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Uptake of the HPV vaccine in girls and boys with an intellectual disability: a systematic review.

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Systematic Review

Keywords: HPV vaccination, cervical cancer, intellectual disability, adolescents, systematic review

Posted Date: November 23rd, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11810030/v1

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Additional Declarations: The authors declare no competing interests.

Uptake of the HPV vaccine in girls and boys with an intellectual disability: a systematic review.

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All authors have approved submission of the manuscript.

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Abstract

Background

Cervical cancer is the fourth most common female cancer and is preventable by (human papillomavirus) HPV vaccination, given to adolescent girls and boys in most World Health Organisation countries. People with an intellectual disability have significantly worse cancer outcomes than the general population, attributable to deficits in prevention, screening, early diagnosis and treatment, and there is concern that rates of HPV vaccination may be lower in this population. The aim was to undertake a systematic review of research into HPV vaccination uptake in people with intellectual disability, and influences on vaccination.

Methods

Multiple databases (Medline; Embase; CINAHL; PsycINFO; Cochrane Central; Overton) were searched to May 2026. Quantitative, qualitative and mixed-methods studies were eligible if they: (i) reported rates of HPV vaccination uptake in people with an intellectual disability, or (ii) reported factors influencing HPV vaccination in people with an intellectual disability.
Two reviewers independently screened studies and took inclusion decisions. Data extraction and quality appraisal (JBI tools) were undertaken by one researcher and verified by another. Data on vaccination initiation and completion rates were synthesised narratively and meta-analysed (risk ratio, RR) as appropriate; influences on vaccination were mapped to the Socio-Ecological Model.

Results

25 studies (18 quantitative; 7 qualitative) from eight high-income countries were included. Meta-analyses showed that girls and boys with intellectual disability were less likely to receive the vaccine (RR 0.74 and 0.56, respectively) and complete a vaccine course (RR 0.63 and 0.55, respectively), compared to those without intellectual disability. Reported barriers were primarily individual but also occurred at interpersonal, institutional or societal levels. The quantitative and qualitative studies were generally of high quality.

Conclusions

Girls and boys with an intellectual disability are less likely than those without intellectual disability to receive HPV vaccines, or complete a vaccine course once started, increasing cancer risk. Identified barriers and facilitators indicate opportunities in the healthcare and education sectors to intervene to reduce this inequity. Future research is needed from a wider range of countries, including data from people with intellectual disability themselves.

Registration

The protocol was registered with the OSF in September 2025: https://osf.io/7h8cz/overview

Keywords

HPV vaccination; cervical cancer; intellectual disability; adolescents; systematic review.

Background

Intellectual disability is a neurodevelopmental disorder that begins in childhood, resulting in significant deficits in intellectual and adaptive functioning (1). It affects an individual's ability to learn, reason, regulate emotion and carry out activities of daily living. Global prevalence is uncertain, given international variation in categorisation and registration, but is estimated to be around 2% of the population (2). People with intellectual disability have consistently poorer health outcomes, with an average life expectancy 19.5 years less than the general population (3).

Cancer outcomes are particularly poor compared with the general population and people with an intellectual disability have shorter overall survival time post-diagnosis (4), explained by a range of factors including lesser uptake of screening and later reporting of symptoms, both of which contribute to later stage diagnoses, and lower rates of referral for specialist treatment. For example, in the UK only one-third of eligible women with an intellectual disability have up to date cervical smear tests, compared to nearly three-quarters of eligible women without an intellectual disability (5).

Cervical cancer is the fourth most common cancer in females worldwide (6) and almost all cases (99.7%) are caused by persistent human papilloma virus (HPV) infection (7). HPV is a predominantly sexually transmitted virus, with the strains HPV16 & HPV18 most widely agreed to be oncogenic. The vaccine, Gardasil, reduces rates of cervical cancer by up to 93.4% (8). Countries initially implemented vaccination programmes for 12–13-year-old girls in 2007, with vaccination of similarly aged boys introduced several years later in many countries. By 2025, 76% of World Health Organisation member states were undertaking HPV vaccination (9).

However, not everyone receives the HPV vaccine in vaccinating countries, and there is concern that non-uptake patterns are predictable across the population, including people with intellectual disability, who may lack capacity to make decisions about healthcare, and be less able to receive routine healthcare due to a number of factors including lack of reasonable adjustments or accessible health information, and having healthcare decisions taken on their behalf. Given the disparities between people with an intellectual disability and the general population in cancer pathways and outcomes, and the recent publication of studies into HPV vaccination in this population, the aim was to undertake a systematic review to collate the published evidence on rates of HPV vaccination in boys and girls with an intellectual disability, when compared to adolescents without intellectual disability, and stated barriers and facilitators of vaccination offer and receipt.

Methods

The review protocol was registered with the Open Science Framework in September 2025: https://osf.io/7h8cz/overview

Search strategy

Relevant studies were identified by searching the following digital databases: Medline, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and the Cochrane

Central Register of Controlled Trials (CENTRAL), for studies published since January 2000. (See Supplementary Figure S1 for an example search). Additional searches of grey literature and policy documents were conducted in Overton. Searches were undertaken in October 2025, following advice from a specialist information scientist, and updated in May 2026. Reference lists of included studies were screened, and forwards-citation searches were conducted using Google Scholar.

The retrieved studies were exported into EndNote and de-duplicated and then imported into Covidence. Screening was initially undertaken through title and abstract, and then by article full text. In both cases screening was carried out independently by two reviewers (from MR, PK, RBM) followed by reconciliation of any conflicts.

Eligibility criteria

Participants were individuals with an intellectual disability, caregivers (including family members, paid care workers), or school and healthcare employees involved in HPV vaccination delivery. Quantitative, qualitative and mixed methods primary studies were eligible for inclusion if they: (i) reported rates of HPV vaccination uptake in people with an intellectual disability (with or without comparison rates in the population without intellectual disability or (ii) reported the factors that impeded or facilitated HPV vaccination in people with an intellectual disability. Studies reporting mixed-disability samples were included when data for people with intellectual disability were reported separately or when individuals with intellectual disability comprised more than 50% of the sample. Studies involving boys or girls with intellectual disability were included. No date or language restrictions were applied.

The primary outcomes were rates of HPV vaccination in people with an intellectual disability, and the factors influencing vaccination decisions (i.e. the barriers and facilitators). Studies reporting uptake for first dose HPV vaccine dose and completion of the HPV vaccination course were included. Course completion rates were calculated based on numbers of individuals who received the first dose. Owing to geographical and temporal variation across studies, the definition of a "completed course" varied, most comprised two or three doses.

Quality assessment

Included studies were appraised for quality using the Joanna Briggs Institute (JBI) checklists for cross-sectional studies (10) (scored 0-8) and qualitative studies (11) (scored 0-10), as appropriate. For both checklists, items rated as 'unclear' were scored 0. Quality appraisal was undertaken by one reviewer (MR) and checked by a second reviewer (PK). Discrepancies were resolved through consensus. Formal sensitivity analysis based on study quality was not applied.

Data extraction

Data extraction was undertaken by one reviewer and then checked by a second reviewer (two from MR, PK and RBM). Any disagreements were resolved through consensus. Data extracted from each eligible study included the following: study aim; study design; data collection; sample size and descriptors; findings related to vaccine uptake; findings related to influences on vaccine uptake.

Data synthesis and presentation

Studies reporting rates of vaccine uptake were combined in meta-analysis using metaanalysisonline.com software, to generate risk ratio statistics. Analyses were undertaken

separately for girls and boys with intellectual disability, given that vaccination in some countries is only provided to girls, whereas in others it is provided to both sexes, and the expected differences in motivations to be vaccinated among boys and girls. Studies were included in meta-analyses when rates were reported for adolescents with and without intellectual disability; otherwise, uptake studies were included in narrative synthesis. Meta-analysis was undertaken separately for vaccine initiation (i.e receiving the only dose or the first dose of a course) and vaccine course completion (i.e receiving the second or third dose of a multi-dose course, with the denominator taken as the number who had received the first dose).

