

# Immunisation against HPV in girls with intellectual disabilities

Rebecca MacLeod,<sup>1</sup> Catherine Tuffrey<sup>2</sup>

Since September 2008 in the UK, immunisation against human papillomavirus (HPV) has been routinely offered to all girls aged 12–13 years as part of the childhood immunisation programme. It has been shown in previous research, that children attending schools for children and young people with intellectual disability are less likely to receive routine vaccines compared with non-disabled peers.<sup>1</sup> Unpublished data from an audit carried out in the Portsmouth district suggests similar issues for HPV vaccination. This paper looks at what we know about HPV infection and the risks to individuals with intellectual disability, as well as why immunisation rates may be lower and what we should do about this.

## RATES OF HPV IMMUNISATION

There has been no research published which looks specifically at HPV vaccination rates in disabled girls and we are not aware of any routine collection of such data. A recent study from Bristol<sup>2</sup> showed that rates in young women in non-mainstream educational settings were significantly lower than those in mainstream schools. This was a heterogeneous group, however, with schools for young people with 'significant additional needs' combined with pupil referral units, young offender units, hospital schools and home-educated girls.

Research in other disadvantaged groups has shown in some populations that HPV vaccination rates are significantly lower in communities with high social deprivation<sup>3</sup> and among ethnic minority girls,<sup>2 3</sup> girls of travelling families, 'Looked after Children', some religious groups and girls who are not in school.<sup>4</sup>

Our own local unpublished data showed uptake in girls in local schools for moderate or severe intellectual disabilities in 2010–2011 was significantly lower than that compared with girls in a local mainstream school (77% vs 93%)

although socioeconomic status and ethnicity were not controlled for. Anecdotal reports from local school nurses indicate that obtaining truly informed consent for the vaccine from the parents of girls with intellectual disabilities is considerably more challenging. Informed consent requires sufficient information to be available to enable the weighing up of the risks and benefits to that individual. So what information is available?

## CERVICAL CANCER RISK

Cervical cancer is the second most common cancer of women worldwide.<sup>5</sup> The introduction of a national cervical screening programme significantly reduced the incidence of cervical cancer and associated mortality. However, in the UK, the lifetime risk remains at 1 in 134 and approximately one-third of women die within 5 years of diagnosis of invasive cervical cancer.<sup>6</sup> Persistent infection with high-risk types of HPV is detectable in more than 99% of cervical cancers.<sup>7</sup> The HPV vaccine is over 99% effective at preventing HPV-associated precancerous lesions.<sup>8</sup>

## CERVICAL CANCER IN WOMEN WITH INTELLECTUAL DISABILITIES

It is difficult to find specific data on cervical cancer rates in the adult intellectually disabled population. There is ample data showing that health outcomes generally are worse than those for the general population, with all-cause mortality rates among people with moderate to severe intellectual disabilities being three times higher than the general population.<sup>9</sup> In part, this has been found to be due to barriers in accessing timely and effective healthcare. Although women with intellectual disabilities appear to be at lower risk of cervical cancer than the general population, their risk is not negligible.<sup>10</sup> Cytological abnormalities are found in between 0.2% and 4% of smears taken from women with intellectual disabilities,<sup>11</sup> compared with a rate of 5.9% in the general population.<sup>12</sup> Whether this is due to suboptimal smears, a lower prevalence of HPV or a combination of both remains to be shown.<sup>11</sup> There is a significant lack of data in the medical literature

on the *actual* risks of HPV infection within this specific population.

## RISK FACTORS FOR HPV

The main risk factors for cervical cancer among HPV-positive women are early age at first intercourse, the most recent sexual relationship starting more than 6 years previously and cigarette smoking.<sup>13</sup> For cigarette smoking, there is a strong dose-response relationship and smoking has been shown to act with HPV to cause cervical neoplasia. Smoking rates among those with mild and moderate intellectual disability have been shown to be similar to or higher than the general population in adolescence.<sup>14</sup> Rates of smoking in adults varies between studies, with rates overall lower than the general population; but in some samples with milder intellectual disabilities, rates are higher than in the general population.<sup>9</sup> Studies looking at contraception in adult women with intellectual disabilities have shown differing patterns to the general population with significantly less use of barrier methods,<sup>15</sup> thus increasing the risk of sexually transmitted diseases, including HPV.

