from the study population are women visiting the clinics due to any type of emergency, women who do not have sufficient Swedish knowledge, or whom, for any other reason, do not have the ability to independently answer the questionnaire.

Women who visit the few private gynecology clinics in Växjö and those who visit primary care due to gynecological health issues are not included in this study. These units can perform Pap-smear testing, on routine or if indicated, but do not have any assignment of GCK summoning and organization.

Reviewing the patient booking lists of 2023 an average of 1000 women visits the clinic's every month. The study is planned to continue over 8 months and would include around 8000 women. With a conservative estimated response rate of 10-15% this would render 800-1200 survey responders.

Method

The choice of method and study design is chosen in purpose to obtain a mapping and information-rich data collection. The intention is to study relationships between the requested variables included in the survey, to investigate whether it is possible to establish patterns and whether there is any generalizability.

The questionnaire (Appendix 2) is constructed for the specific purpose by the author. Inspiration is taken from reviewing several previous studies on the matter including questionnaires or surveys (9, 10, 11, 16, 17, 19). Before start of study the questionnaire is tested and evaluated on a small group of women to make sure the questions are easy to interpret and to answer.

The survey includes five questions on demographic characteristics including age, first language, education level and relationship status. There are six general questions on individual Pap-smear and vaccination history, including if the women have children in age of HPV-vaccination in school. Six questions are on women's general basic knowledge about screening, Pap-smear, and HPV. All fact-based questions are based on the information that the women receive in the national invitation letter to the screening, and/or is accessible on 1177. Three questions are on women's opinion and

potential concerns about the Pap-smear, and six questions are on where the women receive and/or retrieve information and where or/and how they wish to receive the information about GCK and HPV.

The questionnaire is freely available to be self-administered and filled in the clinics' waiting rooms. The working staff are also asked to routinely offer the questionnaire as well as being available to answer any general questions regarding the study format. The questionnaire is supposed to be filled out and submitted before the visitor is leaving the clinic. The filled in form can be handed over to the working staff or placed in a designated collection box in the waiting room.

Attached to the questionnaire is written information about the survey (Appendix 1).

Data from filled in questionnaires are entered into Excel document by the author. Data is then analyzed by SPSS-program using descriptive statistics and non-parametric methods.

Ethics

All women will receive written information about the study and that participation is voluntary, anonymous and will not affect their personal health care further. Consent is assumed when the participant sends in a filled-out questionnaire.

Head of the Women's' health clinic's approval is given to carry out the study.

Ethical review and permission are not required as the study is completely anonymized. GDPR permission is not required as no identifying information is assessed.

Timeline

Presentation of the project plan (datum) as a part of the examination in the obligatory study course of medical science for ST-doctors (delmål A5 SOSFS 2015:8).

Data collection during April – December 2024. Data from submitted complete paper form questionnaires are continuously entered into a digital format (Excel document).

Data analysis and writing of scientific report December 2024- January 2025.

Submission of the scientific report to SFOG on the 1st of February 2025.

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Appendix 1. Enkätinformation

Hej!

Jag heter Felicia Wallon och är ST-läkare på Kvinnokliniken Växjö/Ljungby. Jag vill fråga om du vill delta i ett forskningsprojekt för att förbättra kvinnors hälsa.

Vad handlar projektet om?

Alla med kvinnligt personnummer i Sverige blir från 23 års ålder regelbundet inbjudna till att göra gynekologisk cellprovskontroll (lämna cellprov). Det är ett prov som tas för att upptäcka tidiga tecken på cancer i underlivet. Det är dock många kvinnor som inte lämnar cellprov. Anledningarna till detta är såklart olika, men en orsak kan vara okunskap kring cellprov. För att se om detta stämmer och ha möjlighet att förbättra informationen kring cellprovet önskar jag undersöka vad du känner till och tänker kring cellprov.

Hur går studien till?

Studien innebär att du fyller i enkäten på nästa blad. Du kommer att få svara på frågor som har med cellprov att göra. Det tar ca 5–15 minuter att svara på frågorna. Försök att svara utifrån vad du själv känner till. Det är inget läxförhör!

Vid ditt besök på gynmottagningen ombedes du att (om du väljer att delta i studien) fylla i enkäten på plats och sedan lämna den i enkät-lådan i väntrummet. Du kan också lämna den ifyllda enkäten till personalen på mottagningen. Du kan fråga någon i personalen om du har några frågor under tiden du fyller i enkäten.

Vad händer med mina uppgifter?

Deltagandet är helt frivilligt och fullständigt anonymt. Du ska inte skriva namn, personnummer eller andra personuppgifter på detta papper eller i enkäten. Ingen kommer att kunna veta att det är just du som har svarat. Bara de i studiegruppen kommer att läsa och arbeta med enkätresultaten. Om du har några frågor eller funderingar är du välkommen att höra av dig till Felicia Wallon.

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Appendix 2. Enkät.

1. Vilket år är du född? _____

2. Förstaspråk:

- Svenska
- Annat

3. Avklarad utbildning:

- Grundskola
- Gymnasium
- Universitet eller högskola

4. Har du under det senaste året varit sexuellt aktiv med:

- En person
- Flera personer
- Ej varit sexuellt aktiv

5. Är du i ett långvarigt (längre än 2 år) sexuellt förhållande med endast en person?

- Ja
- Nej

6. Har du blivit kallad till cellprovskontroll någon gång?

- Ja
- Nej
- Minns ej

7. Har du lämnat ett cellprov någon gång?

- Ja
- Nej
- Minns ej

8. Tycker du att det är viktigt att gå på cellprovskontroll när du blir kallad?

- Ja
- Nej
- Ingen åsikt

9. Har du genomgått behandling (operation) för cellförändringar i livmoderhalsen?

- Ja
- Nej

10. Har du hört talas om HPV (humant papillomvirus)?

- Ja
- Nej

11. Har du tagit vaccin mot HPV?

- Ja
- Nej
- Minns ej

12. Är du vårdnadshavare till barn som har gått eller går i årskurs 5?

