Knowledge of HPV and attitudes towards HPV immunisation amongst young people, parents, educators and health professionals

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Contents

List of tables

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Glossary

CDC	Center for Disease Control (USA)
HPV	Human Papilloma Virus
JCVI	Joint Committee on Vaccination and Immunisation
NHS	National Health Service
NRES	National Research Ethics Service
MMR	Measles, Mumps and Rubella (immunisation)
SRE	Sex and Relationships Education
STI	Sexually transmitted infection

Executive Summary

Background

In the spring of 2007, NHS Health Scotland, in partnership with Health Protection Scotland and the Scottish Government Health Department, commissioned research to assess knowledge of Human Papilloma Virus (HPV) and cervical cancer, and attitudes towards HPV immunisation amongst young people, parents, education and health professionals. The health information needs of these groups were also assessed as part of the research.

In the previous few months, it had become apparent that effective vaccines against Human Papilloma Virus (HPV) infection were available and a decision on whether to introduce an HPV vaccine into routine childhood immunisation schedules was expected to be made by the UK Health Departments on the advice of the Joint Committee on Vaccination and Immunisation (JCVI).

Research design

The research design involved a number of separate strands including a brief literature review, a qualitative interview study exploring the views of a sample of parents, young people (S1-S4 of Secondary school) and teachers undertaken in seven schools in a range of local authority areas across Scotland. Qualitative semi-structured interviews with GPs and school nurses were also carried out in the Health Board areas that corresponded to the seven local authorities in which schools were based.

Views of parents and young people

Empirical data revealed that knowledge levels of HPV and its links to cervical cancer are very low in both adults and children. Most parents, young people and professionals, however, welcomed this immunisation programme as a cancer prevention initiative, though they were also aware that there are sexual health issues related to the immunisation.

All parents wanted clear and honest information about the safety of the drug. This included information about drug safety trials and possible side effects. Whilst needing honesty, some parents were concerned by the tentativeness of the language used around the possible need for booster injections for example. Young people interviewed had fewer concerns about drug safety, but had greater interest and need for information on pragmatic issues about catching the virus and its manifestations. They also needed clear information about where the injection would be administered, with some assuming that the treatment would be applied to the lower body or the cervix itself.

Young people and parents all expressed a desire for information to be supplied in a variety of formats, with use of TV programmes and young people's media (e.g. magazines) being clear favourites. Young people expressed a strong desire for Internet sites or interactive media in which questions could be raised and answered.

Parents overall saw schools as an appropriate setting to deliver the immunisation programme, both for pragmatic reasons and due to the amount of preparation time which schools will give to children on this issue. Young people interviewed had more mixed feelings about the school-based service, with reservations

being expressed in connection with hygiene in schools, the potential for hysteria related to a widespread fear of needles, and issues regarding confidentiality.

Some parents interviewed expressed a desire for an individualised service that they could opt into when they felt their child was 'ready'. A minority of adults (teachers and parents) interpreted the uptake of the vaccine as sending out a coded message related to young women's current sexual activity or parental condoning of behaviours that may increase sexual risk. Young people were more practical, with the majority seeing immunisation as a sensible precaution.

The three-dose immunisation did not appear to pose significant problems for children or adults beyond the expressed fear of needles. A majority thought that boys should be immunised too (on grounds that not to do so undermined Sex and Relationships Education (SRE) teaching about shared responsibility for sexual matters). However, although this view was widespread, it was not strongly held.

Although not legally the case, parents felt that they have the final right to determine whether their children are immunised at this age. 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 / realism that this probably would not be allowed in practice.

Views of school staff

Schools were happy to 'host' the immunisation programme and provide a modicum of curricular support through SRE classes. However, the current timing of SRE delivery, particularly around sexually transmitted infections (STIs) does not coincide with the likely timing of delivery of the HPV immunisation programme. Teachers were less willing to support the programme through delivery that went beyond agreed didactic delivery methods, given that they felt their knowledge levels were not high enough. However, the impact of the level of teachers' training in SRE was evident in their responses: teachers with more SRE training being more confident about discussing HPV immunisation. There was strong consensus among teachers that they could not be seen to be advocating for the immunisation programme. Teachers in denominational schools raised particular issues around this issue of support or advocacy of the immunisation programme.

Views of health professionals

Doctors (General Practitioners) and school nurses who were interviewed believed themselves knowledgeable about HPV, the vaccine and the diseases against which it protects. Both groups however indicated a need for a resource containing statistical information and answers to Frequently Asked Questions (FAQs) which would inevitably arise amongst concerned parents. Issues that they anticipated being questioned about included the extent of testing of the vaccine, the length of protection it confers, the possibility of side effects, the interaction with other vaccines being given at this age and why it had to be given in three separate doses. Health professionals also foresaw having to answer a range of questions related to HPV implementation policy. School nurses needed clear and unequivocal guidance about issues of consent.

Health professionals felt they would be supported by media messages that emphasise the cancer prevention aspects of the programme. Those in rural areas felt they would need additional support to

convince parents that their child was maturing and might become sexually active. Both school nurses and GPs noted that their services would need extra resource to manage the programme.

Information needs of parents, young people and health professionals

The research recommends that in addition to any publications NHS Health Scotland, NHS Health Protection Scotland and the Scottish Government are likely to produce about HPV, those organisations should also meet the information needs of parents and young people through resources offered on websites, TV and other young people specific media such as magazines. Any public information campaign should emphasise that waiting for 'readiness' in children is a risky strategy and may effectively negate the benefit of the vaccine.

The research also recommends that a practical information pack for health professionals should be created with answers to questions about the safety and efficacy of the vaccine, as well as 'scripted' responses to queries about the policy decisions that lie behind the implementation programme.

These views of parents, young people, health professionals and teachers, taken together, provide good insights into knowledge about HPV and cervical cancer and awareness and attitudes towards HPV immunisation in Scotland.

1. Introduction

In the spring of 2007 NHS Health Scotland, in partnership with Health Protection Scotland and the Scottish Government Health Department, commissioned this research designed to assess the knowledge of HPV and acceptability of HPV immunisation amongst young people, parents and education and health professionals.

In the previous few months it had become apparent that effective vaccines against Human Papilloma Virus (HPV) infection were available and an imminent decision on whether to introduce any HPV vaccine into routine immunisation schedules was expected to be made by the UK Health Departments on the advice of the Joint Committee on Vaccination and Immunisation (JCVI). In anticipation of this advice, steps were already being taken in England to gather evidence to inform implementation approaches, and a strategy for communications and stakeholder engagement. The Scottish Government was expected to agree to make similar provision available, and so information was required to see whether the Scottish context would, in any way, throw up differing challenges in terms of current attitudes and needs for information amongst the public or health professionals who would be involved in any immunisation programme.

The project thus had the overall aim of assessing the current knowledge levels of HPV and the acceptability of HPV immunisation amongst young people, parents, health professionals and key coordinating school staff.

The specific objectives of the research were to examine some key questions with the particular groups below:

- *With parents (of young people, mainly in S1[1] and S2 of secondary school, with some consideration of those in S3 and S4), to assess:*
  - awareness levels of HPV, HPV related disease and HPV-immunisation
  - degree of safety concerns over new vaccine
  - their views on the acceptable age for their children to receive the vaccine
  - their views on accessibility and attitudes towards delivery
  - their views on the need for and management of parental consent
  - their views on the proposed approach to delivery – is school the appropriate setting?
  - which issues are a priority: Cancer prevention? The promotion of sexual health? Whether girls and/or boys receive the vaccine? The long term health benefits for their child?
  - their attitudes to compliance and acceptance of 3 doses
  - their information needs.

- *With young people* (mainly in S1 and S2, with some consideration of those in S3 and S4), to assess:
  - levels of knowledge and understanding, and perceived risks about cervical cancer, HPV and vaccines
  - their views on the acceptability of receiving the vaccine at school
  - their understanding of long term protection and acceptance of three doses
  - their reaction to whether the vaccination should be given to boys / girls, one or both

[1]Note at the time of commissioning, the anticipation was that the JCVI recommendation would be for girls in S1 to be offered the vaccine. Therefore originally, the main focus of this study was on girls in S1 and their parents. The subsequent recommended target age group was 12-13 year-old girls (S2), and the sample of the study was extended to include more S2 representation.

- their information needs.

- With health professionals, to assess:
  - levels of knowledge and understanding of HPV, HPV-related disease and HPV immunisation
  - what preparation / information they need for successful implementation
  - any anxieties, concerns and insights of school nurses about practicalities
  - their levels of confidence in their own knowledge and in the safety of the vaccine.

- With key school staff, to assess:
  - levels of knowledge and understanding of HPV, HPV-related disease and HPV immunisation
  - what preparation / information they need for successful implementation
  - any anxieties, concerns and recommendations for communications and implementation
  - their levels of confidence in their own knowledge and in the safety of the vaccine.

Chapter 2 sketches in some of the background to the development of HPV vaccines, the adoption of them in policy frameworks and what little research has been undertaken in relation to their acceptability in recent years, and this sets the scene for the empirical evidence which is subsequently presented. In chapter 3 we describe our methods in detail. In chapter 4 and 5 we present the results of our fieldwork and data analysis. In chapter 6 we include a brief discussion which leads to a short set of recommendations.

It should be noted that some sections of this report outlining the policy background around the adoption of the vaccine and the arrangements that have been put in place for its administration were written or revised after the fieldwork was completed. Some references in the data that relate to uncertainties about the arrangements for the vaccine thus reflect the time at which these statements were made and have now been resolved.

2. Exploring the background

This section provides a simple description of the medical problems caused by human papilloma virus (HPV) and the ways in which particular drug treatments have been developed which can be used to immunise against the virus. We look then at the adoption of these immunisation programmes into public policy and the actual and anticipated issues that may arise. The next section reviews the few pieces of relevant work that have begun to explore the levels of knowledge of HPV and the acceptability of the immunisation against HPV amongst the British public. A final section examines what is known about information needs amongst both public and health professionals in order to allow the successful roll out of an HPV immunisation programme.

2.1 Human papilloma virus and immunisation

Cervical cancer is the second most common cause of cancer deaths in women around the world under 40. Around a thousand women a year still die from this disease in the UK annually (Curtis, 2006). Human papilloma viruses are responsible for around 99% of cases of invasive cervical cancer. HPV is spread by intimate skin-to-skin contact, including sexual contact. There are over 100 types of HPV, and of those, about 20 'high risk' types are known to cause cervical cancer. The HPV vaccine will protect against two of the 'high-risk' types, known as types 16 and 18, which together are responsible for over 70% of all cancers. It is expected the vaccines will be effective in reducing the number of cervical cancers attributed to types 16 and 18.

Most HPV infections don't cause any symptoms and, since HPV is usually cleared by the immune system, 90% of infections will clear by themselves with no adverse effects. However, in some cases the infection can persist and some persistent infections cause lesions in the cells of the cervix. If these are left untreated, they can lead to cervical cancer (Moscicki, 2005).

Infection with 'high-risk' types of HPV has also been associated with other genital and non-genital cancers. Other HPV types, can cause genital warts, with types 6 and 11 responsible for the majority of cases of genital warts.

The vaccine is most effective if given before a person has been exposed to the virus. For this reason the HPV vaccine was routinely recommended by the JCVI for girls around 12-13 years of age, equating to the second year of secondary school (S2) in Scotland, although doctors may give it to children as young as 9 years old under the licensing arrangements.

There are two vaccines licensed for use in the UK. Cervarix, manufactured by GlaxoSmithKline is a bivalent vaccine and protects against the two types of HPV (types 16 & 18) that cause around 70% of cervical cancers. The other, Gardasil, manufactured by Sanofi Pasteur, protects against four major types of HPV (types 6, 11, 16 & 18). Like Cervarix it protects against two types of HPV that cause 70% of cervical cancers. It also gives protection against two types of the virus that cause the majority of cases of genital warts.

In June 2008, following a UK-wide procurement exercise for the HPV vaccine, the Department of Health announced that the contract for supply of HPV vaccine in the United Kingdom was awarded to GlaxoSmithKline. Therefore the vaccine supplied for use in the HPV immunisation programme will be Cervarix.

The HPV vaccine designated for use thus helps protect against the two HPV types that cause 70% of cervical cancers. The vaccine won't protect against all other HPV types, so girls who have been immunised will still need to go for routine cervical screening when they are older. This combination of immunisation and cervical screening will offer the best possible protection against cervical cancer. In Scotland the Cervical Cancer Screening Programme is offered from the age of 20.

Clinical trials with thousands of young women have been undertaken, and have shown that the vaccine has a good safety record with no severe side effects recorded. The relative newness of the vaccine does mean that the UK will be amongst the first to use the Cervarix vaccine for a national immunisation programme. Although antibody tests have shown the immunisation to be fully effective for six years (and it is predicted that it will be effective for at least 10 years), trials will need to run for longer before there is full certainty about the need for a booster. The vaccine is given as a 3 dose series over a 6 month period for maximum protection.

2.2 Scottish policy on HPV immunisation

In June 2007 the Scottish Government announced that they would introduce a school-based HPV immunisation programme following a recommendation from the Joint Committee of Vaccination and Immunisation (JCVI), the independent body that provides advice on vaccines to the UK Government and devolved administrations. The routine HPV immunisation programme would commence in September 2008 for girls aged around 12-13 years of age (those in their second year of secondary school).

In October 2007 the JCVI advised that a time-limited catch-up immunisation for girls aged 13 to under 18 years (17 and 364 days) was cost effective. In February 2008 therefore, following an options appraisal, the Scottish Government announced that they would go ahead with a three year catch-up campaign starting at the same time as the routine immunisation of girls in school year S2 from September 2008.

2.3 Knowledge of HPV amongst the public

Research studies have consistently shown that up until now, knowledge levels about HPV are very low. Many studies have found that few women in the UK (or elsewhere) know about HPV, its causes, routes of transmission and effects. An American survey of students by Yacobi *et al* in 1999 found that the majority of respondents knew very little about HPV and significantly less than they did about another six sexually transmitted infections. Respondents perceived that HPV had been given little educational attention in comparison to other STIs. Those who have heard of it are often unclear as to how it is caught and what harm, if any, it can do to a woman.

Similarly Andersson-Ellström and Milsom (2002), in their longitudinal study of young women between the ages of 16 and 23 in Sweden, found that the responses demonstrated that the women in their sample had much less knowledge of HPV and its transmission than other STIs like chlamydia and genital herpes. Pitts and Clarke (2002) showed similar findings in a sample of 400 female employees of a British University. They found that 70% of the women they surveyed had never head of HPV, despite 97.3% of them having a clear understanding of the role of a cervical smear.

Women's knowledge of the causal relationship between HPV infection, abnormal smear results and cervical cancer is also unreliable. Waller *et al* (2005) carried out a study of 74 British women from differing ethnic backgrounds. The women in the study offered many reasons for the development of cervical cancer such as

having a family history of the disease or chance. Some women believed that cervical cancer lived within a woman's body and was 'awoken' by some sort of trigger. However, they were unsure of what the trigger might be. Those women who were aware that HPV is a sexually transmitted infection and that it is the cause of cervical cancer sometimes showed cognitive dissonance and struggled to integrate their existing models of 'sexually transmitted infections' and the stigma which is associated with such condition with their models of 'cancer' being a disease that could strike anyone at any time. Some women rationalised the cause of contracting HPV as 'different' to other types of STI suggesting it was one of those things you got when you were young and inexperienced (a result of inexperienced partners 'getting it wrong' or 'rough sex') or that it was a normal bodily reaction to sperm. Once realisation had been reached, women expressed shock at the discovery that the link between HPV and cancer was not more widely broadcast and felt that health professionals were 'keeping them in the dark'. These findings have been consistent over a number of studies (see also Noakes *et al,* 2006).

There is an obvious need for consistent and clear information to be presented to women about HPV, its implications and its link with cervical abnormalities and cancer in order to raise awareness and minimise distress and stigma. Women interviewed by McCaffery *et al* (2006) expressed their confusion over contradictory and inconsistent information given to them by health professionals concerning their smear and HPV test results and called for a clear protocol for information given by health professionals to minimise distress and distrust. However, how this information is pitched is vital to the uptake of any vaccine as women who were aware of the sexually transmitted nature of HPV and its link to cervical abnormalities and cancer voiced concerns over stigmatisation from partners, friends and family, should they be labelled as at risk of contracting a sexually transmitted infection.

Few studies have looked at men's understanding and role in the transmission of HPV. Clearly men are not at risk of cervical cancer. However, this subject is relevant to men too, as they play an active part in the transmission of the virus and may act as a reservoir where infection persists. HPV has also been connected to anal and penile cancers in men, and men are also at risk from contracting genital warts (Gross & Pfister, 2004). McPartland *et al* (2005) suggest that men should be included within any educational programmes on HPV to raise their awareness of the virus and its consequences for current and future partners so that they are able to make informed choices about their sexual behaviours.

Even fewer studies have been undertaken to assess knowledge about HPV infection in young people. A small number (e.g. Yacobi *et al* 1999, Andersson-Ellström and Milsom 2002) take into account the views of young women down to age 16, but at the time of writing the review there was only one peer-reviewed article found that assessed the knowledge and views of adolescents within the age ranges that will be principally affected by the UK programme of immunisation. In this Canadian study (Dell *et al* 2000) only 13% of adolescents had ever heard of HPV.

We thus have a situation where knowledge of HPV in the current adult population of women is extremely low and in men even lower. The links between HPV infection and cervical cancer are not well understood and many women feel that the topic is stigmatising and difficult to assimilate in respect of their patterns of understanding of cancer.

In Cuscheri *et al's* (2006) review of the literature surrounding public awareness of HPV and potential acceptability of a new HPV vaccine they suggest that any vaccine programme must go hand in hand with public education to improve awareness of HPV, its causes and outcomes. Cuscheri *et al* suggest four main points that should be included in all educational literature:

- the public should be aware that HPV infection is very common (around 80% of women will be affected at some point in their lives). This will help to raise awareness and avoid stigmatisation
- the promotion of 'safe sex' through the consistent use of condoms should still be promoted as this will reduce risk of infection although not provide complete protection from the virus
- the term 'wart virus' should be avoided so as not to confuse the different strains of the HPV virus and their very different outcomes
- information provided to the public should be written in a format which is sensitive to religion and to culturally diverse groups.

