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

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 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 immunisation programme. The results of this research challenge the notion that parents are the sole decision-makers in this context and suggest that young people should be given a greater voice in the decision-making process.

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.
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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 programme. They 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 need 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)

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 you to know what you think about it.’ They’re 13 and 14 at the moment but in a couple of months’ 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)

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

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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.

Parents 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 think you, as a parent, make that decision for their health issues. (Parent)

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. The 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 withheld 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 ‘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.