

HPV vaccination: findings from research on the parent perspective

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Introductions

My research interests

HPV

Gender neutral HPV vaccine

Cervical screening

Healthcare professional

knowledge,

parents, women, young people

Today's talk

HPV

Parents of girls

Parents of boys

Insights from Twitter

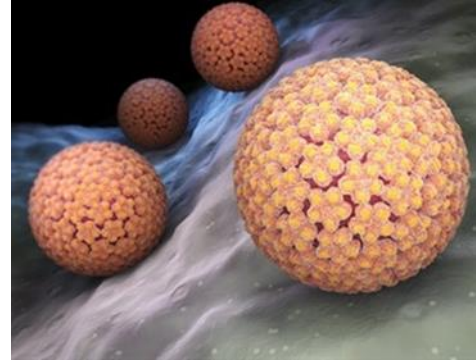
Conclusions

Who's in the room?

Your role

What is HPV?

- Human papillomavirus
- Sexually transmitted infection
- More than 200 types
 - 6 and 11 – low risk types cause more than 90% genital warts
 - 16 and 18 – high risk types cause 70% of cervical cancer but other cancers as well
- 80% of sexually active individuals will come into contact with HPV
 - Condoms
 - Immune response



HPV vaccination in UK

- In 2008, the HPV vaccination programme was introduced for girls aged 12 to 13
 - Catch-up programmes offering the vaccine to all girls born on/after September 1st 1990
 - Quadrivalent vaccine – 2 doses (3 for pre-Sept 2014)
 - Uptake for 2017-18 was 83.8% for both doses by end of school yr
 - NB demographic variation
- September 2019, to be rolled out to boys as well

Background - knowledge

- Marlow et al., (2013) compared international knowledge of HPV and HPV vaccination (online survey)
 - 88% of US women, 72% of Australian women and 62% of UK women reporting awareness and most of those knowing that HPV causes cervical cancer

Parents of girls

- Aims:
 - To find out what mothers of girls age 11-18 know and think about HPV and the vaccine
- Survey:
 - 138 women associated with 6 schools in North Staffordshire took part
 - engagement with the HPV vaccination programme and knowledge of HPV vaccination

HPV vaccination

Daughter aged 12 or older who has had HPV vaccination	n=100; %
Yes	85.0
No	6.0
Don't know	9.0
Daughter aged 11 or 12 intending to have HPV vaccination	n=78; %
Yes	84.6
No	3.8
Don't know	11.5
Reasons for vaccinating or intending to vaccinate	n=124; %
Protection/Prevention of cervical cancer	61.3
Accept all vaccines/medical interventions	4.8
Vaccine is well-researched	3.2
Discussed with daughter	3.2
Reasons for not vaccinating or being unsure whether to vaccinate	n=14; %
Don't know enough about it	6
Not enough research	3
Concerned about side-effects	3
Don't believe in vaccinations	1
Child intends to abstain from sex	1
Do you think girls who are vaccinated will need to go for cervical screening in the future?	n=138; %
Yes	89.1
No	0.7
Don't know	9.4

HPV knowledge

Heard of HPV (n=110); 80%	
What do the letters HPV stand for?	
Correct - Human Papilloma Virus	67.3
Incorrect	32.7
What is HPV?	
Correct - Virus or STI/STD	70.0
Incorrect	30.0
How does someone contract HPV?	
Correct - Sex or sexual contact	66.4
Incorrect	33.6
What is the relationship, if any, between HPV and cervical cancer?	
Correct - Causal/ Increases risk	64.5
Incorrect	35.5
Do you think the HPV vaccine will prevent all cases of cervical cancer?	
Correct - No	63.6
Incorrect	36.4
Knowledge Score (Out of 5)	
Mean	3.32
Std Dev	1.533

Parents of girls - Focus groups

Participant demographics

- 15 mothers; 4 focus groups and 1 interview.
 - Age range 35-51 years, $M = 45$ ($SD = 4.5$)
 - All had daughters aged 11-18.
 - All mothers were of white British ethnicity.
 - Only 2 of the mothers had daughters who had not yet received the HPV vaccine.

Findings

- 2 main themes:
 - Theme 1: Limited knowledge and uncertainty
 - Theme 2: Trusting and unquestioning
- The importance of communication was embedded throughout these two main themes.

Findings

Theme 1: Limited knowledge and uncertainty

- Knowledge of cervical cancer and HPV was generally quite limited and uncertain.
 - For example, the majority of the mothers were aware of the link between cervical cancer and HPV but were uncertain of the specifics, for example:
 - “I don’t really know, I know that there is a connection between the HPV virus and the cancer but I don’t specifically know what that... I don’t know in detail what that is” (Anthea, INT1,).