They suggest that any educational programme would be most successful if these points were taken into account.

2.4 Attitudes towards HPV vaccination of adolescents

In the UK the vaccine is being offered as an intervention for adolescent girls, so it is important to review how these general attitudes (lack of knowledge, fears of stigmatisation and so on) are played out in relation to parents' concerns about the immunisation of their young people.

Simple information-giving to remedy lack of knowledge may not be sufficient on its own however. A study by Dempsey *et al* (2006) in the USA indicated that providing information to parents about the vaccine and the conditions it will prevent is unlikely to encourage uptake amongst all parents. Dempsey and colleagues sent a random sample of 1,600 parents and primary caregivers with children aged 8-12 years a survey assessing HPV knowledge and attitude to vaccination. Half of the sample (randomly assigned) also received an information sheet about HPV. The results showed that though those who received the information sheet scored higher on the knowledge component of the survey, this alone did not significantly alter their views on whether HPV vaccination was appropriate for pre-teens. Instead, the attitudes of peers, family physicians and their own medical history were likely to be more significant. Gender of the child appeared to play a part, as there was considerably less support for the immunisation if caregivers were contemplating immunisation for male children.

In the UK, a population-based survey undertaken in Manchester amongst parents of 11-12 year-old girls found that up to 20% of girls might miss out on the vaccine because of parental opposition (Brabin *et al* 2006). The authors reported that 81% of parents said that they would accept immunisation for their 11-12 year-olds, although only 38% were definite in this view. For those who said they might refuse, long-term safety of the vaccine was an issue, and for a minority of parents the worry was that the vaccine might encourage early sexual debut or riskier sexual behaviour. HPV vaccine acceptance did not vary significantly across socio-demographic groups. Similarly 65% of mothers in Marlow *et al's* (2007) survey worried about potential side effects of the vaccine and expressed concern about the number of vaccines that are given to young people generally. The authors conclude that any educational material given to parents must bear this in mind and give clear information about the reasons for offering the vaccine to adolescents and young women.

Noakes *et al* (2006) carried out a qualitative study in 2005 involving focus groups with parents of 8-10 year-olds in three locations in England. They claim to identify parents from their fieldwork as falling into one of three categories, 'trusting', compliant' or 'resistant', and point out that information material will have to be

geared to answering the different needs of people in each group. Those who are resistant or merely compliant will need much greater levels of reassurance about vaccine safety for instance than those who simply accept that 'doctor knows best'.

Cameron *et al* (2007) compare the case of the introduction of HPV with that of Hepatitis B (Hep B) immunisation, which was introduced as a pilot study in Glasgow for young people in early adolescence. The authors point out that, like HPV, Hep B is primarily sexually transmitted; is associated with long-term health consequences; and that immunisation has had a large impact on global cancer reduction. The encouraging qualitative research results on attitudes towards the immunisation translated into high uptake when vaccination was offered, as for HPV, in a three-dose course.

Some studies have reported parental concerns that vaccinating adolescents against a virus which can be transmitted sexually might send out a message to young people that it is acceptable to engage in risky sexual activities, thus potentially encouraging promiscuity amongst young people (Waller *et al*, 2006). Kimmel (2006) similarly makes the suggestion that parents may be concerned that vaccination against HPV at an early age may increase sexual activity and number of sex partners in young people and encourage sexual risk taking behaviours such as decreased use of condoms and other barrier methods of contraception. However, in an English survey of mothers who had daughters aged 8-14 only 12% thought that accepting the vaccine would lead to increased sexual activity (Marlow *et al* 2007).

The proposed age for vaccination appears to be critical for parents. Whilst it is clear that for maximum effectiveness in protecting against HPV the vaccine must be given before sexual debut (and the vaccines are licensed for use with children as young as 9), some parents feel that vaccinating children around the ages of 10 or 11 would be unacceptable as young people would have had very little specific sex education at this stage and the reasons for the immunisation would be hard to explain to them (Noakes *et al* 2006). Rather surprisingly some parents would be more comfortable vaccinating much younger children as they feel that a much lower level of explanation would be necessary for younger children and they would not face the difficulty of explaining to them the purpose of the vaccine. This, however, would obviously be problematic in the light of the uncertainty about the length of time that the immunisation is effective in offering full protection against infection.

Parents in Waller *at el's* (2006) and Brabin *et al's* (2006) samples (both sampled parents of children aged 11-12) expressed the view that they would be more accepting of the vaccine and any educational programme if it was focussed on cervical cancer rather than on HPV *per se*. It would seem that this would eliminate the need for them to have a potentially uncomfortable discussion with their children. Conversely some parents have called for the immunisation to take place alongside a formal sex and relationships education programme (Noakes *et al* 2006).

Some parents reported in Waller *et al* (2006) were excited at the prospect that this vaccine could eventually eliminate the need to undergo cervical screening, which they felt was an unpleasant experience. However this is a misunderstanding, as cervical screening programmes would still be needed after immunisation. The HPV vaccine provides protection against the two main types which cause 70% of cancers, but not all the types of HPV associated with cervical cancer. Therefore immunisation alongside cervical screening will provide the best protection again cervical cancer.

Several studies examine whether, due to the route of transmission of HPV, faith perspectives may play a part in attitudes towards the immunisation. It is suggested by Noakes *et al* (2006) that parents who belong

to faith groups may be less accepting of the vaccine as it does not sit well with their beliefs that sex belongs within a monogamous lifelong relationship, normally within the constraints of marriage. Marlow *et al* (2007) in a UK study report that religious parents may also be in favour of later vaccination of their daughters as the proposed age of vaccination is felt to be unnecessarily young since their beliefs dictate that sexual activity should not occur until young people are grown-up and married. MacKenzie (2006) has pointed to the fact that religious groups in the USA have protested against the vaccine, and she also notes that in the UK cultural differences may also make it very likely that some ethnic groups might find it difficult to participate in the programme should it carry implicit messages about the conduct of young unmarried women (see also McCaffery *et al* 2003).

However, a review by Zimmerman (2006) cites several 'faith' organisations, largely in America, that support the HPV vaccine suggesting that it can go hand in hand with messages promoting abstinence and faithful relationships and would offer protection for women who had been raped or had a partner who had been infected previously. Zimmerman suggests that an 'ethical' analysis of vaccine policy finds support for universal immunisation, provided that immunisation is not compulsory.

Another potential issue that emerges in one study is the issue of consent for immunisation, and amongst some parents, a misapprehension that they retain the final say in decision-making for their child whilst they are still deemed to be under their 'care'. This is at odds with the reality of the legal situation in Scotland, where young people deemed capable by health professionals of understanding have the right to make decisions regarding their health[2]. Mays *et al's* (2004) in-depth qualitative study of 34 American parents found that almost two thirds of respondents felt that they should have the right to make the final decision, whilst a minority felt that the decision should be made through joint discussion of the vaccine with their child. Only one parent felt that the decision whether to be vaccinated or not should be made by young person on their own. There were differences of opinion within the study as to when this parental control would lapse but many inferred that it would be when they personally felt their child was competent to make informed decisions, usually by the age of 18.

2.5 Information needs amongst health professionals

At the stage when this review was undertaken there were very few published and peer reviewed articles relating directly to the information needs of health professionals to deliver the HPV immunisation programme, not least because this vaccine is relatively new. A recent US study by Sherris *et al* (2006) documents stark knowledge gaps about HPV at all levels, including amongst policy makers, and health care providers. Defining the needs of health care providers for information and support may well be a critical stage in securing more widespread acceptance of the vaccine.

More general lessons can perhaps be drawn from literature surrounding other immunisations (for example the MMR vaccine), which underline the key role of the well-informed health professional in vaccine decision-making (Shucksmith *et al* 2006).

Parents are generally inclined to trust health professionals and the information they give and view health professionals as 'experts in the field' (LoBuono, 2000). This pressure to be an 'expert' can have a negative effect on the health professional. Brownlie and Howson (2006) reported, in a Scottish study, that GPs felt

[2] Under the Age of Legal Capacity Act 1991, those under 16 may consent to medical treatment if, in the health professional's opinion, they are capable of understanding the nature and possible health consequences of the procedure or treatment.

uneasy about admitting gaps in their knowledge and found it difficult to easily locate sources of information which they felt were of sufficient quality and accuracy. These feelings of unease were exacerbated by the difficulty GPs experienced in trying to keep up to date with ever changing information presented to them mainly by the media. Patients armed with pages of information from Internet searches provide a further challenge which many health professionals find hard to meet.

MacDonald *et al's* (2004) survey conducted in the Scottish Highlands suggests that most health professionals rely on materials issued by the relevant health departments, rather than on material from the published literature. In their sample of health professionals a very small number (25% of health visitors and 8% of practice nurses) cited peer-reviewed medical journals as a source of information they would turn to gain up-to-date information. This was somewhat more positive than the finding from Petrovic *et al* (2001) in North Wales, where the authors concluded that some GPs giving advice on MMR immunisation had not in fact even read the official health board advice at all, and a quarter claimed they had not received the Health Education Authority's factsheet on MMR despite its having been circulated to all general practices. About one in five GPs surveyed in Yarwood *et al's* (2005) survey stated that they had not read centrally-provided material on MMR immunisation. This lack of trusted sources of up-to-date information can have a negative knock on effect on parent/ health professional relations, as hesitancy to alleviate parental fears could cause suspicion.

Petousis-Harris *et al* (2005), in a study of telephone calls to an immunisation hotline in New Zealand, found that a significant proportion of users were health professionals themselves or were parents referred to the hotline by GPs and practice nurses who could not themselves answer their questions about immunisation or the contraindications. Maconochie and Lewendon (2004), in a postal questionnaire of practices in southwest England, found respondents very uncertain about the status of current research evidence. They were unable to resolve disagreements about evidence within the medical profession and/or to square this with aggressive coverage by the media. They clearly felt unconfident about the advice they gave to parents as a consequence. These findings are replicated in the work of Petrovic *et al* (2001). Bedford and Lansley (2006), in a recent study undertaken in East Berkshire, concluded that, whilst most parents were satisfied with the information and advice given by health professionals, a significant minority were not. Furthermore parents reported being given conflicting advice by different team members.

Such findings might suggest that it is likely that GPs and practice nurses, as well as school nurses are going to need clear and concentrated information given to them verbally in presentations as well as in written format and that some clear guidance in response to frequently asked questions will be an absolute necessity.

3. Methods

3.1 Research Design

The overall research design involved a number of separate strands:

- a brief literature review
- a qualitative interview study to explore the views of a sample of parents, young people and school teachers undertaken in 7 schools in a range of local authority areas of Scotland
- qualitative semi-structured interviews with GPs and school nurses in the health board areas that corresponded to the 7 local authorities in which schools were based.

Each is now described in turn.

3.2 Literature review

A large body of relevant literature on this topic had already been accumulated through our ongoing interest in sexual health issues and immunisation programmes generally. This body of literature was further complemented by establishing search strings and searching databases available through our library systems. Databases were chosen which had a health and social science focus as well as medical in accordance with the aims of the study. In respect of the articles thus uncovered, abstracts were assessed for relevance and those articles which were deemed to be relevant were then obtained either electronically or via inter-library loan from the British Library. The literature was then brought together in a narrative review.

3.3 School study

The fieldwork sampling strategy was intended to reflect the regional diversity within the Scottish population and also to include where possible the voices of ethnic, religious and disadvantaged communities within Scottish society. The schools selected were distributed across mainland Scotland, though geographical identifiers have been omitted in this report in order to preserve anonymity. This sampling strategy was discussed with the steering group and approved before fieldwork began. However, it must be noted that the sample was not representative in statistical terms but was designed to fit with the qualitative design of this research study.

Table 1: Distribution of sample schools

Area	Number of schools
1	1 school
2	1 school in area of social disadvantage
3	1 school
4	1 school
5	1 school
6	1 denominational school
7	1 school with high level of BME pupils

Directors of Education were contacted by letter in each of the seven local authority areas and asked to nominate three schools in their locality that matched any specific inclusion criteria for that area. Only one area refused to take part in the research and so a neighbouring locality was invited to become involved.

Once schools had been nominated they too were initially contacted by letter which explained the reason for contact. Included with the letter was an information sheet (which explained what would be required from them should they decide to take part in the study). The letter was then followed by a courtesy call from one of the research team to discuss any issues they may have had and verify if they would be happy for their school to take part in the study.

Each school which agreed to take part in the study was sent a pack which included detailed descriptions on how to sample the young people and letter packs to be given to teachers, school nurses and parents. There were two separate letters for parents. One for those invited to take part in the study themselves and one letter to give consent for their child to take part in the study. The latter included an invite and some information for the young person to read too. Each pack contained the relevant invite letter, information sheet and consent form. A date for members of the research team to visit the school and carry out the fieldwork was then secured in each school.

Initially the number of young people's focus groups concentrated on the inclusion of S1 girls, as at the time of commissioning, this was predicted to be the main target cohort for the programme. However, after the recommendation from the JCVI in June 2007 that girls aged 12-13 in the second year of secondary school should be offered the immunisation as part of the routine immunisation programme, the focus of the sample was changed from S1 to S2 giving the final achieved sample distribution shown in table 2.

Table 2: Achieved sample distribution across age groups

School	S1	S2	S3	S4
1	12 girls (2 groups)			
2 (Disadvantage)		12 girls (2 groups)	3 girls (1 group)	3 girls (1 group)
3	6 girls (1 group)	15 girls (3 groups)		
4		3 girls (1 group) 3 boys (1 group)		3 girls (1 group) 3 boys (1 group)
5		9 girls (2 groups) 5 boys (1 group)		
6 (Roman Catholic)		7 girls (2 groups)		
7 (BME)		11 girls (2 groups) 3 boys (1 group)	7 girls (1 group) 3 boys (1 group)	
Total no. of young people	18	68	13	9

Focus groups with young people were purposively chosen to include friendship groups to help the young people feel at ease within the group situation. Within each group of six young people, two were initially chosen from the year group register using random numbers. Each randomly chosen young person was then asked to nominate two friends to join them in the discussions. This process was followed for each of the required number of focus groups in each school.

The fieldwork took place at each school site during the course of the school day. Normally, the young people took part during lesson time and the team spoke to teachers at the end of the school day, or at a time when they were free from teaching. Parents were invited to discussion groups, most of which took place in the evening with only two exceptions which were organised within the school day.

Focus groups with young people began with an introduction by the researchers about the project followed by a short quiz, which was completed anonymously and placed into a closed box. (Appendix A) The quiz was designed to assess knowledge and was based on the content of the information sheet sent to them previously. It was explained to the participants that there were no right or wrong answers and that it was merely to assess the utility of our information sheets not an assessment of pupils themselves. Once the quizzes were completed the researchers reiterated that all discussions were confidential, that the young people would remain anonymous in the final reporting of the study and that it would be helpful to the team if the discussions were tape recorded for accuracy. Once agreement for tape recording had been obtained from the young people, five vignettes (Appendix B) were distributed amongst the group. Each group member was given a different vignette to read aloud to the group and the discussions which followed were semi-structured, using a focus group discussion schedule (Appendix C). Young people were able to talk freely and ask questions throughout the session. Once the discussions were over the young people were thanked for their time and given further opportunity to ask any questions they may have had. A total of 108 young people were included within the study. Of these 84.3% were female (n=91) and 15.7% were male (n=17). Sixty three percent of the overall sample were from the S2 year group (n=68) with the remainder made up from the remaining year groups.

Teacher focus groups also began with a short introduction from the researchers and a little background information to the project to reiterate the information sent to them previously. Consent was obtained to tape record discussions and, again, confidentiality and anonymity were assured to the teachers. These sessions were more relaxed than the young people's focus groups and generally led by the teachers. A semi-structured focus group schedule (Appendix D) was used by the researchers to direct thought around pivotal issues and prompt where necessary. Again teachers were able to ask questions and speak freely in these sessions. Once the discussions came to an end the teachers were thanked for their time and given opportunity to ask further questions.

In each school, parents of all the children in the year groups that were participating in focus groups were sent letters inviting their own participation in discussion groups. In most schools this large volume of invitations resulted in one or two focus groups being formed, which obviously makes this a self-selecting sample. Parent focus groups followed the same format as that of the teacher focus groups. However, a different focus group schedule (Appendix E) was used to direct thought and conversation.

3.4 Interview study with health professionals

Once the seven local authorities had been identified GPs in the Health Boards corresponding to these local authority areas were also randomly selected and approached to take part in the study. This proved ineffective as an approach and no GPs agreed to take part. A further seven GPs were selected at random and approached, and again this yielded no participants. Immunisation coordinators were then approached in each of the localities and asked to nominate GPs in their areas who would be happy to give their views on the forthcoming vaccination programme. This approach did yield 3 GPs who were happy to be contacted. However, the target of seven GPs was not achieved. After discussions with the funding organisation the research team were passed details for the Scottish Primary Care Research Network (SPCRN). This yielded a further three GPs, making a total of six in all.

School nurses associated with the schools we visited were contacted to take part in the research through several routes. In the first instance schools were requested to invite their school nurses to an interview on the day that the researchers were in school. However, only two schools were able to make this arrangement. Due to sickness and other absences their inclusion proved difficult in many areas. A further two nurses were contacted via the Scottish Primary Care Research Network, and another contact was made who agreed to a telephone interview. Thus, in total, 5 nurses were interviewed.

A semi structured interview schedule was used with health professionals where appropriate (see Appendix F) and interviews were usually recorded with permission and later transcribed.

3.5 Ethical approval

Ethical approval for the school-based phase of this study was granted by the University of Teesside's School of Health and Social Care Ethics committee, and from the ethical committee in the School of Education at the University of Aberdeen.

