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RESEARCH ARTICLE

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Young men with intellectual disabilities' perceptions of HPV and HPV vaccine: A qualitative study on how to communicate HPV vaccine information

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ABSTRACT
The success of vaccination programs relies on acceptance of recommended vaccines by communities and individuals. There is a paucity of evidence regarding how young men with intellectual disabilities actively produce or receive inclusive and accessible HPV information. As part of a larger qualitative study, we explored how young men with mild-moderate intellectual disabilities contend with information on HPV and how they negotiated safer sex prior to the introduction of the Scottish schools-based gender-neutral HPV vaccination program in 2019. Objectives included identifying strategies for reaching young men with intellectual disabilities; identifying modes of communication that enable young men with intellectual disabilities to discuss HPV; exploring knowledge, awareness, relevance, and participant experiences of HPV vaccination; perceived barriers and facilitators toward vaccination behavior; perceptions of publicly available HPV information and formats. Working with institutions of further education to identify participants, 18 young men chose to participate. Three focus group discussions using activity-oriented questions were conducted. Regardless of ability, a series of activities enabled them to explore questions about their knowledge of HPV and any experience of the vaccination program. Communication aids included familiar objects and symbols from daily life breaking down barriers and power inequities. Data were analyzed drawing on critical discourse analysis. Designed and tailored communication interventions were effective in reaching this population group. Adopting a participatory activity-oriented approach and spending significant time looking at pictures and artifacts enabled young men with mild-moderate intellectual disabilities to discuss behavioral risks and consequences of HPV and to identify design factors for accessible health information.

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Introduction

HPV are a group of more than 150 related viruses and are the most common sexually transmitted infections world-wide.[1] More than 40 types can be passed from one person to another through skin-to-skin and sexual contact. Most men and women who are sexually active will acquire an HPV infection at some time in their lives. Serotypes HPV16 and HPV18 are associated with 70% of cervical cancer cases in women and one third of cancer-induced cases in men.[2] HPV transmission from males can contribute to genital warts, vaginal, vulvar, anal and oral cancer in females and genital warts, penile, anal and oral cancers in males, with higher rates of oral cancer being observed in males than females.[3] Communication with young men about the HPV vaccine continues to be a challenge for health services across the globe. Findings from a European systematic review indicated that only 12.0% (pooled percentage) (ranging from 2.0% to 27.5%) of adolescents were aware that males are at risk of contracting HPV.[4]

Information alone is inadequate to influence vaccine behaviors. Current evidence is supplied through social media, videos and information materials.[5] Evidence regarding the HPV vaccination status of young people with intellectual disabilities is limited.[6] Over the last decade there has been minimal evidence of young people with intellectual disabilities being asked their views on the HPV vaccine.[7–9] HPV vaccination is part of national immunization programs in most developed countries.[1] Since 2008 the HPV vaccine was offered in Scotland for girls/young women with 92·4% being fully vaccinated during 2008–09.[10] In 2019, the HPV vaccine was extended to boys through the national immunization schedule in Scotland at schools in line with many gender-neutral programs. Similarly to other English-speaking countries, male coverage is lower than in females – female coverage in 2022/23 has since reduced to 76.3%, and male coverage to 69.7%.[5,11] However, it is not known how many boys with intellectual disabilities are receiving the vaccine, what type of information they are receiving nor how to engage with them about the topic. In addition, evidence suggests that knowledge and understanding of HPV does not always lead to vaccine uptake thus leading to risk of exposure.[12]

In 2015, the United Kingdom (UK) Joint Committee for Vaccination and Immunisation (JCVI) recommended that genito-urinary medicine (GUM) clinics offer the vaccine to men

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who have sex with men.[13] They were also considering offering the vaccine to young men across the UK and we wanted to explore how young people felt about this proposal. Simultaneously, HPV Action (a coalition of 25 patient groups and health organizations) were campaigning for a gender-neutral vaccine program claiming that boys were being denied protection from risk of cancer. This study was part of a larger qualitative study ($n = 59$) on marginalized groups' engagement with the HPV vaccine in Scotland during 2015/16.[14] This included young people from Black Minority Ethnic (BME) communities and young people with intellectual disabilities. The study aimed to explore:

- Knowledge and awareness of HPV and the HPV vaccine and its relevance for young people.
- Experiences of young people with HPV vaccination.
- Sources of information accessed amongst young people for decision-making about the HPV vaccine.
- Perceptions of the available information and format of this information for the HPV vaccination.
- Perceptions of barriers and facilitators toward vaccination behavior.