Theme 1: Limited knowledge and uncertainty

- Knowledge was particularly limited and uncertain when it came to the HPV vaccine.
 - “All I really knew was that it was a couple of injections over a period of time. That was about it really” (Isobel, FG3).
 - “I think the concern, the talk amongst my colleagues when it first came out was: why are we giving these children a vaccine that’s something to do with something to do with, something that you can pick up sexually? Are we encouraging them to become promiscuous?” (Debbie, FG1).

Theme 1: Limited knowledge and uncertainty

- Despite limited knowledge and uncertainty, the importance of the HPV vaccine and cervical screening were really emphasised.
 - “I think it’s massively important” (Hannah, FG2)
 - “It’s life-saving isn’t it?” (Grace, FG2)
 - “It’s always been important to me” (Kate, FG3)

Theme 1: Limited knowledge and uncertainty

- Limited knowledge of daughters. Importance of daughters being informed was emphasised.
 - Missed opportunities in school (e.g. PHSE classes).
 - Child appropriate literature needed.
 - Responsibility of the parents (mothers).
 - “So I definitely think it’s down to the parent to make that decision and instil, you know, the awareness for the future” (Kate, FG3).
 - Honesty and open communication important.

Findings

Theme 2: Trusting and unquestioning

- Vaccine - “went with the flow” (Debbie, FG1) and “rolled along with it” (Claire, FG1), a natural follow-on from other vaccinations.
 - NHS wouldn’t invest in something not effective.
 - Anticipated regret.
 - Little discussion, not open to negotiation.
 - Already made up minds.
 - Would take a lot to deter them from consenting.

Theme 2: Trusting and unquestioning

- “I didn’t really question it, I just assumed it was a good thing to do” (Belinda, FG1).
- “I think we’re just so used to giving consent for MMRs or tetanus, your school nurse visits and everything else that you just didn’t question it at all” (Claire, FG1).
- “I don’t think we did discuss it that much. We just went...it’s here, you’re having it, get on with it (laughs)” (Isobel, FG3).

How does HPV affect men?

- Genital warts (10% lifetime risk for males and females)
- HPV implicated in 5% of cancers
 - Cancers of the anus, tonsil, base of the tongue, penis, larynx and head, and neck
- The incidence of head and neck cancers in Europe attributable to HPV16/18 is five-fold higher in men (12,707 new cases yearly) than women (2,531 new cases yearly) and is increasing.
- 90% of anal cancers
 - Age 50+ more women than men
 - Age 20-49 more men than women
 - Highest in men who have sex with men (incidence = cervical cancer in unscreened population)
 - Even higher in men living with HIV who have sex with men

Background - knowledge

- Mortensen et al., (2015) conducted pan-European survey of parents to explore their attitudes to the vaccine
 - 75% of UK parents were in favour of their sons being vaccinated
 - respondents provided with “brief oral information on HPV-related disease in males” prior to answering the questions

Parents of boys

- 186 parents of boys aged 11-18 (age range 28-65, mean age 42.99, SD 6.31)
- Self-report survey
 - Part 1 was socio-demographic information
 - Part 2, *for ppts who had heard of HPV*, included a 23 item HPV knowledge scale (responses: T/F/DK)
 - Part 3, *for ppts who had heard of vaccine*, included a 9 item HPV vaccination knowledge scale
 - Willing to vaccinate boys? Y/N – then rated importance of 13/14 reasons
 - Part 4, *completed by all ppts*, explored attitudes and beliefs about HPV and HPV vaccination in relation to sons.

Results

- 53.2% had heard of HPV
 - Median HPV knowledge score (out of 21) = 14
 - 'Most sexually active people will get HPV at some point in their lives' (32.3% correct)
 - 'HPV can cause cancer of the penis' (35.4%)
 - 'HPV can cause anal cancer' (45.5%)
- 54.8% had heard of vaccine
 - Median vaccine knowledge score (out of 6) = 5
 - 79.4% definitely/probably willing to vaccinate sons
- After being provided with information
 - 85.5% of all participants believed boys should receive the vaccine

Results 2

- Top 4 reasons in our survey why parents would want sons vaccinated
 - Both sexes are equally responsible for preventing sexually transmitted infections (98.8% very or somewhat important)
 - Because my son is also at risk of HPV infection (just as girls are) (98.8%)
 - I welcome any protection of my children against cancer (98.7%)
 - To protect my son's future partners from cancer and/or genital warts (96.3%)

Possible barriers to gender neutral vaccination from PLOS One survey

Reason	Very important	Somewhat important
I fear side effects (incl. that the vaccine is new)	42.9	52.4
I don't know enough about HPV vaccination	71.4	19.0
I don't know enough about HPV related diseases (in males)	57.1	28.6
I might regret vaccinating my son, if he later experiences side effects	23.8	38.1
Lack of recommendation from healthcare professionals	14.3	47.6

