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## PERCEPTION AND KNOWLEDGE OF HUMAN PAPILLOMAVIRUS (HPV) AND HPV DNA SELF-SAMPLING AMONGST WOMEN IN WEST MALAYSIA.

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### ABSTRACT

**Introduction:** Cervical cancer is a potentially preventable disease due to the availability of an effective cervical screening programme. However, uptake of Pap smears is often affected by patient's reluctance and other healthcare barriers. Thus Human Papilloma Virus (HPV) self-sampling may help to eliminate the screening deterrent and helps widen the screening population. The aim of this study was to assess the perception and knowledge of HPV and HPV DNA self-sampling amongst women in West Malaysia. **Methods:** This was a cross-sectional study done in Pusat Perubatan Pakar Universiti Teknologi MARA, West Malaysia, from February until May 2017. All women aged between 18 to 55 years old who attended the Gynecology Clinic were selected randomly to participate. They were shown the actual size picture of the HPV self-sampler and were asked to complete a questionnaire. The data were analyzed using SPSS v24. **Results:** The mean age of the sample was 32 (SD 7.7) years, mainly of Malay ethnicity. One hundred and forty-five (65.9%) were aware of HPV and 148 (67.3%) women knew HPV causes cervical cancer. Although only 33 (15%) women were aware of HPV self-sampling, 186 (84%) women were willing to do self-sampling in the future and 147 (66.8%) were willing to buy the self-sampling kit in the future. **Conclusion:** Participants have high perception and knowledge about HPV and cervical cancer risk but low awareness of HPV DNA self-sampling. However majority were willing to self-conduct HPV DNA self-sampling. Efforts are required to introduce and gain support from women to perform HPV DNA self-sampling in Malaysia.

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**Keywords:** Awareness, Cervical cancer screening, Cervical cancer prevention, Human papillomavirus, Knowledge.

## INTRODUCTION

Cervical cancer is a potentially preventable disease. The link between human papillomavirus (HPV) as an aetiological agent with cer-

vical cancer has been well established. Persistent HPV infection leads to cervical intraepithelial neoplasia, and if it is left undetected, it may progress to cervical malignancy.<sup>1</sup> Common HPV types distribution in Malaysia are HPV 16, HPV 18, HPV 33 and HPV 58 seen amongst cervical cancer patients.<sup>2</sup> A total of 1682 new cases of cervical cancer were reported by the GLOBOCAN 2018 Malaysia data-

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base, and it is the third common cancer seen in the female population after breast and colorectal cancer.<sup>3</sup> Malaysian Study on Cancer Survival 2018 (MySCan) has reported a five-year relative survival of cervix uteri cancer amongst Malaysia population of 51.6%, which is similar to India. However, it is lower compared to Thailand, China, Singapore, Japan, Korea and most of the European countries.<sup>4</sup>

A cervical screening test has been available in Malaysia since 1965 and offered free at all government health facilities under the Ministry of Health since 1995. Despite the availability of the screening test and structured guideline, it fails to attract women to attend the screening with the uptake of 47.3%.<sup>5</sup> Lack of participation in cervical screening is due to embarrassment, fear, time constraint and lack of knowledge.<sup>6</sup>

Apart from pap smear, HPV testing has been found to be the most effective screening method in cervical intra-epithelial grade two or three with high sensitivity of 94.6% (95% CI, 84.2-100) with a comparable specificity.<sup>7</sup> About 10% of pap smear result may be false negative despite having positive HPV infection. Thus, HPV DNA testing is more sensitive than pap smear in identifying cervical cancer and its premalignant precursors in the population screening. Developed countries are incorporating HPV testing with the pap smear, known as co-testing. However, this method only increases the cost and doubles the number of tests, complicating the follow-up procedure. HPV DNA testing is suitable as a stand-alone screening test. The absence of high risk (hr) HPV infection ensures low cancer risk for the next five to seven years as a persistent infection is needed for cervical carcinogenesis to develop.<sup>8</sup> Therefore, it allows a longer interval between each cervical screening and potentially, this makes it more appealing to women.

HPV DNA self-sampling has emerged

as an attractive alternative in the cervical screening method. It requires self-collection of genital samples by a woman herself, either in the clinic or at home. It no longer involves speculum examination, and there is no need for long waiting in the clinic for it to be carried out. It can potentially expand population screening uptake, coverage and access for women. The identified barriers against cervical screening can be further reduced, overcome and attracting more participants, including the non-attenders. Thus, this study aims to assess the perception and knowledge of HPV and HPV DNA self-sampling amongst women and their willingness to perform the self-sampling test.

## METHODS

This is a cross-sectional study conducted in Pusat Perubatan Pakar Universiti Teknologi MARA (PPUiTM) in Klang Valley, West Malaysia. The study was conducted from February until May 2017. The inclusion criteria was that the women must be in the reproductive age group. These were selected randomly and consented to participate in the study. Women who were less than 18 years of age were excluded from the study. A total of 220 women were enrolled into the study. They were asked to fill in a questionnaire which was written in the Malay language; to evaluate the perception and attitude towards HPV self-sampling. The questions set was validated by three experts (who were not involved in the study) in the Obstetrics and Gynaecology Department of the institution.

The questionnaire is divided into three parts: Part I of socio-demographic data including age, race, education level, occupational status, marital status, monthly family income, sexual activity and cervical cancer screening. Part II is composed of questions regarding attitudes and perception towards HPV self-sampling. The front page of the Part III questionnaire was printed with a 1:1 scale

of HPV self-sampling kit with sequential step by step instruction on how to use the kit and perform the self-sampling.

Background study information sheet was provided for all women who met the inclusion criteria. All participants gave written informed consent before completing the questionnaire. Approval was obtained from the Human Research Ethics Committee of the Universiti Teknologi MARA Research Ethics Committee (600-RMI) (5/1/16). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

The sample size was calculated using epitools software to measure a single proportion. The parameters were estimated proportion =0.78 (9), confidence level=95%, precision of estimate= 0.05 and population size =500. From the calculation, the sample size required was 173 and the addition of 30% non-response rate gave the final sample size of 225.

Data analysis was performed using Statistical Package for Social Sciences (SPSS) version 24. The questionnaires data were entered into SPSS and checked for accuracy. Both descriptive (mean and frequency) and analytical methods are used. The Pearson Chi-square test was performed to determine the relationship between demographic, pap smear variables and the outcomes (HPV awareness and HPV self-sampling). Variables with  $p < 0.05$  were considered statistically significant.

## RESULTS

A total of 220 women responded to the questionnaire. The mean age was 32 years (s.d = 7.7). The majority of the participants were

**Table I: Participants socio-demographics.**

Socio-demographic variables	N (%)
<b>Marital Status</b>	
Married	176 (80%)
Divorced	38 (17.3%)
Single	6 (2.7%)
<b>Education</b>	
Up to secondary	46 (20.9%)
College / University	174 (79.1%)
<b>Employment</b>	
Employed	179 (81.4%)
Non-employed	41 (18.6%)
<b>Income (MYR)</b>	
<1500	13 (6.9%)
1500 – 4000	80 (36.4%)
>4000	127 (57.7%)
<b>Sexual intercourse</b>	
Never had	50 (22.7%)
Had	170 (77.3%)

Malay (95%). Socio-demographic data is illustrated in Table I. The number of participants who had cervical screening within three years, who had a history of cervical screening more than three years ago and who never had any cervical screening was 80 (36.4%), 24 (10.9%) and 116 (52.7%) respectively.

The majority of women (65.9%) were aware of HPV infection. They obtained the information from various sources, including audio-visual media (56.4%), health talks by health professionals (55%), internet (55%), social media platform (44.5%) and friends and family (28.6%). Some participants got the information from more than one source.

More than half of women (70.5%) perceived that HPV infection was a serious infection and caused cervical cancer (67.3%). One hundred forty-one (64.1%) and 99 (41%) women perceived that HPV infection could be detected by pap smear and HPV infection is a form of the sexually transmitted disease, respectively. A minority (21.8%) perceived that HPV infection is avoided by a wearing condom and 15% perceived that it

**Table II: Association of participants socio-demographic data & pap smear practice with HPV awareness and HPV self-sampling.**