Data on the barriers and facilitators of vaccination were interpreted using the Socio-Ecological model (12), due to the complex multi-factorial influences on vaccine uptake. The model organises influences on behaviour into five key domains (individual factors, such as attitudes and beliefs; interpersonal factors, such as relationships among clinicians, parents and educational staff; organisational factors, affecting educational and healthcare organisations, and the logistics of vaccine delivery; the impact of community and the wider society; and the role of relevant public policy.

Results

A total of 464 publications were identified through database searches, with a further 25 studies identified through citation searching. After removal of duplicates, 369 articles (see Figure 1 PRISMA) were screened by title and abstract, of which 79 were screened by full text. Twenty-five studies met the entry criteria and were included (see Table 1).

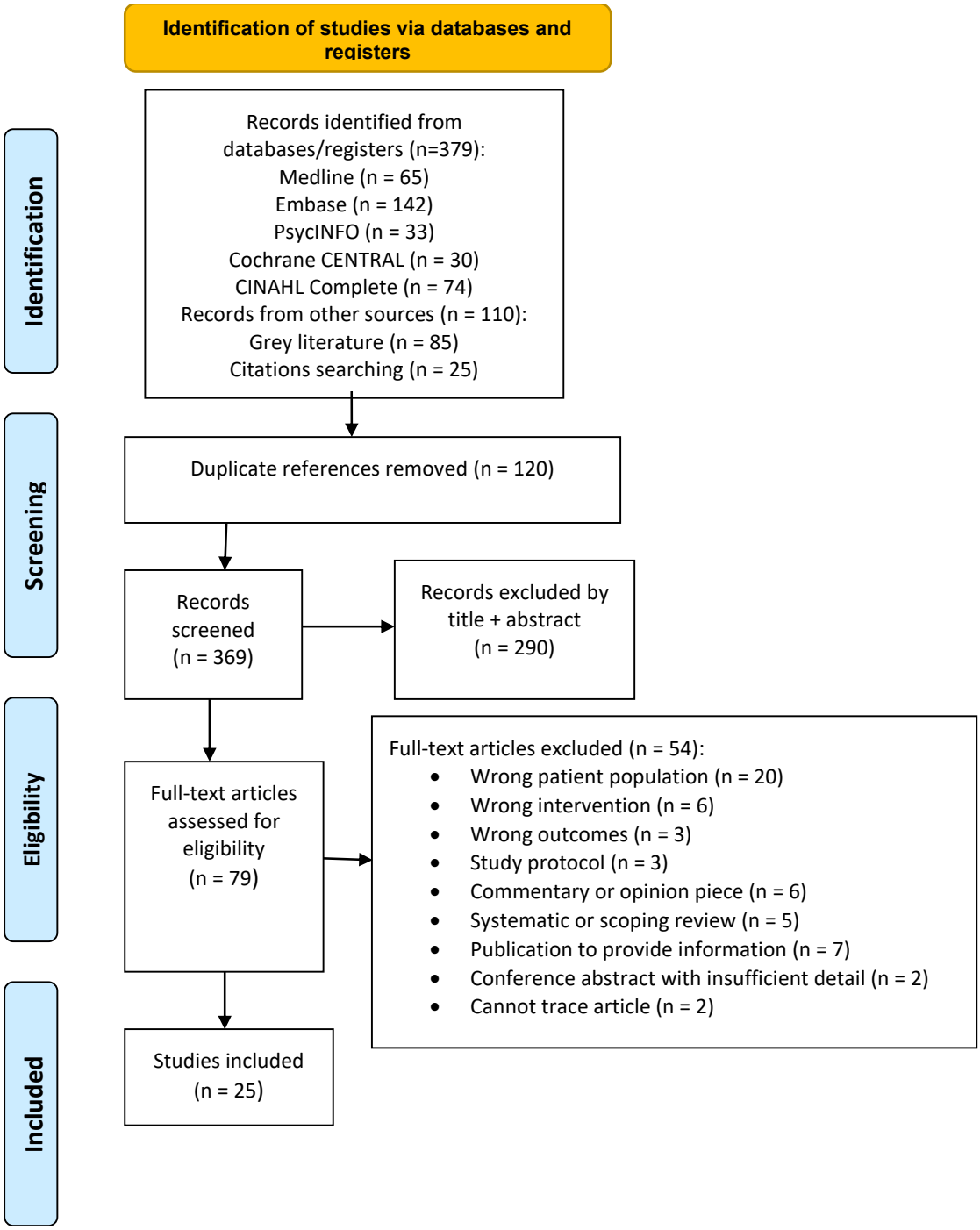


Figure 1. PRISMA chart.

Of the 25 included studies, four assessed both rates of uptake and factors affecting HPV vaccine uptake in adolescents with intellectual disability, 13 studies reported only uptake data, and eight reported only factors affecting uptake. All studies were undertaken in high income countries: eight studies were included each from Australia and the USA, four studies were from the UK, and France, Sweden, Canada, Germany and Denmark each generated a single study respectively. Studies were published 2009 to 2026.

Fifteen studies included a population of people with an intellectual disability, without conditions specified, two studies included data on people with Down's syndrome, one study focussed on Rett's syndrome, and one study focussed on people with both autism spectrum disorder and intellectual disability. Ten studies used schools or colleges for recruitment, usually special educational schools (sometimes called 'special schools'), in which all or most students have an intellectual disability.

Data sources varied, including clinicians (13-20), patient records or surveys (15-20), schools (21-24), or mixed stakeholder groups such as healthcare and education staff, patients and carers (25-28). Eight studies used data from larger studies or databases in which people with an intellectual disability were identified as a subgroup (29-36). Consequently, study sample sizes ranged from 18 patients in a focus group study (15) to more than 24 million adolescents from the French National Health Data System (29).

A wide range of study designs were included: cross-sectional surveys (n=9), cohort studies (n=6), qualitative studies (using interviews and/or focus groups (n=7), 'ecological studies' (n=2), and a retrospective audit (n=1).

Quantitative Results

Eighteen studies reported quantitative vaccination uptake data, with sex-specific data on vaccination initiation and completion synthesised in four meta-analyses.

Quality Appraisal of Quantitative Studies

The 18 quantitative studies scored in the range 2 – 8 on the JBI checklist for cross-sectional studies (10), see Table 2, with a median score of 7 and five studies scoring the maximum of 8 (16, 23, 29, 32, 33). Three studies had low scores (2 or 3)(14, 18, 24). Aspects of the checklist that were not scored well across the 18 studies were: item 3, 'was the exposure measured in a valid and reliable way' (2 'no' ratings; 4 'unclear'); item 4, 'were objective, standard criteria used for measurement of the condition' (6 'unclear'); item 5, 'were confounding factors identified' (6 'no', 1 'unclear'); item 6, 'were strategies to deal with confounding factors stated' (8 'no').

Vaccine uptake in girls

The meta-analysis assessing intellectual disability female initiation rates (Figure 2) pooled data from 11 studies and more than 15 million adolescents and found that those with intellectual disability had an uptake rate of 0.74 (95% Confidence Interval 0.62-0.88), compared to the population without intellectual disability. Individual study risk ratios varied from 0.46 (0.44; 0.49) (29) to 1.00 (0.53; 1.9) (20). Statistical heterogeneity was very high (97.6%, $p<0.01$).

In the meta-analysis one study is an outlier, both in terms of its reported risk ratio and its sample size (contributing more than 96% of all participants) (29), and so we ran the analysis having excluded that study. It confirmed the finding that girls with intellectual disability had vaccination initiation rates significantly lower than girls without intellectual disability (0.80; 95% CI 0.73-0.87) (see Supplementary Figure S2).