With respect to the that part of the study which sought the views of health professionals, an application was made through the NHS NRES procedure and permission was given to proceed at both national level and then through the research ethics committees for each of the health boards included within this study. Each local NHS Board Research Management and Governance Committee also examined this proposal and raised no objections to this research being carried out. This process took eight months in total with applications prepared immediately upon commissioning in May, submitted in June to MREC and with the final research governance approvals being received in early December.

3.6 Data analysis and reporting

All interview and group discussion sessions were audio recorded with the permission of participants and transcribed. Transcripts were read by all research team members. In the final phase of the work we aimed to review and synthesise the information in the form of a narrative literature review and then to analyse the data in a way which provided straightforward answers to the research questions which framed the study. Material was roughly grouped according to source to see what themes emerged within each group. Members of the research team read transcripts individually and then shared views to establish thematic categories of interest. Material was then reviewed again to ensure that data supporting or refuting categories was captured.

4. Views of parents and young people

In this chapter we present the views of the young people and parents who participated in our study. Interviews were carried out in the latter half of 2007. At that point in time some preliminary announcements had been made about the likelihood of HPV immunisation being introduced, but no firm decisions had been made in the UK about which vaccine was to be used. Decisions about the target age group and the restriction of immunisation to girls (excluding boys) were made as fieldwork started. Decisions about the catch-up programme for older adolescents were not made until after the fieldwork was completed. Data was thus gathered against an evolving policy background. Major discussion of the vaccine programme had not taken place in the media, though some information was obviously available on the Internet for those concerned enough to search for it, including the *Tell Her* website, which was starting to advertise itself in women's and girls' magazines.

With parents we were concerned to assess:

- awareness levels of HPV, HPV-related disease and HPV vaccine
- degree of safety concerns over new vaccine
- their views on the acceptable age for their children to receive the vaccine
- their views on the proposed approach of delivery – is school the appropriate setting?
- their views on the need and management of parental consent
- which issues are a priority: Cancer prevention? The promotion of sexual health? Whether girls and/or boys receive the vaccine? The long term health benefits for their child?
- their attitudes to compliance and acceptance of 3 doses
- their information needs.

With young people (mainly in S1 and S2 of secondary school, with some consideration of those in S3 and S4), our brief was to assess:

- levels of knowledge and understanding, and perceived risks about cervical cancer, HPV and vaccines
- their views on the acceptability of receiving the vaccine at school
- their understanding of long term protection and acceptance of three doses
- their reaction to whether the vaccination should be given to boys / girls, one or both
- their information needs.

4.1 Parents' views

In each school visited by the researchers parents were invited to participate from all the year groups in which children were participating in focus groups (the sample age groups varied from school to school as shown in Chapter 3). Despite the large number of invitations issued, only one or two groups in each school were formed, and at one school only one mother attended, so this clearly represents a self-selecting group of interested or concerned parents. In addition the views of some teachers who were also parents are included in this section where they were reflecting on issues in their capacity as parents rather than professionals.

4.1.1 Awareness levels of HPV, HPV-related disease and HPV vaccine

The majority of parents interviewed admitted that they knew little or nothing about the virus, the virus-related diseases or the link with cervical cancer. One or two had heard on the radio or seen in the newspapers short articles hailing the new vaccine as a breakthrough but had no idea of the complexities of the issue.

Even the information provided to them as part of the process of seeking permission for their involvement in the study did not appear to have gone very far to inform them. Indeed it was evident in many cases that parents had come along and volunteered for the study precisely so that they could find out more about the subject.

I How much do you actually know about the HPV virus?

P Nowt, nothing! It was sprung up on us last night like a bolt from the blue. (All laugh). 'Do you know anything about this (inaudible),' 'No.' Immunisation for cancer, I thought someone's up for the Nobel prizes in Switzerland for this.

L It's not an immunisation against cervical cancer, it's gonna protect against catching it, is that it?

(Parent group, area 1)

Whilst one or two had spoken to nursing friends for instance, that had moved them no further forward in their knowledge because these people were no more helpful as sources of information, given the newness of the topic. Relatively few mentioned having done any further research on the Internet. Of those that had, many found the plethora of information they encountered unhelpful and confusing.

> I think coming to this discussion, I went to the Internet to have a research and I found out that sometimes the Internet is not the best place to go because you don't get a reasonable argument or picture. I feel maybe that I don't really know enough background information in terms of studies and what's been done and research and clinical trials, so maybe that's why some of these questions being raised are being raised.
>
> (Parent, area 5)

Most parents did not aim to understand the complex science behind the identification of the virus and the countervailing measures, but simply required a story that made sense to them and was coherent. The information supplied in the leaflet or in the news bulletins to date did not seem to answer that requirement, leaving gaps in their understanding of HPV and immunisation/cervical cancer that they could not themselves fill.

4.1.2 Degree of safety concerns over new vaccine

Concerns were voiced in most parent groups about vaccine safety. Some parents were under the misapprehension that the first batch of children to be given the vaccine in Scotland would be the guinea pigs, the first round of drug testing. Sometimes these doubts were nebulous and arose from the general decline in trust over such issues inherited from the MMR debacle of previous years.

In some cases parents referred back as far as the thalidomide scandals that must have occurred well before most were born, the link being made in their minds between diseases of the generative organs and childbirth. Parents and young people (presumably after conversations at home) raised questions about whether the immunisation might affect children's progress through puberty, might affect their ability to reproduce, or might result in them giving birth to deformed children.

P1: I mean how much research has been done? Are you just thinking, what if we just made a big mistake?

P2: I know, with the likes of Thalidomide and the MMR and things like that, I don't mean to make it like a scare story but if we go back into history these things are there and you wonder if there's been proper testing…

(Parent group, area 2)

The one thing I was wondering as well of course… if they're doing a trial they'll have done it on children aged 12. I assume when they did it … how old are those children now? Are they at child sort of pregnant stages? Does it have any effect on fertility? We won't know that, so you have to wait 10-15 years from the start of it to just make sure it hasn't affected anything like that I assume, unless they can do a test to check their fertility levels, but how accurate would that be?… You wouldn't like to prevent cervical cancer and then find out you've made them sterile.

(Parent, area 3)

A further concern that arose, a number of times was in relation to the way the vaccine worked. It was clear that the principle of the original 'vaccinia' for smallpox, i.e. give a small dose of the original illness in order to induce a reaction that produced antibodies which then conferred protection for life, was uppermost in many parents' minds. We were asked on a number of occasions whether the vaccine would be giving people a low dose of cancer or whether there was a chance that a small proportion of recipients would get genital warts. The much more complex biochemistry of the way in which the immune response is invoked with the new vaccine was not known by anyone.

I don't mind being told there is a downside 'one in a million children may end up with genital warts'. Because initially I always thought vaccine was made up of something that you're giving them. Obviously it's a very weak strain of something to innoculize you. That's how your body builds up antibodies and stuff. So you could say 'one in a million will end up with genital warts, it's ok you can give them antibiotics, it's fine'. But if that's the worst case scenario as a downside to it, then that's fine.

(Parent, area 1)

Beyond these specific concerns was a more general fear, that the degree of pre-testing had not been sufficient. One teacher in area 4 noted that she was speaking as a parent as well as a teacher. She felt that the literature she had seen so far regarding the immunisation had been far too tentative and noted that it had sown doubts rather than been reassuring.

T1: I think the sentence 'How long are you protected?', where it says you actually don't know… you might need a booster after 2 years…. You're giving somebody something and you actually don't know how long it's going to last. I think I would be worried as a parent in that situation.

I: There's 2 or 3 things coming out here; 1 is about clarity, wanting clear answers and guidance, wanting to know what the side effects might be and the kind of effectiveness of the vaccine

T2: It seems there is a phrase that comes up a lot - '<u>may</u> cause' and '<u>may</u> protect'. I've just noticed that in the literature. It's not definite yet.

(Teachers, area 4)

The tentativeness of the language obviously stirred up memories of previous vaccine 'scares'.

T1: Even the last couple of paragraphs, 'since the vaccines are new, more studies need to be done' … There have been so many scares in the past that as a parent you would really want to know everything that they tested, every side effect.

T2: Whether the stories are scientifically rubbish or correct or wrong or whatever, the perception is still in the general public that vaccines are dangerous rather than that they are not.

(Teacher group, area 4)

Some parents indicated that they were happy enough to see the programme go ahead on other people's children but that they might hold their own back. Those parents who remained unconvinced that their children might be sexually active in a few years talked about holding back from school immunisation and having it done separately at the GP after they had seen the evidence of one or two cohorts going through the system.

P I don't necessarily know if I think it's an age-related thing. It's more from my point of view, how experimental it is, and I feel almost I would like to have seen 3 or 4 years of girls having it before I would be willing to commit my daughter, rather than an age issue

I: Yes, so it's an issue about evidence really?

P: Yeah

(Parent, area 5)

Parents referred to the fact that as a parent it might be better to make an error of omission (i.e. not have a child immunised with the risk that they might suffer from a disease in later life) rather than commit an error of commission (i.e. opt for immunisation and see the child suffer as a consequence of the immunisation itself).

The information has to be spot on, like. Oh aye, you'd have to weigh it up. If there was any downside, you'd have to make it pretty clear. How would you feel if you were a parent and you'd got your bairn inoculated for this and then later in life they developed something and it was linked to this inoculation? You'd feel pretty bad knowing that you'd given your kid something… that you had the chance to tick that box and say 'yes I want it.'

(Parent, area 1)

4.1.3 The acceptable age for their children to receive the vaccine

At the start of the fieldwork the focus was on S1 as the main target group for the vaccination programme. In these early stages, young people themselves – newly arrived from primary school – were reluctant to agree to take part and many parents, teachers and colleagues expressed dismay at the thought of young people even being engaged in the research project, let alone involved in an immunisation programme that would obviously involve an explanation of the transmission routes of the virus. The changed target to S2 was much more acceptable to parents and teachers. However, many parents commented on the fact that it was difficult to come to a sensible conclusion on this topic given the wide range of readiness within a single

school cohort. Parents could accept that it would be the right timing for children who were 'precocious', but felt that their own were often very young. By this, they meant not only that the children were not likely to be sexually active, but that they were too uninterested or too dependent still on parents to engage with the topic.

> 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, area 2)

Parents in area 3 pointed out a much more pragmatic reason for not delivering the vaccine in S1, namely that there is huge variability amongst primary schools in the amount of preparation children will have received in SRE lessons and that S1 is often the time for bringing this all together and ensuring that children all at least have the same basic level of understanding of their bodies and issues pertaining to sexual health.

> P1: What we find with the sex ed programme is in first year it allows us sometimes to bring all pupils from different primaries to the same point but a lot of primaries (even though there is a 5-14 curriculum there), because of the primary they might not have gone into as much information as some others have. So what we try to do in first year is maybe bring the same points in and then in third year when you're adding onto that information and knowledge base they can then take on that information.
>
> P2: Mine all went to [named primary] and they certainly started end of P6 and they had a wonderful run through. But …I found some of the other schools when you spoke to mums and teachers, they did very little, if any.
>
> (Parent group, area 3)

Speaking as parents, teachers in a Catholic school in area 6 noted the fact that, although parents might welcome the immunisation as a way of protecting their child's health in the longer term, the difficulty would be that it would be hard to introduce the topic to youngsters without getting into a dialogue about sex.

> T1 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.
>
> I: Yes that's interesting.
>
> T2: 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.
>
> (Teacher group, area 6)

Parents in some of the most rural areas found it very difficult to accept that children in their area would be sexually active before the age of 16, implying that this was something that only happened in larger towns and cities.

P1: Well my reaction as a parent is well our children are 13 and in [this area] it's just a sort of different scenario

P2: Well I wondered if this vaccine has to be given at a young age. Is that part of the vaccination, I mean it works better if it's given at…

I: Well it's not effective once you're sexually active, so that's the rationale behind it being at an early age

P1: So, then as a parent I would make the decision… Well I would take the risk. I don't think my daughter is going to be [sexually] active for 2 or 3 years hopefully, then lets wait. Let's see how everyone else gets on. That would be my reaction

I: So what do you think would be an appropriate age?

P1: My feeling would be particularly for an area like this …S5, S6, when the child is much more able to make their own decisions.

(Parent group, area 4)

4.1.4 Their views on the proposed approach for delivery – is school the appropriate setting?

Most parents accepted that school was the most appropriate place for delivery of the immunisation if the goal was mass coverage.

> The easiest way to get them is to get all the children at school 'cos some people are quite complacent and some people won't really bother, 'yeah we'll give her it'.
>
> (Parent, area 1)

Area 5 parents discussed the appropriateness of the school as a setting for the delivery of the immunisation programme.

P1 I think it's a good place to catch the bulk of the population and it's convenient I guess and, in terms of cost, it's probably a good idea as well. It means they're not away from school some other time to go to a doctor and have it. It then becomes part of the kind of folklore and mythology of being in school 'oh it's second year, we get our HPV vaccines' as it was BCG in our day and you kind of dread it for 3 years before you get there.

I: Yes, I mean certainly for convenience for the health staff and cost as you say. If you think about your own daughters, what do you think they would feel about school based immunisation, as compared to going to a GP or somewhere else?

P2: I would imagine speaking for our daughter it would be better for her that they were (inaudible) all of her year, her friends, it was something they were doing together at the same time and they would have fun discussing it, even if it grew arms and legs.

P3: It would probably be the same for my two actually. It kind of takes away the (inaudible) of dragging them down to the GP or the practice nurse cos that's kind of isolating them. If it's something they're going to have done and it kind of isolates them from the rest of their peers, something that's kind of mystical, whereas if it's done in bulk it's not so mystical, they can chat to each other and come out and go 'oh that was horrible'.

(Parent group, area 5)

In area 2 where the school was part of the Healthy Respect SHARE[3] initiative, parents thought that education about the vaccine and HPV should become part of the broader education of their children.

P1: Yes, I think if it's going to be the whole of Scotland or probably eventually the whole of Britain, why would it not be part of their sex education if it's such a big thing. It's part of their health and respecting each other and respecting their own bodies so it should be part of that.

P2: It should go hand in hand.

(Parent group, area 2)

Area 4 parents agreed that mention of the vaccine in SRE classes might be appropriate, but, on the whole tended to share the view of teachers that the school was simply a host for this activity and that the main responsibility for information-giving, lay with the medical profession.

I: I suppose this is a difficult one about how you think the schools and professionals should communicate with parents.

P4: I think an open evening or an invitation to attend something like this where you get a chance to actually discuss it openly. A newsletter or something isn't always necessarily the most informative and can easily be forgotten to be handed out of the school bag or whatever.

I: Do you think that parents feel quite confident about going to parents' evenings on matters like this?

P2: Some people might not be, but then there's also the people who are very keen to show up to these sort of things. But then there would obviously be a medical input. I would imagine somebody who could answer questions. So the school in a way is just really hosting, I wouldn't expect the school to be laying down all the information. They're there just as you say, to host really

[3] The SHARE programme, an NHS Health Scotland initiative, originated in the early 1990s to address concerns about young people's sexual health. Further information can be found at http://www.healthyrespect.co.uk/professionals/our-education-work/share.htm

P4: Yeah I would imagine it would be the nursing staff [4]that would be delivering the vaccinations so I would expect them to come fully armed.

P1: Or one of the GPs.

(Parent group, area 4)

4.1.5 Their views on the need for and management of parental consent

Parents were unanimous in feeling that their consent as parents should be sought for immunising their children, but divided 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. The sample did not take demographic details from focus group participants, but a general impression is that better educated parents were more likely to concede the right of their child to self determination or consultation on this issue, whereas the remainder were more likely to insist that their decision should be final and that it would be fine in certain circumstances to vaccinate a child against his/her will.

I And, what about the kids, would they need to consent as well?

P1 No because they're not 16. A child's best interests is with their parents. I mean my son is 17. He's in the army but he still needs my permission to leave the army barracks at the weekend cos he's still classed as a junior soldier.

P2: Obviously parents have got to have the best interests of their children at heart. Now if you give it to a child to decide they're gonna…

P1: 'Do you want a jag?' 'No, I'm not having a jag'.

P2: Would they actually understand what the jag is about?

(Parent group, area 1)

I'd be inclined to go with what you're saying… ok (inaudible) the collaborative agreement. But should the child say yea or nay that's the wish that should be respected, because it's their body and at that age they have got a certain amount of independence and understanding of what it is they're agreeing to get into, and that has to be respected.

(Parent, area 4)

4.1.6 Which issues are a priority?

The research with parents had been prefaced by a letter inviting parents and children to take part. This letter had stressed the role of this immunisation as a cancer preventative, a strategically- made decision about how the campaign should be presented. A number of parents implied that this was in fact a little deceitful since their further reading of the information we had supplied made it clear that this was not a guaranteed cancer preventive and that other purposes might be served by inoculation against HPV. In other cases it was clear that though parents accepted that the overriding aim of the programme was about cancer prevention, it was essentially an issue that revolved around sexual health.

> When I spoke to my girls about it 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, area 2)

Similarly a parent in area 4 noted what a wonderful opportunity this presented for some enlightened sex and relationships education in which parent, young person and professionals were brought together to discuss the issue.

> 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, area 4)

For a mother in the area 6 denominational school it was clear that the vaccine's role as a cancer preventive was a major factor, not least because she had experience of a friend who had been unfortunate enough to suffer a cancer scare.

> Through the coverage that this injection has had on the news, that's where I first heard about it on the news and I thought right away that's a good thing, there's something good there. But as I said I've got a friend who's had it [cervical cancer]and she's just lucky she went for a smear test. It wasn't until she was all kind of clear that the nurse come back to her and said, 'You were a lucky lady, weren't you, that you came for your smear test? Somebody must have been looking over you.' She was just taken aback. She didn't realise how bad it was. So it just shows you it's easy for you to have it [cervical cancer] and you don't know you've got it. It's a silent killer as they say. That's what you've got to think about.
>
> (Mother, area 6)

Area 2 parents felt that it was important that information for young people was tailored to the needs of particular ages and that it should be clear enough to dispel playground myths. Similarly information on the virus and vaccine should be timetabled and integrated into SRE. Within this group, one participant noted that no-one had suggested that the vaccine would encourage promiscuity. Asked to sit back and think about the overall value of HPV immunisation and what its chief value might be, most parents did accept its role as a cancer preventive and as an initiative that would ensure the future health of their children.