Prior to this study, we identified an absence of qualitative research which examines how young people with intellectual disabilities understand HPV and the HPV vaccine. Even though this may be perceived as a sensitive subject to broach by carers and families, opportunities to participate in research around sensitive or taboo topics have been welcomed by people with intellectual disabilities in the past.[15,16] Having failed to recruit eligible young women with intellectual disabilities to the parent study, this arm of the study aimed to explore how young men with mild to moderate intellectual disabilities contend with information on HPV and how they negotiated safer sex prior to the introduction of the Scottish schools-based gender-neutral HPV vaccination program in 2019. Personal and social education (PSE) within Scottish schools' curriculum considers health and well-being or religion and moral discussions about sex. However, content is at the discretion of each school and therefore it was deemed useful to discover what the young men with intellectual disabilities knew about HPV with a view to increasing awareness with an impending vaccination for all and ascertaining a knowledge base. To our knowledge this was the first study to explore views and understanding of HPV with young men with intellectual disabilities and HPV vaccination.

Young men with intellectual disabilities are not a homogenous group. Some may not identify with the label of intellectual disability or the traditional grading of ability.[15] It was therefore important to view participants as experts where reciprocal relationships characterized the interactions enabling all participants and researcher to be equal parties within the process,[17] adopting a relational approach that focuses on an ability to connect and understand the complexity of human experience.[18] We wanted to find out how to reach stakeholders as well as how to communicate HPV vaccine information in partnership with young men with intellectual disabilities. Objectives included:

- To identify effective strategies for reaching young men with intellectual disabilities when recruiting to an exploratory HPV study.
- To identify modes of communication that enable young men with intellectual disabilities to discuss HPV.
- To explore knowledge, awareness, relevance and participant experiences of HPV vaccination and perceived barriers and facilitators toward vaccination behavior.
- To understand perceptions of publicly available HPV information and formats.

The aim of this paper is to describe communication modes and strategies employed when engaging with young men with intellectual disabilities about the HPV vaccine.

Materials and methods

The study was conducted within a critical paradigm that questions all forms of truth and reality acknowledging that what can be known is formed by many different positions of power and knowledge created by different discourses,[19] 237). Discourse analysis enables researchers to discern rules or regulated practice which govern bodies of texts and utterances,[20] 123). Critical discourse analysis moves beyond description and interpretation, illuminating why and how discourses work.[20] It can reveal how discourses limit what can be said or done at one historical moment, how they open up or close down opportunities for action and how lay people engage or alter these discourses.[21] We were particularly interested in how discourses were used by young men with intellectual disabilities to shape identities, relationships, social worlds, and what were their purpose, prior to the UK government's decision whether to offer a gender-neutral vaccination program.

Using inclusive research principles, three focus groups[22] were conducted with 18 young men, aged between 16–22 years, who had mild to moderate intellectual disabilities (Table 1). Focus groups were chosen as the method to generate data because they can create a reciprocal space, enable exploration and analysis of group norms, group meanings and group processes[22] and they can act as a site for discursive events and the social construction of reality.[23]

Ethical statement

Ethical approval was obtained from Edinburgh Napier University (UK) Research Integrity Committee (Project 50,096; 22/04/15). Participants were included if they were able to engage in a conversation using short sentences with the researcher and peers, able to understand the nature and process of the study and provide informed written consent. The study was not participatory in design, however consultation with young people with intellectual disabilities commenced at the stage of developing accessible materials prior

Table 1. Focus group composition.

Focus group	Number of young men	Age range
FG1	8	18–20
FG2	5	16–22
FG3	5	17–18

to recruitment and data collection. All data were anonymized, and pseudonyms used to protect participant identities. Educational coordinators were gatekeepers to these students. Owing to ethical and data protection we were only given their name and age by both the participant and the teacher. We were unable to collect data on ethnicity, race or gender. All students lived in the community and attended institutions in urban settings. None of the students indicated that they lived outside of their family home. The authors are aware this sample may not represent experiences of young men with intellectual disabilities from rural and remote areas of Scotland.

Sampling and recruitment

For six months, we attempted to contact young men with intellectual disabilities through traditional routes including statutory and non-statutory organizations: friendship groups, day centers, care homes, charities, social services, family support groups and special schools. Colleges of further education were the only organizations to offer access to the research team. This may reflect the anxiety of family and parents regarding explicit discussion of a sexually transmitted virus. The sample was derived from an ethnically diverse group of people with mild to moderate intellectual disabilities attending post-school further education institutions. Access to institutions was obtained through "additional needs" coordinators. The researcher (EC) met with four classes to discuss a pictorially based information booklet explaining all aspects of the study. There were mixed responses, with some indicating that they did not want to participate. However, some changed their minds during the following weeks prior to the focus group. Participation in the focus groups was maximized by encouraging participants to choose whether to bring a supporter with them to the group. Two participants chose to do this. Participants were offered expenses for taking part in the study, in the form of a gift token for a shop of their choosing. None of the participants had been invited to participate in research prior to this study.