The meta-analysis of completed vaccination course rates in females with intellectual disability (Figure 3) pooled data from six studies and more than 311,000 participants and showed a mean risk ratio of 0.59 (0.48; 0.72). This finding showed that, having had the first dose of the vaccine, girls with intellectual disability were less likely than girls without intellectual disability to complete the course. Risk ratios ranged from 0.13 [0.04; 0.42] (22) to 1.0 [0.37; 2.70] (20). Statistical heterogeneity was very high (70.6%, p=.01).

Vaccine uptake in boys

The meta-analysis pooling data on male initiation rates (Figure 4) included four studies and more than 9 million adolescents and showed a mean risk ratio of 0.56 (0.37; 0.85). Risk ratios ranged from 0.31 [0.14; 0.70] (20) to 0.83 [0.76, 0.90] (21). Statistical heterogeneity was very high (95.3%, p<0.01).

As above, given the dominance of one study in the overall sample (contributing more than 99% of all participants) (29), we ran the analysis having excluded that study. It confirmed the finding that boys with intellectual disability had vaccination initiation rates significantly lower than those without intellectual disability (0.64; 95% CI 0.44-0.94) (see Supplementary Figure S3).

The meta-analysis assessing vaccination completion rates in males with intellectual disability (Figure 5) pooled data from three studies and more than 70,000 adolescents, generating a mean risk ratio of 0.55 (0.43; 0.69). As for girls with intellectual disability, this finding showed that, after receiving a first dose of the vaccine, boys with intellectual disability were less likely than boys without intellectual disability to complete the course. Risk ratios ranged from 0.18 [0.05; 0.73] (20) to 0.57 [0.48; 0.68] (21). Statistical heterogeneity was not high (20.9%, p<.05).

Four studies could not be included in meta-analyses but their results largely concur with their findings. Humphrey (2021) (17) reported that fewer than a quarter (22.9%) of women with Rett's syndrome had received the HPV vaccine. Macleod (2014)(18) reported that vaccination rates in adolescents with intellectual disability were significantly lower than in peers without intellectual disability: 77% compared to 93%. The study by Tiley (2019)(24) included non-sex specific data from schools, showing that fewer than a third (33.5%) of 'special schools' in England, i.e. those for pupils with special educational needs (SEN), most of whom have intellectual disability (37), had vaccine coverage rates of at least 80%, compared to two-thirds (67.1%) of mainstream secondary schools. Sisnowski (2021)(23) also reported on school vaccination rates in three Australian states, showing that schools for pupils with SEN had lower vaccine initiation and completion rates than mainstream schools (p<.01), with the difference being particularly marked in female pupils. In England and Australia HPV vaccination is primarily delivered through schools.

The meta-analyses show clearly that for males and females, for first dose and full course, adolescents with intellectual disability are less likely to receive the HPV vaccine compared to peers without intellectual disability. However, two studies included evidence inconsistent with this pattern: Chen (2026)(16) found that among adults with autism spectrum disorder, the presence of intellectual disability did not affect the rate of vaccination; and Lyons (2026)(33) reported that HPV vaccination rates were higher in a mixed-sex sample of people with intellectual disability, generating initiation rates of 79.9% in the population without intellectual disability and 83.6% in those with intellectual disability.

Emerson (2019)(30) reported that the HPV vaccination rates were lower in people with intellectual disability than those without intellectual disability (87.4% vs 93.1%), but the disparity was less marked than for vaccines given earlier in childhood.

Qualitative Results

The review included twelve studies reporting data on barriers and facilitators of HPV vaccination in adolescents with intellectual disability, of which seven were exclusively qualitative in design. The data set comprised six studies from Australia, four from the USA and two from the UK, published between 2010 to 2026. Findings have been reported according to the factor structure of the Socio-Ecological model (see Figure 6).

Quality Appraisal of Qualitative Studies

The seven qualitative studies scored in the range 7 – 9 on the 10-item JBI checklist (11), see Table 3. Aspects of the checklist that were not scored well across the studies were: item 1, 'is there congruity between the stated philosophical perspective and the research methodology' (6 ‘unclear’); item 6, 'is there a statement locating the researcher culturally or theoretically' (6 ‘no’); and item 7, 'is the influence of the researcher on the research, and vice-versa, addressed' (7 ‘no’). On the remaining seven items, all studies scored 'yes'.

Individual factors

Individual factors were the most often cited barriers to HPV vaccination (see Figure 6), some of which were not specific to HPV. They included: the adolescent being unwell on the day of vaccination (26), which was more likely among those with complex medical histories and/or living in an institution. The process of vaccination itself was stated as too distressing for some (21), and the cost of vaccination or health insurance was cited as a barrier in several studies (13-15). Two studies cited parental refusal due to a misunderstanding that their child’s autism had been caused by childhood vaccination (25, 26).

Other barriers were specific to HPV vaccination, and were often based in misbeliefs, sometimes related to low levels of parental health literacy (26). The most common misbelief, referenced in six papers, is that adolescents with intellectual disability only require the HPV vaccine if they are, or are likely to be, sexually active (13, 14, 17, 25, 26, 28). However, to be fully effective the vaccine needs to be given prior to any sexual activity and secondly, many adolescents with intellectual disability are sexually active, although their sexual agency may be unacknowledged (15). Risk of sexual abuse, which is higher in this population (38), is also said to be a factor considered by clinicians when deciding whether to offer the HPV vaccine (13), with some clinicians more inclined to offer the vaccine to those more vulnerable to sexual abuse. Other misbeliefs include the vaccine[i] being unnecessary for boys (25, 28), that children of 12-13 years are too young to have it (17, 25), and that the vaccine is unsafe (14).

Another common theme for HPV vaccine refusal centred on the negative effects of the vaccine or its administration, including anticipated distress, particularly if restrictive practices would be required (25). Other parents were concerned about injection pain (13) or side effects (13, 16, 17).

These concerns may be heightened in a population more likely to have a complex health history (17, 25) and when parents show high levels of 'health vigilance' (26).

Finally, not all adolescents with intellectual disability are recommended the HPV vaccine by their doctor (16). While most clinicians do support vaccination (13) stated barriers include the child's ability to give consent, severity of disability, and the clinician's estimate of their likelihood of being sexually active in future (13).

Interpersonal factors

Interpersonal factors were less often cited as barriers, although a common theme was the difficulty in communicating about sexual health to people with intellectual disability and their family carers. Parents were hesitant to have conversations with clinicians about sexual health and sexually transmitted infections (14), which acted as a barrier to discussing the HPV vaccine. Another study found some nurses avoided explaining the sexual nature of HPV transmission to adolescents with intellectual disability during health education (25), due to a discomfort in discussing sexual health topics with this population.

Institutional or organisational factors

Organisational and logistical factors played a large role in creating barriers to vaccine uptake, with a substantial emphasis being placed on the role of schools. Globally, HPV vaccination delivery often happens in school, (a key exception is the USA, where vaccination is delivered at clinics), but we found a lack of consistency, regulation and transparency in delivery (26). These influences may be exacerbated in children with intellectual disability, with vaccine delivery less organised and more susceptible to service or administrative errors (30). Other studies highlighted a lack of clarity for the role of schools, particularly around whether to promote vaccination and whether staff can restrain a student for vaccination, if needed (25, 27).

A lack of institutional reasonable adjustments was also influential. These included: a lack of accessible information on HPV vaccination (26), lack of disability-specific training for nurses (26), or vaccinating nurses being unable to adjust pre-set delivery schedules to accommodate any additional needs of students with intellectual disability (26, 27). These factors are compounded by insufficient resources for individual student preparation (26) to reduce levels of vaccination day distress and anxiety. If not vaccinated at school, it can be difficult to access the HPV vaccine, often requiring General Practitioner referral. Alternative vaccination locations may be noisy, busy and more challenging for people with intellectual disability, reducing completion rates (26, 27).