Reason	Very important	Somewhat important
I am against (too many) vaccines	28.6	23.8
It is unlikely that my son will be HPV infected	19.0	19.0
I prefer that my son makes his own decision later	9.5	28.6
It is sufficient that females are vaccinated	14.3	14.3
Pre-marital sex and HPV vaccination goes against my cultural/ religious beliefs	4.8	9.5
My son is too young – it is not yet relevant	4.8	9.5
My son is afraid of needles – does not want to see the doctor	0.0	14.3
It is too late – my son already had his first sexual experience	0.0	4.8

Parents of boys – focus groups

- Lack of knowledge about HPV before survey
- Trust
 - Trust the NHS website
 - Trust that research will be done about adverse effects
- Equality of responsibility
- Questions/comments
 - Is it the same vaccine for girls and boys?
 - Can they have it later if they decide not to have it now?
 - The boys hear it makes the girls poorly
 - How long does it protect you for and to what extent?
 - How much research has been done?
 - Might make them more promiscuous

Parents of boys – focus groups

- **Communication**
 - Mothers rather than fathers
 - Sons know more than mums
 - Some uncomfortable talking to sons
- **Education**
 - Responsibility of school and parents
- **Celebrities against HPV**
 - Melinda Messenger

Insights from Twitter

- Boys don't have a cervix
- Safety concerns
- Why so young?

- Why is there no catch up programme?

Safety of vaccine

- World Health Organisation (June 2017)
 - 270 million doses administered worldwide
 - Rate of serious adverse events same in vaccinated and unvaccinated populations
- NHS website
 - 80 million people have been vaccinated worldwide
 - Clinical trials have shown vaccine to be safe

Why should we vaccinate boys?

1. Herd immunity (community immunity) doesn't cover everyone
 - Men who have sex with men
 - Men who have sex with unvaccinated women
 - Variable coverage across country
2. Cost
 - Earlier modelling estimates were flawed
3. Professionals support gender neutral vaccination
 - HPV Action (includes BDA, Terrence Higgins Trust, Stonewall)
 - Jo's Cervical Cancer Trust
4. Other countries (20+) offer the vaccination to boys as well as girls
 - E.g., Australia, New Zealand, US, Austria

Why should we vaccinate boys?

5. Gender equity

- Shared responsibility for sexual health
- Equal access to protective effect of the vaccine

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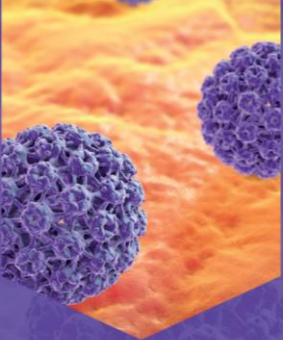
Conclusion

- Pressing need for education
 - Parents
 - Lack knowledge about impact of HPV on males
 - Lack details about vaccine (cervical cancer jab)
 - Concerns about safety
 - General trust in NHS from many parents
 - Also some HCPs lack knowledge re males
 - Important to ensure uptake and prevent scare-mongering from impacting uptake

What next?

- For further information about vaccination and girls:
 - Jo's Cervical Cancer Trust <https://www.jostrust.org.uk/about-cervical-cancer/hpv-vaccine>
- For further information about vaccination and boys:
 - Jabs for the Boys (HPV Action) <http://jabsfortheboys.uk/>
- I'd like to get in touch in a month – if you are happy for me to do so, please complete the contact details sheet
- For more information about me, the work I do, a copy of this presentation, or the links above, please take one of these postcards

Thanks for listening!



Human Papillomavirus (HPV)

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HPV is a very common virus. It infects the skin and any moist membrane (mucosa), such as:

- in women: the cervix, vagina, vulva
- in men: the penis
- in men and women: the lining of the mouth and throat, the anus

There are several ways individuals can protect themselves against HPV, including:

- use a condom, this will reduce but not eliminate the risk of getting HPV
- HPV vaccination
- cervical screening

Most genital HPV infections are passed on through sexual or skin-to-skin contact and at some point during our lives, 4 out of 5 (80%) of us will get at least one type of HPV.

In most cases, your immune system will get rid of HPV. If it doesn't, some low-risk types of HPV cause genital warts while some high-risk types cause around 5% of all cancers.

Some sources of further information

About HPV and girls/women:
jostrust.org.uk/about-cervical-cancer/hpv

About HPV and boys/men:
jabsfortheboys.uk

About the HPV vaccine:
nhs.uk/conditions/vaccinations/hpv-human-papillomavirus-vaccine



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About Dr Sue Sherman and her research on HPV, HPV vaccination, and cervical screening: keele.ac.uk/hpv-vac-card

Contact Sue at s.m.sherman@keele.ac.uk

Information adapted from jostrust.org.uk and jabsfortheboys.uk

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Over to you

- For the last few minutes, it would be great to hear your thoughts about possible issues you might face.
- Or questions about the presentation.