

Literature review of women's understanding of HPV: Australian research and current gaps

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1. Literature review brief

After meeting with the PapScreen team, the following two questions were proposed as the basis for the literature review to be conducted on the psychosocial aspects of human papillomavirus (HPV):

- (1) What is the local research to date on women's understanding of HPV?
- (2) What are the gaps in knowledge that we still need to research?

2. Introduction

As the media increases its coverage of the HPV vaccine, women in Australia will gradually become more aware of HPV and its connection to cervical cancer. This is therefore a critical time in which education about HPV can be communicated to the public, at the early stages of their learning about HPV and ideally before they consolidate their opinions and responses to the virus and its vaccine. It is also a critical time in which research can be conducted to determine whether current awareness and/or beliefs about HPV will have any future impact on women's cervical screening behaviour in the Victoria.

Before research can be conducted in Victoria, a review is needed to determine what researchers currently know about Australian women's awareness of HPV. From there we can determine what gaps there are in our knowledge and how to fill these gaps with strategically designed research projects.

This literature review is aimed at summarising the research to date on women's awareness of HPV in Australia. As it is anticipated that this literature will be limited, topics found in the international literature will also be reviewed, as they may serve as a guide as to the areas for future Australian research.

The literature review was conducted using two online databases: Medline and PsychInfo. The literature was searched from 1995 to present (Feb 2006) using combinations of the following keywords: human papillomavirus, HPV, cervical screening, understanding, knowledge, and vaccine. Additional literature and project information was collected via personal correspondence with Australian researchers involved in the field:

Ms Sue Dyson (PhD candidate, Latrobe University. Evaluator, Community Liaison & Education Unit, Australian Research Centre in Sex, Health & Society (ARCSHS), Latrobe University)

Ms Margaret Heffernan (PhD candidate, University of Melbourne.)

Dr Julie Leask (Researcher, National Centre for Immunisation Research & Surveillance of Vaccine Preventable Diseases, Children's Hospital at Westmead, NSW, & University of Sydney)

Dr Kirsten McCaffrey (Senior Research Fellow in Clinical Decision Making, School of Public Health, University of Sydney)

3. What do we know? A Summary of local studies conducted:

A total of six Australian studies¹ were identified that related to psychosocial aspects of HPV: four have been completed (Asquith & McCaffery, 2005; Dyson & Pitts, 2005; Fernbach, 2001; McCaffery & Irwig, 2005); and two are being conducted currently (Heffernan, Garland, McCaffery, Sawyer, & Quinn, ; McCaffery et al.). A summary of each of these projects is presented below.

3.1. Female undergraduates' knowledge of HPV

An Honours project has been conducted on a sample of Sydney-based female undergraduates to explore their awareness of HPV and its connection with cervical cancer:

Researchers:

Catherine Asquith and Kirsten McCaffery
The University of Sydney

Topic:

Social and psychological impact of HPV in cervical screening

Project Status:

This was an Honours project conducted in 2005, the findings from which were reported on at the presentation listed below.

Publications and/or Presentations:

Paper presented at the Australian Society for Colposcopy and Cervical Pathology's 19th scientific meeting on Queensland's Gold Coast (Sept, 2005)

Synopsis:

Aim: To explore undergraduates' understanding of HPV. **Method:** 140 female undergraduates from Sydney University, aged 18-45 years (mean 19yrs, SD 3.3yrs). **Results:** 25.7% of students reported "having ever heard of HPV", compared to the 89.3% who reported "having ever heard of genital warts". When asked whether HPV infection is the main cause of cervical cancer, 11.6% said yes, 5.8% said no, and 82.6% said they didn't know. **Conclusions:** Low awareness of HPV per se and low awareness of the link between HPV and cervical cancer.

¹ An additional study run by Kirsten McCaffery at the University of Sydney is also in progress however details about this project were unavailable at the time of writing.

3.2. Knowledge of HPV and the HPV vaccine

Dyson and Pitts (2005) conducted a study, funded by GlaxoSmithKline, to understand women's knowledge of HPV, its connection to cervical cancer, and the HPV vaccine:

Researchers:

Sue Dyson & Marion Pitts

Joint project between Australian Research Centre in Sex, Health & Society, Latrobe University and the Royal Women's Hospital

Topic:

HPV, cervical cancer and vaccination – What do women know?