- Ja
- Nej

13. Är du vårdnadshavare till barn som någon gång fått erbjudande om vaccin mot HPV i skolan?

- Ja
- Nej
- Vet ej

14. Vilken del av de kvinnliga könsorganen undersöks med cellprovet? Kryssa i vad du vet.

Du kan kryssa i flera alternativ.

- Blygdläpparna, vulva (de yttre, synliga, delarna av underlivet)
- Slidan (vagina)
- Livmoderhalsen/livmodertappen (nedre delen av livmodern)
- Livmoderkroppen (övre delen av livmodern)
- Äggledarna
- Äggstockarna
- Vet ej

15. Kryssa i vad du känner till om cellprovskontrollen (alla påståenden stämmer).

Du kan kryssa i flera alternativ.

- I cellprovet kontrolleras om det finns cellförändringar på/i livmoderhalsen.
- I cellprovet kontrolleras om det finns en HPV-infektion (en virusinfektion) i underlivet.
- Cellprovtagningen är gratis.
- Cellprovet kan tas av vårdpersonal eller så kan du själv få ta ett prov och skicka in. Båda sätten är lika bra.
- Genom att du deltar i cellprovtagning minskar risken att du ska drabbas av cancer i livmoderhalsen.
- Att inte gå på cellprovskontroller är den största riskfaktorn för att drabbas av livmoderhalscancer.

- Känner ej till något av ovanstående.

16. Kryssa i vad du känner till om cellförändringar i livmoderhalsen (alla påståenden stämmer). Du kan kryssa i flera alternativ.

- Cellförändringar är ofta inget man märker själv.
- Cellförändringar läker oftast av sig själv.
- Cellförändringar är inte samma sak som cancer, men en del cellförändringar kan utvecklas till cancer.
- Rökning ökar risken för cellförändringar.
- Att sluta röka gör att cellförändringar lättare kan läka ut.

- Känner ej till något av ovanstående.

17. Kryssa i vad du känner till om HPV – Humant papillomvirus (alla påståenden stämmer).

Du kan kryssa i flera alternativ:

- HPV är en sorts virus som kan orsaka cellförändringar på livmodertappen.
- Vissa sorter HPV kan orsaka cellförändringar, medan andra sorter HPV kan orsaka ofarliga könsvårtor (så kallade kondylom).
- HPV sorter som orsakar kondylom orsakar inte cellförändringar på livmodertappen.
- De allra flesta har någon gång under livet haft en HPV-infektion.
- HPV infektion brukar inte ge några symptom.
- HPV infektion läker och försvinner oftast av sig själv.
- HPV är ett sexuellt överförbart virus.
- HPV smittar genom vaginalt samlag.
- HPV smittar genom oralsex (munsex).
- HPV smittar genom analsex.
- HPV smittar genom smeksex, petting (genom att man tar på varandra).
- Kondom skyddar mot HPV-infektion.
- Känner ej till något av ovanstående.

18. Kryssa i vad du känner till om HPV-vaccin_(alla påståenden stämmer). Du kan kryssa i flera alternativ:

- HPV-vaccin skyddar mot HPV-typer som kan orsaka cellförändringar i livmoderhalsen/livmodertappen.
- HPV-vaccin skyddar mot HPV-typer som kan orsaka kondylom (könsvärtor).
- Alla barn i grundskolan erbjuds vaccination mot HPV (i årskurs 5).
- Kvinnor i Kronoberg födda mellan 1994 - 1999 erbjuds just nu gratis HPV-vaccin.
- Om du är vaccinerad mot HPV innan 2019 kan du vaccinera dig mot HPV igen och få ett bättre skydd

- Känner ej till något av ovanstående.

19. Upplever du att vården har informerat dig tillräckligt om cellprovtagning?

- Ja
- Nej
- Ingen åsikt

20. Upplever du att vården har informerat dig tillräckligt om HPV?

- Ja
- Nej
- Ingen åsikt

21. Känner du dig orolig inför cellprovtagning?

- Nej
- Ja, lite orolig
- Ja, mycket orolig

22. Om du svarat Ja ("lite orolig" eller "mycket orolig") på föregående fråga, vad är du orolig för? Du kan kryssa i flera alternativ.

- Cellförändringar
- Cancer
- HPV infektion i underlivet
- Annan infektion i underlivet
- Annan sjukdom i underlivet
- Att provtagningen (cellprovet) skall göra ont
- Utsatthet och nakenhet vid provtagningen
- Personalens bemötande
- Sjukvårdsmiljön
- Annat. Beskriv gärna vad:

23. Har du sökt information på egen hand angående cellprovtagning, HPV och/eller cellförändringar?

- Ja
- Nej

24. Har du sökt information om cellprov, cellförändringar i livmoderhalsen, HPV och/eller HPV- vaccin på *1177.se*?

- Ja
- Nej

25. Har du sökt information om cellprov, cellförändringar i livmoderhalsen, HPV och/eller HPV- vaccin på *umo.se*?

- Ja
- Nej

26. Hur skulle du vilja bli informerad om cellprov, HPV och HPV vaccin? Du kan välja flera alternativ.

- Muntlig information från barnmorska vid cellprovskontroll
- Hemskickat brev med information
- Mail med information
- Sms med information
- Information till din mailinkorg på 1177
- Själv söka information på nätet (tex på 1177 eller umo.se)
- Information från vården via sociala medier
- Annonser i massmedia
- Informationsföreläsningar för allmänheten

- Annat. Skriv gärna vad:
