

Parents' and children's negotiations around health: the case of the HPV vaccine

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For a copy of the full report, Knowledge of HPV and attitudes towards HPV immunisation amongst young people, parents, educators and health professionals: Final Report (2008), see www.healthscotland.com/documents/2839.aspx

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In 2007, the Scottish Government announced an in-school vaccination programme for teenage girls to protect against cervical cancer. In Scotland a young person under the age of 16 is deemed to have the legal capacity to consent to health care and treatment in certain circumstances. This raised a number of issues with schools and parents about the programme and choices around the vaccination decision. This briefing examines research findings that explored parents' and young people's understanding of these issues prior to the introduction of the new vaccine.

Key points

- Parents were unanimous in believing that their consent as parents should be sought for immunising their children, even though this is not strictly the legal position for children of this age. They were divided, however, on whether or not a child's consent was also necessary and how any difference in opinion between parent and child on this issue should be resolved
- Young people's strong views that they should themselves be involved in the choice about what happened to their body were always tempered with a degree of pessimism, or realism, that their views would probably be disregarded in practice
- In some cases young people were unaware of their legal rights to give or withhold consent and thought that ultimately this kind of decision lay with their parents. This was a view that was also expressed by the parents themselves
- Both parents and young people felt the best way to reach a decision about immunisation would be through open discussion between parent and child
- Some parents felt this new immunisation programme provided an excellent opportunity to discuss wider health issues, including sexual health, with their child

Background

The Scottish Government announced in October 2007 that it was to introduce a new vaccine in Scotland against the Human Papilloma Virus (HPV). This decision followed advice from the Joint Committee on Vaccination and Immunisation (JCVI), the independent expert body that provides advice on vaccines, that there was sufficient evidence that HPV vaccines can protect against cervical cancer to proceed with an immunisation programme in the UK.

Under the programme the HPV vaccine is to be delivered routinely to girls in S2 (usually 12-13 years old). Under the Age of Legal Capacity (Scotland) Act 1991, a young person under the age of 16 is deemed to have the legal capacity to consent to health care and treatment, where the health professional involved deems that the young person is capable of understanding the treatment and consequences. Previous studies suggest that parents feel they should be the ones to make final decisions relating to their children's healthcare. This consensus

view therefore lies at odds with current Scottish law and thus needs careful negotiation in practice.

NHS Health Scotland, in partnership with Health Protection Scotland and the Scottish Government Health Department, commissioned a research study in the spring of 2007 to assess attitudes of parents, young people, teachers and health professionals about the forthcoming immunisation programme. The research aimed to assess current knowledge of cervical cancer and HPV and attitudes towards a school-based immunisation programme. The results of this research fed into the ways in which NHS Health Scotland approached the roll out of the programme and gave insight into the acceptability of introducing the HPV immunisation into a school-based programme.

This briefing focuses on findings around consent for the immunisation and young people's perceived readiness for information relating to their bodies, conduct and overall health.

The study

The researchers conducted interviews with young people and parents, as well as with some teachers and school nurses in seven areas of Scotland. Young people and parents took part in separate focus group discussions about many aspects of the proposed immunisation programme.

In total, 108 young people (91 girls and 17 boys from S1 to S6) and 34 parents (30 mothers and 4 fathers) took part in the discussions. The young people took part in focus groups based around a set of vignettes designed to prompt discussion around different aspects of the immunisation programme.

This paper relates to the data provided by young people in S2, the target age for the routine delivery of the HPV immunisation, and their parents.

Findings

Parents' and young people's views

All parents were in agreement that for an immunisation programme delivered in S2, it should be the responsibility of parents to make an informed decision as to whether or not to allow their child to receive the immunisation.

They felt that any decision they made on behalf of young people should be final. However, when considering what approach should be taken to involve young people in the decision-making process, parents were torn between feelings of what was right and appropriate for their own children and understanding that there were vast differences in maturity between young people.

This was most apparent with the parents of S2 children. Parents felt that at this age, young people were generally very dependent on their parents to make decisions for them or were just not interested in making their own health decisions. For example:

I think you, as a parent, make that decision for their future. I think it is a difficult thing for a child to be asked because if you ask a first or second year, the first thing they're gonna say is, 'I don't wanna jag, I don't wanna needle'. They're not actually looking into why they're getting it. Whereas, I think they would feel better with the mum, the dad, the parents saying, 'I think it's a good thing'. I think it's adding pressure to the child by asking the child. (Parent)

I think it comes down to your daughter, and my daughter is quite immature for her age. She handed me the packet of information she was given at school and said, 'I can't understand that, you'll need to read that and tell me what it is'. It's just, like, you know, she is quite immature for her age, but I fully understand other girls will not be. (Parent)

Young people voiced strong opinions about the characters in the vignettes and about their own ability to consent to immunisation without their parent's permission. Young people felt torn between feelings that they wanted control over their own bodies and what the upshot would be if they opposed their parent's wishes. Responding to a vignette in which a character faced the dilemma of wanting to have the vaccination despite parental opposition, one participant noted:

I think she [character in vignette] shouldn't get it [vaccination] because she may lose her mum's trust and even if she does have HPV then her mum will still be there to help her through it. But, if she loses her mum's trust by getting it [the vaccination] behind her back then she's lost her mum's trust! (S2 girl)

Some young people however felt that if parent and child disagreed over something like immunisation then the child should have ultimate control over her body and medical staff should be prepared to go ahead and administer the injection without parental consent.

Interviewer:

Well if they disagree, the parents and children, do you think that Sally should be given the vaccine 'cos she wants it but her parents say no?

Girl 1:

Yeah, 'cos it's her decision, it's her body, she's being given the vaccine and not her parents, so it's up to her.

Interviewer:

Does everyone agree with that?

All:

Yeah. (S2 girls)

In some cases the young people were unaware of their legal right to consent (or withhold consent) for themselves before they reached the age of eighteen. Some also thought that if they were to do so, they would not only be getting themselves into trouble with parents but would also be putting the school nurse in an awkward or potentially dangerous position.

The parents are in charge of the child until they're like eighteen, or something. So, it's kind of like 'cos the parents could then sue the nurse or something or get her into trouble for going behind their back and doing something that they said they weren't gonna let her do. (S2 girl)

Role of the school

Young people thus felt that they should be able to give consent themselves, but few were confident that this right would be supported, particularly in the school context.

Were this intervention taking place outside of school, i.e. in a doctor's surgery or hospital ward, a different set of assumptions about young people's rights to have a say over what happens to their bodies would be in play.

Whilst parents were adamant that they should have the final say over what medical interventions are given to their children, school nurses interviewed separately in our study were equally clear about the legal position on consent. This stands at odds with parents' and teachers' understanding of what is acceptable protocol within the school context. This may lead to some delicate negotiations for the school nurse between parent, child and school.

Parent and child dialogue - joint decision making?

Both parents and young people in our study felt that it was the parents' place to make the final decision about consent for health care and treatment. The majority of them felt that the best way to make a decision about procedures such as immunisation would be to discuss the pros and cons openly and work out disagreements together. One mother commented:

I like to explain it to them [her children] and see the benefits they've got. They've got to see the benefits. I say, 'Look, it's for your health and you'll get it [the vaccination] and that's another thing hopefully, you'll never, ever have to be bothered with. You'll never need to go to the doctor's and get checked and find out that you have got it [cervical cancer].' They still have to go for a smear test obviously. (Parent)

Some parents even felt that this immunisation programme would provide a vehicle to discuss health issues with their children. Whilst parents were aware that this particular immunisation programme was about cervical cancer, many parents acknowledged this could also provide an ideal vehicle to have an open discussion about sexual health issues.

When I spoke to my girls about it [the information pack about the research project] when they brought it home from school, the 3 of us sat together and spoke about it and my husband was there as well. I explained what it was all about and I said to them, 'Well what do you think about it, although you haven't had a lot of time to think about it? I'm not saying I need a definite answer. I just want to know what you think about it.' They're 13 and 14 at the moment but in a couple of month's time they will be 14 and 15. They both said it was a good idea because they've got a bit of understanding about sexual health. (Parent)

The whole sort of vaccination thing could be a massive sexual education opportunity really if it would work in a school like this, but say if the

parents could come with their child and there could be a little chat, 'Why do you think you're getting this vaccination?' and then any misconceptions can be ruled out like, 'No, this won't stop you getting pregnant' or whatever and then the child could just understand but it would just give a bit of importance to sort of protection, sexual protection and I don't know whether that would make it financially impossible. It would certainly make it much more attractive to somebody like me, I would be much more interested if I felt it was going to be more like a holistic thing really. (Parent)

However, what was seen as an opportunity for some parents was seen as an obstacle in one Catholic school in the study. Teachers who were themselves parents expressed concern that it would be difficult to open a discussion with their children about HPV immunisation without introducing the topic of sex.

Teacher 1:

I think this kind of thing as well would require parents to actually bring up the topic of sexual activity as well, and a lot of them would probably be very uncomfortable about doing that and therefore would probably say 'no', so that they probably wouldn't have to enter into a dialogue about it.

Interviewer:

Yes, that's interesting.

Teacher 2:

I think there is still that fear that if you start talking about sexual activity, even with teenagers, you're letting them know that you're aware that they possibly might be even thinking about doing it you know.

Policy and practice implications

- Understanding of the law regarding consent is low amongst both young people and parents. These findings underline the need for an awareness campaign and accurate information and guidance about the legal position regarding consent
- Further research and discussion is needed to investigate how the law regarding consent is carried out in practice and how the interests of schools, parents, young people and health practitioners may conflict
- There may be an opportunity to incorporate discussion about issues relating to the vaccination programme with wider discussions about young people's sexual health