> 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 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.

(Mother, area 6)

4.1.7 Their attitudes to a 3-dose vaccine schedule

Many parents noted that their children were fairly needle shy and the thought of having three injections to achieve full immunity was rather off-putting.

I: Somebody mentioned earlier that it needs 3 doses, 3 vaccinations

P1: My daughter wasn't very enthusiastic when she read it was 3

P2: [If] they feel rotten after the first one, they'll dread the second.

(Parent group, area 4)

Few parents seemed to understand why three injections were necessary and felt that none of the information they had been offered as part of the research study made this clear.

Parents in the area 5 group distinguished between their own attitude to the immunisation schedule and what they thought might prevail in some other social groups.

> This may be an unfair thing to say but socially you might actually just find that those who maybe are really needing the vaccine are the ones that might not perish [sic] the thought of having 3 vaccinations, whereas those of us sitting here… our children would probably be told 'Well it will be a bit sore but better to have it'.
>
> (Parent, area 5)

There was some confusion about what the effect would be of missing one or more parts of the dose. In the following extract parent 3 is a doctor himself, but parents are still struggling to make sense of the need for three doses by analogy with the immunisation schedules for their pet animals.

P1: And what happens if they have 1 or 2 parts of the vaccine and don't comply for the third or will there be a sweep up to make sure that even if they miss the date at the time?

I: Oh there will have to be some kind of fall back position for children not in school on the day, for sure. There will have to be some way of mopping them up.

P2: Cos obviously there will be a time schedule, it will have to be done within a certain time schedule, these 3 vaccinations, so if they fall foul in the second one then they'll have to start again the process, if they miss it ,and it's then too late they'll have to start again.

I: I don't know exactly what the time scale would be

P3: I doubt the science would be that exact around the timings of them. It's almost guesstimating when the next dose should be with most vaccines. There are no exact patterns. I presume there would be quite a big window.

P2: I'm thinking of animals where it has to be done within a certain time scale.

(Parent group, area 5)

4.1.8 Their information needs

Parents were clear that the information they required would have to be detailed and honest. Whoever was providing it would need to be aware that trust in matters of immunisation had been depleted by the MMR affair, and that any information would have to tackle this head on. Fears about drug safety are not necessarily very coherent, as the next quote shows, but they do need to be assuaged.

P1: Yeah but you know (inaudible) the new wonder drugs etc, etc, I wouldn't want to take it just as severely as that but they come out with these new all-singing all-dancing drugs, you know… this is the new penicillin but 5, 10, 15 years down the line, you know….

I: So I guess what you're saying is that the information that's got to come out has got to address those issues?

P2: Yes it has to start somewhere and like your MMRs and that as well…

(Parent, area 2)

The parent group is not homogeneous however, so whereas the more middle class group of professional parents in areas 5 and 7 felt that they would like very detailed information about drug trials, comparative risks and so on, other parents felt that something simpler, snappier and jargon free was more what was required.

P1: I need as much information as possible about the trials and the outcomes and all this type of thing

P2: That's it, how long have the trials been run for and at what point are they completely certain that this is to go on the market and be put out to the general public?

(Parent group, area 7)

Aye I mean you have to keep it very simple. You can't bamboozle them with big long names and stuff like that. You have to keep it very simple cos folk just pick up the leaflet and go… They don't really pay much attention to it, but you'd like it nice, short, snappy and clear

(Parent, area 1)

A compromise solution came from parents themselves in area 1.

P1 Obviously you could have a brief leaflet with some information, quite simple and then if you had a website it could have more details for these people who want to read up on it.

P2: Or a helpline number or something.

I: So, present the basic information in, say, a mail out to all parents and then if you want to know more ring this number, log on here or send away for an information pack?

P3: Something like that where …obviously information packs cost money to get it up and running, but at least if you want more I mean you could log on line or a free phone number.

(Parent group, area 1)

A similar suggestion came from parents in area 4.

I: What sources of information would you look to that you feel that you could trust with an issue like this?

P1: Probably information from the doctor's surgery. I'm sure the school would… if we had information from school nurses.

P2: And a trial, trial results … Just the whole thing so you could see as a parent and the clear information on what to expect.

I: So pretty detailed …you're talking about stuff about the trials. I think the difficulty of that is having the volume of information but making it accessible.

P1: But now with websites it's so easy. Click on this for more [information]. It's easy to get as much or as little as you want for things. Maybe that would be the way to do it, to have a website people could go to.

(Parent group, area 4)

When asked who parents should turn to if they had further queries, it emerged that there were mixed views about the quality of the NHS call-in services.

I: who do you think should have the responsibility for answering parents' questions?

P1: Just 'phone up' the health visitor and ask her who to ask. Or the school nurse.

P2: But then of course that leaves you to have to therefore give that information to somebody. There's no point phoning up NHS 24 or something. You don't really want to phone some helpline and the person on the other side of the phone hasn't got a clue cos he's just started today and he was doing car sales last week for Loans Direct or somewhere and today now he's doing this for the health board.

P1: I would just bypass NHS 24 and go straight to the hospital

P2: You could get the information from the health visitors and stuff but you'd have to make sure they're all clued up on it before cos you can get some pretty thick parents like me coming up and asking some stupid questions, something that's totally irrelevant.

(Parent group, area 1)

Parents in area 7 were interested, however, in having some sort of interactive website or forum where they could raise questions and receive replies.

> P1: If you did have a dedicated website for the subject that you could go onto as a parent that would be helpful as well cos sometimes getting information from the kids you know, bring back the leaflet from school, well it never comes back. But if we can actually go onto something ourselves which is not like the world news or a little story some place but an actual…
>
> P2: Yeah, like a comprehensive question and answer.
>
> P1: And even a forum! I don't know, just something that you could actually have a chat to someone about it… like a chat room.
>
> I: So, like an interactive format?
>
> P1: hmmm…
>
> (Parent group, area 7)

More than a few parents made the point that material informing parents of HPV could not satisfactorily be left for schools to distribute via children. The comment made by one parent in area 5 would be familiar to many parents.

> Yeah, I think you have to make people aware of your [information] sheets here. People need to read them. I know these were sent home from this school and probably 20% of the parents actually took the time to read them. 20% will never probably have got out of the school bag.
>
> (Parent, area 5)

In some schools the suggestion was made that presentations should be made (by NHS staff) at school fairs or parents' evenings. Others were more sceptical about whether any parents would turn up for an evening that many would find potentially embarrassing. One area 6 mother pointed out how difficult it had been in her child's school to find sufficient parents for a discussion group as part of the research.

> That's 150 parents' that's had that information sent out to them and 1 parent came. I think it's pretty… disappointing.
>
> (Mother, area 6)

As mentioned elsewhere, parents were keen that any campaign in the schools was backed up by widespread television advertising and the use of chat shows and TV magazine programmes to press home the issues and also allow them windows in which they could interact with their children in response to issues raised on screen.

4.2 Young people's views

Young people from S1 to S4 were interviewed in groups for this study. Boys were interviewed as well as girls, though always in single sex groups. Given the significant differences that are shown in children's knowledge and attitudes with age, all quotations are attributed by age and gender.

4.2.1 Levels of knowledge and understanding

Some understanding of the levels of young people's knowledge was ascertained by presenting them with a 'quiz' (see Appendix A) at the start of each of the focus group sessions, which was then reviewed at the end of the session by the interviewer. These paper forms were handed in by the young people and the results collated. It must be remembered that young people (and their parents) had received an information sheet as part of the invitation to participate in the study, so in theory they should have known more than the average 'man in the street'. Despite this, levels of understanding of the information sheet given to young people varied greatly across all aspects of the quiz responses.

When responding to the question 'had you heard of HPV before we contacted you?' A small number of girls responded 'yes' (n=17) whilst the majority of girls (n=69) responded 'no' and four responded 'don't know'. Conversely, distribution of answers by male respondents was almost equal as eight answered 'yes' and seven 'no' with only two stating they 'didn't know'. It became clear after further scrutiny of the questionnaire data that whilst young people felt they had heard of HPV before there was some confusion between this and HIV (Human Immunodeficiency Virus) so assessment of this data must be undertaken with caution.

Whilst most of the young people did not want to mention 'sex' in the verbal discussions with relative strangers, many in the written quiz correctly ascribed the route of transmission of the HPV virus as being through sexual contact. However, this level of understanding was not apparent in all respondents. For example one girl expressed it as 'It's passed by forming a lump where you don't normally find it' (13 year-old girl). The HPV virus was associated with cancer in many cases but in some circumstances was confused with HIV and other sexually transmitted infections.

Interestingly, over half the girls who responded (n=45) and six of the boys did not believe that boys could carry the HPV virus as well as girls. Seventeen girls thought boys could catch it too, as did five of the boys. A number of both girls and boys (n=27 and n=6 respectively) were not sure about this. This could have been a result or the information sheet presented to the young people being focussed on the prevention of cervical cancer. However it was acknowledged within the information sheet that boys too could be carriers of the virus.

Suggestions as to how to protect oneself from the threat of HPV varied greatly from 'have the jags' (13 year -old girl), to 'use protection' (14 year-old girl) to 'exercise' (13 year-old girl).

The majority of young people (n=85) knew that the immunisation was most likely to be offered to girls around the age of 13. However some variation in understanding about the likely target age for the immunisation was seen across the sample with some stating girls as young as 11 years would be vaccinated and others thinking it would be girls around the age of consent (16) who would be offered the immunisation. Many theories were offered as to why these age groups of girls might be offered the immunisation:

> 'Because that is the legal age to have sex' (13 year-old boy)
>
> 'Because they are sexually maturing' (14 year-old girl)
>
> 'Because you are not old enough to understand what it is and what it is for' (12 year-old girl)

'Because it is not likely that you would have had sex' (15 year-old girl)

Variation was also seen across understanding of how many doses of the vaccine would be needed for it to be effective. Answers ranged from one to four, with many respondents stating that they were not sure.

When asked what side effects might be experienced after vaccination many respondents thought they could feel 'dizzy' or a little bit 'ill'. Others suggested:

'You might not be able to have a baby' (12 year-old girl)

'Irregular bleeding for girls, mood swings etc…' (15 year-old girl)

The general consensus was that there was no one who should not receive the vaccine although it was mentioned by a small number of respondents that those who had allergies should take advice.

Inevitably knowledge and understanding varied as children got older. In the S1 groups interviewed there was only weak understanding of the fact that HPV was sexually transmissible. Asked why they thought children of this age were being vaccinated against the virus, few young people of this age thought it was to do with them being on the cusp of adulthood and possible sexual activity, citing instead that the injection might have hurt them more when they were little, for instance.

It is clear that some of the thoughts and views expressed by young people reflected discussions they may have had at home following the invitation to take part in the research. Asked to respond to a vignette in which a child's parents had been uneasy about their daughter having the immunisation, and to speculate on why they thought this might be so, various thoughts emerged (though not well formed) on natural immunity, on relative risks, on the fact that previous generations had managed without the immunisation.

> Her parents might not think she won't get it cos like a lot of people don't get it and her parents might just think she might be one of the people who won't get it.
>
> (S2 girl, area 3)

> The parents might be thinking that none of their elders or them themselves have never had any genetic problems so they think that she can never get it or the chances are very, very small.
>
> (S2 girl, area 3)

Some of the same issues expressed by parents in relation to the safety of the vaccine arose in young people's comments.

> If you're still in primary the drug might be too strong for you to actually handle and it could give you puberty problems.
>
> (S2 girl, area 3)

G1: Or maybe she doesn't think it would work, or she thinks it might give her it.

I: So the injection might actually give her the HPV instead of protecting her against it?

G2: And like if she comes from a family that doesn't agree with injections and think they just put other infections into you.

(S1 girls, area 1)

Like they put it [the immunisation] in you and some people think that there's a wee bit [of the virus] that goes in. What if that's the problem?

(S4 girl, area 2)

Young people had pragmatic concerns about the level of exposure that would give them HPV.

What if the boy had sexual intercourse and had it [HPV], would it only take the one time to have sex or would it take more times to take the girl to get it?

(S2 girl, area 3)

Many were confused about the transmission routes of the virus, despite the information given in the leaflet inviting them to participate. A number were prepared to believe that the virus could be transmitted on the mouthpiece of a musical instrument or from frequent use of the swimming pool, for example, when led astray by the background detail in some of the vignettes used to stimulate questioning.

A number of questions arose about the connections between genital warts and those found on the hands or feet (verrucas). Since neither of these conditions is life threatening, though undoubtedly unsightly and unpleasant, there was clearly some mystery about why warts on the genitalia would be other than an embarrassment or cause slight discomfort.

A number were concerned about the site of the injection, a belief seeming to have taken hold that the injection was given directly into the cervix or somewhere in the lower body because of the association with the genital areas and HPV infection.

Cervical cancer was seen by most as a remote, but rather scary possibility, and worth immunising against.

4.2.2 Their views on the acceptability of receiving the vaccine at school

The majority of young people accepted that school was an appropriate place to receive the immunisation, not least for pragmatic reasons.

I think it's good to have it at school cos my mum doesn't drive and it means I would be taking time off school just to go to the doctor's and then back and forward.

(S1 girl, area 3)

> I think it's an OK place to do it because it's making sure that you offer all the children the vaccine, to have a chance to get it.
>
> (S2 girl, area 3)

However, some expressed fear at the thought of needles and were aware that they might be embarrassed by their own apparent feebleness in front of peers.

> I think it's better to have it at your doctor cos then you would not be embarrassed in front of everybody and in pain in front of everybody.
>
> (S1 girl, area 3)

> If you're scared of getting it done, you might cry and you don't really want to cry in front of your class.
>
> (S2 girl, area 3)

Pupils were only too aware of how groups of young people often 'wind each other up' over issues like this, making the fear of immunisation even worse.

A few young people raised queries about hygiene in schools and about the expertise of those administering the injections.

> It should be the doctor's office cos I think they're more cleaner and there's less chance of infection from the needles cos it would be (inaudible) sterilised. So it may be sterilised better in a doctor's office instead of a school.
>
> (S2 boys, area 7)

Others would have preferred to use a GP surgery because they would have their parents with them, rather than their peers.

Some pupils mentioned lack of confidentiality at schools as an issue. It is not entirely clear whether they were imagining that only a minority of pupils would be asking for or consenting to the procedure, perhaps leading to them being labelled or stigmatised in some way.

> Or like if you get it done somebody might think 'oh my god they've got cancer' or 'stay away from them.' I think it's better to get it done at the doctor's cos it's confidential.
>
> (S4 girl, area 4)

In one case at least it was clear that children were confusing HPV with HIV and were worried that the immunisation procedure would reveal that there was someone in the family who already suffered from the disease.

Young people were particularly exercised about the issue of consent and this raised the strongest debate in the focus groups.

> Well do you have to have your parent's permission to get it cos I don't think that's very fair? … I just don't think it's right for Sally [character in vignette] if she wants it but her parents don't let her have it.

(S2 girl, area 3)

I: 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?

G1: 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

I: Does everyone agree with that?

All: Yeah.

(S2 girls, area 5)

Young people appreciated being consulted about the decision as to whether to choose immunisation, even though the choices felt like difficult ones for them.

> Well I think … they always say your parents know best but they don't. I done stuff before that my mum and dad told me not to, and then I realised they were right. But then I done stuff before and I thought it was right and my mum and dad thought it was wrong, but it was right! So I really think it should be your own decision because people call us young adults now. So like as you get older you need to make decisions for yourself and not just have your mum and dad do it for you because it would just be easier. Cos like I know I don't want it, but I do want it, and my mum and dad told me it was my decision. But they suggested I should have it and I also think I'm going to have it because of my mum and dad's friend dying.
>
> (S2 girl, area 3)

Most young people felt that disputes should be settled by discussion with parents, perhaps using the school nurse as a mediator in difficult circumstances. Few felt that they could or would defy their parents' wishes. In the event of them wanting the vaccination but parents still resisting some claimed that they would wait until they were 16 and then organise it themselves by going to the doctor, not realising that this remedy lay within their grasp of course, at a much younger age. Despite their vehement protests that it was young people's right to choose for themselves what happened to their body by this age, most were not sanguine that their views would be taken into account in reality. Most believed that school nurses could not administer drugs or any medical procedures in school without their parents consent.

> A nurse can't give a child under 16 any chemicals or anything like pain killers or any drugs without their parent's permission, even if they wanted it.
>
> (S2 girl, area 3)

Several mentioned that a child could go to the doctor and ask for treatment, implying an understanding of the law around consent and that a GP could assess whether a child had sufficient understanding to consent for themselves or whether parental consent was necessary. Some understood quite well at a young age that schools found themselves in a difficult position between parents and young person on such matters.

I: So what would happen if you didn't have that consent form from your parents? Do you think they [school nurses] would still give you the jag?

G1: No, cos the school are strict.

G2: If you go to your doctor's they might give you it [the immunisation].

I: Do you think doctors are different in some way from….?

G3: Yeah, they understand more.

G1: Do they?

G4: Well the school is just scared in case they get like in an argument.

G3: Yeah, they'll get sued.

I: So is the school going to be more worried about …..?

G3: What your parents think.

(S2 girls, area 5)

If the school did something against the parents well I think they would get the battering for it and not the nurse. That would be such a problem for the school and that's something they don't need. So if it [the immunisation programme] is out of the school, there's the doctor that's there and he can say 'Look she's the right age, she wanted it herself and she wanted it because…'. But the school can't defend itself in that way.

(S4 girls, area 4)

In the case of a parent wanting the immunisation but a young person resisting the idea, young people liked to think they would not be forced physically to endure the ordeal, but were not entirely convinced that this was indeed the case.

4.2.3 Their understanding of the three dose regime

There was relatively little discussion of the three dose regime. The objections to the immunisation programme were mostly in terms of fear of needles.