Project Status:

Project was completed in 2005.

Publications and/or Presentations:

No publications to date however one paper has been submitted to the *British Medical Journal* and a qualitative based paper is currently being written.

Synopsis:

Aim: To understand women's current knowledge, attitudes and behaviours related to HPV, the HPV vaccine, cervical screening and cervical cancer.

Method: 1000 Victorian women using telephone survey plus 5 focus groups (young, older, Iraqi, TAFE, nurses). **Results:** Overall low awareness of HPV, however once explained, women were accepting of a vaccine. Focus groups initially believed a vaccine would promote promiscuity, but when further information was provided, the women did not believe this was an issue any longer. Cost and inconvenience of a vaccine were not barriers to intent to vaccinate. Women reported regular cervical screening behaviour, trust in screening, and satisfaction with the current 2 yearly screening interval. Women did not understand what an abnormal Pap test result actually meant.

Conclusions: Overall women were positive about cervical screening and the vaccine. Framing HPV as an STI may present a barrier to understanding and acceptance of the vaccine. There were no apparent differences between groups (ethnicity, profession) however it was not possible to statistically measure differences between groups due to sample size.

3.3. Issues associated with Pap tests

Only one study has been conducted by CBRC that included questions relating to HPV. Fernbach (2001) conducted a qualitative study of Victorian women's knowledge, attitudes and behaviour associated with Pap tests in order to inform the development of an educational campaign.

Researchers:

Madeline Fernbach
CBRC, The Cancer Council Victoria

Topic:

Young women's attitudes related to Pap tests including HPV

Project Status:

Project was completed in 1999.

Publications and/or Presentations:

Fernbach, M. (2001). Young women's issues associated with Pap tests: A qualitative study of Victorian women. *Health Promotion Journal of Australia*, 12(3), 254-257

Fernbach, M. (June 1999). *Young women's issues associated with cervical screening: Focus group report*. Centre for Behavioural Research in Cancer. Report to PapScreen Victoria.

Synopsis:

Aim: To examine younger women's knowledge of, attitudes and behaviour associated with Pap tests to inform the development of educational campaigns for this target group. **Method:** Ten focus groups were held with a total of 57 women: five groups with women aged 15 to 23 years, and five with women aged 25 to 44 years. Women were recruited from a range of socio-economic backgrounds as well as from rural and urban areas. **Results:** In general, women of all ages lacked knowledge about HPV and its association with cervical cancer. None spontaneously mentioned HPV, and "very few" had heard of HPV, with some women confusing the virus with Herpes. One urban group wanted to know if it could be cured. HPV was talked about in the form of genital warts, with some of the older women understanding that it was a sexually transmitted disease. When discussing possible causes of cervical cancer, HPV was not mentioned, however other things listed included hereditary factors, smoking, the Pill, sexual activity, sexually transmissible diseases, presence of dirt or grime in the vagina, not having babies at a young age, having too many babies, and "putting talcum powder in one's underwear". **Conclusions:** In general, participants of all ages lacked knowledge of HPV and its connection to cervical cancer, which could be targeted in educational campaigns.

3.4. HPV information needs and preferences

McCaffery and Irwig (2005) conducted a small qualitative interview study of 19 women who had tested positive for HPV during routine cervical screening, researching their information needs and preferences:

Researchers:

Kirsten McCaffery and Les Irwig

Topic:

Australian women's needs and preferences for information about human papillomavirus in cervical screening

Project Status:

Completed

Publications and/or Presentations:

McCaffery, K., & Irwig, L. (2005). Australian women's needs and preferences for information about human papillomavirus in cervical screening. *Journal of Medical Screening*, 12, (134-141).