Data collection

Focus group sessions were conducted in a classroom in the participants' further education institution, lasted around 15 minutes and involved a topic guide, visual aids, stimulus material and activities. A teacher or member of the research team acted as an observer during each focus group for safety and accountability. Group one was supported by a teacher owing to their communication needs. The topic guide had been developed and tested in our parent study and utilized trusted resources developed by government and patient groups.[24,25] Activities were purposefully selected to engage the young men meaningfully, for example by expressing themselves through language, cognition, memory, emotion or participation.[26] Activity-oriented questions can be particularly useful for young people who may become bored with a sequence of verbal questions, and who are more likely to act out and express themselves and their ideas non-verbally using a variety of strategies. Activity-oriented questions can also be useful to tackle novel, sensitive and potentially embarrassing topics of exploration[16] and can enable participants to recall, enjoy and relate the experience of the focus group to other potential participants.[27] Based on an understanding that knowledge construction is influenced beyond cognition to life experience and socialization,[28] we utilized a mix of participant observation and group activities during focus groups. We drew on principles and practice of drama therapy for people with intellectual disabilities that aim to help people express themselves, share thoughts and emotions, through storytelling, verbal and non-verbal interaction.[29] Observing group dynamics in response to the topics and material introduced, such as jokes, anecdotes, non-verbal communication, discussions and arguments, enabled the researcher to interpret and understand complex and hidden meanings surrounding the group interactions.[30] Prior to commencing each focus group, we discussed and agreed ground rules to ensure equality of power where participants are in control of the process and can leave the group at any time. Activities were designed to engage participants in each stage of the discussion (Table 2). The researcher brought personal artifacts to the group to share something of herself and minimize any issues of power or perceived expertise between researcher and students. She emphasized that the focus group was not a quiz or exam to reduce any performance anxiety.

Table 2. Topic guide.

Focus group activities and tools	Prompt questions
(1) Getting to know each other: sharing hobbies (books, DVDs, magazines).	What do you do outside college that you're particularly interested in?
(2) Talking about school memories and current provision of the vaccine in Scottish schools (photo of TV series, Waterloo Road).	Did you wear a school uniform? Did you receive any vaccinations? Did you receive health or social education? Did you receive vaccine information?
(3) Talking about biology (biology magazine) and about cancer (diagram of cancer cells, anatomical models of pregnant female, poster of androgynous body).	Did you receive biology lessons at school? Do you know of anyone who has had cancer? Where does HPV attack the body?
(4) Talking about friendships (photo of friends)	Where do you go to meet friends? Do you go clubbing? How can we protect ourselves from catching the virus? Would you feel comfortable asking your partner if they have had the vaccine? How can we stop spreading it to others?
(5) Talking about who we trust – to get help about HPV (photo of consultation); Looking at HPV information for men and women (US CDC male sheet in poster form and one page of Jo's Trust easy read in poster form).	Do you find it easy to discuss HPV? What might constitute a safe and accessible setting? What questions would you ask this person about HPV? What type of information would be helpful? At what age should you be offered the vaccine, and in which setting; What information would be good to offer parents or family?
(6) Political advocacy/choosing whether to be vaccinated (photos of Scottish referendum campaign from the media).	If offered, would you choose to get the vaccine? What message would you send to the first minister of Scotland about vaccine availability?

Data analysis

Each focus group was audio-recorded and transcribed verbatim and supplemented by detailed analytic field notes written by the lead researcher/focus group moderator (EC). Transcripts were read in full by EC, who developed an initial coding frame to identify key themes, discursive strategies and emerging discourses whilst constantly reflecting on and questioning the effect of her own social position, gender, age, ethnicity, personal experiences, political and professional beliefs. Members of the research team (AW, RH) checked initial analytic themes and discourses, signified through language use, and these interpretations were discussed with other team members at monthly meetings.[31] Drawing on critical discourse analysis and discursive psychology;[20],[32] we explored how participants used the focus groups as a site for performative work to construct, comprehend and display their understandings of HPV, as well as their identities and social world, using discursive strategies, discourses and social interaction. To ensure credibility and rigor, all field notes were shared and discussed with the research team for feedback; all transcripts were analyzed by both the lead researcher and other members of the team. Analytic summaries were discussed and refined during monthly research group meetings. Drawing on critical discursive psychology, we explored participant accounts to examine which discourses were used and what purpose this served. Finally, we examined participant accounts for the ways in which they might inform policy and practice.

Results

We present the six activities below that facilitated the focus group discussions alongside data extracts and analysis.

Activity 1: getting to know each other

Group discussions began by getting to know each other. The researcher began by showing DVDs and books to illustrate her interests. Each of the participants then shared their hobbies with the group.

Activity 2: school memories

Looking at a photo of the actors in the TV series "Waterloo Road School," we reflected on our memories of school – both positive and negative. We shared NHS easy read vaccine information supplied to young women at school. Participants appeared to have been not only excluded from the vaccine program as all boys were, but from all forms of knowledge and understanding of HPV, stating it was "something private:"

John: Well I've not been told the whole lot about it, but I heard … the last time someone rather did tell me that, it's not … they did say that it's something private and we're not allowed to find out.
Interviewer: Is … that's what the girls said to you?
John: No, one of the teachers told me that, that it's private. So …
Interviewer: Had you asked the teacher what it was about?
John: Yeah, I have, but there's … well they put it in this way, you don't want to find out.
(FG3)

In John's account above, where he says, 'it's something private and we're not allowed to find out' he invokes an identity and a world where he and his peers are 'in need of protection,' and their exclusion from knowing about HPV is 'for their own good.' This signals that young men with intellectual disabilities are excluded from knowing and talking about HPV, but that this is not something that they have decided for themselves. That is, their access to information on HPV is regulated by 'others.' So, even though participants introduced sexual health into the conversation rather than the researcher, parental and/or institutional regulation was evident in their narratives.