Community & Societal factors

There were several wider societal barriers to young people with an intellectual disability receiving the HPV vaccination. Post-Covid-19 vaccination 'fatigue' was cited as an influence (25), as was a societal belief that having an intellectual disability precludes sexual activity (15), contributing to education staff feeling conflicted between their responsibilities for pupil safeguarding and the promotion of safe sexual health (15). Studies suggest many people with an intellectual disability are not sexually naïve and have a need for accessible sexual health information. Paternalistic attitudes persist in the education of young people with intellectual disability, such as their exclusion from important information on topics such as HPV and cancer (15).

Policy factors

According to the included research, public policy plays a comparatively small role in barriers to vaccination. However, the change in many countries from a three-dose vaccination course of HPV to a single dose has resulted in fewer catch-up opportunities (26). Additionally, there are policies in place in some countries that prevent school staff from holding or restraining students to vaccinate (36).

Facilitators

Overwhelmingly the data obtained from clinicians showed that they were supportive of adolescents with an intellectual disability receiving the HPV vaccination, with one sample of clinicians all stating it to be either “very important” or “important” (13). Parents of adolescents with an intellectual disability who were supportive of vaccination were more likely: to have higher levels of health literacy; to have had an illness that was preventable by vaccination; to understand the vaccine’s effectiveness in preventing cancer; or be more likely to conform to social norms and health guidelines (25). Another study found parents of intellectually disabled children tended not to express HPV-specific vaccination beliefs, rather they were more broadly pro- or anti-vaccines, with parental attitudes towards HPV vaccines mostly not differentiated from attitudes to vaccines generally (28). Positively, Emerson (2019)(30) reported that “family disorganisation” was cited as a barrier to vaccination in 11% of children without intellectual disability, but not at all in children with intellectual disability. High levels of satisfaction were reported with the school vaccination programme, for its convenience, accessibility and support given to pupils by known staff. Finally, one study reported that adolescent boys with intellectual disability have capacity to give informed consent to vaccination if provided with a verbal explanation, supported by accessible written information (15).

Discussion

This systematic review of published research found that adolescents with intellectual disability were much less likely to receive the HPV vaccine and, when they did receive one dose, were less likely to complete a multi-dose vaccine course, compared to peers without an intellectual disability. These findings applied to males and females. The qualitative evidence found that although there was some research on vaccination facilitators, the overwhelming focus was on barriers to vaccination. Individual barriers were common and reported in more than one country, particularly misbeliefs around vaccines causing autism, the HPV vaccine being unnecessary for boys or those who were not sexually active. This finding is particularly pertinent given previous research showing lesser understanding of the risks associated with sex among people with intellectual disability, who may engage in riskier sexual activity, increasing risk of contracting HPV. There were also several identified interpersonal, institutional and societal barriers.

The review design, which incorporated quantitative and qualitative findings, allowed us to generate a more integrated picture of HPV vaccination in people with intellectual disability. The review included 25 studies, sufficient to permit meta-analyses of vaccination in girls and boys, and of both initiation and course completion. These findings may map onto possible interventions to increase vaccination rates. Although not conclusive in the included qualitative evidence, boys with intellectual disability and their parents may need different interventions to

girls with intellectual disability and their parents, and successful course completion may require different interventions to course initiation. It is notable that none of the qualitative studies covered HPV vaccine course completion and instead had their focus on uptake more generally, and whether adolescents would receive the vaccine at all. Given that girls and boys with intellectual disability were not only less likely to receive any dose but also much less likely to complete a vaccination course, there is a need to understand the factors underlying parent and child decisions on second and third doses, and whether there are opportunities for intervention. Clearly, this issue only applies to countries that administer multi-dose courses.

There was a striking lack of data and discussion of policy in the included qualitative studies, and it is likely that this omission reflects the lack of relevant policy itself rather than a research omission. A recent systematic review of public policy on intellectual disability and cancer screening and prevention, found an absence of explicit, relevant policy in almost all European countries (39); this is troubling given the significantly worse cancer outcomes experienced by this subset of the population, and the crucial role of decisions that are taken right across the cancer pathway, including prevention, screening, early detection and treatment. These inequities are reflected in the perceptions of social injustice and lack of agency about health seen in some people with intellectual disability (15), and the invidious situations of education and healthcare practitioners, who may find themselves torn between wanting to encourage young people's decision-making autonomy about sexuality and making paternalistic 'best interests' decisions on their behalf.

Other limitations of the review findings include the geographical distribution of the studies, undertaken only in high income developed countries, and no data from lower income countries or from Asia, Africa and South America. This is not just an academic point: given the cultural influences on uptake of preventive healthcare, including vaccination, place matters, as do the higher rates of HPV infection and mortality associated with cervical cancer that are found in some lower income countries (40). The meta-analyses had high levels of statistical heterogeneity, reducing their certainty, which may be due to the variation in the geographical and sectoral origins of the studies, although this may also be due to the complex interplay of different individual, interpersonal and societal influences on vaccination, as established in the qualitative studies. Most of the studies reporting vaccine uptake had not taken account of confounding factors in the analysis and, given that vaccine uptake in the general population is not universal and is often socially patterned, this is an important omission, particularly when considering interventions to increase uptake. However, it is notable from the meta-analyses that 10 of the 11 studies on initiation in girls reported lower uptake in girls with intellectual disability (as did five out of six studies on girls and course completion). A similar pattern was seen with boys: four out of four studies on initiation, and all three studies on course completion. In the initiation meta-analyses on girls and boys, removal of one outlier study did not change the finding substantively. Furthermore, the included studies used an objective outcome measure (vaccine uptake), increasing certainty in the findings.

The main weaknesses in the qualitative studies were a lack of researcher reflexivity and clarity on theoretical foundations to the work. A final limitation is the lack of qualitative evidence from adolescents themselves and a much smaller data set specific to males with intellectual disability. Overall, the strength of the evidence in the review is robust: the review includes 25 studies, with consistent findings being reported in both the quantitative and qualitative aspects of the work.

The review used established good practice in systematic reviewing, including multiple database searches, citation searches, dual independent assessment, quality appraisal, and translation of studies in other languages (although in the end this was not required); all of these elements were intended to increase study yield, reduce error and bias, and gain oversight of the strengths and weaknesses of the relevant evidence.

Conclusions

Data from 25 studies were synthesised, collating both the quantitative and qualitative evidence on HPV vaccination in this population, and this review includes the first meta-analyses of HPV vaccination uptake and completion in this population. The review shows that males with intellectual disability, like their female counterparts, are less likely than their peers without intellectual disability either to initiate or complete a course of the vaccine. Our qualitative analysis also established some gender-specific barriers, notably the misbelief that HPV vaccination is unnecessary in males (as cervical cancer can only affect women). Our findings on females with intellectual disability largely concur with a previous systematic review which demonstrated that females with any type of disability are less likely to receive the vaccination (41). Not only is this finding important in terms of equitable access to preventive healthcare, but it is also of particular importance given the identified poor cancer outcomes in this population (3, 4).

This review has strengthened the case for further research to reduce health outcome disparities in this population. There is a need for research from more countries, as well as data obtained from people with intellectual disability themselves. None of the included qualitative studies provided findings on course completion, which is an important omission given the quantitative meta-analyses we were able to undertake.

The implications for vaccination delivery and policy are likely to be country-specific, influenced by whether vaccinations are provided free or incur a cost for families, and whether vaccine delivery is undertaken within the health or education sectors. However, some implications pertain to any country, such as the need for accessible information, not only to inform consent decisions but also to counter misbeliefs about vaccine science, and the need for reasonable adjustments in vaccine delivery that may enable higher rates of HPV vaccination coverage in adolescents with intellectual disability, to reduce the substantial inequities that currently exist.

References

1. Schalock RL, Luckasson R, Tassé MJ. An overview of intellectual disability: Definition, diagnosis, classification, and systems of supports. American journal on intellectual and developmental disabilities. 2021;126(6):439-42.
2. Nair R, Chen M, Dutt AS, Hagopian L, Singh A, Du M. Significant regional inequalities in the prevalence of intellectual disability and trends from 1990 to 2019: a systematic analysis of GBD 2019. Epidemiology and psychiatric sciences. 2022;31:e91.
3. White A, Sheehan R, Ding J, Roberts C, Magill N, Keagan-Bull R, et al. Learning from lives and deaths-people with a learning disability and autistic people (Leder) report for 2022. King's College London. 2023.