Synopsis:

Aim: To explore women's understanding of HPV, their information needs and experience of HPV infection. **Method:** Nineteen women diagnosed with HPV infection during routine cervical screening were recruited from general practice, family planning clinics, and gynaecologists in Sydney. In-depth semi-structured qualitative interviews were conducted during June and December 2002, using an interview topic guide. The topics included: (a) screening history and background knowledge, (b) information needs and understanding about HPV and cervical cancer, (c) experience of recent Pap test results and HPV diagnosis, (d) women's understanding and perceptions of test results, (e) psychological impact of test results, (f) experience of treatment or follow-up, and (g) improvements to cervical screening in the future. The Framework Analysis method (matrix of themes x cases) was used to identify emerging themes.

Results: None of the 19 women were aware that HPV caused cell changes.

Their lack of awareness led them to make inferences about HPV and its prevalence. Women wanted further information on different HPV viral types

Conclusions: Women need high-quality information about HPV and its role in cervical cancer prior to screening rather than afterwards, when they may face an abnormal result. The clinician potentially plays an important role in moderating the effects of diagnosis through the manner and mode in which an HPV diagnosis is delivered. Revision of cervical screening policy and practice in light of the changes in the understanding of HPV (women now knowing of HPV) is recommended.

3.5. Multicultural responses to the HPV vaccine

Work is currently being conducted on the acceptance of the HPV vaccination within Anglo, Indigenous and Chinese Australian women:

Researchers:

Ms Margaret Heffernan

PhD student at Melbourne University

Supervised by Prof Sue Garland.

Other investigators: Dr Kirsten McCaffery, Prof Susan Sawyer, Prof Michael Quinn.

Title:

Human Papillomavirus vaccine and Australian community intent to vaccinate pre-adolescent children with HPV vaccine.

Project Status:

One year into a three-year project. Data collection about to begin (Phase 1).

Synopsis:

Aims: To understand the responses of Anglo, Chinese and Indigenous Australians to the HPV vaccine. **Method:** Two phases: (1) qualitative interviews with 45-60 participants, including GPs, (2) quantitative questionnaire administered to 900 parents across Australia.

3.6. Development of a decision tool related to HPV testing

A Sydney University research group (The Sydney Health Decision Group) is currently testing a decision aid that has been developed to assist women to make informed choices before choosing a management option for a mild abnormal Pap test result.

Researchers:

Kirsten McCaffery, Les Irwig, Kirsten Howard, Elizabeth Davey, Mary Lewicka, Alex Barratt, Glenn Salkeld, and Edith Weisberg
University of Sydney

Topic:

Development of a decision aid to facilitate informed choice in the management of mildly abnormal Pap smears: HPV testing or repeat Pap smears?

Project Status:

Current

Publications and/or Presentations:

None to date

Synopsis:

Aim: To develop a decision aid to assist women with making an informed choice for the management of a mild cervical abnormality and to evaluate the impact of this decision aid on psychological well-being and decision quality. The decision aid will assist women to choose between the two management options of HPV test or repeat Pap test by providing unbiased information about the two options and their possible outcomes. **Method:** A randomised controlled trial will be used with 300 participants. Women will be allocated to one of three arms to receive: (1) HPV test, (2) repeat Pap test, or (3) a decision aid to support an informed choice between the two management options. **Results:** Primary outcomes for the study will be: psychological well-being and informed choice. Secondary outcomes will be: knowledge, values, preferences and satisfaction with decision-making. A 12-month follow-up measurement time-point will be included for the psychological measures.

4. Summary of international studies

Compared to Australia, far more research has already been conducted and published on the psychosocial aspects of HPV internationally. Table 1 lists the range of HPV related topics that were found in the search of international literature (see Appendix A for a full list of the studies matched to each theme).

The entries in Table 1 indicate that most International studies related to the psychosocial aspects of HPV are being conducted in the UK and the USA. Multiple studies were found that related to the themes of HPV knowledge and HPV vaccine acceptance, suggesting that these two areas of research have been more prominent than others. Knowledge/awareness studies were more prolific in the UK whereas vaccine acceptance studies were more prolific in the USA.

Table 1: Summary of themes found in the International HPV literature

Theme	Number of Studies	Country of Study/Studies
Attitudes towards HPV testing	2	UK
Awareness/knowledge of HPV:	8	Belgium (1), Iceland (1), UK (4) & USA (2)
- Adolescent females and adult females (1)		
- Adult females only (4)		
- Adult females & males (3)		
Information needs related to HPV	1	UK
Psychosocial impact of HPV diagnosis	2	UK
Response to vaccine:	12	USA (10) & Iceland (1) & unknown (1)
- Adolescent females and adult females (2)		
- Adult females only (2)		
- Health professionals (4)		
- Parents (4)		

Note: This list excludes review, discussion and editorial articles.