B1: People might think that cos you're getting 3 jags that it's really important and if they're scared of needles they're really not gonna want to do it. If it's just for 1 vaccination, but you've got to get 3 needles and they're really not gonna like it or want to do it and they'll be terrified of it.

B2: If the first one hurts they might not want to come back for the others.

B1: They might think it's really freaky if they find out that they've got to get 3 cos like if you don't like needles you wouldn't want to get 3 of them but if you don't even like 1 you wouldn't want to get 3.

(S2 boys, area 7)

4.2.4 Their reaction to whether the immunisation should be given to boys

Boys as well as girls believed that young men should be given the immunisation too, but there was no very strong conviction on this issue. It was seen as 'fairness' issue, rather than arising from a strong understanding of the epidemiological consequences of trying to stop the transmission of the virus when less than half the population were likely to be immunised, though the older ones were more likely to understand this concept.

> G1: Yeah because it's not fair if it's just the girls. If it's just the girls then there's not much point in getting it [the immunisation], because girls can carry it [the virus] as well and pass it onto boys, just the same as boys can pass it onto girls.
>
> G2: I think boys should get it as well because I remember in SRE we get taught about all different things and girls just have so much to learn and the boys were just laughing at the back. Boys should have the equal chance that girls do.
>
> G3: I think that boys should get it as well.
>
> (S4 girls, area 4)

Young people talking about boys being immunised demonstrated their low level of understanding of the HPV transmission route, the effect of having the condition caused by HPV, and the cancer associated with it. They checked with the interviewer on occasion that men didn't have a cervix, and also wanted to know if having HPV had implications for other types of cancer which did affect men in other organs, e.g. lungs.

> It's lower risk for boys than what it is for girls but there's still a bit of a risk you could get it and by the sounds of it, it's a lot worse for girls if they do get cervical cancer. It's a lot worse for them as obviously cancer can kill but if boys get it there's a chance they'll just become a little bit ill or something. So it's a big risk for girls, it's still a risk for boys if they don't have the immunisation and stuff, but it's a bigger risk for girls for the cancer.
>
> (S2 boys, area 7)

4.2.5 Their information needs

Young people did not offer particularly original insights into how they would like to be given information. Leaflets that were to be taken away and read in conjunction with parents, topics covered in SRE lessons, whole school meetings at which questions could be asked were some of the suggestions made. Young people were much more likely than parents to suggest the Internet as a source of information, but also offered the school nurse or the doctor as other suitable information sources.

Girls in area 7 were adamant that they wanted a different type of information from that given to their parents and felt that they were more likely to read it if it was in their teen magazines or on TV programmes that they watched.

5. Views of education and health professionals

5 .1 Teachers' responses

The specific objectives which the research was asked to explore with key school staff were as follows:

- levels of knowledge and understanding of HPV, HPV related disease and HPV immunisation
- their levels of confidence in their own knowledge and in the safety of the vaccine
- what preparation / information they need for successful implementation
- any anxieties, concerns and recommendations for communications and implementation.

We thus look briefly at what teachers know already about HPV and the vaccine, and then explore their own confidence about their knowledge. The latter is expressed in two quite separate ways, namely in their willingness to include some formal teaching about HPV and the vaccine in the context of the SRE curriculum and secondly in relation to their willingness to be the provider of answers on a less formal level to any queries that might be raised by pupils or parents. The obvious reluctance that emerges in response to the latter is a reflection both of teachers' insecurity about their knowledge base but also (for most) a certainty that to move in this direction goes beyond their teaching role and encroaches on that of other agencies or steps beyond what they feel can be legitimately asked of them. Evidence emerges that some form of information may be required for teachers despite this reluctance. The section concludes by looking at specific issues commented on by teachers in respect of consent.

5.1.1 Teachers' knowledge about HPV

With a few exceptions, most teachers had only picked up information about HPV from the newspapers or radio programmes. A minority had been unaware of the virus or the proposed vaccine prior to their invitation to participate in the research. Being asked to take part in the interview had prompted them into conversations with colleagues and neighbours about the whole issue and they admitted that they had deepened their knowledge as a consequence. One or two expressed a little scepticism, feeling that the early completely 'good news' stories about the vaccine that had appeared in the print press in particular did not quite hold water once one went into the matter in more detail.

> Again I mean I always understood that it was just a one off vaccine but it sounds like having spoken to various people that it's actually a series of vaccinations that will be needed and they don't know if there would need to be further booster vaccinations in the future, so as far as I'm concerned I don't think it's this great thing I thought it was going to be at the start.
>
> (Teacher, area 1)

Teachers with responsibility for SRE who taught young people about STIs had some knowledge of genital warts, but had not made the link with the virus or with cervical cancer. Even SHARE-trained teachers, who were generally much better informed about sexual health issues than their counterparts elsewhere, expressed their dismay at the speed with which this new issue had appeared over the horizon.

> I How much, how aware were you of the virus before you heard from us, before we contacted you?

T1: I wasn't at all, which came as a bit of a surprise and, just at the moment with third year doing AIDS … and Chlamydia has been the thing for the last couple of years and it was like 'Gosh, is this something else?' you know, but I wasn't aware of it at all as a specific virus.

T2: I was exactly the same as T1.

(Teacher group, area 2)

It is probably fair to say that few of the teachers interviewed had the detailed knowledge already that would have made them comfortable and confident to answer detailed questions.

5.1.2 General responses to the HPV immunisation

Teachers tended to respond both as parents and as professionals to questions about their general feelings about the introduction of HPV immunisation. Like other parents, they were generally welcoming about the introduction of an initiative that would reduce cancer risk for young women, but they had concerns about the safety of the vaccine.

> I think as a parent that the question mark over the long term impact or consequences of any kind of vaccine would be one that worried me. You know, it's fine to say just now, we know it's effective … but I mean history is littered with medical developments, thalidomide and all sorts of things. Years on we discover there was an impact and I think that would be a worry for a lot of parents, that there haven't been long term trials. I can understand the sort of pressure to get it into the system.
>
> (Teacher, area 6)

Like parents, they too felt that the decision to immunise only girls rather undermined the messages they were trying to impart through the SRE curriculum and more generally to young boys about their responsibility.

> … just to vaccinate the girls for an STD is almost like giving a subversive message that girls are responsible and not boys but that's not the case and that's something that I'm sure PSC would be very keen not to promote.
>
> (Teacher, area 1)

> It wouldn't be so bad if the boys were getting it done as well. If it was like the BCG programme when everyone in the year was getting it and it was explained, that would be fine… but to single out the girls to take them away to get this jag from the nurse against a sexually transmitted disease is kind of putting them down before we even start.
>
> (Teacher, area 4)

In most schools teachers also had views on the age appropriateness of the immunisation schedule, but these views were more closely aligned with the views of young people than with the general parent body, tending to the view that the earlier the immunisation was delivered the better if it was ineffective once sexual activity had commenced. This difference reflects their knowledge of the whole age group.

I: It's proposed the vaccination is going to be given to girls in S2. Do you think that's an appropriate age?

T1: Yes I think it is, in fact it could even be younger

T2: I was thinking 12

T3: It's very hard to know the figures and I'm sure there are other agencies that will give you details, but just of what we feel is happening amongst pupils… It's certainly not the majority, but there are one or two that are experimenting with sex, sometimes in primary.

(Teacher group, area 2)

One teacher in this group, having read the literature prior to the interview, was even more adamant that S2 might be too late for a significant minority.

T1: What I read - put me right on this - but what I read from your material is that it doesn't have to be penetrative sex to transmit the virus. It could just be experimenting and touching and that kind of thing that they can pass on the virus…

T2: Oh God, even more reasons [to opt for earlier immunisation]!

T1: So I would say for that reason alone….Young people are experimenting younger and younger.

(Teacher group, area 2)

In the denominational school, however, teachers felt that the question of suitable age might be determined in terms of `readiness' which varied within age cohorts.

> Given that as 50, 40 and 20 year-olds we're having difficulty coming to terms with the moral and the complex issues, how can you expect a 13 year-old, no matter how good the information is you give them, how can you expect them to process that in a way that they can make an informed decision? We will have kids who won't even have had a period at that stage. We will have kids who will have led very, very sheltered lives who don't actually understand that sex happens between a man and a woman. So how you can cater for that whole spectrum of awareness? It could be quite distressing for some kids, which is another reason why I think parents are the ones who know what level their children are at and should be the ones, in an ideal world, that can either raise these issues and discuss them or say 'No, my daughter's not ready for this. Maybe next year' or whatever and schools are not necessarily the places.
>
> (Teacher, area 6)

Teachers were on the whole happy enough to see the immunisation programme carried out in schools, given that this was the norm for other immunisations, and did not want to see HPV singled out and delivered through another route because of its transmission route through sexual contact.

T1: You know if you make it different and you have to go to the clinic it's for THAT vaccine, I think it sets it apart.

T2: Yeah I think we should try to normalise STIs, it's not something that you don't talk about, we need to bring it all out in the open and be able to sort of talk openly about these things and to take it as an exception away from the school vaccination programme is doing exactly that.

(Teacher group, area 7)

The exception to this was in the denominational school in area 6, where teachers felt that the decision to implement the immunisation programme in school imposed a level of peer pressure to accept the vaccine when the decision should be made by parents on a confidential and personal basis.

> Can I ask why it [the responsibility for the immunisation programme] is not being given to GPs? Why school? I think that's a big onus on having it in schools and I really feel it should be a very personal GP/parental discourse. Because of the issues, social issues and the collapse of families etc, the onus has now come back onto schools to do these things… My concern is, what I would be looking for is… I would be looking for a GP/Patient clause where that's quite a private thing and you've got your confidentiality and you've not got peer group pressure you know. We've got a very large Muslim community in our school so I'd be very interested to see how the Muslim parents react.
>
> (Teacher, area 6)

5.1.3 Providing curricular support for HPV immunisation

Teachers were asked if they would feel happy or able to provide support for the immunisation programme through the curriculum. Rather against the spirit of this being sold as a cervical cancer initiative and not a sexual health one, most saw the appropriate slot for any such support as lying in that bit of the SRE curriculum in which STIs were touched on. It is also clear that such topics were treated in a somewhat cursory fashion for the most part.

> T1: I'd say that it's something we would mention as part of our sex and relationships education 'cos if we were just talking about STIs and how you protect yourself, it's something we would mention, I don't think we would spend a huge amount of time on it.
>
> T2: We'd certainly update what we do with them just now to include 'and there is this vaccine….'
>
> (Teacher group, area 1)
>
> T1: I think when they come round to doing the STDs I probably will talk about the vaccine. I try to talk about the more up-to-date forms of contraception you know, I always talk about the male pill, implants and all these sorts of things so now that I'm aware of the vaccine there I'd probably include that as well. It may just be a short input.
>
> (Teacher, area 4)

This posed problems with timing for some schools where STIs were not usually covered until S3. There was some debate about whether the SRE curriculum could or should be shuffled at short notice to reflect the appearance of HPV immunisation (and debate) in S2.

However, it was clear that most felt that their responsibility to inform children was marginal and that the primary responsibility lay with the health authority and health professionals more generally.

> T2: Yeah I think the ultimate responsibility is with health, the same as the information about the BCG. We wouldn't be expected to give accurate information as to whether you need the BCG.

T1: There's no guarantee that every kid will be in school on that lesson day so information has to come from other sources.

(Teacher group, area 4)

It is clear from what most teachers said that classroom education on STIs is largely didactic, and teachers recoiled in some dismay at the thought that they might be called upon to answer questions for example, either from pupils or parents.

I: And do you think you would need training yourselves to prepare you for any responses you would get from parents?

T1: No … I would immediately direct that to the likes of the health profession, to the school nurse I mean I don't see that I have a role in that at all.

T2: Like handing out the vaccination stuff we did a couple of months ago and one of the pupils said 'so I have to get this' and I said 'I don't know, you'll have to get in contact with the school doctor or whoever is running that.' I think that would be a similar situation.

T3: If we get asked anything we would answer it as best we can but more likely than not, direct them to a health professional who can have greater confidentiality with them you know if they were starting to talk to us about any kind of sexual activity.

T2: Or any other sensitive issue presumably.

T3: Yes we would listen, do the best we could and then point them in the right direction but particularly with issues of a sexual nature we would direct a health professional because there is greater confidentiality and they can talk about things in more detail.

(Teacher group, area 4)

This reluctance to engage at a more personal or advisory level clearly lay in both an insecurity about their level of knowledge and ability to answer questions satisfactorily, but also in an understanding that such matters were not just scientific but also heavily value-laden.

When they had questions to ask they would have to have someone in health because no matter how much we read about it there's too many anomalies in it. It's quite hard even to do the sexual health - you know the PSE lesson - because we all have our own inner beliefs and feelings.

(Teacher, area 4)

One exception to this was found at a school in area 2 where the SRE teachers had been trained in the SHARE scheme and where their appetite for taking on what other teachers clearly perceived as very difficult issues was quite remarkable by contrast.

I: Do you think that school is the most appropriate place for the programme?

T1: I think it's the <u>only</u> place, and being backed up by big adverts on television, but they'll ask us questions and we can put it over in a way that is appropriate because we have a

significant sexual health programme. I don't know if you know about SHARE, the programme, yes I think it should be built into any one of these programmes as a significant and very positive part of it.

T2: And it's a small thing and not a massive thing but we tend to know the kids quite well and they know the issues around the SHARE training of confidentiality and I think they would come to any of us with their problems.

I: So you would actually see it as part of your role within the PSD programme to actually explain about this vaccine before it happens and support?

All: Definitely.

(Teacher group, area 2)

Teachers in area 7 were also keen to support the implementation of the immunisation programme by altering their PSE lessons and so on to prepare the children for its arrival. They weren't enthusiastic as such, but did see themselves as having a role in this. Although not a SHARE school, it is notable that the area 7 school falls into a local authority that has a comprehensive framework of support and training for teachers around their delivery of SRE and has been shown to be innovative in a number of ways (see Van Teijlingen *et al* 2008). This is in contrast to the majority of teachers who were absolutely clear that it was not part of their professional role to advocate on behalf of the immunisation, however welcoming they were of its introduction.

I: So there's a big concern about parents generally - informing them and getting them on board. What about parents or young people, individuals that have particular concerns or anxieties about the vaccine, would you see yourselves as having a role?

T1: You would have to be professionally trained.

T2: I think the answer to that is 'no' from me anyway. It's not my job. If a parent has concerns and they don't want it my role is to say 'fine'.

T3: I would never dream of giving advice on that issue.

T4: You would have to refer them.

T2: I don't know if I'm talking out of turn but there is enough loaded onto schools and teachers and expectations are increasing daily, why are we getting the remit for this, if we are, I'm not saying we are I'm just going down that path. I would say 'no, it's not my place to deal with this type of thing'.

(Teacher group, area 4)

Although maybe, looking at it from the government's point of view or from the NHS the trick is to present it through the media as a package. In other words, 'this is what's been decided, this is where the money's going' and they'll probably start feeding it through like that…so that it goes into the national consciousness like that and then it feeds into school so that we're not the first line. A lot

of all that will be all discussed before, because we can't be the people that justify it.

(Teacher, area 5)

The same group of teachers expressed concern that the school might even be seen as applying inappropriate pressure on children to have the immunisation if a reluctant child who asked questions was referred onto the school nurse.

Teachers in the denominational school in area 6 felt even more strongly that they could not be asked to advocate for the immunisation, and that it placed the school at the nexus of an impossible debate about parents' and children's' rights.

> To me that is part of my difficulty because I don't see it as my role to be putting it in front of parents - information about a decision which is essentially medical. You know there are other groups out there who have that responsibility. In some ways I think we need to understand the dynamics both of school and parent relationships and of parent and child relationships because from the perspective of this school, I would think the very youngsters that you would think would benefit from this are the very ones whose parents don't give a monkeys what they sign, what they do, wouldn't sign forms, would be too drunk to sign them or whatever and may not be able to access them because of language or experience or reading ability. At the other end of the spectrum you have parents who feel very strongly and who take great interest in their children's emotional, medical or whatever well-being and would resent the school being part of this dynamic. Then at the very end you would have fundamentalist parents who would actually complain that the school was getting involved with this and before you know it you've got a headline in the Evening Times saying 'Catholic School Promoting Sex'. That is the kind of spectrum that makes me feel a bit uncomfortable, I mean it was different when it was like polio vaccination.
>
> (Teacher, area 6)

At best, in this school teachers could consider the school being an impartial host, but any attempt to drawing them over this line into support of the immunisation programme was seen as extremely problematic.

> I don't think the model … where the schools 'take ownership of it' is a runner. I just don't think schools have that responsibility or would want that responsibility or even have the kind of background where they could take it on. I mean any kind of vaccination programme that's happened in the past the school has been used like polling stations - as a host. We've tried to manage bringing kids and groups in, but that is the level and I don't think that we would want to cross that level. In some ways I think probably we'd be happier if it didn't in some ways happen in schools you know, [better if] it happened in local health centres.
>
> (Teacher, area 6)

5.1.4 Education's links with the school nursing services

Teachers did not feel particularly well supported by the school nursing service in many areas. They acknowledged that individuals were extremely helpful but there were many comments on the extent to which the service was under pressure and the effect that this had on the frequency with which nurses were seen in school.

> Well we do work very closely with them in the school when they are available but the service has diminished to such an extent that I think she [school nurse] has probably only been in once in the last 8 weeks.
>
> (Teacher, area 4)

Teachers in several regions commented in an unsolicited way on their observation of the strain that the school nursing service was under, and wondered whether they had the capacity to carry out the programme satisfactorily when they saw that it involved carrying out three separate visits to get all children fully immunised.

> T1: There is also a big problem in this area as to the input we have from health in the school and the old school nurse as it was is now an assistant and even routine screening is up to 3 years behind. To introduce something new like this, where maybe 3 sessions a year are needed, it's going to need additional staffing.
>
> T2: So there's a whole capacity issue as well in this.
>
> (Teacher group, area 4)

Teachers, pupils and school nurses in area 7 pointed to the role of health workers (who often worked in tandem with school nurses) as acceptable sources of advice and information for young people.