Activity 3: biology

To facilitate discussing disease development we looked at a pictorial biology magazine "how a body works." We explored if and where they learned about the human body. Having explained that the HPV vaccination was invented to prevent cancer, we looked at a line drawing comparing normal and cancerous cells. This led to participants sharing personal and family experiences of cancer demonstrating familiarity with the disease. Participants in group one struggled to define cancer, appearing shocked at its connection with HPV. Narratives of helplessness were presented in relation to cancer thus thwarting the potentially "lifesaving" message of the HPV vaccination:

Mark: Dying.
Interviewer: You think of dying, yeah. Because it's such a strong word, isn't it?
Fraser: Sounds like a blooming death sentence.
Cameron: Does it not kill cells in your body, but basically, I was agreeing with him, it's, like, probably death punishment or something.
Derek: Well anyone can get it. You can be, like, really healthy.
(FG2)

Using anatomical models of the pelvis and an outline of a human body on flip chart paper enabled participants to point to the areas where they perceived the virus to attack and how it might spread. We discussed similarities and differences with other well-known viruses such as influenza and HIV. We distributed current information sheets from the US and the UK. Most participants appeared confused about how HPV is transmitted:

Interviewer: Can you think where it might affect men if it affects women …
Mike: Is it behind your back?
Sahel: Here.
Interviewer: You're pointing higher up at the stomach area.
Sahel: Yeah.
(FG1)

Interviewer: How does this virus spread?
Derek: Through the blood.
Fraser: The bloodstream probably. That's what I'm thinking.
Cameron: Yeah. Probably by touching another person. I don't know.
Colin: Can it be having underage sex and not using protection?
Cameron: 'Cause they've not really got protection, not thinking about it.
Fraser: True.
Interviewer: It affects, mouth, throat and area down here.
Fraser: Well we've covered one of them, that's for sure. But it's the other two, though, how would that . . . not eating through, surely.
Interviewer: It cannot be passed on by blood.
Fraser: Really?
(FG2)

Five of the participants reported that they had heard of HPV prior to the study, but most had no understanding of the nature of HPV, routes of transmission or associated illnesses. As the men talked about their knowledge of HPV, a discourse of vulnerability emerged which signified the young men were 'kept in the dark' about how HPV might affect their bodies, the bodies of women, and sexual relationships. Clearly, most young men were estranged from HPV discourse at school and elsewhere, perhaps because appropriate information resources were unavailable or because there were no expectations of being offered the vaccine at that time in Scotland.

Taking time to discuss an easy read poster on HPV enabled participants to think further about the subject. They were able to follow, with guidance, four pictures on an A3 poster (depicting the virus, two people embracing, HPV being destroyed by immune system, HPV causing cancer in genital area) and relate them to the earlier discussion demonstrating a growing understanding of the advantages of an HPV vaccine:

Billy: Because better with injection, the cancer will go away.
Steve: You can't beat cancer though. You can't beat . . .
Mike: Well, if you get rid of the virus and the cancer then it won't come back and it won't happen again.
Aidan: That's right
(FG1)

Activity 4: talking about friendships

We began by talking about where we go to meet friends online and in the community. Looking at a photograph of two friends holding hands, participants were asked if they have had a close friendship or sexual partner. Several participants disclosed previous intimate relationships rather than current relationships. Their responses indicated difficulty in exercising agency or negotiating risk owing to lack of information but also indicated varied understanding of sexual health and protection:

Ken: I've got an ex-girlfriend, but . . . well, put it in this way, I just found she rather cheated me for another girl.
Mohan: I don't have any girlfriends.
Ken: Harry does.
Harry: No, no, not.
Simon: I've got a couple of exes.
(FG3)

Colin: Is it protection when and if you have sex at a young age?
Derek: Never have sex.
Colin: Older age, you should also use protection.
Fraser: Yeah, but there's not enough research to say how else you can protect yourself.
Cameron: That is true, though.
Fraser: It's easy to say, oh just keep wearing a condom and whatnot, but if there's not enough research to say, right, wear a condom, but on top of that do this or do that. It's, kind of, unfair on us not knowing what to do apart from that.
(FG2)

Vulnerability was indicated by common narratives of applying knowledge of HIV and safe sex to HPV but finding it does not fully tackle routes of transmission leading to a sense of powerlessness and confusion. However, they were able to negotiate protective strategies such as obtaining the vaccine (hypothetically) and abstinence – remarks which could have been made "tongue in cheek."