5. What do we still need to know? A summary of the literature gaps

The limited number of studies conducted within Australia about women's knowledge of HPV indicates that there are many opportunities to develop future research in the area. From the review of both Australian and overseas research, the gaps have been identified using a matrix methodology. Table 2 outlines the matrix of potential topic areas by whether this topic has already been researched, either in Australia or internationally. Cells in the matrix for which there are no studies listed, indicate gaps in the literature and hence opportunities for future Australian research:

Table 2: Summary of HPV research gaps

Topic	Australian	International
Attitudes towards HPV testing (including self-sampling):		
		➡➡
Awareness/knowledge of HPV:		
• Adolescent females	➡➡ (Fernbach)	➡➡
• Adolescent males		
• Adult females	➡➡ (Fernbach – limited sample; Asquith; Dyson & Pitts)	➡➡
• Adult males		➡➡
• Multicultural groups	➡➡ Chinese, Indigenous & Iraqi	➡➡
Decision making for HPV testing:		
	➡➡ (McCaffery et al.)	
Information needs on HPV (e.g., content, framing):		
	➡➡ (McCaffery & Irwig – but small study)	➡➡
Psychosocial response to HPV diagnosis:		
	➡➡ (McCaffery & Irwig – but small study)	➡➡
Response to vaccine introduction (e.g., acceptance, barriers):		
• Adolescent females		➡➡
• Adolescent males		
• Health professionals		➡➡
• Multicultural groups	➡➡ Chinese, Indigenous & Iraqi (Dyson & Pitts; Heffernan)	➡➡ African-American, Hispanic
• Parents	➡➡ (Heffernan; McCaffery & Irwig)	➡➡

Note: ➡➡ denotes at least one study has been conducted on this topic.

6. Conclusions

Research into the psychosocial aspects of HPV is very limited within Australia compared to the international context. Thus there are many opportunities available to Australian researchers to conduct quality local research projects.

The gap analysis included in this literature review has revealed several topic areas in which there is limited or no current knowledge within Australia, including attitudes towards HPV testing, awareness/knowledge of HPV (especially adolescents, males and multicultural groups), the range of psychosocial responses to a HPV positive test, and response to the introduction of a HPV vaccine (especially adolescents and health professionals).

Please refer to the Recommendations section 7.1 below for a full list of suggested research topics.

The findings from the few Australian studies conducted so far suggest that awareness and knowledge of HPV is very low. This presents the opportunity for PapScreen to conduct population based educational campaigns, to not only educate the public about the link between HPV and cervical cancer but also to inform the public about the need to continue to have regular Pap tests despite the introduction of the HPV vaccine.

Please refer to the Recommendations section 7.2 below for a list of suggested communication messages.

7. Recommendations:

7.1. Research topics and project suggestions

The literature review has confirmed that there are many opportunities in Victoria for research to be conducted into the psychosocial impact of HPV, HPV testing and response to the HPV vaccine. The task remains for PapScreen to consider which research topics are most relevant to the overall aim of the cervical screening program, to increase cervical screening rates in Victoria.

The following two topics have been recommended with this in mind. For each topic, a set of potential research questions has been listed. Each set includes general questions that will help fill the current knowledge gaps identified, but also includes specific questions that relate to the relationship between HPV and cervical screening attitudes, intention to screen and actual screening behaviour. Suggested research projects have also been added.

1. Evaluate the impact of HPV awareness/knowledge on cervical screening attitudes and behaviours. What do Victorian women currently know about HPV? And how does this knowledge relate to screening behaviour or intention to screen?

- a. Do women know that HPV is an STI (i.e. how HPV is transmitted)?
- b. Do women know the high prevalence of HPV in the population?
- c. Do women understand the link between HPV and cervical cancer?
- d. Do women understand there are different types of HPV (some linked to cervical cancer, some to warts)?
- e. Do women understand the low likelihood of cancer due to having tested positive for HPV?
- f. Does education about HPV lead to differences in screening behaviour/intention to screen?