Variables	HPV Awareness		<i>p</i> -value	HPV self-sampling Awareness		<i>p</i> -value
	Yes N=145 (65.9%)	No N=75 (34.1%)		Yes N=33 (15.0%)	No N=187 (85.0%)	
<b>Education</b>						
Up to secondary	25 (17.2%)	21(28.0%)	0.063	4(12.1%)	42(22.5%)	0.178
College / University	120 (82.8%)	54(72.0%)		29(87.9%)	145(77.5%)	
<b>Employment</b>						
Employed	118(81.4%)	61(81.3%)	0.993	31(93.9%)	148(79.1%)	<b>0.044</b>
Non-employed	27(18.6%)	14(18.7%)		2(6.1%)	39(20.9%)	
<b>Pap smear</b>						
No	80(55.2%)	36(48.0%)	0.532	18(54.5%)	98(52.4%)	0.619
Yes	49(33.8%)	31(41.3%)		13(39.4%)	67(35.8%)	
Yes, 3 years ago	16(11.0%)	8(10.7%)		2(6.1%)	22(11.8%)	

has no cure. Table II summarises the association of demographic data and pap smear practice with HPV awareness and HPV self-sampling. There is a significant association between employment and HPV self-sampling ( $p < 0.05$ ).

A total of 184 (84%) participants were willing to do self-sampling in the future. They were mainly those who were married (80.1%), attended university/college (80.6%), and those with employment 64.9%. Sixty-nine women (31.4%) were worried that the self-sampling might cause injury. Eighty-three (37.7%) and 116 (52.7%) women, concerned that they would drop the device during the self-collection and get an inadequate sample for the test respectively. Thirty-one (14.1%) women did not feel that the self-sampling was needed as they were asymptomatic, and 30 women (13.6%) thought that the HPV self-sampling was unnecessary if they had frequent check-ups with the doctor.

The majority of women (69%), felt that a step by step chart was helpful, and 145 (65%) women preferred demonstration from health care personnel on how to carry out the self-sampling prior to doing it themselves. About 67% (147) of women were willing to buy the self-sampling kit in the future.

## DISCUSSION

This study has revealed wide variation in perception HPV, HPV DNA self-sampling and acceptance of HPV DNA self-sampling. From this study, the awareness of HPV in our population was 65.9%. More than half of the women perceived that HPV causes serious infection (70.5%) and that HPV infection leads to cervical cancer (67.3%). This is similar to what was found among Romanian women with 69.2% of the women were aware of HPV, and more than half were able to relate HPV infection with cervical cancer.<sup>10</sup> On the other hand, lower figures are found amongst the Chinese women<sup>11</sup> and the Nigerian<sup>12</sup> gynaecological clinic attendees, which are 26.5% and 29.1%, respectively.

Our finding on a higher level of awareness could be contributed by the media exposure and campaign efforts from the Ministry of Health of Malaysia. Educational posters regarding HPV and cervical cancer, encouraging cervical screening; are commonly seen in health clinics. In addition, Malaysia has the ongoing free HPV vaccination school programme since 2006, which may further contribute to general awareness regarding HPV within the population.

Our participants use multiple platforms as sources of information, similar to a study amongst the population in Romania by Grigore *et al.*<sup>10</sup> Electronic, printed and social media played an essential role in disseminating information regarding HPV and its relation to cervical cancer. A study done in Southern Region in Saudi Arabia found that three quarters of women respondents obtained health information from social media, mainly Facebook and Twitter.<sup>13</sup> In Malaysia, 2018 statistics showed that 87.4% ( 28.3 million from the total Malaysian population of 32.4 million ) were internet users, and 85.5% used the various platforms on the internet to get information.<sup>14</sup> With that evidence shown, more content regarding HPV and its self-sampling method should be created on the internet platform, in the hope of reaching the targeted population. The content should also be monitored by responsible bodies to ensure reliability and accuracy.

In this study, despite satisfactory awareness regarding HPV infection, the awareness regarding HPV self-sampling was low (15%) amongst our participants. This is probably due to the fact that pap smear test is still widely used as a method of cervical screening in Malaysia. Only limited health facilities in Malaysia offer HPV sampling, mostly require health personnel to perform it and require the patient to pay for the kit. In Malaysia since 2019, there is an ongoing project called ROSE (Removing Obstacles to Cervical Screening), an initiative from the University of Malaya and the Ministry of Health, integrating HPV self-sampling, HPV screening and digital health platforms at selected chosen clinics all over Malaysia. The project aims to increase women interest in performing HPV self-sampling, thus reaching more non-attenders of cervical screening.<sup>15</sup>

In 2016 Esber *et al.* reported that only 67% of Malawian women were willing to do HPV self-sampling,<sup>16</sup> which is lower than

our study where we found 84% participants were interested in performing HPV self-sampling. Interestingly, a study from Bangkok by Kittisiam *et al.* reported an even lower acceptance rate, where only 40% of participants willing to do HPV self-sampling.<sup>17</sup> The reasons for this were the perceived lack of reliability of the test and the participants had no confidence in performing the test correctly by themselves.

