



**The Human Papillomavirus (HPV) vaccine:
The voices of young people with learning disabilities;
The voices of young people from Black, Asian and Minority Ethnic backgrounds.**

**PUBLIC ENGAGEMENT EVENT, OCTOBER 11, 2016
School of Health and Social Care,
Edinburgh Napier University, Sighthill Campus.**

Overview

This research study was conducted in 2015. The aim was to understand the views and experiences of the HPV vaccine in order to inform policy and practice. The researchers conducted seven focus groups and four paired interviews with 40 young people, aged 16-26, from BAME communities and three focus groups and one individual interview with 19 young people, aged 16-22, with learning disabilities.

On October 11, 2016 a public engagement event was held in Sighthill Campus bringing together 48 guests including research participants, researchers, practitioners, members of the public, and policymakers. Organisations represented included Edinburgh City Council, Edinburgh College, Robert Gordon University, MEHIS, NHS Lothian, Frae Fife, NHS Health Scotland, People First, RE-EM, and Edinburgh University. The morning session focused on the voices of young people with learning disabilities and the afternoon session focused on the voices of young people from Black, Asian and Minority Ethnic backgrounds.

Aims of the event included:

- Presentation of study findings
- Table-top discussions
- Exploration of findings and solutions offered by the research participants

The meeting was chaired by Dr Anne Whittaker (Principal Investigator). Dr Kevin Pollock (Health Protection Scotland) opened each session by explaining the importance of the HPV vaccination, the nature of vaccine, and current Scottish policy.

Key points

- 300 cases of cervical cancer per year in Scotland
- HPV vaccine could reduce cervical cancer in Scotland in 75% cases
- Since programme launched – it has been discovered that HPV can cause head and neck cancer, penile cancer, vulva cancer
- Since 2012 and implementation of vaccination programme – there has been significant reduction in genital warts and HPV in women
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Dr Elaine Carnegie (Research Fellow) and Nahida Hanif explained reasons for conducting the study, the research process and main messages conveyed by participants regarding the virus and the vaccine.

Table top discussions

Session 1

Participants discussed two solutions proposed by people with learning disabilities during the research study:

- (1) HPV information should include easy read posters, leaflets, and booklets for parents and carers, online, simple words and pictures
- (2) Young men to have opportunities to talk about HPV, at school, college and health centres

Key Recommendations:

Online Media

1. Provide information to young people with learning disabilities about HPV regarding prevention, protection and vaccination
2. Utilise symbols and pictures in Snapchat; Instagram; WhatsApp, YouTube; Twitter
3. Create an HPV app
4. Utilise Boardmaker for posters, app and online information
5. Put up easy read posters in health centres, shops and college
6. Include pictures of young men and young women in information resources
7. Post HPV information and guidance on the Clan information pages
8. Disseminate HPV information across and through all our own social networks

Education at school and college

9. School nurses to supply the easy read HPV immunisation information for girls in hard copy
10. Provide booklets/leaflets for all boys and girls in school
11. Provide booklets/leaflets specifically for young men

12. Discuss HPV during PSE Class - face-to-face events in class, groups or related events are very useful to clarify facts and receive advice
13. Disseminate HPV messages through colleges – easy read posters with signposting to a link, and put them on intranet
14. Alter culture at school – increase openness about sexual health and reduce embarrassment so people will be able to receive important sexual health information

Multidisciplinary approach

15. Educate and inform other “trusted” people like those we go to for help such as parents, teachers, dentists, social workers, youth workers, third sector
16. Target young people who miss schooling and will not get school-related HPV information - Work with community learning disability team to help inform young people who miss schooling
17. Provide real time open and frank discussions - not just on line – utilise role play

National Campaigns

18. Persuade government to offer vaccine to men. Start an online petition.
19. Public Campaign to include:
 - An NHS TV advert about HPV and the vaccine during peak time
 - HPV messages within programmes like EastEnders
 - Sign post people to HPV information within the TV adverts and on YouTube

The way forward – concrete proposals

- Use Boardmaker to design HPV information and media
- Design a LearnPro – online training for workers
- Allocate finance to the NHS for the development of online and accessible materials for HPV
- Sexual Health Services to train teachers/educators
- Allocate finance to the NHS for the development of online and accessible materials for HPV for people with learning disabilities
- Provide seminars for nurse students so they are more aware and able to discuss with others.

Commitments from participants:

- CLDN shared information and ideas with their team after the event
- One young man with a learning disability described how he was going to disseminate the information about HPV on YouTube through his online community.