Project suggestions: (a) An HPV education session could be run, with pre-post measurement of cervical screening attitudes and intentions to screen in the future, as well as psychological responses. (b) The education session could be replaced with the presentation of the PapScreen HPV brochure, or viewing of the HPV page on the PapScreen website, which would provide a test of the effectiveness of these communication materials/mediums.

2. Evaluate the response of health professionals to the introduction of the vaccine and what assistance they need to communicate effectively with patients regarding HPV and the need to continue with cervical screening:
 - a. Acceptance levels
 - b. What age they feel is appropriate to start vaccination
 - c. Intention to promote vaccination
 - d. Perceived barriers to vaccination
 - e. Demographic characteristics of physicians and practice variables
 - f. Do they know how to communicate with patients about HPV?
 - g. What are the information needs of health professionals? (i.e., What can PapScreen provide, on the website or in printed form, to aid them in communicating with their patients?)

Project suggestion: Conduct focus groups with a cross-section of health professionals to ascertain their HPV information needs, their experiences of patient questions relating to HPV, and how they communicate with their patients about HPV in relation to cervical screening.

7.2. Communication

The review articles (see Appendix B) canvassed for this literature review contained some useful suggestions about the type of messages that will need to be conveyed to the public and health professionals about HPV. Whilst communication needs was not the focus of this literature review, the key messages will be repeated here for the benefit of future communication strategies of PapScreen.

1. Promote PSV (especially the website) as a credible and accurate source of information about HPV and the vaccine for both the public and health professionals

2. Educate the public about what HPV is (an STI, types, transitory infection versus persistent disease) and its link with cervical cancer
 3. Normalise the occurrence of having HPV (80% of the population) to reduce stigma and emotional distress
 4. Educate the public about the fact that HPV persistence is a risk factor for cervical cancer, not HPV infection (which is mostly transitory)
 5. Educate the public about the need for women to continue to have Pap tests once the vaccine is introduced as the current vaccine options currently do not cover all high-risk HPV types that may lead to cervical cancer
 6. Reinforce to older women and women in stable relationships that Pap tests are still necessary (some women believe that as they are in a stable relationship they are not at risk for an STI)
 7. Provide health professionals with information on how to answer questions or deal with concerns about HPV and the vaccine from their patients (see Zimet, 2005, pS21, for suggestions)
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9. Appendix A: List of International studies published by HPV theme

Theme	Title	Author/s & Year	Country of Study	Sample Ethnicity	Sample Size	Method
Attitudes towards HPV testing	Attitudes to self-sampling for HPV among Indian, Pakistani, African-Caribbean and white British women in Manchester, UK	(Forrest et al., 2004)	UK (Manchester)	African-Caribbean, Indian, Pakistani, & white British	200 (women)	Quantitative: in-person questionnaire
Attitudes towards HPV testing	Attitudes towards HPV testing: A qualitative study of beliefs among Indian, Pakistani, African-Caribbean and white British women in the UK	(McCaffery et al., 2003)	UK (Manchester)	African-Caribbean, Indian, Pakistani, & white British	71 (women aged 20-59)	Qualitative: Focus groups
Awareness/ Knowledge of HPV	Risk factors for cervical cancer development: What do women think?	(Baay, Verhoeven, Avonts, & Vermorken, 2004)	Belgium	Not reported	162 (women & female students)	Self-report questionnaire
Awareness/ Knowledge of HPV	Knowledge of human papillomavirus infection among young adult men and women: Implications for health and education research	(Baer, Allen, & Braun, 2000)	UK (New England)	Native American, Asian or Pacific Islander, black (non-Hispanic), Hispanic or Latino, white (non-Hispanic),	322 (men & women undergraduates)	Quantitative: postal questionnaire
Awareness/ Knowledge of HPV	Adults' knowledge and behaviours related to human papillomavirus infection	(Holcomb, Motino Bailey, Crawford, & Ruffin, 2004)	USA	Asian, Black, Hispanic & White	289 (men & women 18 years & over)	Quantitative & qualitative: questionnaire