Studies from various countries, such as in Germany,<sup>18</sup> and the United States of America<sup>19</sup> showed high acceptability of self-collected HPV testing. The high acceptance rate was mainly amongst women who were generally up to date with new information regarding HPV and its evolution of the screening method.

In Malaysia, cervical screening done in government health facilities is fully subsidised comparing to private health facilities. In our study, if women are required to pay for the self-sampling kit, more than half (66.8%) of our participants were willing to pay if necessary, especially those who are married, the tertiary educated and who are in employment at the time of the study. This may explain the significant association between employment and HPV self-sampling. In 2018 Abdullah *et al.* found that 69.1% of the women were willing to buy self-sampling if it was available over the counter.<sup>20</sup> However, in this study, we do not explore the acceptable range of estimated cost of the self-sampling kit.

The percentage of women willing to perform self-sampling themselves may be higher with prior experience of self-sampling, as found in the previous study done by Abdullah *et al.* who found that 93.2% willing to do the self-sampling in the future after experiencing the self-sampling themselves.<sup>20</sup> In addition, Trope *et al.* also found in their study that 91% would self-sample after performing

the test themselves.<sup>21</sup> In contrast, in our study, a lower number of 84.6% participants were willing to do the self-sampling. This is probably because they were not given the chance to experience themselves first, instead were shown the full-size picture of the HPV self-sampling kit on print.

Majority of participants expressed their worry about getting an inadequate sample (52.7%), self-inflicted injury during self-sampling (31.4%) and dropping the sampling device (37.7%) during the sampling. A study in Thailand in 2014 by Oranratanaphan *et al.* showed that majority of women who had the opportunity to experience the self-sampling reported less pain, no complexity and no discomfort felt during the sampling and they were willing to repeat the self-sampling in the future.<sup>22, 23</sup> Malaysian women should be encouraged to use the HPV self-sampling kit if availability permits to promote and further increase the uptake of HPV self-sampling.

The other main concern of the participants is whether they can perform the sampling correctly. More than half of our participants requested a step-by-step chart or demonstration technique by health care personnel. Brandt *et al.* found that having a proper explanation of the procedure using 'demonstration brush' and a description video managed to gain confidence amongst Ethiopian women to perform self-sampling.<sup>24</sup> Furthermore, Hanley *et al.* found that in their study, 96.9% of Japanese women had no trouble comprehending pictorial instructions on a self-sampling kit.<sup>25</sup> Thus, the provision of instructions will increase the acceptability of self-sampling and increase the women's confidence in their ability to carry out the test independently.

As the HPV self-sampling method is still new in Malaysia, a robust and active promotion of HPV self-sampling is needed. Malaysian women must be informed regarding

the advantages and benefits of the self-sampling HPV method as seen in other developed countries.

## STUDY LIMITATIONS

There are several limitations in our study. First is that majority of our participants were of Malay ethnicity and hence the findings of this study cannot be generalized to women of other racial ethnicity. Secondly, the study was conducted 4 years ago in 2017 and the availability and uptake of HPV DNA self-sampling in West Malaysia may have change in the last 4 years. Lastly, this study was conducted in one centre only and hence findings may not represent the perception and knowledge of women in other parts of Malaysia.

## CONCLUSION

There is good perception and knowledge on HPV infection and cervical cancer risk in our studied population. Despite the current level of knowledge, majority were not aware of HPV DNA self-sampling but expressed interest in conducting the HPV DNA self-sampling themselves if the kit is available in Malaysia, along with simple instructions. Campaigns are needed to further promote HPV DNA self-sampling, to reach a wider screening population, especially targeting those non-attendees.

## CONFLICTS OF INTEREST

There are no conflicts of interest in this study.

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