Ken: Well easy, well you're going to say condoms.
Harry: Get the jag.
Simon: Condom.
Ken: Well you should not do it in the first place.
Mohan: Yeah, just don't do it.
Ken: Well . . . well not me. I just . . . not me. I'm not going to have sex in my life.
Mohan: If you want to do it, you can do it. If you don't want to do it, don't. Your life.
Interviewer: How could we stop passing it on?
Simon: Just don't do it.
(FG3)

Echoes of safer sex campaign messages such as "just say no" highlight a societal tension and double-bind that these men are playing out in daily life – HPV cannot be viewed outside of the sexual lives of people with intellectual disabilities thus their reactions to HPV become veiled as their sexuality remains a taboo subject.

Activity 5: talking about who we trust

Focusing on a photo of two people talking during a consultation, we asked participants to think of someone they trust to provide health information. Even though doctors were usually identified as experts and ideal providers of HPV information, there was no evidence that this was currently being provided:

Interviewer: If you were going to go for help or get information about the vaccination and virus, who is it that you would trust?
Aidan: Your GP.
Steve: A doctor.
Billy: Your nurse.
Aidan: Your GP.
Mamoud: GP.
Mahir: Your girlfriend
Mamoud: Your parents.
(FG1)

One group perceived that health is a female issue and that people did not care about men's health:

Interviewer: Who would you trust to talk about this kind of thing? Is there anyone you can think of . . .
Simon: Not really.
Ken: Doctor.
Mohan: If there was any question, then I would. It's not really embarrassing. It's interesting, but nobody . . . no one really knows about it, and no one really cares.
Ken: Yeah. That's it.
Interviewer: You don't care or other people don't care?
Mohan: Like, other people care . . . other people don't really care. It's, like,
Interviewer: Are you talking about other people not caring about your health, men's health?
Mohan: Yes. Yeah. That's one . . .
Harry: Well . . . yeah.
Mohan: Yeah. That's who. I think mostly as men, we don't really care. Mostly it's women's . . . in the UK.
(FG3)

Dependency on gatekeepers and lack of opportunities to exercise agency were illustrated by participants in group two who now viewed HPV as a serious threat and expressed frustration that gatekeepers are not meeting their information needs making them vulnerable to illness:

Interviewer: What's your opinion on [HPV] compared to the cold or flu virus.
Derek: A lot more deadly.
Fraser: A lot more deadly. It needs to be taken a lot more seriously.
Cameron: Yeah. I agree with him. They should get more doctors to help them.
Derek: Kind of, like, learn more.
Fraser: That's when doctors can actually care and actually say, I'm going to help you instead of sitting on their computers just thinking they're helping, but they're not.
(FG2)

The groups were able to offer recommendations about future communication formats and content favoring easy-read cards and pictorial information:

Interviewer: What would help explain it best?
Harry: More information.
Simon: More information. Because most people when they're 11 or even 10 can easily read . . .
Interviewer: Are you all confident in reading?
Ken: No.
Interviewer: Would you prefer then to have more pictures?
Harry: No.
Ken: Yeah.
Harry: I think there should still be more information on it.
Mohan: At the same time . . . yeah. If a person who goes to read it . . .
Simon: Yeah. Kind of, should still be more information.
Mohan: We can read it and at the same time we can actually put one big picture and that's you done.
Harry: Aye
Mohan: And just have one big . . .
Ken: Well think of it . . . I think there should be more pictures and more information.
(FG3)

Interviewer: Is there anything that's surprised you today or shocked you?
Aidan: No.
Steve: It's all about . . . .
Billy: Cards, give cards about . . . getting cancer.
(FG1)

These men were unable to negotiate risk as they were lacking information. Colin described an "ideal world" where a person might have power and influence if they are fully informed about HPV. However, as yet he does not have power or permission to exercise his agency:

"If we know a lot of information about it, then we'll be able to tell our children about it if we ever have kids. We as parents would have to tell them, just look out for these types of things, 'cause if it happens . . . if it happens to you, you've got certain things to worry about. And then we can tell them."
(FG2)

Activity 6: political advocacy/choosing whether to be vaccinated

Participants were able to engage and reflect on the current HPV campaign and the previous Scottish referendum campaign. We introduced the topic of choosing by looking at a picture from the Scottish referendum campaign. We discussed their memories of voting in the referendum and the meaning of consent:

Aidan: Yes, I know because . . .
Mike: Vote . . .
Mahir: So who's been to the vote? Hands up, who's been to the vote?
Billy: I've been to the vote.
Steve: That was for Scotland vote.
Aidan: It's like a party, different . . .
Billy: Yeah, I voted.