## ACCESS TO CERVICAL SCREENING

Studies have widely reported that women with intellectual disabilities have significantly reduced access to screening. In a population of nearly 400 women in an English district who had intellectual disabilities and were eligible for cervical screening, only 13% had a record of a smear test in the previous 5 years.<sup>16</sup> This was significantly lower than the 88% coverage for the general population in the same geographical area. A recent literature review identified several main barriers for women with intellectual disabilities accessing screening services: uninformed attitudes and lack of training of professionals, carers and service users; inadequate resources and invitation letters; and issues around a perceived difficulty in obtaining consent.<sup>17</sup>

Recommendations for future practice to break down these barriers are endorsed without hesitation, but changing culturally embedded professional and lay attitudes is never a quick process. Achieving an equitable HPV vaccine coverage for girls with intellectual disabilities could go some way towards protecting a vulnerable population from a disease where access to screening is reduced.

## INFORMATION PROVISION

The Department of Health publishes a standard fact sheet that is designed for obtaining parental consent for HPV

<sup>1</sup>Department of Paediatrics, Hampshire Hospitals NHS Trust, Basingstoke and North Hampshire Hospital, Basingstoke, UK; <sup>2</sup>Child Health Services, Unit A4 Alpha Court, Segensworth Business Centre, Fareham, UK

**Correspondence to** Dr Catherine Tuffrey, Child Health Services, Unit A4 Alpha Court, Segensworth Business Centre, Fareham PO15 5RQ, UK; [tuffrey@yahoo.co.uk](mailto:tuffrey@yahoo.co.uk)

vaccination. No specific information leaflet for parents of girls with intellectual disabilities exists nationally. An 'easy read' version of any information should be available for those girls and young women who have capacity to consent but find standard information too complex to access. It must also be remembered that some of these girls' parents may also have intellectual disability and would also benefit from more accessible information.

### WHY PARENTS WITHHOLD CONSENT

It is well recognised that the parents of girls, in general, may withhold consent because of unfounded concerns around the safety of the vaccine,<sup>18</sup> although there are very few individuals who cannot receive the vaccine. The only contraindication is a confirmed anaphylactic reaction to a previous dose (or any component) of HPV vaccine.<sup>19</sup>

The objective of the programme is to vaccinate all females before they reach an age when the risk of HPV infection sharply increases. Many parents have expressed the opinion that they feel their daughters are given the vaccine at an inappropriately young age, and thus may construe that by consenting at such a time they are condoning underaged sexual activity.<sup>18</sup> Some parents of intellectually disabled girls may share these opinions.

### SOCIETAL ASSUMPTIONS

There may also be parental assumption that the vaccine is unnecessary because their intellectually disabled daughters will not be sexually active in the future. Societal views and attitudes are often incorrect, with a tendency to infantilise disabled adults and to perceive them as asexual.<sup>20</sup> Professionals too may hold such views. Empirical research has challenged this view for adults with intellectual disabilities. Reid found that around half the individuals in a population of adults with profound intellectual disabilities were engaged in some sort of sexual activity.<sup>21</sup> He found no correlation with intellectual ability.

Peckham reviewed the available evidence and concluded that intellectually disabled individuals are highly vulnerable to, and indeed at increased risk of, sexual abuse.<sup>22</sup> Prevalence rates cited in the literature vary hugely but are reported to range from 8% to as much as 83%, depending on definitions used. So, should health professionals be sensitively sharing this evidence with parents as part of the routine process for obtaining informed consent for HPV vaccination? It would

present an ethical challenge and may have significant time and training implications for staff.