Theme	Title	Author/s & Year	Country of Study	Sample Ethnicity	Sample Size	Method
Awareness/ Knowledge of HPV	Eligibility and willingness of young Icelandic women to participate in a HPV vaccination trial	(Gudmundsdottir et al., 2003)	Iceland	Not reported.	163 (women aged 18-23)	Quantitative: postal questionnaire
Awareness/ Knowledge of HPV	Human papillomavirus, genital warts, Pap smears, and cervical cancer: Knowledge and beliefs of adolescent and adult women	(Mays et al., 2000)	USA (Chicago, Indianapolis)	African American, white (non-Hispanic)	40 (women & adolescent girls)	Qualitative interviews
Awareness/ Knowledge of HPV	Human papillomavirus and the value of screening: Young women's knowledge of cervical cancer	(Philips, Johnson, Avis, & Whyne, 2003)	UK (Nottingham)	Predominantly white (no further specification)	222 (undergraduate women)	Quantitative: Postal questionnaire
Awareness/ Knowledge of HPV	Beliefs about the risk factors for cervical cancer in a British population sample	(Waller, McCaffery, & Wardle, 2004)	UK	Representative mix of ethnicities	1940 (men and women)	Face-to-face population survey
Awareness/ Knowledge of HPV	Awareness of human papilloma virus among women attending a well woman clinic	(Waller et al., 2003)	UK (London)	Asian, black, white, other	1032 (women)	Quantitative: questionnaire
Information needs	Making sense of information about HPV in cervical screening: A qualitative study	(Waller, McCaffery, Nazroo, & Wardle, 2005)	UK	African Caribbean, South Asian (Pakistani, Indian, East African Asian), & white British	74 (women)	Qualitative: interview
Psychosocial impact of HPV diagnosis	An observational study of pre-colposcopy education sessions: What do women want to know?	(Neal, Pitts, Dunn, Hughes, & Redman, 2003)	UK	Not stated	47 (women requiring colposcopy, 20-60 years old)	Qualitative discussion after video

Theme	Title	Author/s & Year	Country of Study	Sample Ethnicity	Sample Size	Method
Psychosocial impact of HPV diagnosis	Testing positive for human papillomavirus in routine cervical screening: Examination of psychosocial impact	(McCaffery et al., 2004)	UK (London)	Predominantly white British	428 (women)	Quantitative: postal questionnaire
Response to vaccine – Female adolescents & adults	Eligibility and willingness of young Icelandic women to participate in a HPV vaccination trial	(Gudmundsdottir et al., 2003)	Iceland	Not reported.	163 (women aged 18-23)	Quantitative: postal questionnaire
Response to vaccine – Female adolescents & adults	Attitudes of adolescent/young adult women toward human papillomavirus vaccination and clinical trials	(Hoover, Carfioli, & Moench, 2000)	USA	White predominantly	60 (15 to 28 year old females)	Qualitative & quantitative: Role play & questionnaire
Response to vaccine – Female adolescents & adults	Attitudes about human papillomavirus vaccine in young women	(Kahn, Rosenthal, Hamann, & Bernstein, 2003)	USA (Ohio)	Black, Hispanic, white	52 (18 to 30 year old females)	Quantitative: questionnaire
Response to vaccine – Female adolescents & adults	Acceptability of human papillomavirus immunization	(Zimet et al., 2000)	USA	African American, non-Hispanic white	20 (adolescents aged 14-18) and 20 (women aged 20-50)	Quantitative & qualitative: individual interviews
Response to vaccine – Health professionals	Pediatricians' intention to administer human papillomavirus vaccine: The role of practice characteristics, knowledge, and attitudes	(Kahn et al., 2005)	USA	Not reported	513 (male and female paediatricians)	Quantitative: postal questionnaire
Response to vaccine – Health professionals	Recommending STI vaccination to parents of adolescents: The attitudes of nurse practitioners	(Mays & Zimet, 2004)	USA	Not reported (abstract only)	Not reported (abstract only)	Quantitative: questionnaire using scenarios

