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# The human papillomavirus and HPV vaccine: accounts from young people from Black, Asian and Minority Ethnic groups in Scotland aged 16-26 years

Elaine Carnegie, Anne Whittaker, Carol Gray-Brunton, Catriona Kennedy, Rhona Hogg, Janette Pow, Kevin Pollock, Shona Hilton, Seeramanie Hardy, Diane Willis, Nahida Hanif

Email: [e.carnegie@napier.ac.uk](mailto:e.carnegie@napier.ac.uk)



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# HPV and the HPV vaccine

- *Human Papilloma Virus* (HPV) associated with cervical cancer (1980's)
- HPV is associated with other genital, head and neck cancers **in men and women**
- HPV transmitted mainly through sexual or intimate contact, but usually quickly resolve on their own
- **HPV vaccine** offers the possibility for primary prevention of relevant infections and potentially cancers
- Administered before the on-set of sexual activity

# International context

<b>School-based HPV vaccination programmes</b>	<b>Clinic-based programmes</b>	<b>Universal/gender neutral vaccination programmes</b>
Australia	Belgium	Australia
Brazil	United States	Austria
UK		United States
Canada		Canada

# Evidence and Policy

- High uptake of bivalent and quadrivalent vaccine within Scottish school programme
- JCVI recommendation for MSM
- Nine-valent vaccine licensed in 2015
- Lack of research in Scotland focusing on the needs of BAME groups

# Study Objectives



To explore:

- knowledge and awareness of HPV and the vaccine
- its relevance and participant experiences of HPV vaccination
- perceptions of the available information and format
- perceived barriers and facilitators towards vaccination behaviour

# Methodology

- Qualitative, critical, exploratory study
- Informed by Foucauldian Discourse Analysis (Willig 2008)
- University Ethical Approvals
- Voucher incentives offered as reimbursement
- Community groups as sampling frame
- Focus groups and paired interviews utilising topic guide, stimulus material, sociodemographic questionnaire
- Interviews audio-recorded, transcribed verbatim, anonymised
- Multiple coders for analysis

# Community recruitment

Focus group composition		Number of participants
1	Black African/Christian women	3
2	Asian Muslim women	5
3	Asian Muslim women	5
4	Asian Muslim women	2
5	Black African men	2
6	South Asian men	3
7	Women of South Asian and West Indian descent	2
8	Women of Arab/Muslim descent	4
9	Men of Arab/Muslim descent	2
10	Sikh men of Indian descent	5
11	Sikh women of Indian descent	7
Total		40

# Awareness and attitudes prior to study

	Yes	No	Unsure	Total
Heard of HPV	26	12	2	40
Heard of Vaccine	30	9	1	40
Virus is linked to cancer	20	18	2	40
Boys should be offered vaccine	25	3	12	40
Young women received vaccine	23	5		28

# Discursive Tensions

- Decision-making/acquiescence in relation to vaccination programme
- Young men being detached observers of HPV vaccination
- White Northern hemisphere norms and assumptions challenging age of sexual debut
- Obligation and identity constraining decision-making

## Narratives of decision-making in relation to vaccination programme

- R2: We were just told it's to prevent cervical cancer. That's it.
- R3: I think I just take vaccine because they say it's to prevent...what, I don't remember.
- R2: Some disease.
- R2: No. It was just queued up. I think by class and alphabetical order. We got it...we were told to sit down for 15 minutes after that and go back to the class.
- I: Any discussion with the nurse about what it was for or why you had it?
- R2: No. I think it's just the precautionary stuff like, are you allergic to anything? Do you take any medicine? And whatnot. But nothing specific.

(FG1 Three Black African women aged 16-23)

## Narratives of decision-making in relation to vaccination programme

R1: Yeah, like **when we got the injection we got a leaflet about it, just know the name of it, not much about it.**

I1: Do you remember anything about the leaflet?

R1: Yeah, it was like some kind of cancer and it mostly affects girls, or something. That's all I remember.

(FG3 Five Asian Muslim women aged 16-19)

R3: I didn't know anything about it back then but a lot of people kept saying that there would be some sort of side effects in the long term. **But I thought maybe in an NHS scheme would be a good thing.**

(FG2 Five Asian Muslim women aged 16-19)

## Young men as detached observers of HPV vaccination

R4: **I thought like why do they get exclusivity, like I wanted one as well**, if you know what I mean.

R5: Yes, like where have all they gone, like why is it only the guys in class?

R4: I didn't actually know like why, like it was for girls, but I knew it was HPV and then that was it, it wasn't really like clear to us but.

I: Did you ask anyone?

R4: No, like it was during class time, but obviously I did ask the girls and like then they just said, it was just a jag like to make sure they're okay or whatever.

R5: They didn't really know themselves what they were getting, they just knew that it was good.

R4: It was recommended to have.