5.1.5 Information materials required in schools

Teachers were asked directly whether they had views on the sorts of material that could be provided to help them in the classroom on this issue. A teacher group in area 5 felt that it wasn't only the teachers who delivered SRE but the wider teacher group that would need information.

> I think your average teacher… it's not really going to affect them in their day-to-day teaching because they're used to people coming in, and nurses and that coming in and kids get out of class. That's the only effect it really has on the average teacher. I think it's important that they know what it [HPV] is so that if they do have to deal with any questions… Because you know what kids are like, they can ask anybody, anything at anytime. So if all the staff have got some sort of pamphlet or leaflet I suppose explaining that these [immunisations] are taking place in the school, I think that would be really enough. I think it's important that everybody knows 'cos as I say this was quite a shock to me. I was like 'what!'
>
> (Teacher, area 5)

The SHARE-trained teachers who were keen to take on the challenge were clear what they wanted.

> T1: Fact sheet, just a simple fact sheet - what we're trying to get across to the children, the points we're trying to get across.
>
> T2: And possible sort of questions and answers that you might be bombarded with, just so that we can give the right information without being alarmist … that it's the right level of information without alarming young people, and obviously we're giving that information to boys and girls and we're reassuring them.

T3: The AIDS material was really good in that respect. They have questions for the youngsters. It was really good and really straight forward and it was, if you like, a lesson complete that you could deliver.

(Teacher group, area 2)

They were also keen to see attractive material on DVD being produced that could be shown to young people, and cited the campaign to get young men to check for testicular cancer.

T1: The level that is pitched at and the humour that goes with it …! But the message is there and I think if you can deliver it rather than just factually but with a bit of humour or perhaps a celebrity or somebody endorsing that is very good.

T2: And young examples of people who have suffered from cervical cancer.

T1: Yes cool men are in that one, so I mean if you could get cool women…

(Teacher group, area 2)

The same group were clear that any information supplied through schools or health boards should also be backed up by a media campaign, highlighting that this should not just be in newspapers but also targeting young people's media.

5.1.6 Teachers' views on consent

One group of SHARE-trained teachers in the school in area 2 felt that young people over 14 (i.e. those in S3 and upwards who might be involved in the catch-up programme) should be able to sign consent forms for themselves if parents had not signed.

The way we view it in school, particularly with anyone over 14… you know. OK their parents haven't signed it, but they can sign it themselves.

(Teacher, area 2)

In other schools, there was a greater lack of clarity on whether both child and parent consent would be required, and whether children could in fact consent in their own right. Some teachers in the area 4 group were quite alarmed when one of their numbers pointed out that if the school insisted on parent consent up until the age of 16, this was counter to the treatment a child would find if he/she went independently to a GP. She believed children should be told of their rights, whereas her colleagues felt this to be a rather incendiary viewpoint.

T1: I think within the parental consent you would need to put in it that the child has the right to go and demand it off their doctor under their own. I can't see many circumstances where it would happen, but there might be some teenage girl that definitely would want it and her parents were totally against it.

T2: I don't know. I think that's putting us in a really difficult position.

T1: But if the letter is coming from the NHS and it's got that written in it. It's not coming from us.

T3: It would have to be from outside the school totally and we could be a distribution point.

(Teacher group, area 4)

Even when aware of the true legal position that allows a young person, under the age of 16 to give consent themselves if a suitably qualified medical professional deems they are capable of understanding what is being proposed, teachers were very uneasy about allowing this to take place on school premises as it could be construed as undermining parents.

5.2 The views of health professionals

All health professionals contacted as part of this research were aware of HPV, its routes of transmission and its causal link to certain types of cervical cancer. They were also all aware of the forthcoming immunisation programme and many had entered into discussion of the issues surrounding this immunisation with colleagues, parents and in some cases, young patients.

5.2.1 Parental acceptance

The feeling amongst health professionals was that the vaccine was going to be generally well received. However it was noted by one school nurse that the publicity about the vaccine and its promotion should be focussed on its role in preventing cervical cancer and not as a preventative against sexually transmitted infections.

> I think it's probably going to be well received in the general population, I do. Obviously we haven't got the publicity material but talking to colleagues and, you know, the general public about it… as long as it's connected to cervical cancer and not STIs I think it's going to be very well received. That's the impression I get from other mums.
>
> (School Nurse, area 1)

However, some school nurses and GPs could foresee potential tensions arising from certain groups within their respective communities. The age of vaccination and the implication that young people might soon be sexually active was raised as a possible barrier to parental compliance with the immunisation programme, especially in more rural areas.

> I think a lot of parents will find it insulting and offensive suggesting their children could be sexually active at this age.
>
> (GP 2, area 6)

> I think a lot of them will be horrified because your own child is not going to be sexually active at that age until you find out they are. But I think we will have to do it and it will be the GPs that will have to deal with the parental slack, not the school people because they only have doctors in just every so often. I think we'll get quite a bit of that fall out.
>
> (GP, area 3)

> It's a slightly difficult question to answer because one answers it partly as a mother and partly as a GP (laughs). I can see the reason for choosing that age to try and ensure good coverage in the population and starting it hopefully before sexual activity begins. I think that particularly in the area that we live it is going to be harder to promote it and justify it in that age group, mainly because there will be an awful lot of people with Presbyterian church backgrounds who don't accept that

> anybody is sexually active at that sort of age. I think that's very possibly why they haven't started publicising it at all because yes, I think there could be a huge uproar. Living in the North West tip of Scotland, Presbyterianism has a very strong influence over a lot of things here and it will not prove popular.
>
> (GP, area 4)

However, many health professionals thought that S2 was an appropriate age to immunise and felt that this was around the time that girls might be beginning to think about becoming sexually active.

> I think it's quite an appropriate age. I think the point of the vaccination is that it's got to be available prior to people beginning their sexual activity so I think sometimes its not young enough for some of the girls. But at the end of the day, it's going to be a mature and adult discussion you're going to have to have about the nature of the vaccine. In the first place you've got to be having that at a point in their lives where it's going to be of benefit as a preventative … there's little reason to leave it until 15½ because the age of consent is not 16 in the real world.
>
> (GP, area 7)

> Well I think it's reasonable. I think it's just before many of them are starting to think about having sex, so I'm not sure if it's too young. I don't think it's too young! Is it too old? Well no, but if you leave it much longer then you're into the realms of girls who are either not living with their parents and maybe are escaping the system and are maybe not being aware of the importance of it. So I suppose at the age of 13 you're catching them at a reasonably good age and you're more likely to get consent and more likely to get a hold of them, so I think it sounds appropriate, yeah.
>
> (GP 1, area 6)

5.2.2 Portrayal of the vaccine in the media

Health professionals were aware of the early media coverage surrounding the introduction of the immunisation programme and were disappointed by some of the negative remarks that had been hitting the headlines. They felt this was the media trying to whip up a storm in the community purely for sensationalism, and was irresponsible.

> I must admit I was disappointed at the way the media were handling it because they were obviously picking up from the anxiety in America - the bible belt. They were picking up on 'Oh it's gonna make girls more promiscuous' and I was really disheartened that they were taking their eye off the main object of why we are giving them HPV [immunisation]. Instead of focusing on the lives they were going to be saving through this, instead they were focusing on something which is really not an issue. I think they were stoking up something that was probably not an issue.
>
> (School Nurse, area 4)

> My first listening to the media events, I was dismayed that the questions were reflective of that kind of aspect of it [earlier promiscuity], and I didn't think the speaker was forceful enough to turn it around. You know when the media is pursuing this they should have said 'Yes that is an issue but we're really trying to save lives'. I think the spokesperson could have been a bit more media savvy to turn it around and diffuse it. They [the press] were trying to inflame the situation, as they do.
>
> (School Nurse, area 4)

5.2.3 Vaccine safety

Health professionals felt that this vaccine is an important breakthrough. It is new, and that could cause issues in uptake, not least because they acknowledged some uncertainties existed about issues like the length of protection conferred by the vaccine. They felt, however, that any anxieties brought up by parents should be answered straightforwardly and honestly, in order to protect the next generation from certain types of cervical cancer.

> Yes there is always anxiety around something new … but if you look at the population you know we've got to try to do something to protect the youth haven't we? If we delay it then people are going to develop cancer. You've got to raise up [the question]: is it a real anxiety or is it just a question that we need further research into? Are we really so anxious that you would delay it? I think the balance in my head is tipping towards thinking we should get the girls vaccinated so we give some a chance to survive.
>
> (School Nurse, area 4)

There were concerns that parents would be worried about vaccine side effects in light of the MMR scares of recent years, especially as this is a new vaccine to this country and there is no information about the long term effectiveness of the vaccine. GPs were anxious about their own ability to defend the immunisation in the teeth of such worries, given that the evidence base did have some acknowledged gaps.

> Yes I mean we've lived through a number of vaccine concerns. A number of these parents will have lived through the MMR/Crohns/Autism scare. There have been a number of whooping cough scares over the years. Yes, I think they [parents] will be very concerned … and we don't have a huge evidence base on this occasion.
>
> (GP, area 3)

> Are there any unknown long-term side effects at this time? You can't answer that really. You've got to try and trust the data and trust that it has been thoroughly enough tested. But sometimes it's difficult if one has got to act as an advocate for it from a health professional point of view and to say, hand on heart, that you absolutely think it's the right thing to do.
>
> (GP, area 4)

> Again there will always be anxieties in any medicine with regards to side effects… I haven't had an opportunity to look at the evidence and review the evidence. In terms of the information to go out to the general practitioners, a pocket guide to the evidence to support it [the immunisation practice] is actually not a bad thing and that's around efficacy for immunising ahead and also efficacy in terms of the impact upon an individual and the potential side effects for an individual. That would be quite helpful.
>
> (GP, area 7)

However one GP who was already administering the vaccine in his/her practice already felt that the evidence supporting the vaccine was strong and he/she had no concerns.

> No, I think it's been well tested and it's been around and been in use. Because of the nature of our practice we have a lot of students who come across from the States who have obviously started on their [immunisation] courses and are looking for completion of their course. But there don't seem to be any problems with the safety side of it as far as I've heard.
>
> (GP, area 2)

5.2.4 The information needs of health professionals

Health professionals felt that some information was beginning to drip feed through to them and many had attended training days put on by their local health boards. It was felt by some GPs and school nurses that they had not been informed about this forthcoming vaccine early enough and that they should have been given information before it was released to the general public.

> I think Health Protection Scotland or whatever needs to be a bit…What's the word? We're often last to hear you know and I think the practitioners really need to be in the loop a lot earlier than the public.
>
> (School Nurse, area 1)

> Yes there has been [information] in the news and on the radio. I had been listening to it obviously and filtering through the politics of it all, but I was a bit dismayed that the first I heard of it was through the news media and not through work. The school nurses weren't contacted first.
>
> (School Nurse, area 4)

When asked what kind of information they were likely to need to implement this programme effectively, all health professionals felt that they needed statistical information about the vaccine and its efficacy and effectiveness. Many felt that a set of 'frequently asked questions' would be needed to ensure everyone was 'singing from the same hymn sheet'.

> I: What kind of information do you feel you would need from NHS Health Scotland to be able to actually go out and deliver this vaccine? You've already mentioned that you would need information about the research and possibly the trials and statistics and things like that?
>
> SN: And also the efficacy of that and how soon it works. I think some questions have been asked about how effective it is, say, if a young person has already had one sexual encounter…
>
> I: So you would need information to be able to, sort of, fend off these kinds of questions?
>
> SN: Yeah, absolutely, and also a very clear understanding (and written down so that we have the same message) as to why boys are not being given it [the immunisation] and why girls over the age of 18 are not being routinely offered it. Things like that.
>
> (School Nurse, area 1)

> Yes I do think there will be a cohort of parents that will want statistics. They'll want to know what is the rationale, is it well researched, is it really going to save lives? They would want that type of detail, or at least want to know where to access it.
>
> (School Nurse, area 4)

A similar set of 'easy answers' was requested by an area 7 GP who wanted information he could download from a website so he could 'print something on a single laminated side of A4 that could come in and out of the drawer very quickly'.

Information about the inter-effects of different vaccines would also be useful alongside FAQs.

> GP: Frequently asked questions can be very helpful. Again I think some leaflets (which I presume they're going to produce) which will talk about the side effects and why they [young people] need to have 3 injections. Also I think a statement that 'while this will protect against a lot of cervical cancers, it's not fool proof'. [Also answers to] 'if my child isn't sexually active do I need to have my child vaccinated now, or will there be an opportunity later?' There's also 'my child already had immunisations for x, y, z and what's this going to do to their immune system?' Because at 13 this is actually not far away from the tetanus, polio and diphtheria booster and also around that stage the TB as well
>
> I: So like, the possibilities of vaccine overload?
>
> GP: Well that's the kind of thing parents get very concerned about, yeah.
>
> (GP, area 3)

Most health professionals contacted had received the Health Protection Scotland Immunisation Newsletter late in 2007. This information was deemed valuable and gave answers to many questions they felt might be asked by parents and young people.

> There is a lot of information in this document. I mean I think this document has got a lot of information that GPs would find very helpful in terms of the background, just reminding us about the risks and exactly which strains are involved and which are covered by which vaccination. It's that kind of information that, again, I think would be useful just to remind everybody about.
>
> (GP 1, area 6)

5.2.5 Obtaining consent

It is deemed good practice to have both parental and young person consent to vaccinate and school nurses were happy to use their initiative when it came to obtaining consent, subject to their professional guidelines.

> If a child has produced a consent form and they've said that they've spoken to mum and mum wants them to have it but has forgotten to sign it, I don't think that's a reason not to give it [as long as] you get the child to sign it and explain the background to it, what they're having, that sort of thing. Or you could get telephone consent from the parent. But I think in practical terms you have to take each case individually but bearing in mind the age of legal capacity.
>
> (School Nurse, area 4)

In some situations, however, where it was clear that a parent had refused consent it was felt tricky to proceed and immunise a young person without parental consent. If after entering into a dialogue with the parents they still refused consent then one nurse felt she could not move past that.

> That's probably the most difficult. I wouldn't immunise on that session. I would discuss it with the parents, what their reasons were for saying 'no' and if they had legitimate reasons. If they'd really thought about it thoroughly and weighed up the balance and said 'no' then I'd have to accept that.
>
> (School Nurse, area 4)

However, GPs were much more comfortable administering a vaccine as long as they deemed the young person to be capable of understanding what is being proposed.

> Absolutely, she should be able to consent so - age 13 - if she understands what the implications are of what she's being offered and she wishes to have the vaccination then I have no difficulty in her receiving that vaccination even if her parent/guardian has said that they don't give consent for it.
>
> (GP, area 2)

> If that child had sought me out to say 'I would like it' and by spending time to them and talking to them I believe that they understand why it's being offered to them, what benefits it is offering them and they have appropriate understanding of what they're asking for, then I would be willing to consider giving it to them, yes.
>
> (GP, area 4)

5.2.6 Being prepared

It was felt that whilst health professionals were prepared to take on another immunisation programme, careful planning must be made as they are already busy and they may need extra resources to be effective.

> We were quite quick to realise it would need to be made very clear that we couldn't just drop everything and do it, so we've been involved in [developing] a business plan to try to get some extra resources to take it on board, with the recognition that school is the best place to give the bulk of it, and also that school nurses are best placed to manage their individual area.
>
> (School Nurse, area 1)

> The extra workload and the planning have to be kept absolutely spot on, so fridges have to be bought and vaccine transporters and things like that. It's a pre-packed [vaccine] and some areas are not set up for holding these big syringes that are already pre-filled which makes it a bulkier immunisation to give. With BCGs for example, we did a whole year group but we made the immunisation up at the session from little boxes. We do Polio immunisations that are in pre-filled syringes but we don't have so many of those to give as it's only a mop up that we do in school; most of those are given through the GP. Logistically, from that point of view, this is a big campaign and we will need more resources.
>
> (School Nurse, area 4)

Others had concerns that the programme was going to be difficult to implement and felt anxious that they had not heard from their health board, how it was going to be organised. The exercise of giving out information, achieving consent and so on, given a limited school nurse resource, was giving cause for anxiety.

> Yeah and we've got one school nurse who covers all the primary schools and the high school with 700 children in it so it's a big thing obtaining consent for it and getting adequate information in an area where there is going to be a lot of questions raised by parents because of their religious background. It's something they [the health board] have got to have thought through.
>
> (GP, area 4)

Whilst some GPs are willing to mop up the residue of young people who do not manage to complete their course of vaccinations at school they felt they would need additional resources to make such a system effective and that the extra pressure on practice nursing staff could be great.

> We're not particularly geared up to do a proper recall system … so we'd have to rely on being notified of who hadn't completed their course or something like that. I mean it could be organised I daresay, but there would need to be some funding behind it because it's extra work and the practice nurse would probably be the one who would end up doing it.
>
> (GP 2, area 6)

> We would struggle to take it on. [Practice] nurses are all involved in chronic disease management as well as other vaccination programmes and they're pretty stretched and to have yet another vaccine in the fridge, I think is going to be quite stressful for them.
>
> (GP, area 3)

5.2.7 Immunisation for older adolescents

There was much discussion from GPs about immunisation for older girls and women over and above the catch-up programme suggested. There were issues over whether the immunisation should also be given (and given free) to anyone in an older group who had never been sexually active, and even more difficult judgements to be made when a request was made from someone who had been sexually active but who still felt that they would benefit from the immunisation.