4. Kennedy OJ, Chauhan U, Gorman L, Lorigan P, Merriel S, Van Staa T, et al. Cancer diagnoses, referrals, and survival in people with a learning disability in the UK: a population-based, matched cohort study. The Lancet Regional Health–Europe. 2026;60.
5. NHS-Digital. Health and Care of People with Learning Disabilities Experimental Statistics 2019 to 2020 England: NHS England; 2021 [Available from: https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2019-to-2020.
6. World-Health-Organisation. Cervical Cancer 2026 [Available from: https://www.who.int/news-room/fact-sheets/detail/cervical-cancer.
7. Walboomers JMM, Jacobs MV, Manos MM, Bosch FX, Kummer JA, Shah KV, et al. Human papillomavirus is a necessary cause of invasive cervical cancer worldwide. The Journal of pathology. 1999;189(1):12-9.
8. Falcaro M, Soldan K, Ndlela B, Sasieni P. Effect of the HPV vaccination programme on incidence of cervical cancer and grade 3 cervical intraepithelial neoplasia by socioeconomic deprivation in England: population based observational study. Bmj. 2024;385.
9. Han J, Zhang L, Chen Y, Zhang Y, Wang L, Cai R, et al. Global HPV vaccination programs and coverage rates: a systematic review. EClinicalMedicine. 2025;84.
10. Moola SMZ, Tufanaru C. Chapter 7: Systematic reviews of etiology and risk Aromataris EMZ. Joanna Briggs Institute Manual for Evidence Synthesis The Joanna Briggs Institute Critical Appraisal. 2020.
11. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. JBI Evidence Implementation. 2015;13(3):179-87.
12. Kilanowski JF. Breadth of the socio-ecological model. Journal of agromedicine. 2017;22(4):295-7.
13. Bouza B, Hammig B, Schaefer Whitby P. Physicians' experiences of recommending the HPV vaccine to females with an intellectual disability. Sexuality and Disability. 2021;39(4):731-50.
14. Cody P, Lerand S, Schroeder J, Simpson P, Nugent M. Protecting Those with Disabilities: HPV Vaccination Practices. Journal of Adolescent Health. 2010;46(2):S70.
15. Carnegie E, Gray-Brunton C, Kennedy C, Pow J, Willis D, Whittaker A. Young men with intellectual disabilities' perceptions of HPV and HPV vaccine: A qualitative study on how to communicate HPV vaccine information. Human Vaccines & Immunotherapeutics. 2025;21(1):2491857.
16. Chen Y, Powers J, McDougle CJ, Zürcher NR, Thom RP. Cervical cancer screening and prevention uptake in females with autism spectrum disorder. Journal of Autism and Developmental Disorders. 2026;56(1):1-12.
17. Humphrey BSKN, Horn PPS, Olshavsky MDL, Reebals CNPL. Well-woman care and HPV vaccination rates in women with Rett syndrome. Disability and Health Journal. 2021;14(1):100982.
18. MacLeod R, Tuffrey C. Immunisation against HPV in girls with intellectual disabilities. Archives of disease in childhood. 2014;99(12):1068-70.
19. O'Neill J, Elia S, Perrett KP. Human papillomavirus vaccine uptake in adolescents with developmental disabilities. Journal of Intellectual & Developmental Disability. 2019;44(1):98-102.
20. Roden RC, Oholendt K, Lange H, Noritz G, Bonny AE. Primary care provider adherence to reproductive healthcare guidelines in adolescents and young adults with disabilities: A retrospective matched cohort study. Journal of Pediatric Rehabilitation Medicine. 2019;12(3):317-24.

21. O'Neill J, Newall F, Antolovich G, Lima S, Danchin M. The uptake of adolescent vaccinations through the school immunisation program in specialist schools in Victoria, Australia. Vaccine. 2019;37(2):272-9.
22. Roggendorf H. Preliminary experiences with the acceptance of HPV vaccination. 2009.
23. Sisnowski J, Vujovich-Dunn C, Gidding H, Brotherton J, Wand H, Lorch R, et al. Differences in school factors associated with adolescent HPV vaccination initiation and completion coverage in three Australian states. Vaccine. 2021;39(41):6117-26.
24. Tiley K, White J, Andrews N, Tessier E, Ramsay M, Edelstein M. What school-level and area-level factors influenced HPV and MenACWY vaccine coverage in England in 2016/2017? An ecological study. BMJ open. 2019;9(7):e029087.
25. Carter A, Klinner C, Young A, Strnadová I, Wong H, Vujovich-Dunn C, et al. "I thought it was better to be safe than sorry": factors influencing parental decisions on HPV and other adolescent vaccinations for students with intellectual disability and/or autism in New South Wales, Australia. Vaccines. 2024;12(8):922.
26. Klinner C, McCormack B, Young A, Newman CE, Szanto T, Brogan D, Carter A. Improving School Vaccinations for Adolescents With Intellectual and Developmental Disabilities: A Person-Centred Approach. Journal of Advanced Nursing. 2026.
27. Tuckerman J, Mohamed Y, Justice F, Andersson T, Wyatt K, Broun K, et al. Optimizing school-based delivery of HPV and other routine vaccines for adolescents with disability in specialist schools in Victoria, Australia: a co-design study. Journal of Public Health. 2025;47(3):469-77.
28. Tuckerman J, Mohamed Y, Justice F, Andersson T, Wyatt K, Broun K, et al. Stakeholder perspectives of immunisation delivery for adolescents with disability in specialist schools in Victoria, Australia:'we need a vaccination pathway'. BMC Public Health. 2024;24(1):1973.
29. Dufour L, Drouin J, Dray-Spira R, Le Vu S. Uptake of HPV vaccination and associated factors in France: a nationwide study from 2007 to 2023. Vaccine. 2026;76:128308.
30. Emerson E, Robertson J, Baines S, Hatton C. Vaccine coverage among children with and without intellectual disabilities in the UK: cross sectional study. BMC Public Health. 2019;19(1):748.
31. Hoyle JN, Stevens JD, Valentine A, Smith L, Li FS, Horner-Johnson W, Mitra M. Sexual and Reproductive Health Care Receipt Among Female Adolescents and Young Adults With Disability in the United States, 2011–2019. Journal of adolescent health. 2025.
32. Hu K, Barker MM, Herweijer E, Wang J, Feldman AL, Lu D, et al. The role of mental illness and neurodevelopmental conditions in human papillomavirus vaccination uptake within the Swedish school-based vaccination programme: a population-based cohort study. The Lancet Public Health. 2024;9(9):e674-e83.
33. Lyons AJ, Mhatre MM, Argenio K, Day S, Ternier A, McDermott S, Jones HE. Does human papillomavirus vaccination status differ by disability status in New York city public schools? Vaccine. 2026;78:128404.
34. Rager T, Gillespie W, McCaffery H, Dendrinos M, McCracken K, Rosen M. 11. Addressing Cervical Cancer Disparities in Adolescents with Disabilities through HPV Vaccination. Journal of Pediatric and Adolescent Gynecology. 2025;38(2):234-5.
35. Remes O, Smith LM, Alvarado-Llano BE, Colley L, Lévesque LE. Individual-and regional-level determinants of human papillomavirus (HPV) vaccine refusal: the Ontario Grade 8 HPV vaccine cohort study. BMC Public Health. 2014;14(1):1047.
36. Zaina D, Aemehdoust Z, Klinner C, Young A, Strnadová I, Wong H, et al. Stakeholder Perceptions of the School Vaccination Program in Special Schools for Adolescents With Intellectual and Developmental Disability. Journal of School Health. 2025;95(6):379-88.