### THE FUTURE

There should be no inequalities in the delivery of any immunisation programme, and this includes that for HPV. However, for a variety of reasons, girls with intellectual disabilities may be particularly vulnerable to remaining unprotected and health professionals will, therefore, need to go the extra mile to ensure equity. We suggest the following:

- ▶ Routine data collection of immunisation rates in girls with disabilities attending both special school and mainstream settings.
- ▶ Targeted training of school nurses, general practitioners, paediatricians and other relevant professionals to highlight the issues and plan local responses to ensure optimal uptake.
- ▶ Development and widespread availability of specific and relevant patient information to ensure that truly informed parental consent is obtained.
- ▶ Provision of techniques, such as social stories, should be explored in addition to written information to help young women themselves understand, where possible, the risks and benefits of immunisation.
- ▶ Services seeing adults with intellectual disability need to be aware that immunisation may have been missed in adolescence and to offer it to women at risk.

**Acknowledgements** We would like to thank Dr Helen Daley for commenting on a draft of this paper. The local audit referred to in the text was undertaken on behalf of the Community Paediatric Department of Solent NHS Trust by Dr Nick LeProvost.

**Contributors** CT had the idea for the paper. RM wrote the initial draft, and both authors were involved with editing and finalising the paper.

**Competing interests** None.

**Provenance and peer review** Commissioned; externally peer reviewed.

**To cite** MacLeod R, Tuffrey C. *Arch Dis Child* Published Online First: [please include Day Month Year] doi:10.1136/archdischild-2013-305919

Received 16 April 2014

Revised 7 August 2014

Accepted 13 August 2014

*Arch Dis Child* 2014;0:1–2.

doi:10.1136/archdischild-2013-305919

### REFERENCES

- 1 Tuffrey C, Finlay F. Immunisation status of children attending special schools. *Ambul Child Health* 2001;7:213–7.
- 2 Fisher H, Audrey S, Mytton JA, et al. Examining inequalities in the uptake of the school-based HPV

vaccination programme in England: a retrospective cohort study. *J Public Health* 2014;36:36–45.

- 3 Roberts S, Brabin L, Stretch R, et al. Human papillomavirus vaccination and social inequality: results from a prospective cohort study. *Epidemiol Infect* 2011;139:400–5.
- 4 Boyce T, Holmes A. Addressing health inequalities in the delivery of the Human Papillomavirus vaccination programme: examining the role of the school nurse. *PLoS ONE* 2012;7:e43416 (accessed Apr 2013).
- 5 Munoz N, Castellsague X, de Gonzalez AB, et al. Chapter 1: HPV in the etiology of human cancer. *Vaccine* 2006;24(Suppl 3):S1–S10.
- 6 Cancer Research UK. Cervical cancer statistics. <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/cervix/> (accessed Apr 2014).
- 7 Walboomers JM, Jacobs MV, Manos MM, et al. Human papillomavirus is a necessary cause of invasive cervical cancer worldwide. *J Pathol* 1999;189:12–19.
- 8 Lu B, Kumar A, Castellsagué X, et al. Efficacy and safety of prophylactic vaccines against cervical HPV infection and diseases among women: a systematic review and meta-analysis. *BMC Infect Dis* 2011;11:13.
- 9 Emerson E, Baines S, Allerton L, et al. Health inequalities and people with learning disabilities in the UK, 2011. [http://www.improvinghealthandlives.org.uk/securefiles/140406\\_2055/1Hal%202011-09%20HealthInequality2011.pdf](http://www.improvinghealthandlives.org.uk/securefiles/140406_2055/1Hal%202011-09%20HealthInequality2011.pdf) (accessed Apr 2014).
- 10 Wood R, Douglas M. Cervical screening for women with Learning Disability: current practice and attitudes within primary care in Edinburgh. *Br J Learn Disabil* 2007;35:84–92.
- 11 Quint E, Elkins T. Cervical cytology in women with mental retardation. *Obstet Gynecol* 1997;89:123–6.
- 12 Screening and immunisations team, Health and Social Care Information Centre. Cervical Screening Programme, England 2012–13. Published 24th October 2013. <http://www.hscic.gov.uk/catalogue/PUB11889/cerv-scre-prog-eng-2012-13-rep.pdf> (accessed Aug 2014).
- 13 Deacon J, Evans C, Yule R, et al. Sexual behaviour and smoking as determinants of cervical HPV infection and of CIN 3 among those infected. A case-control study nested within the Manchester cohort. *Br J Cancer* 2000;83:1565–72.
- 14 Emerson E, Turnbull L. Self-reported smoking and alcohol use amongst adolescents with intellectual disabilities. *J Intellect Disabil* 2005;9:58–69.
- 15 McCarthy M. 'I have the job so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Stud Int Forum* 2009;32:198–208.
- 16 Stein K, Allen N. Cross sectional survey of cervical cancer screening in women with learning disability. *BMJ* 1999;318:641.
- 17 Gribben K, Bell M. Improving equality of access to cervical screening. *Learn Disabil Pract* 2010;13:14–20.
- 18 Hutton S, Finlay F. Allaying parental concerns about the human papillomavirus vaccine. *Paediatr Nurs* 2009;21:20–3.
- 19 The Green Book: Information for public health professionals on immunisation. <https://www.gov.uk/government/publications/human-papillomavirus-hpv-the-green-book-chapter-18a> (accessed Apr 2014).
- 20 Murphy N, Young P. Sexuality in children and adolescents with disabilities. *Dev Med Child Neurol* 2005;47:640–4.
- 21 Reid D. Sexual activity in people with profound learning disabilities. *Br J Learn Disabil* 1995;23:56–8.
- 22 Peckham J. The vulnerability and sexual abuse of people with learning disabilities. *Br J Learn Disabil* 2007;35:131–7.