## Young men as detached observers of HPV vaccination

Like I said before, when I first heard about HPV, it was in high school. All the guys in my year, **we thought, oh, it's only for females, it's only for girls, that's it, it's nothing to do with us. You feel kind of detached,** this is not related to me or males, so I'm going to ignore it, but if they had this, if they showed this, like it would make you think a lot more.

(FG9 Two young men of Arab/Muslim descent aged 19 and 20)

# Challenging White Northern hemisphere norms and assumptions about age of sexual debut

R1: I think it is because like in our culture you wouldn't have a talk, as in like you would in like other cultures. Like Indian culture it's more taboo to like be sexually active at a young age.

R4: **You wouldn't be sexually active until after your married anyway, so you shouldn't be needing all this, that's what you think.**

FG11 Seven Sikh women of Indian descent aged 17-20)

## Challenging White Northern hemisphere norms and assumptions about age of sexual debut

R2: You should get the information then, yeah. Well lots of people are sexually active in second year, so...

R1: When we're getting...well whenever we get married, so...

R2: **You're saying it's...it depends...your first time when you're sexual...your first sexual experience, but it's not...it's not for everyone.** It's when you have had sex before...sorry, not you, your partner's had sex before. So it doesn't matter if we marry someone who's never had sex before, which we should hopefully...well...so, no, it doesn't really affect us.

(FG8 four women of Arab/Muslim descent aged 16 and 17)

## Narratives of obligation and identity constraining decision-making

- R2: **It seems like, I think from an Islamic perspective, it might seem that, well it's encouraging people to have more, you know, non marital relations. So, it might not be taken very well.**
- R3: If you're talking about people born with their background in the West, selling it as a sexually transmitted - or, displaying it as a sexually transmitted disease, is probably the best way to go about it. **But if you're aiming it at a specific, like a Muslim culture, then you could definitely, you know, it would be more receptive if it was sold almost like common cold.** Like, where anyone can get it through physical contact, but you're more likely to get it if you have sex, you know. So, if you were to do it like that, I suppose the community would be a little bit more receptive to that kind of thing.

# Narratives of obligation and identity constraining decision-making

- I: And do you think there's anyone in terms of...for example, your parents or your aunts or uncles who perhaps would like this information too who maybe haven't got it yet or...?
- R3: No.
- R1: I don't think so. [Voices overlap ] I hope not. Yeah.
- I: You mean it might cause them embarrassment?
- R2: No, no.
- R1: No, I mean, like...
- R2: She just means have a disease.
- R3: Oh God.

(FG8 four women of Arab/Muslim descent aged 16 and 17)

## Narratives of obligation and identity constraining decision-making

I think it depends on who it's for. Because at that age, we were told that it's for mainly girls who are more sexually active. So obviously for them it would be more beneficial. But in terms of...and for our religion and certain cultures and issues, it would...**it seemed a bit irrelevant for us, or at that age anyway.**

(FG4 Two Asian Muslim women aged 22 and 23)

## **INFORMATION FOR YOUNG PEOPLE**

*Maybe later on in their school, obviously sex education isn't for, like, 12, 13 year olds. I think it's more older, so then that's when they can introduce it in, and make the connection.*

## **VACCINE PROVISION ACROSS THE LIFE COURSE**

*For me it would be like, the later years, maybe even as late as university or something like that.*

## **CROSS-CULTURAL COMMUNICATIONS**

*I think extensive education, awareness and research should be done, events, clubs, in fundraising events as well.*

## **INTER-GENERATIONAL INFORMATION**

*Discuss it in older groups, with everything related to sex, try and make it so that it's not something that isn't talked about.*

# Discursive Tensions

- Focus on cancer versus focus on sexual transmission
- Openness versus taboo indicating potential stigma
- Parental versus young person's attitudes and values indicating intergenerational conflict
- Norms of society versus rules of religious communities/practice
- Public health procedures versus effective health communications

# Implications for policy and practice

- **Would general and specific strategies work from a policy and practice perspective?**
- **Would they be stigmatising or encourage non-discriminatory practice?**
- **Should practitioners provide a range of information opportunities across the life course in order to raise awareness beyond current boundaries of a school-based, gender-specific programme?**
- **Will participant recommendations challenge and problematize current programme/public health policy regarding how and where information and the vaccine is delivered?**

- **Who should be responsible for developing HPV promotion strategies across schools, colleges, primary care and BAME communities?**
- **Could policymakers accept the invitation of communities to work in partnership when considering risk communication messages?**
- **Can we offer both universal and targeted context-specific strategies that could increase the profile and uptake of the HPV vaccine?**
- **Could NHS Scotland extend its vaccination programme to sites of higher education?**

# Conclusion

- Understandings of HPV and engagement with the vaccine programme are embedded within social identities and practices such as gender, culture, religion, intimate relationships
- Vaccination within BAME populations may be hindered by public health strategies which do not take account of these factors
- A collaborative cross cultural approach incorporating general and specific strategies

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