> Well I think it's been used in America and Australia, but I know that patients are starting to ask for it for their children and also adults, girls in their early 20s really, and I think I'd quite like to know where they fit into the vaccination process and what we would be saying to them and how we would do that.
>
> (GP 1, area 6)

> I anticipate there will be some women in that [older] age group who will ask for the immunisation and what are we going to do about that? It will be frowned on if we give it privately. You know obviously we'd want to take a sexual health history and we'd have to make some kind of judgement as to whether it was worth giving or not. It's quite judgemental isn't it? You're going to ask the girl how many partners she's had and in your mind you'll say, 'Well if it's more than 3 or 6 or 10 or however many it is you're going to say 'no, don't have it'. What's the stand point on that, and what about young women who are eligible and don't want to pay the £240 private fee or whatever because, given the cost of the vaccine, not many people are going to pay for it privately, they're going to get it through the health service or not at all.
>
> (GP 2, area 6)

> Our problem will not be the folk up to the age of 18 who will be involved in the catch up. Our problem is everybody else that wants it who is not sexually active over the age of 18. We already have a significant number of patients wanting this vaccination.
>
> (GP, area 2)

6. Discussion

6.1 Introduction

In this chapter we summarise what has emerged from the fieldwork undertaken across Scotland amongst the groups with whom we were concerned, namely young people, their parents, teachers, and the health professionals most likely to engage with the HPV immunisation programme and look at how what we found relates to previous work. Having briefly summarised the views of parents and children in general towards the HPV immunisation, we follow this with a discussion of the school setting in which immunisation will take place for the majority, which incorporates parent beliefs about the school's role; children's more grounded understanding of how things will be delivered in practice; and teachers' concerns about their professional roles in respect of the programme.

The following section describes the views of GPs and school nurses, exploring their confidence in their own knowledge levels and then their expressed needs for information and support.

We conclude with some final recommendations for a communications strategy around the promotion of HPV immunisation.

6.2 Knowledge and information needs amongst parents

Parents interviewed as part of this study exhibited for the most part relatively low levels of knowledge about HPV. At the time when the fieldwork was undertaken, discussion in the media was limited and very little information had filtered through from other sources. Even with the benefit of information supplied by the research as part of the information pack and with the opportunity to research it further as some parents had taken the trouble to do, the relationship between the virus, virus-related illnesses and cervical cancer was only poorly understood by adults. These concur with findings from other recent UK studies (e.g. Waller *et al* 2004; McCaffery *et al* 2003). Whilst acknowledging their own inability to understand the aetiology of the disease, most parents welcomed the immunisation as a cancer preventive, though a small number commented on what they felt was a rather perfidious attempt to engage them and sell the immunisation in this way when it was clearly an issue about sexual health.

Parents were keen to learn more and to know how they could safeguard themselves and their children, but it became clear that not all parents have the same information needs. Noakes *et al's* (2006) characterisation of parents as either 'trusting', 'compliant' or 'resistant' is potentially useful here, with the latter two groups demanding a much higher level of information and 'proof', with less taken on trust from medical authority. There were differences between groups in this study with parents in more advantaged areas demonstrating a stronger desire for gathering information for themselves and querying professional positions. Such observations, not measurable in a qualitative study, are, however, consistent with what we know from the literature on other immunisation topics like MMR. This does not necessarily presuppose that a higher or lower level of uptake amongst different social groups is inevitable. Brabin *et al* (2006) note that studies of the implementation of Hepatitis B vaccination (also a disease with a sexual transmission route and a programme of immunisation involving the same age group and multiple doses of vaccine) have had encouraging take up across all classes, citing Hinds and Cameron's (2004) study in Glasgow (which achieved about a 90% uptake) and a US study (Wallace *et al* 2004), where the provision of education and free vaccination in a convenient location, followed by careful follow up, diminished many of the socio-economic obstacles to uptake.

All parents wanted clear and honest information about the safety of the drug. This included information about drug trials, possible side effects and the need for booster immunisation. The information that their children might be the first cohort to be immunised in Scotland led some to believe their children were being used for testing. Tentative language in some documents provided as part of the study (use of the word 'may' for instance) was seen as indicating a level of insecurity in the knowledge of those administering the intervention. Some parents would clearly be satisfied with clear unambiguous statements about the immunisation from trusted authorities or sources; others would prefer to be given more background information and allowed to feel that they were participant in deciding what was best for their child.

It may be particularly important to address issues of disinformation or misinformation amongst the parent group. Some misconceptions are already sown in the minds of adults through their experience of other vaccine programmes. These concerns, for instance, whether the vaccine is 'live' and gives a small dose of either HPV or cancer itself. Other parents mentioned that the fact that the immunisation is given as a three-dose schedule implies that it is such a powerful drug that it can't be given all at once, for fear that it will overwhelm the child's immune system. This resurrects some of the lay understandings about 'immunity' that Hilton discovered amongst Scottish parents in relation to MMR procedures (Hilton *et al* 2006).

Few parents reflected on the need for 'herd immunity'. It is clear from other studies that most parents make decisions based on the needs of their own child rather than the cohort or population as a whole.

The link that some other studies have made with parental fears that HPV immunisation will encourage promiscuity or early onset of sexual activity (e.g. Waller *et al* 2006; Kimmel 2006) was only occasionally voiced in this Scottish sample, a finding more akin to Marlow *et al's* 2007 study where only 12% of parents seemed concerned on this front This is not the same as saying that most parents thought that children as young as 11 or 12 were necessarily ready or needing to be given a preventive against sexually transmitted disease. A number (particularly in more rural northern areas) accepted the rationale that the immunisation should be given prior to onset of sexual activity but challenged whether S2 was not far too young, and would have preferred to have their child given the immunisation when they judged their child was personally ready. It should be noted that parental views on this notion of 'readiness' were decidedly at odds with those of teachers and young people themselves.

Parents had another reason for thinking children were too young at S1/2, which related more to the fact that the act of discussing the immunisation and giving consent was likely to engage them in discussions of a sexual nature with their children which they did not always welcome. A number noted that if the immunisation had been offered to primary age children, they would have simply required the child to comply and not necessarily given an explanation of what it was for. Parents may well need therefore, not just information which helps them understand what HPV is and what the immunisation does, but also some materials which will allow them to interact and discuss the issues with their children in an unembarrassed way. Brabin *et al* (2006), citing Raffaeli *et al* (1998), suggest that 'HPV vaccination could become the starting point for parents who find it problematic to discuss sexual issues with their children' (p3093).

Perhaps as a consequence of this perceived need, both young people and parents expressed a desire for information to be supplied in a variety of formats, formal and informal, with use of TV programmes and young people's media (e.g. magazines) being clear favourites, and with young people expressing a stronger desire for internet sites or interactive fora in which questions could be raised and answered.

Most parents, once they had started to explore transmission routes for HPV and understood a little of the way in which the immunisation worked, advocated that boys should be immunised too on grounds of fairness. Parents who were also teachers noted that not to do so seemed to undermine SRE teaching about shared responsibility for sexual matters. However, there did not seem to be a strong groundswell on this issue.

All parents believed that they were acting in the best interests of their child and that they had the right to determine whether the child received the immunisation or not. Some claimed to have this right (and responsibility) because their children were under-16, in spite of the fact that children are legally considered able to make medical decisions for themselves from a much younger age if a medical practitioner can satisfy him/herself that the child is competent to make such a decision and understands the consequences. Thus under 16s have a right to confidential medical treatment without parental consent. Other parents were clear that children should be involved in decision making. Such divergence of opinion is consistent with findings explored by Brabin *et al* (2007) in a study of parents of 11-12 year-olds in Manchester. Whatever the legal position, Brabin *et al* argue that an emphasis on adolescent autonomy in this regard is likely to lead to more parental resistance to the HPV vaccine, and that the matter requires careful discussion and handling.

6.3 Knowledge and information needs amongst children and young people

Children and young people interviewed as part of this study showed a very low level of knowledge and understanding about HPV and its connections with cervical cancer. This accords with the only other study on adolescent knowledge of HPV which was located (Dell *et al* 2000) where only 13% of adolescents interviewed in a Canadian study had even heard about HPV. The lack of knowledge in this Scottish study was despite the fact that parents and children were issued in advance with some basic information about HPV and the proposed vaccine. Some had obviously discussed the matter with parents prior to interview as a consequence of receiving this information, but few seemed much the wiser. Some children were clearly confused between HPV and HIV.

Discussions with children also revealed some interesting misconceptions which might not have been evident to adults or health professionals, such as worries about where the immunisation would be delivered, with some thinking it would need to be given directly into the cervix, a notion fostered perhaps by what they or their parents know about cervical smear testing procedures.

Young people had fewer concerns about drug safety, but had greater interest and need for information on pragmatic issues, about catching the virus and its manifestations, i.e. in those issues which will affect them most immediately.

Unlike parents, the young people across all religious and ethnic group that we interviewed were not distracted by arguments that administration of the vaccine would impact upon sexual behaviour. They took a pragmatic view that the vaccine was a ‘sensible precaution’.

The three dose immunisation schedule did not appear to pose problems for children beyond the expressed fear of needles by many.

Young people held strong views that they should themselves be involved in the choice about what happened to their body, but this was always tempered with a degree of pessimism / realism that this probably wouldn’t be allowed in the school setting.

6.4 The school's role in delivering the HPV immunisation programme

Parents generally saw schools as an appropriate place to deliver the programme, both for pragmatic reasons and also because they probably over estimate the amount of preparation which schools will give to children on this issue. It was clear that many believed (usually erroneously) that the school nursing service and the sexual health and relationships education curriculum would be integrated so that children received significant preparation in advance of immunisation. However, as several teachers noted, the current timing of SRE delivery, particularly around STIs, is unlikely to be very helpful to the immunisation programme, since commonly schools don't teach about sexually transmitted infections until S3.

Schools seemed reasonably happy to 'host' the immunisation programme and provide a modicum of curricular support, but individual teachers expressed concern about being asked to support the programme through methods which went beyond a straightforward and 'safe' didactic method, which did not expose them to questioning or become personal. They were not keen to be engaged in answering pupils' or parents' questions, given that they felt their knowledge levels were not secure enough. The impact of level of teachers' training in SRE was evident in their responses. The two most positive groups of teachers were the SHARE trained teachers in area 2 and those in area 7 who we know have access to a high level of local authority support around SRE. They are areas with high level of teenage pregnancy, which also has implications for teacher attitudes to their role.

Five of the seven schools involved were absolutely clear that they could not be seen to be advocating for the immunisation programme. Schools were also keen to maintain some distance between themselves as educationalists and the health service that was delivering the vaccine. In part this was to avoid being caught up in any controversy which the vaccine might generate. Denominational schools understandably face particular issues around this issue of support or advocacy of the immunisation programme. Staff were agreed that within the Catholic lifestyle of monogamy and marriage there was no need for the vaccine, but their responses to the realities of modern life varied. At one end of the spectrum staff voiced hostility towards the vaccination programme. At the other end, staff acknowledged 'human frailty' and felt it was their duty to support the vulnerable by allowing the programme to go ahead. Fears of receiving parental complaint were high – from Muslim parents as well as Catholic. Studies undertaken in anticipation of the introduction of HPV immunisation and relating to HPV testing within cervical smear procedures (McAffery *et al* 2003) suggest there may be ethnic, cultural and religious sensitivities raised by the issues around the aetiology of disease spread and so on. Despite this, studies like Hinds and Cameron (2004) on the introduction of Hep B vaccination have shown relatively even take up across religious groups. Teachers in denominational schools caught up in this dilemma felt they were most likely to turn to church leaders for advice and it is thus clearly very important for Scottish health agencies to work closely with the leaders of different faith groups as policy and guidance is developed.

Young people themselves had mixed feelings about immunisation being delivered though a school-based service. It clearly had implications for them in terms of whether what they got was a GP-type personalised service which took account of their information needs and feelings and gave some semblance of autonomy and privacy or whether they were directed in groups or cohorts towards a much more mass-produced system where they were dealt with rapidly and in a fairly summary fashion. Reservations were expressed about hygiene in school and the difficulty of maintaining confidentiality in this setting and pupils noted the potential for hysteria and 'wind ups' related to a widespread fear of needles.

Parent's misconceptions about children's rights to make choices about medical treatment have a strong bearing on schools, who tend to see parents as the consumers rather than children. This makes schools wary of parental dissatisfaction, and this consideration seems to override the children's actual legal rights. Whilst there are good practical reasons for delivering the vaccines in schools, this raises a lot of issues around consent that would not exist in a different location. School nurses may be operating with different ethics and procedures from school staff.

6.5 The information needs of health professionals

GPs and school nurses who were interviewed felt knowledgeable about HPV, the vaccine and the diseases against which it protects. Both groups of professionals indicated a need for a handy guide containing statistical information and answers to FAQs which would inevitably arise amongst concerned parents. Issues that they anticipated being questioned about included the extent of testing of the vaccine, the length of protection it confers, the possibility of side effects, the interaction with other vaccines being given at this age (they foresaw potential for the hoary old 'vaccine overload' questions), and why it had to be given in three injections.

Health professionals also foresaw having to answer a range of questions related to HPV implementation policy, e.g. why aren't boys being offered the vaccine, why can't older girls and young women who aren't sexually active access the vaccine, at what point in a young woman's sexual career does the balance of probability swing against the utility of being immunised? They felt these were not medical questions, but ones which related to cost effectiveness and political decisions about implementation, and they felt it would be helpful if there were scripted answers so that everyone 'sang from the same hymn sheet'.

Nurses going into schools where young people's autonomy and consent was often differently construed needed particularly clear and unequivocal guidance about issues of consent. GPs were happy with the existing guidance and felt confident about their ability to interpret it. Nurses needed reinforcement about what to do in a range of circumstances where parent and child differed in their views.

All health professionals felt they would also be supported by continuing attempts to manage the media, with health agencies stressing the cancer prevention aspects of the immunisation rather than its role as something which would improve the sexual health of the young. Those in rural areas felt they would need particular support to convince parents that their 12/13 year-olds were on the cusp of becoming sexually active. Doctors and nurses in the more rural and remote areas felt that conservative views might undermine the universal application of immunisation in a cohort, with parents thinking they could safely leave the immunisation until later when it was easier to discuss such issues with their children

School nurses noted the heavy demands on their staff resource in terms of visiting schools and acquiring consent as well as the administration of the vaccine on three separate occasions. They were also required to manage a complex vaccine storage system, since the injection system through which the vaccine was delivered was bulky to store. GPs noted that they would also need extra resource to manage recall or mop up systems. The bulk of the work would fall on practice nurses who had new roles in managing chronic illness in the practice, so extra capacity would need to be found. The scale of the requirement was also hard to predict in advance.

6.6 Recommendations

On the whole the research shows a general mood of support for the introduction of HPV immunisation. It is widely seen as an appropriate way in which to prevent young women from being at risk of developing

cervical cancer. The focus of this work was on providing evidence which would help drive a communications strategy on HPV immunisation. The first set of recommendations concentrates on those issues which need to be addressed in the short term for the initial delivery of material in support of the immunisation programme.

Short term recommendations

- NHS Health Scotland, Health Protection Scotland and the Scottish Government will be concerned to produce attractive information leaflets which inform and reassure parents about the immunisation programme. In all likelihood these will comprise of written or printed materials. We recommend that the above agencies should also aim to meet the information needs of parents and children through the addition of further supportive material being offered in a supplementary fashion through websites, online Q and A fora or through young people's media.
- Any public information campaign must be clear about how the vaccine is administered, must explain the need for a triple dose, must reassure about the extent of prior testing and must dispel myths about vaccine overload.
- Any public information campaign must also emphasise that waiting for 'readiness' in children is a dangerous strategy and may effectively negate the benefit of the vaccine if children are already experimenting with sexual behaviours.
- It would be advisable to have talks at the highest level with leaders of faith groups to ensure that materials produced in support of the vaccine campaign have regard to ethnic, cultural and religious sensitivities whilst maintaining the importance of protecting young people's long term health.
- A handy information pack for health professionals should be part of the preparation, with answers to questions about the safety and efficacy of the vaccine, as well as 'scripted' responses to queries about the policy decisions which lie behind the implementation programme.

Whilst there are some difficulties foreshadowed in the comments of those interviewed as part of this study there are clearly also opportunities for better engagement of parents with young people on matters to do with sexual behaviour and health, opportunities to forge stronger links between school nursing services and the curriculum content of SRE and so on. There thus follows a small number of recommendations which deal with activities which would support the communications strategy around the HPV immunisation programme in the longer term.

Longer term recommendations

- The need for parents and young people to discuss HPV immunisation at the start of S2 offers an opportunity for NHS Health Scotland to think about developing materials which might help parents raise the issues around sexual behaviour and sexually transmitted infections with their children in a positive way
- If schools are to be expected to play a continuing role in supporting the roll-out of the immunisation, discussions should take place with the Scottish Government Department for Education and Training, to explore the production of appropriate curriculum materials and better ways of integrating the immunisation programme with curriculum materials and teaching in secondary SRE, specifically in respect of the timing of teaching about STIs.

- Wherever possible HPV awareness should be included in SRE training for staff delivering SRE to facilitate less emphasis on didactic teaching.

This project was a qualitative one, which cannot therefore claim to be representative of the views of all in Scotland with an interest in this subject, though an attempt was made to select a sample in a way which was impartial and which reflected the range of views that might exist. Qualitative studies are, among other things, used to develop initial insight on topics which are relatively poorly understood or are under researched. The strength of such studies is in their flexibility and potential for reflecting the views of those most intimately concerned with the topic without forcing their answers into pre-ordained categories of response. This study offered a range of useful insights to guide communications policy as the HPV immunisation programme was developed and also gives clues to where further research is clearly required.

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8. Appendices

Appendix A: Young people's knowledge quiz

Getting the facts straight on HPV

When we asked you to take part we gave you a leaflet that told you a little bit about HPV. This quiz is designed to show how good our leaflet is at telling young people about the HPV virus.

We would like you to work on your own. Put your answers in the boxes next to the questions. If you don't know the answer, just write 'don't know'.

You do not have to put your name on the sheet - your answers are anonymous. When you have finished, please post the sheet of paper in the box.

Please just write down your age and whether you are male or female below

Age?…….. Male /Female?…….