37. National-Audit-Office. Support for pupils with special educational needs and disabilities in England.: Department for Education, UK Government.; 2019 05/09/2019.
38. Tomsa R, Gutu S, Cojocaru D, Gutierrez-Bermejo B, Flores N, Jenaro C. Prevalence of sexual abuse in adults with intellectual disability: Systematic review and meta-analysis. International journal of environmental research and public health. 2021;18(4):1980.
39. Vukovic V, Knapp P, Sykes K, Denny M, Kowalczyk O, Denieffe S, et al. Cancer prevention and screening for people with intellectual disabilities in Europe: a systematic review and recommendations for policy and practice. Frontiers in Public Health. 2026;Volume 14 - 2026.
40. Singh GK, Azuine RE, Siahpush M. Global inequalities in cervical cancer incidence and mortality are linked to deprivation, low socioeconomic status, and human development. International Journal of MCH and AIDS. 2012;1(1):17.
41. Kumar P, Bateson D, Costa T, Ahmed S, Naidu C. HPV vaccination coverage and determinants in adolescent girls with disability: a scoping review. Vaccine. 2025;68:127968.

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List of abbreviations

CI: Confidence interval
HPV: human papilloma virus
ID: intellectual disability
JBI: Joanna Briggs Institute
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SEN: Special educational needs
UK: United Kingdom
USA: United States of America

Funding declaration

This work received no specific funding.

Acknowledgments

We thank Professor Su Golder for advice on database searching. We would also like to thank the study authors who responded to questions and data requests in relation to their published studies.

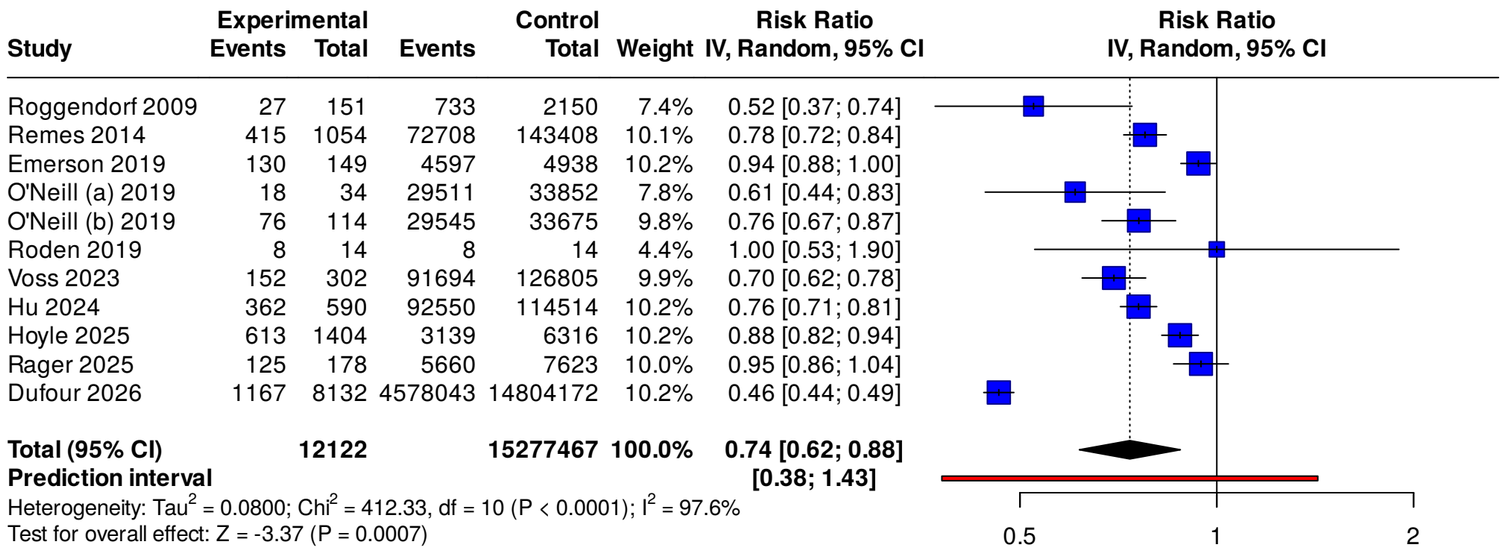


Figure 2. HPV vaccine initiation in girls (meta-analysis)

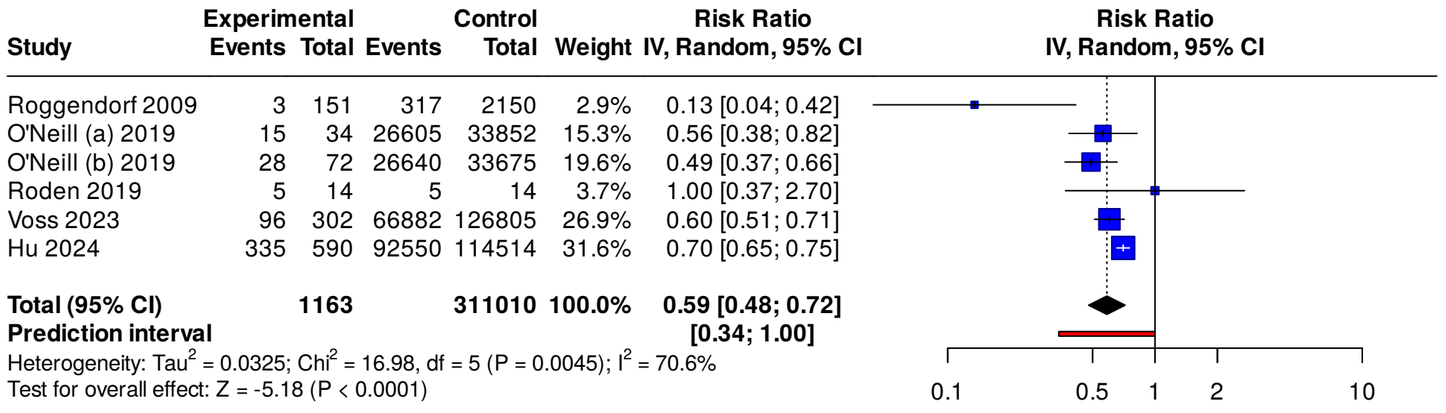


Figure 3. HPV vacine course completion in girls (meta-analysis).

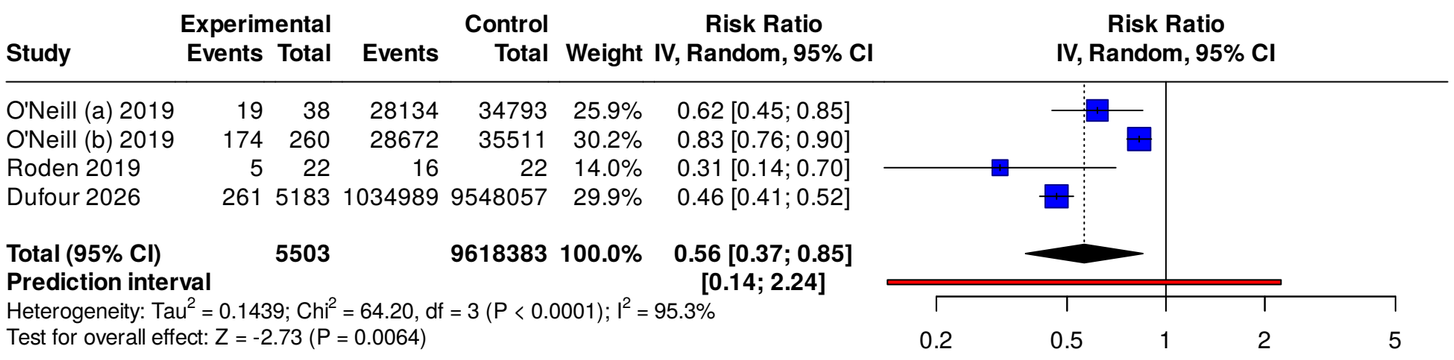


Figure 4. HPV vaccine initiation in boys (meta-analysis).