Theme	Title	Author/s & Year	Country of Study	Sample Ethnicity	Sample Size	Method
Response to vaccine – Health professionals	Gynecologists; attitudes regarding human papilloma virus vaccination: A survey of Fellows of the American College of Obstetricians and Gynecologists	(Raley, Followwill, Zimet, & Ault, 2004)	USA	Not reported	181 (male and female obstetricians & gynaecologists)	Quantitative: postal questionnaire using scenarios
Response to vaccine – Health professionals	Attitudes about human papillomavirus vaccine among family physicians	(Riedesel et al., 2005)	USA	Not reported	145 (male and female GPs)	Quantitative: postal questionnaire
Response to vaccine - Parents	Human papillomavirus vaccine acceptability among parents of 10-to-15-year-old adolescents	(Davis, Dickman, Ferris, & Dias, 2004)	Unknown	Not reported (abstract only)	506 (parents)	Quantitative: questionnaire
Response to vaccine - Parents	Parental perspectives on vaccinating children against sexually transmitted infections	(Mays, Sturm, & Zimet, 2004)	USA	African American, white	34 (parents – predominantly female)	Qualitative: interviews
Response to vaccine - Parents	Parental acceptance of the human papillomavirus vaccine	(Olshen, Woods, Austin, Luskin, & Bauchner, 2005)	USA	Black, Hispanic, white, other	25 (parents – predominantly female)	Qualitative: focus groups & interviews
Response to vaccine - Parents	Parental attitudes about sexually transmitted infection vaccination for their adolescent children	(Zimet et al., 2005)	USA	Not stated	278 (parents 69% female)	Quantitative: computer based questionnaire

10. Appendix B: List of HPV related review articles, editorials and discussion papers, with recommendations

Themes	Title	Author/s & Year	Type	Psychosocial-based Research Recommendations
<ul style="list-style-type: none"> • Epidemiology & pathogenesis • Clinical use of HPV DNA testing • Clinical guidelines • Awareness and knowledge of HPV • Psychosocial responses to HPV testing and diagnosis • Patients' desired information about HPV • Sources of HPV information 	HPV communication: Review of existing research and recommendations for patient education	(Anhang, Goodman, & Goldie, 2004)	Review	<ul style="list-style-type: none"> • Lists recommended communication topics • Recommends that practitioners should use a shared decision making model with patients when deciding HPV management • Tailor information according to person's characteristics: especially age, HPV type diagnosed and literacy level
<ul style="list-style-type: none"> • Adolescent risk for HPV • Outcomes of HPV infection • Vaccination • HPV knowledge 	Understanding and preventing human papillomavirus infection during adolescence and young adulthood	(Adams Hillard & Kahn, 2005)	Editorial	<ul style="list-style-type: none"> • Provide adolescent patients with accurate information on HPV • Put risks associated with HPV infection into perspective • Recognise potential of disease burden for individuals
<ul style="list-style-type: none"> • Possible role of HPV testing in three clinical settings: screening tool, triage, test of a cure • Psychological impact of positive HPV test 	Human papilloma virus and cervical screening	(Damasus-Awatai & Freeman-Wang, 2003)	Review	N/A (Full article not available by the time of writing)

Themes	Title	Author/s & Year	Type	Psychosocial-based Research Recommendations
<ul style="list-style-type: none"> • HPV as a sexually transmitted infection • Natural history and nomenclature of HPV infection • Current follow-up and screening guidelines • Fear, guilt, anxiety and psychological distress • Shared decision making 	<p>Why am I scared of HPV?</p>	<p>(Harper, 2004)</p>	<p>Discussion</p>	<ul style="list-style-type: none"> • Provide information on HPV to patients before the test is taken • Use shared decision making as a communication tool with patients to ease psychological distress and increase awareness
<ul style="list-style-type: none"> • Identification & diagnosis • HPV types • DNA testing • Relationship between HPV & cervical cancer • Incidence of cervical cancer • Vaccination 	<p>Human papillomavirus: Beware the infection you can't see</p>	<p>(Heley, 2003)</p>	<p>Discussion</p>	<p>N/A (Focus on advice for health professionals)</p>
<ul style="list-style-type: none"> • Epidemiology of HPV in adolescents • HPV vaccines in development • Delivery of prophylactic HPV vaccines 	<p>Vaccination as a prevention strategy for human papilloma related diseases</p>	<p>(Kahn, 2005)</p>	<p>Review</p>	<ul style="list-style-type: none"> • Further research on how long vaccines protection last will impact on screening • Guidelines will need to be developed regarding the safety of lengthening the screening interval for vaccinated women