Table top discussions

Session 2

Participants discussed the solutions proposed by young people from Black, Asian and Minority Ethnic communities during the research study:

- (1) Provide age-appropriate information throughout school years, across adolescence and early adulthood - explain how the virus is transmitted
- (2) Offer the vaccine at school to girls and boys; Extend the vaccination programme to a culturally acceptable stage and age; Offer it through GPs; Offer it to older people
- (3) HPV public campaign; Better outreach to parents and young people; Peer support; Try to desexualise and avoid stigmatising the message

Key Recommendations

Supporting parents

1. Utilise parent evenings to maximise communication re HPV vaccine
2. Value the mother/daughter relationship when considering how to maximise information transfer
3. Parental attitudes vary and may need further education regarding reason for age of vaccination prior to hormonal changes when immunity most responsive

School and education

4. School nurses should provide HPV information to both girls and boys
5. Provide HPV information at college such as at Entry for learning at Sighthill college, through occupational health, counselling services and on student portal, student unions, fresher's week, induction week
6. Provide resources to teachers to use within PSE classes

Online technologies

7. Use online technologies to contact cultural groups on their own community online sites such as – WhatsApp, Facebook, Instagram, YouTube
8. Utilise social media including WhatsApp – provide online information that links in with parental help

Effective communications

9. Ask Young Scot to conduct campaign using Snapchat for young people aged 16-25
10. Incorporate HPV messages within soap operas

11. Utilise the celebrity culture to influence men and women and challenge patriarchal society
12. Utilise drama and theatre to convey HPV messages

Destigmatising key messages

13. Explain immunological reasons for early age of vaccination rather than age of sexual debut
14. Challenge stigma around the HPV vaccine being given to MSM
15. Normalise the vaccine by giving it to both boys and girls, and by educating everyone that HPV affects all majority and minority ethnic groups.

Community focus

16. Tackle stigma and disseminate HPV information to mosques and their community centres
17. Employ lay presenters for the community adding HPV to other health messages, offer support/ training
18. Emphasise the “safety” of the vaccine
19. Offer alternatives to school vaccination such as through GPs
20. Authority of GPs ought to be further utilised to disseminate and discuss HPV vaccine
21. Focus on lay training, train the trainers approach and self- management models. Employ dynamic and effective outreach workers to implement.
22. Focus on capacity building of communities to deliver HPV information
23. Consider wide range of attitudes within religious buildings and parishes - progressive or conservative – a focus on education or not

Future research

24. Examine other dimensions of cultural groups such as religious, sexual, refugee status, where attitudes vary and also vary within microcosms of these groups
25. Explore issues with other vulnerable groups such as trafficked men and women and those with history of sexual abuse

Service delivery

26. Should we be thinking differently about whether vaccine should be opt out or opt in?
27. Need to be cognisant of differing age limits across the globe of cervical screening programmes potentially influencing young people and adult migrants and refugees re HPV services in Scotland
28. NHS Health information organisations should develop HPV information working closely with GPs to respond to any increased demand for services

The way forward – concrete proposals

1. Apply for funding to Health and Social Care partnerships and the Robertson Trust for funding to deliver HPV intervention integrated into proven and current prevention programmes such as Keep Well and Healthy Hearts.
2. Work with Young Scot to design comic strip messages explaining how to prevent transmission of HPV
3. Create a Wartsapp
4. Provide accredited training workshops to local government/NHS/education staff
5. Conduct international research into the needs of migrant men and women regarding cervical smear tests, HPV vaccine and information resources, contraception and HPV
6. Offer PhD studentships in this field
7. Conduct research into the needs of young people within arranged marriages

Common themes across both sessions included a focus on health literacy – ensuring that audio-visual media is used as primary means of conveying information. Participants emphasised the use of pictures and symbols, minimal use of jargon and cross-cultural media such as drama and role play. There was a desire for targeted information support for parents in order to help them feel comfortable discussing HPV. Most participants wanted HPV information to be provided online, and HPV messages to be publicly conveyed through television programmes and adverts. Information ought to be provided to young people/students at college and at health centres as well as resources to teachers to use during PSE classes. Several stakeholders called for secure funding for effective communications as well as community development approaches.

Evaluation

The aim of the event was to offer an interactive and accessible space for stakeholders to reflect on the solutions posed by research participants and for them to offer substantial proposals for implementation. Feedback from those who attended the event suggests that most found the event accessible and useful. The majority of people with learning disabilities reported that they felt listened to and that they had everything they needed during the event. Other stakeholders said that information was clearly presented and the atmosphere was inclusive and positive. They felt that they had the opportunity to share ideas and engage in conversation and reported that the proceedings were inclusive of everyone's ideas and suggestions. It was viewed as an opportunity to mix with people from varying disciplines and gain views across agencies. It was an opportunity to discuss why sexual health is so important with the voices of young people being heard and how to improve services. Concerns for the future included where will the report will be disseminated and whether budget-holders shall be influenced by it.