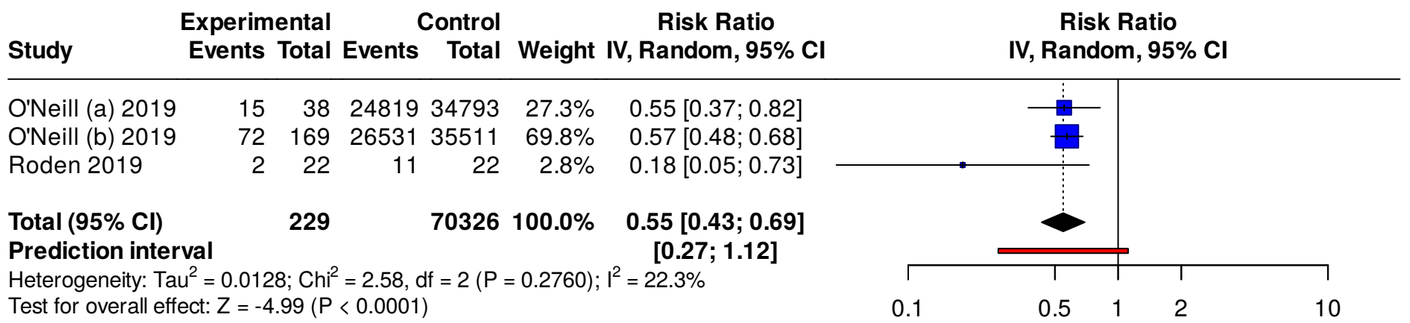


Figure 5. HPV vaccine course completion in boys (meta-analysis).

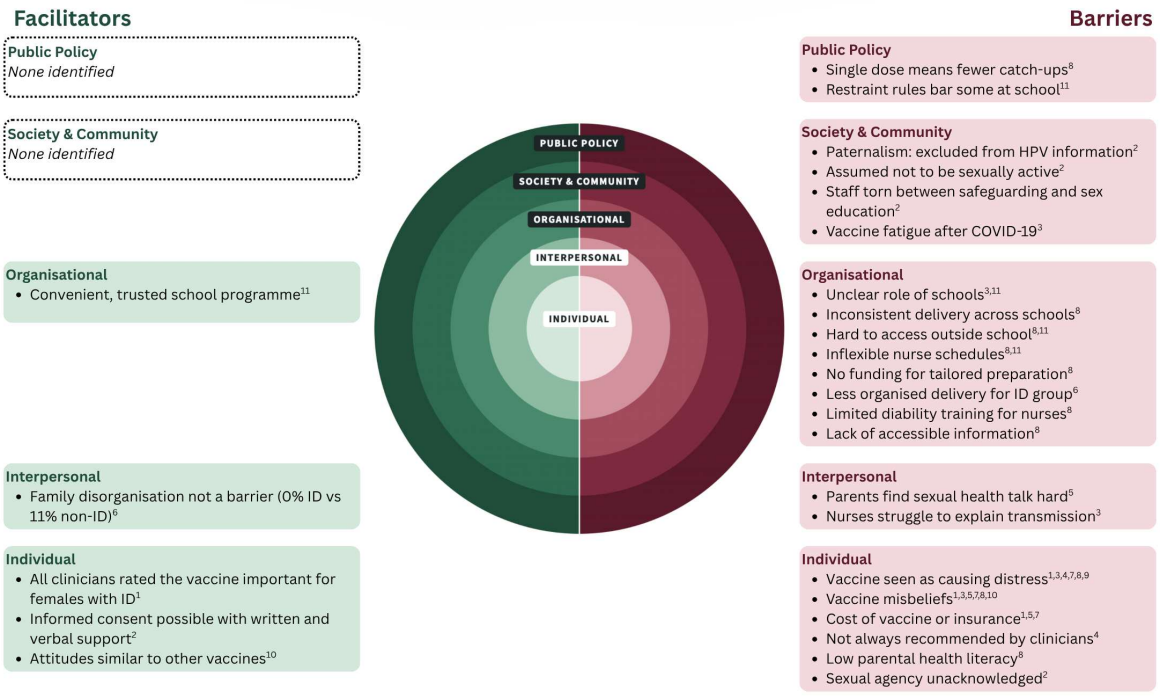


Figure 6. Barriers and facilitators to HPV vaccine uptake mapped to the Socio-Ecological Model

TABLE 1: SUMMARY OF INCLUDED STUDIES

Author, year, country	Study aim	Study design	Data collection methods	Sample size & descriptors (sex; age; ethnicity; disability descriptor)	Findings: Vaccine delivery or uptake (rates in LD; rates in general population, when relevant)	Findings: Reported influences on HPV vaccine delivery or uptake

Bouza, 2021, USA	To examine physicians' experiences of recommending the HPV vaccine to females with an intellectual disability.	Cross-sectional survey, analysed qualitatively	Online survey via Qualtrics. Registered doctors specialising in family medicine, pediatrics, or obstetrics & gynaecology.	N=51. Age 46.6 (SD 11.5); Female n=33. White n=31; Asian n=13; Black/African American n=4; other n=3.		"HPV vaccine importance in females with an ID": Very important 34 (66.7%); Important 17 (33.3%). "Sense of obligation to convince parents to consent to the HPV vaccine": No 14 (27.5%); Yes 37 (72.5%). Q1. Factors considered prior to HPV vaccine recommendation Same as patients without an ID 11 (10.5) Age 23 (22.0) Contraindications 6 (5.7) Cancer prevention and if it is necessary 4 (3.8) Pap smears not well tolerated 2 (1.9) Family health history 3 (2.9) Sexual Activity 26 (24.8) Severity of the patient's intellectual disability 8 (7.6) Ability to obtain informed consent 12 (11.4) Patient's living situation 10 (9.5) Q2a. Questions parents have after recommendation Questions are the same from all parents 2 (2.3) Side effects 15 (17.4) Pain of the injection 5 (5.8) Vaccine's safety 6 (7.0) Inquiring about why their child needs the vaccine 15 (17.4)

						Why the vaccine is needed if their child is never sexually active 10 (11.6) Request information about HPV or cervical cancer 9 (10.5) Vaccine efficacy 9 (10.5) Cost/insurance coverage 4 (4.7) HPV vaccine guidelines 11 (12.8) Q2b. Responses from parent after recommendation Positive/receptive response 16 (29.6) Unfavourable/nonreceptive feelings toward the vaccine 10 (18.5) Uncertain about its necessity 6 (11.1) Excuses to not get it 6 (11.1) Not sexually active 13 (24.1) Concerns about cost/insurance coverage 3 (5.6) Q5. Why the vaccine is important for females with an ID The same as reasons for other patients 16 (22.5) Prevention of HPV and cancer 32 (45.1) Importance depends on potential to be sexually active 5 (7.0) More important for females with an ID 3 (4.2) High risk of sexual abuse 9 (12.7) They do not understand the risks associated with sexual activity 3 (4.2) Contextual factors associated with having an ID 3 (4.2)

						Q6a. Physician feels they can convince patients to accept the vaccine Yes 14 (50.0) No 3 (10.7) Sometimes 7 (25.0) Does not try to convince 4 (14.3) Q6b. Physician's strategies to convince patients to accept the vaccine Education 15 (31.2) Education about HPV 10 (20.8) Education about the HPV vaccine 10 (20.8) Encouraging vaccination prior to sexual debut 4 (8.3) Fear appeals 6 (12.5) Empathy 3 (6.3)

Carnegie, 2025, UK.	To describe communication modes and strategies employed when engaging with young men with intellectual disabilities about the HPV vaccine.	Qualitative study.	Focus groups held in further education institution.	N=18, all males, mild or moderate LD, age range 16-22.		After the focus groups, educational staff commented to the researcher about their concerns regarding sexual behaviours reflecting a conflict between responsibilities of safeguarding versus the promotion of sexual rights. Concerns expressed by educational staff echo fears of taking responsibility for providing sexual health information and perpetuating stereotypes that deny the students' sexual maturity. Young men with an intellectual disability can give informed consent for medical treatment and tests when provided with a verbal explanation and supported by accessible written information. Paternalistic attitudes may infringe on a person's right to information. Understandings of cancer varied but perceived powerlessness indicates a need for future discussions with opportunities to discuss facts, implications, or emotional impact of severe life-threatening disease. There is a need for allocated time, in a variety of educational, social and medical contexts, to discuss

						behavioural risks and consequences of HPV, as active listening, repetition and practice is required. Access to health literature regarding HPV and levels of health literacy and digital health literacy ought to be explored, facilitated and provided. Most participants were not sexually naive but operated within a hinterland where their sexual agency was unacknowledged. Many people were being protected from a basic level of cancer information.