Themes	Title	Author/s & Year	Type	Psychosocial-based Research Recommendations
<ul style="list-style-type: none"> • Epidemiology of HPV • Transmission • Risk factors • Cervical cancer progression; • Screening & treatment guidelines for adolescent & young women 	Impact of HPV infection in adolescent populations	(Moscicki, 2005)	Review	<ul style="list-style-type: none"> • Adolescent sexually active females should be encouraged to screen for STIs & cervical cancer • All adolescents should be educated regarding HPV and risks associated with infection • Condom use should be recommended for the control of HPV infections in all sexually active adolescents
<ul style="list-style-type: none"> • Demographics & vaccine acceptability • Vaccine efficacy & disease severity • Behavioural prevention strategies • Methods for assessing acceptability 	Parental acceptability of vaccines for sexually transmitted infections	(Rosenthal & Stanberry, 2005)	Editorial	<ul style="list-style-type: none"> • Examine characteristics of vaccines that influence decision making • Examine how parents and adolescents process information about HPV & vaccination • Examine characteristics of parents and adolescents associated with vaccine acceptance • Examine barriers to vaccination
<ul style="list-style-type: none"> • HPV types • Vaccine mechanism • Vaccine types • Effectiveness of vaccines • Questions still remaining related to vaccines • Who and when to vaccinate • Responses & acceptance to vaccine (ethnic differences) 	Prophylactic vaccines for human papillomavirus: A bright future for cervical cancer prevention	(Szarewski, 2005)	Editorial	<ul style="list-style-type: none"> • Evaluate responses to vaccine in different ethnic groups • Determine most effective way to disseminate information on vaccine • Evaluate attitudes to vaccine and likely uptake • Continue to promote Pap tests to generation for whom vaccination is too late

Themes	Title	Author/s & Year	Type	Psychosocial-based Research Recommendations
<ul style="list-style-type: none"> • Background: HPV & cervical cancer • Public understanding of HPV • Psychosocial impact of participation in HPV testing (emotional, stigma, relationships, perception of risk) • Impact of HPV testing on uptake of cervical screening (especially on those groups already underscreeners – older women, less educated women, and women of minority ethnicities) • HPV persistence: Bio-behavioural mechanisms (smoking, boosting immune function, social support & disclosure) and interventions • Prevention of HPV (vaccination and changing health-related behaviour) • Impact of women & men’s sexual behaviour • Change the focus to minimising HPV persistence rather than sexual behaviour • Focus on normalising HPV to reduce stigma 	<p>Human papillomavirus and cervical cancer: Issues for biobehavioral and psychosocial research</p>	<p>(Waller, McCaffery, Forrest, & Wardle, 2004)</p>	<p>Review</p>	<ul style="list-style-type: none"> • Determine current levels of public awareness of HPV and its link to cervical cancer • Develop well-validated, standardised measures of HPV awareness • Use representative population samples (across SES, age & ethnicity) • Clearly distinguish in projects between the cancer causing and wart causing HPV types • Determine information needs of the public • Evaluate psychosocial impact of HPV testing (include stigma & uncertainty of progression to cancer, distress from non-disclosure of pos HPV test result) • Evaluate women’s perceptions of cancer risk associated with pos HPV test result, and perception of psychological outcomes • Research into the links between smoking, stress, coping style, social support and HPV persistence
<ul style="list-style-type: none"> • Knowledge of HPV • Vaccine acceptance (adolescents, parents, health care providers) • The importance of the difference between transitory HPV infection and persistent HPV infection • High degree of misinformation in the media • Importance of the role of health professionals 	<p>Improving adolescent health: Focus on HPV vaccine acceptance</p>	<p>(Zimet, 2005)</p>	<p>Review</p>	<p>N/A (Focus on advice for health professionals)</p>