Mahir: I voted.
Interviewer: What was the vote for?
Aidan: For independence.
Mahir: For independence.
Aidan: Some people put some yes, some people put no. Why is it the old party always wins though?
(FG1)

The age for being offered the vaccine to men was being considered by the JCVI. When the topic was raised about the current campaign for a gender-neutral HPV vaccine in the country, the participants varied in their views as to who would take it and at what age. This may reflect cultural and religious differences illustrated in our parent study:

Interviewer: If I was Nicola Sturgeon [First minister for Scotland at the time] what might you be saying to me?
Steve: Get the injection. But I don't want it.
Interviewer: Should men be offered the vaccination? They don't have to take it but should men be offered it?
Steve: Yes.
Sahel: I would . . .
Interviewer: You would take it?
Billy: Because I'm brave, I never scream.
Interviewer: What age groups of men should be offered it?
Steve: Sixteen.
Billy: Eighteen.
Steve: Twenty-five to sixty.
Mahir: Oh my goodness, that's very long, 60.
(FG1)

They discussed health and social justice as well as what they would like in the ideal world:

Mark: Not enough information, so how can we know how to stop it which is ridiculous.
Colin: It's either that or we're just trying to fix it all the time which is probably not ideal.
Mark: Look at the modern age right now and look at the resources we've got. Google is a classic example. Why is there not enough information on there where we can just go on a computer or laptop or whatever you use and just type up, how to prevent . . . bang. And then you know what to do. Why?
Fraser: It's all high risk with men with women . . . Men that are with women anyway.
Derek: Everyone's vulnerable.
Fraser: So that's, kind of, them being hypocrites.
Derek: But everyone who has sex is vulnerable in some way.
Fraser: But other countries are saying, ah right, let's give the vaccination to these men and not give it to the girls, but over here, it's like the exact opposite and that is wrong. If you want to protect everybody, make sure everybody is available to get it.
Cameron: And do it for both the species. It's sexist to do it for one species, for girls . . . which is a bit, kind of, mean, on the low side.
(FG2)

Passionate pleas for equality were linked to shock at discovering men receive the vaccination outside the UK (at the time of the study) and men who have sex with men (MSM) in the UK may be offered the vaccination prior to them. They appeared indignant, highlighting their own risk, yet were being discriminated even although they were a vulnerable group. Underlying anxiety surrounding narratives of cancer and HPV risk was accompanied by extreme forms of "othering" signifying deeper levels of vulnerability and therefore distancing themselves from being the most at-risk group. These positions indicate a harrowing appeal to social justice for themselves even though they are unable to articulate their own position in society and are alluding to a discriminating social world:

Colin: But it's more dangerous in places like Africa and Syria. Those types of places. They're poorer countries than we are.
Cameron: They should give it [vaccine] to all seven billion of us, even in countries like Iraq and Afghanistan who . . . well they live far away but those countries are full of war.
Fraser: Homeless maybe.
Derek: Everyone . . .
Colin: Like a kid that's maybe left home or has maybe been abused and it's left home.
(FG2)

Toward the end of the focus group the young men offered their new understandings about HPV regardless of ability:

Interviewer: Can you remember any of it? Do you want to say a wee bit about any of it?
Billy: The jag.
Interviewer: And what was the jag to try and . . .
Steve: Stop it from getting cancer.
(FG1)

Participants engaged in performative work which positioned themselves as excluded from the public health agenda around HPV and the HPV vaccine. Participant narratives highlighted the struggle to figure out HPV without any public information. Their exclusion from mainstream HPV digital and offline information surpassed that of other young men without "known" disabilities in the wider research project.[14] Within the political, social and public health contexts emerged discourses of vulnerable bodies and identities, overprotection, discrimination and marginalized citizenship, and inequality of information. The purpose of their performative work was an appeal for health and social justice to enable them to exercise agency and negotiate risk.

Discussion

Effectiveness of the communication strategy to explore HPV

The groups varied in ability with group one being the least able to articulate their views; group two being viewed as the most capable by staff and group three having a mix of abilities. Regardless of ability, all participants were able to engage and respond emotively and non-verbally. This was confirmed by their ability to respond to political issues outside of the research topic. The activities enabled all the participants to contribute to the discussion demonstrated by the levels of engagement within the room and the observed non-verbal responses, humor, jokes, range of emotions and volatile atmosphere. Humor was recommended by teachers when delivering sex and relationship education to people with intellectual disabilities in a previous qualitative study.[33] This enabled participants to relax, maximize their receptivity, memory and enjoyment.