## Immunisation against HPV in girls with intellectual disabilities

Rebecca MacLeod and Catherine Tuffrey

*Arch Dis Child* published online September 3, 2014

doi: 10.1136/archdischild-2013-305919

---

Updated information and services can be found at:

<http://adc.bmj.com/content/early/2014/09/03/archdischild-2013-305919.full.html>

---

*These include:*

- |                               |  |
|-------------------------------|--|
| <b>References</b>             | This article cites 18 articles, 3 of which can be accessed free at:<br><a href="http://adc.bmj.com/content/early/2014/09/03/archdischild-2013-305919.full.html#ref-list-1">http://adc.bmj.com/content/early/2014/09/03/archdischild-2013-305919.full.html#ref-list-1</a> |
| <b>P&lt;P</b>                 | Published online September 3, 2014 in advance of the print journal.  |
| <b>Email alerting service</b> | Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.   |

---

Advance online articles have been peer reviewed, accepted for publication, edited and typeset, but have not yet appeared in the paper journal. Advance online articles are citable and establish publication priority; they are indexed by PubMed from initial publication. Citations to Advance online articles must include the digital object identifier (DOIs) and date of initial publication.

---

To request permissions go to:

<http://group.bmj.com/group/rights-licensing/permissions>

To order reprints go to:

<http://journals.bmj.com/cgi/reprintform>

To subscribe to BMJ go to:

<http://group.bmj.com/subscribe/>

## Topic Collections

Articles on similar topics can be found in the following collections

[Cervical cancer](#) (3 articles)  
[Oncology](#) (553 articles)  
[Immunology \(including allergy\)](#) (1399 articles)  
[Vaccination / immunisation](#) (254 articles)  
[Cervical screening](#) (2 articles)  
[Drugs: infectious diseases](#) (634 articles)  
[Child health](#) (2531 articles)  
[Adolescent health](#) (238 articles)  
[Epidemiologic studies](#) (1174 articles)  
[Screening \(epidemiology\)](#) (375 articles)  
[Screening \(public health\)](#) (375 articles)  
[Child and adolescent psychiatry \(paediatrics\)](#) (473 articles)  
[Disability](#) (203 articles)  
[Informed consent](#) (33 articles)  
[Legal and forensic medicine](#) (63 articles)

---

## Notes

---

Advance online articles have been peer reviewed, accepted for publication, edited and typeset, but have not yet appeared in the paper journal. Advance online articles are citable and establish publication priority; they are indexed by PubMed from initial publication. Citations to Advance online articles must include the digital object identifier (DOIs) and date of initial publication.

---

To request permissions go to:

<http://group.bmj.com/group/rights-licensing/permissions>

To order reprints go to:

<http://journals.bmj.com/cgi/reprintform>

To subscribe to BMJ go to:

<http://group.bmj.com/subscribe/>