The first questions are about the virus

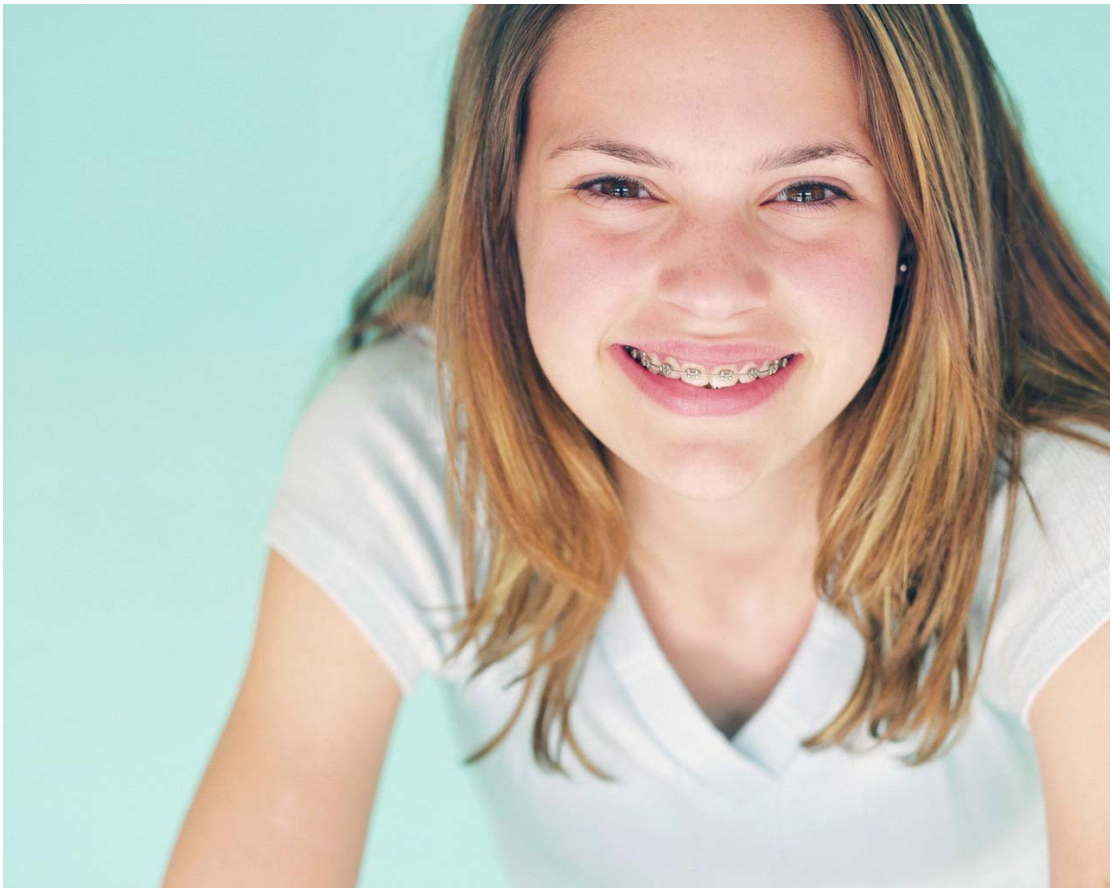
1	Had you heard of HPV before we contacted you?		
	Yes	No	Don't know
2	How is HPV passed from one person to another?		
3	What diseases can people develop from HPV?		
4	Does everyone who gets HPV become ill?		
5	Do men/boys get HPV as well as women/girls?		
	Yes	No	Don't know
6	What can people do to keep themselves safe from HPV?		

There is a new vaccine which can protect people from HPV. This section is about the vaccine

	Who is likely to be given the vaccine?		
Boys	Girls	Both	
	At roughly what age is it best to give the vaccine?		
	Why do you think it is best to give the vaccine at this age?		
	How many injections (jags) are needed for the vaccine to be effective?		
	What side effects might there be for some people?		
	Are there people who should not be given the vaccine?		

Thank you for completing this quiz.

Appendix B: Vignettes

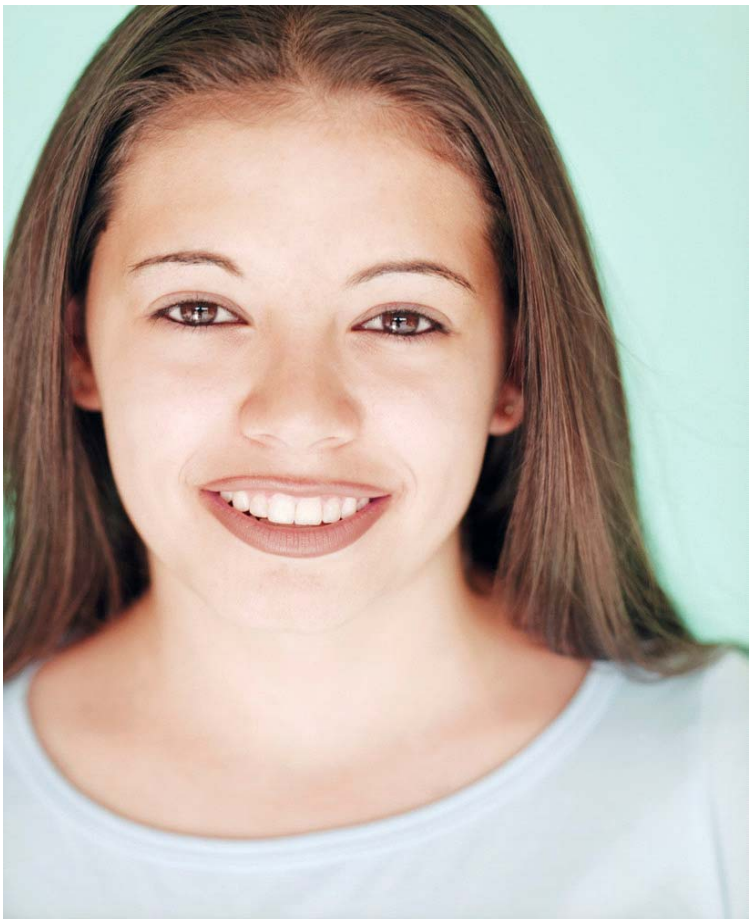


Anna is 13 and lives with her mum and dad and two brothers in a seaside village. They have lived in the area for five years. Anna spends a lot of her spare time downloading music on her computer.

Anna has a serious allergy and is not sure if she should be vaccinated.

Brian is 13 and lives with his mum during the week and with his father and step mother at weekends. He is very keen on music and plays in the school orchestra.

Brian would like to be given the chance to have the HPV vaccination.

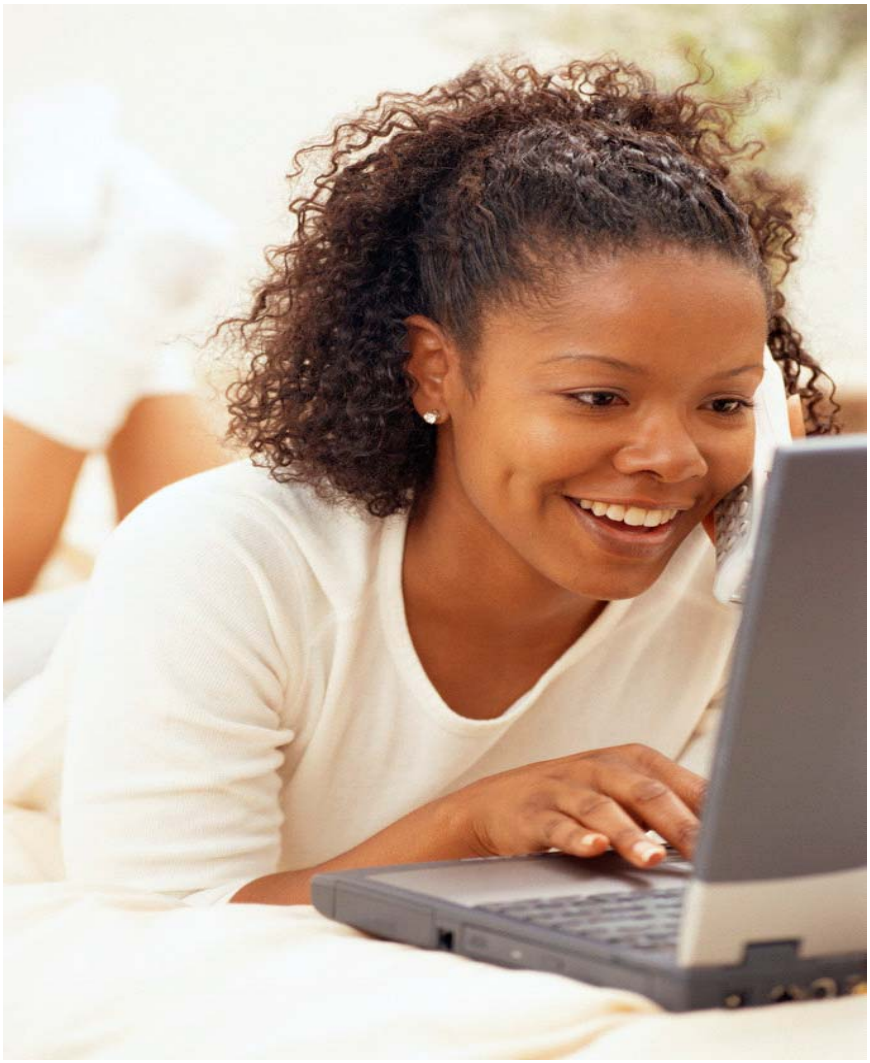


Julie lives with her grand parents and sees her mum in the holidays. She is very involved with a youth group at her local church.

Julie doesn't want to be vaccinated against HPV

Sally lives with her parents and her two older sisters and younger brother. She has lived in America and in Scotland as her father works in the oil industry. She hopes that they will stay in this area until she finishes secondary school as she has made some very good friends.

Sally wants to have the HPV vaccine, but her parents are unwilling to give permission



Samia lives with her parents and is an only child. They have recently moved into the area and she is still getting to know people. Samia is very health conscious and spends a lot of time at the swimming pool as a member of the school team.

Samia has heard about the HPV vaccine and thinks it is a good idea. She is keen to make sure she gets all her jags.

Appendix C: Young people's focus group interview schedule

These discussions will take place in single sex groups of approximately six S1/S2 pupils Discussions will last about 45 minutes. Prior to the interview both pupils and parents will have been issued with information sheets. Permission will be sought from participants to tape the session, consent forms explained and completed.

Ground rules will be set at the start to avoid personal disclosure and to confirm the confidentiality of the discussions. Interviewers will identify their role as non-expert – unable to answer detailed medical questions, but will be able to refer young people on to sources of information and advice tailored for their age group. Warning that disclosure of anything that researcher feels may bring young person into immediate harm will have to be reported to guidance teacher.

Exploring existing awareness/knowledge of HPV, HPV related disease and HPV vaccine

This first section of the discussion will be conducted as a 'quiz' session, with young people filling in a quiz sheet anonymously and posting it into a box.

Exploring attitudes to issues pertaining to the proposed vaccination

This section will be explored through the use of a series of vignettes. Young people will be asked to read aloud the vignette they have been given, to allow all to discuss the issues raised on each one. Interviewers will prompt and probe to expand answers or explore whether views expressed are common in group or not and whether the young people think this is a view shared more widely in their class/friendship group.

End with thanks, details of how findings will be disseminated and sources of further information.

Appendix D: Teachers' (and headteacher) focus group interview schedule

These interviews will take place individually with head teachers/guidance/health education staff. Prior to the interview staff will have been issued with information sheets. Consent forms will be explained and completed at the start of the interview, assurances of confidentiality given, permission to tape the interview requested. Interviews will last approximately 30 minutes.

Interviewers will identify their role as non-experts – unable to answer detailed medical questions, but will be able to refer teachers on to specialist sources of information and advice.

Exploring existing awareness/knowledge of HPV, HPV related disease and HPV vaccine

Introduce this section as being about finding out how well the information has already been disseminated (Reassure that this is not a test of individual teacher's knowledge)

- What do you know about the HPV virus?
- Where did you hear about it?
- What do you know about the HPV vaccine?

Exploring teachers' attitudes to issues pertaining to the proposed vaccination

- It is proposed that the vaccination would be given to twelve/thirteen year-old girls in S2. Do you think this is an appropriate age? *Explore reasons by asking why / why not/ and exploring any reasons for concern and whether a different age would be preferred.*
- It is proposed that only girls will be vaccinated. How do you feel about this approach?
- The vaccination programme requires 3 vaccinations (jags) over a six-month period. How do you feel about this?

The role of schools and teachers in the vaccination programme

- Do you think that school is the most appropriate place to deliver the vaccination programme? *Explore reasons for answers given*
- Do you foresee any difficulties in implementing the HPV vaccination programme in schools?
- How would you see your role, if any, in the following:
    - Providing information to children
    - Providing information to parents
    - Supporting individuals who may have particular concerns (children and/or adults)
    - Any other roles?
- How would your role mesh with that of health professionals e.g. school nurse, GP?
- What support, (training??) and information would you need in order to undertake the role you describe?
- Are there other ways in which the school would require support in preparing to host the vaccination programme?

Consent

- In your opinion what should be the consent process before young people are given the vaccine?
- Is parental consent essential? Is young people's consent essential? Whose opinion carries most weight if there is disagreement within the family?
- Would you envisage yourself having a role if there was unresolved disagreement?

Summing up – the pros and cons

This section offers an opportunity to voice any opinions which have not been raised earlier.

- What do you see as the main benefits of the HPV vaccination? *(listen for cancer prevention / STD protection but do* ***not*** *prompt)*
- Do you have any concerns about the implications of the proposed HPV vaccination programme?
- Are there any particular issues in this school catchment that might make the experience here different from that in other schools? *(listen for ethnicity, religion, disadvantage, local cultures etc)*

End with thanks, details of how findings will be disseminated and sources of further information.

Appendix E: Parents' focus group interview schedule

These interviews will take place in groups of approximately six parents, of S1/S2 girls. Prior to the interview parents will have been issued with information sheets. Permission will be sought from participants to tape the session, consent forms explained and completed.

Ground rules will be set at the start to avoid personal disclosure and to confirm the confidentiality of the discussions. Interviewers will identify their role as non-expert – unable to answer detailed medical questions, but will be able to refer parents on to specialist sources of information and advice

Exploring existing awareness/knowledge of HPV, HPV related disease and HPV vaccine

This first section of the discussion will be conducted as a 'brainstorming' session, with parents' comments being written on a flip chart. Questions are open-ended. Each question will be explored in some detail:

- What do you know about the HPV virus?
- Where did you hear about it?
- What do you know about the HPV vaccine?

Exploring parents' attitudes to issues pertaining to the proposed vaccination

- It is proposed that the vaccination would be given to twelve/thirteen year-old girls in S1/S2. Do you think this is an appropriate age? *Explore reasons by asking why / why not/ and exploring any reasons for concern and whether a different age would be preferred.*
- It is proposed that only girls will be vaccinated. What is your opinion on this?
- The vaccination programme requires 3 vaccinations (jags) over a six-month period. How do you feel about this?
- Nowadays children have the opportunity to be vaccinated against a wide range of diseases, and many young people have had a number of vaccinations during their childhood and early teens. How do you feel about vaccinations generally? Do you feel any differently about the HPV vaccine? *(Listen for previous history of immunisation refusal and reasons)*

Parents, schools, and young people – communications about the vaccine

- Do you think that school is the most appropriate place to deliver the vaccination programme? *Explore reasons for answers given*
- How do you think the school / school health professionals should communicate with parents about the proposed vaccination? *Explore what information parents should be given and in what format?*
- How should young people be informed of the vaccine and the diseases it protects them against? *Explore what information they feel young people should be given and in what format. Picking up in particular whether this should be tackled as part of sex education or more general health education.*
- What opportunities should be available to young people and parents to discuss any concerns? Which professional groups should be responsible for this?

- How should consent to participate be obtained? Is parental consent essential? Is young people's consent essential? Whose opinion carries most weight if there is disagreement within the family?

Summing up – the pros and cons

This section offers an opportunity to voice any opinions which have not been raised earlier. These issues may have entered the conversation earlier - but this allows us to clarify and explore further any areas of controversy.

- What do you see as the main benefits of the HPV vaccination *(listen for cancer prevention / STD protection but do* **not** *prompt)*
- Do you have any concerns about the proposed HPV vaccination programme?

End with thanks, details of how findings will be disseminated and sources of further information.

Appendix F: Health professionals' interview topic guides

School Nurses	General Practitioners
• Awareness of HPV • Awareness of HPV related disease • Awareness of vaccine for HPV	• Awareness of HPV • Awareness of HPV related disease • Awareness of vaccine for HPV
• What age would be 'acceptable' to give vaccine • Should the vaccine be given to girls/boys/both	• What age would be 'acceptable' to give vaccine • Should the vaccine be given to girls/boys/both
• Anxieties/ concerns about the vaccine • Safety issues surrounding vaccine • What information would be needed to recommend/ implement vaccination • What communication aids would be needed to recommend/ implement vaccination: o Differentiate between what they require as communication to present/share with the young person etc o And what they would require for themselves: where would they look for information for themselves, who would they go to.	• Anxieties/ concerns about the vaccine • Safety issues surrounding vaccine • What information would be needed to recommend/ implement vaccination • What communication aids would be needed to recommend/ implement vaccination: o Differentiate between what they require as communication to present/share with the young person etc • And what they would require for themselves: where would they look for information for themselves, who would they go to
• Is school an appropriate venue to carry out vaccination • Same questions as with GP: are they willing prepared to provide information and advice? • Is school an appropriate venue to carry out vaccination • Implications of this increased workload on other roles of school nurses • Willingness to incorporate HPV vaccination into existing work schedule	• Willingness (and preparedness, ie do they feel they have the necessary knowledge, feel confident, or do they have any misgivings) to advise young people about vaccination • Willingness (and preparedness) to advise parents about vaccination • Willingness (and preparedness) to offer a catch up programme for older adolescents
• Explore issues related to adolescent versus parental consent (given the age groups concerned)	• Explore issues related to adolescent versus parental consent (given the age groups concerned)