The researcher was acutely aware of the danger of acquiescence and deference throughout the session. Participants were told that they did not need to answer any questions if they did not feel comfortable. The tone and nature of the discussion was informal enabling participants to reflect on a potentially sensitive issue. The researcher allowed the group to lead the conversation as much as possible but being directive at times. Most participants were frank and assertive, often encouraging others to express themselves. Within groups two and three, participants were very vociferous and not afraid to demonstrate their protest verbally and non-verbally regarding questions posed and when tired and wanting the session to end. In contrast, several participants indicated that they may have wanted to talk in depth about their concerns and this was most strikingly demonstrated by the narratives of one young man who appeared to be from a BME community. He emphasized the need for abstinence. He appeared to be raising an existential question of how to take his religious responsibilities seriously. Most were familiar with concrete topics such as addiction issues. When discussing PSE classes another participant from a BME community challenged cultural norms by mentioning his moral value of not drinking alcohol. Nevertheless, within discourses of overprotection, marginalized citizenship and inequality of information revealed a distinct contrast between the men who described themselves as being active participants in society (those who were active during the Scottish referendum campaign on independence) and passive actors in society (when discussing sexual health and HPV). Our study involved young men talking about HPV and the HPV vaccine prior to the availability of the HPV vaccine for boys in Scotland from 2019. The men constructed a social world where people with intellectual disabilities are largely excluded from public health and sexual health initiatives such as the national HPV immunization program. A dominant discourse of social injustice pervaded the men's accounts, suggesting that they both want and need health justice. In doing so, the men drew attention to their direct experience of health inequalities and lack of respect of their human rights. This performative 'socio-political' work that the men engaged in, served to highlight tensions that remain between overprotection of their perceived vulnerability and fears of their behavior becoming out of control or dangerous for reproduction or sexual deviation. Exclusion from public health programs served to reinforce this tension and lock them in a double bind where they are both deprived of knowledge production environments and the ability to exercise their own agency within these environments. Thus, their sexual lives remain regulated and constrained through professional and material discourse. Our data suggests that preventing people with intellectual disabilities from engaging in sexually related health promotion may thwart their ability to achieve equal "health chances."

Tensions between provision of sexual health information and paternalism

After the focus groups, educational staff commented to the researcher about their concerns regarding sexual behaviors reflecting a conflict between responsibilities of safeguarding versus the promotion of sexual rights.[33] Many students were involved in sexual relationships in groups two and three and frequently changed partners within their class. During regular classes, teachers had stopped discussing issues of a sexual nature with students in group one as it led to them attempting to have sex with classmates. This challenges the notion of young people with intellectual disabilities not requiring the vaccine or being sexually inactive.[34] When constructing the abilities of people with intellectual disabilities as being in need of specialist care and training, a medical discourse perpetuates the binaries of "independent versus dependent," "a danger to others versus vulnerable."[21] Concerns expressed by educational staff echo fears of taking responsibility for providing sexual health information and perpetuating stereotypes that deny the students' sexual maturity.[33,35] A perceived need to maintain sexual boundaries during curriculum delivery by institutional staff confounds "independent living" denying capacity to exercise agency and seems out of kilter with the threat of non-blood borne viruses such as HPV. This contrasts with how participants actively engaged in this research, the Scottish referendum debate as well as their intentions to become sexually active.[36] Calls from other young people in previous research include aspirations for autonomy and privacy (requiring material and financial support) and being supported in their quest to become knowledgeable about sexuality issues, free to develop relationships and express their sexual needs.[35] Ultimately they require supportive and egalitarian relationships to achieve this goal rather than being expected to operate within a cognitive and linguistic consumerist model of health promotion.[37] In this study, participants had clear boundaries and were in control during the process. They demonstrated strength and support of each other during the focus groups. A strengths-based approach toward HPV education focusing on resilience and agency ought to be employed to increase coping mechanisms and reduce anxiety.

Our findings support previous research that young men with an intellectual disability can give informed consent for medical treatment and tests when provided with a verbal explanation and supported by accessible written information.[38] Paternalistic attitudes may be an infringement on a person's right to information. In order to reduce anxiety it may be necessary to firstly assume comprehension, and as evidence of good practice, non-disclosure ought to be justified and made explicit.[28]

Understandings of cancer varied but perceived powerlessness indicates a need for future discussions with opportunities to discuss facts, implications, or emotional impact of severe life-threatening disease. Evidence from a qualitative exploration of understanding of cancer by people with intellectual disabilities affected by cancer revealed a similar theme to this study where people said 'nobody told me' and expressed a desperate need for cancer information.[39] They were able to understand information offered in an accessible format such as a picture book. The researchers were also struck by how many people were being protected from a basic level of cancer information. Similarly to this study, lack of cancer information has been linked to increasing levels of anxiety for people with intellectual disabilities.[40,41]

Our findings indicate there is a need for allocated time, in a variety of educational, social and medical contexts, to discuss behavioral risks and consequences of HPV, as active listening, repetition and practice is required.[37] Access to health literature regarding HPV and levels of health literacy and digital health literacy ought to be explored, facilitated and provided. Most participants were not sexually naive but operated within a hinterland where their sexual agency was unacknowledged, and they were not offered resources to equip them to take decisions regarding their sexual health. Capacity to exercise agency was demonstrated when participants were able to moderate the discussion around the 2014 Scottish referendum and keep passions under control. In comparison, discussion about their role and HPV was constrained. This may have been owing to embarrassment, its irrelevancy for marginalized citizens who are (wrongly) assumed to lack capacity to exercise their own agency in relation to sexual health or a wider dearth of HPV discourse within society. One participant from a BME community questioned the relevance of HPV in general and in particular to his values indicating a lack of discussion regarding HPV rather than an inability to discuss the issues. Some participants appeared to cope with the emotional impact of the information by offering veiled comments and dry wit to maintain a sense of control. Similarly, observers of 35 students with mild intellectual disabilities during a quantitative study on sexual knowledge, attitudes and behavior reported embarrassment was related to talking about body parts, masturbation, sexual intercourse and condoms.[42] They reported that even though five students appeared embarrassed throughout the interview and others were embarrassed at times, none of the participants wanted to terminate the interview with no display of anxiety, distress or inappropriate sexualized behavior after the interview.

Strengths and limitations

The rigor of this study is demonstrated by the convergence of arguments leading to an appeal by the young men with intellectual disabilities for health and social justice. The findings were corroborated during a dissemination event in 2016 where 12 young people with intellectual disabilities including some of the study participants offered recommendations for policy and practice (authors). The findings apply to related data collected across differing cultural and religious communities mirroring our parent study (authors) where participants called for accessible, interactive, experiential and memorable information. In this article we describe in detail the data collection methods for other researchers to follow. Providing valuable insights for practitioners, this study has made visible tensions between vulnerability and overprotection and between provision of sexual health information and paternalism thwarting their sexual agency and ability to negotiate risk.

This was a small sample of young men recruited from colleges of further education within the United Kingdom, at a particular time point prior to the HPV vaccine being offered to boys in 2019. Their lack of knowledge and limited access to HPV information may not be reflective of other young men with intellectual disabilities living in Scotland or across the globe. Current rates of genital warts caused by HPV are reducing in young men within the UK, however it is important to ascertain whether this applies to young men within all cultural and socio-economic groups and across gender, sexual identity and disability.[43] Participants were self-selecting and from two urban areas where the majority of Scotland's population reside. The sample cannot represent all men with intellectual disabilities. However, the data does identify some of the barriers these men might face since introduction of the schools-based gender-neutral vaccine program across the UK. As a heterogeneous group young men with intellectual disabilities will require further opportunities to work in partnership to explore these areas of sexual health. Our participants may have been free to engage in sexual activity in comparison to others living in supported accommodation, attending special schools or experiencing parental restrictions. No further evidence of young men's views of the HPV vaccine from this neglected group has emerged since this study was conducted. This again indicates that there is a lack of awareness in terms of ensuring that young men with intellectual disabilities are partners in sexual relationships and are equally responsible for the prevention of cervical cancer. While our data collection occurred in 2015/16, our study utilizing activity-based engagement with young men with an intellectual disability is important. These modes of communication could be applied and transferred to other young men with intellectual disabilities in differing cultural contexts given the paucity of research in this area.

Recommendations for accessible health messages

- This activity-based approach based on creativity rather than verbal or written ability could be used across geographical and sociocultural contexts, with young people with disabilities, or diverse learning needs, regardless of ability, language and culture.
- Staff from a range of disciplines ought to work with this group of young men to ensure that there is tailored and appropriate sexual health education that meets their needs and that is accessible. This could be hosted on an easy read website incorporating sign language, videos and leaflets.

- Culturally sensitive and gender-neutral education ought to be offered to caregivers by the third sector and local government with support from public health organizations.
- Sexual health education focusing on the nature and risks of HPV for young people with intellectual disabilities and their partners ought to be delivered in all schools and colleges of further education. This must include face to face, open and frank discussions in real time and off-line.
- Health and education departments should disseminate easy-read posters with HPV messages and links to trusted information sites.
- The provision of leaflets, booklets, easy read posters for parents and carers online using simple words and pictures focusing on cancer prevention and HPV.
- Future research could adopt our creative methods when exploring knowledge of HPV and the vaccine with young women with intellectual disabilities.

Conclusion

This study demonstrates that information alone is inadequate to explain and discuss HPV for young men with intellectual disabilities. Activities that are mutually shared incorporating concrete artifacts are effective in communicating HPV messages amongst young men with an intellectual disability. Understanding of cancer varied and most participants had no understanding of HPV indicating a need for future opportunities to discuss facts, implications, and emotional impact of risks and severe life-threatening disease. The findings suggest that young men with intellectual disabilities are at risk of health inequalities and require concerted time and effort, or risk being actively excluded. Time is the most important factor incorporating visual and sensory artifacts that are culturally relevant to the participants. Excluding them from HPV discourse will serve to reduce their expectations for health within society. Young men with intellectual disabilities can be equal partners in shaping public health policy and health messages.

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Elaine Carnegie: Produced first draft of manuscript, conducted participant recruitment, data collection, and analysis.
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Carol Gray Brunton: Made a substantial contribution to the concept and design, critically appraised and contributed to intellectual development of paper.
Catriona Kennedy: Made a substantial contribution to the concept and design, analysis and interpretation of data and contributed to development of paper.
JanettePow: Made a substantial contribution to the concept and design, analysis and interpretation of data and contributed to development of paper.
Diane Willis: Made a substantial contribution to the analysis and interpretation of data and contributed to development of paper.

Data availability statement

Raw data (recordings and associated raw transcripts) for this data are not publicly available to preserve individuals' privacy.

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