Carter, 2024, Australia.	To explore the factors believed to influence parental decision making regarding the uptake of HPV and other adolescent vaccines for students with intellectual disability and/or on the autism spectrum.	Qualitative study.	Semi-structured individual interviews and focus groups.	Adolescents with LD and/or autism (n=10); parents (n=6): all female, aged 42-50. Special School staff (n=24): teachers or administrators or executive staff; health staff (n=10) (nurses; policy makers; managers).		Parents attitudes fell into three types: (1) pro-vaccination without persuasion, (2) anti-vaccination and unlikely to change their minds, and (3) vaccination-hesitant and needing information personalised to their concerns. Perception as that more parents feel like this about children with disabilities due to complex health needs and medical history, and no guaranteed advantage to having the vaccine. In addition to the emotional stress placed on child during the procedure and possible use of restrictive practices. Some were undecided as believed their children were unlikely to be sexually active. Some believed not necessary in boys or that children "too young" to receive it Carer burnout and COVID-19 induced vaccination fatigue and confusion around number of vaccines needed.

						Several participants also attributed vaccine rejection to the belief that their child's childhood vaccinations had caused their autism. Attitudes stemmed from a) being well educated in health, b) having had a vaccine preventable illness, c) conforming to social expectations and health guidelines. Well informed about efficacy against cancer or "erring on the side of caution". The information pack for parents was not tailored to the needs of families with adolescents attending special schools due to two issues in these communities: low health literacy and marked sensitivities regarding the impact of vaccines and vaccinations on the wellbeing of their child. Some parents in this study expressed perceptions of low HPV-related disease risk on account that disability precludes sex. The data also showed an avoidance by some nurses to discuss the sexual nature of the viral transmission in health education, likely due to lack of comfort in general about sexual health topics with adolescents with disability.

						There was a lack of clarity around who is responsible for educating parents about vaccines and addressing their questions and concerns. Schools refrain from providing medical advice, ie they want to remain neutral and hence do not particularly promote or advise the vaccines.

Chen, 2026, USA.	To 1) report on uptake rates of HPV vaccination and cervical cancer screening and 2) identify barriers to receiving cervical cancer prevention and screening from a large, clinically-referred cohort of adolescent and adult females with ASD.	Cross-sectional study.	Recruited through hospital autism centre. Survey completed by participant or legal guardian / healthcare proxy, depending on capacity.	All females. Adults and children. Most participants also had LD as well as autism. 134 participants completed survey but only 108 adults included in HPV vaccination status, for various reasons. Adults: Age 18-65 years; 84% White ethnicity; 16% non-white. Children: Age 11-17; White 78%; non-white 22%.	Among adults (n=95), those who were partly or fully vaccinated were: less likely to have language impairment (65% vs 36%; p=.006). less likely to have LD (69% vs 82%; p=0.16) Among children (n=73), those who were partly or fully vaccinated were: More likely to have language capability (80% vs 54%; p=.017). less likely to have LD (37% vs 54%; p=0.08) 41% adults with ASD unvaccinated, 47% had received at least 1 dose, 12% unsure of status. 34% full vaccinated.	Of the adult participants who did not receive the HPV vaccine and reported the reason(s), 19 selected: "concerned about side effects," 15 selected "other," 13 selected "vaccination was never recommended/offered," & 0 responded "not convenient." Of the child participants who did not receive the HPV vaccine and reported the reason(s), 9 responded "concerned about side effects," 7 responded "vaccination was never recommended/offered," 7 responded "child is too young to receive the vaccination," 6 responded "other," and 3 responded "not convenient."

Cody, 2010, USA.	To describe health care providers' HPV vaccination practices of females with developmental disabilities.	Cross-sectional survey.	Practitioners recruited through the Wisconsin & Illinois chapters of the US Academy of Paediatrics, using Survey Monkey (Feb to June 2009). Eligible if they provided vaccinations & saw disabled patients as part of their practice.	N=77. 66% aged 29-48; n=46 (80%) female.		N=69 (90%) have vaccinated patients with disabilities with HPV. The most common reason (46%, n=6) providers have not vaccinated is ''parental refusal.'' Other reported reasons include ''child unlikely to be sexually active'' and ''insurance would not cover cost.'' Providers' perceived barriers to acceptance of HPV vaccine of parents of developmentally disabled children include: safety of HPV vaccine (74%, n=57), necessity of vaccination targeting an STI (66%, n=51), and hesitancy to discuss sexuality and STIs (50%, n=39).
Dufour, 2026, France	To assess HPV vaccination uptake and associated factors in France, considering boys and girls and all population subgroups, over the entire period since introducing the HPV vaccine.	Cross-sectional study	Data taken from French National Health Data system. All individuals aged 10-29 years and covered by French health insurance from July 2007 to December 2023.	N = 27.9 million, males and females aged 10-29. N= 1,596 with Down's syndrome.	People with Downs syndrome had deceased odds of HPV vaccine in all age subgroups of both sexes compared to general population, (adjusted ORs ranged from 0.23 to 0.38)	

Emerson, 2019, UK	The primary aim of our paper is to determine whether, in the UK, children with intellectual disabilities are at risk of non-vaccination, including HPV.	Cross-sectional study	Data taken from the UK Millennium Cohort Study, a birth cohort study (of 18,000 children) born 2000-2002. Sampling intended to over-recruit children who are ethnic minorities or from disadvantaged backgrounds.	Analysis of HPV uptake in girls only. Children identified as having LD from cognitive assessments within the study (n=671; 3.6%)	Uptake (age 14) in LD 87.4% (77.9-93.2); without LD 93.1% (92.1-94.0); NS. Unadjusted RR 1.83 (0.99-3.37). Adjusted RR (for family socio-economic position) 1.59 (0.83-3.03). Adjusted RR for family SEP plus other factors) 1.52 (0.78-2.98). (Other vaccines given at 9 months and 3 years showed a bigger and significant gap between LD and non-LD children).	Reasons given by parents for non-vaccination (at age 14): Parental choice LD 46.7%; non-LD 42.0% Service/admin errors: LD 14.7%; non-LD 12.8%. Child unwell at time: LD 13.5%; non-LD 9.3% Adverse reactions (or risk of): LD 0.0%; non-LD 1.6% Family disorganisation: LD 0.0%; non-LD 11.0% Other: LD 25.1%; non-LD 26.4%.
Hoyle, 2025, USA	To report rates of sexual and reproductive health (SRH) care receipt among female adolescents and young adults (AYA), comparing results for those with and without disability.	Cross-sectional study	The National Survey of Family Growth includes information on general, reproductive, and sexual health among women and men aged 15—44 years (2011—2015) and 15—49 years (2015— 2019).	Total n = 8,242 Cognitive disability n= 1,404 Physical disability n= 733	43.7% of those with cognitive disability had received HPV vaccination, compared with 49.7% in those with no disability (p=0.012), adjusted Poisson regression 0.89 (0.81-0.99).	

Hu, 2024, Sweden	To investigate the association of mental illness and neurodevelopmental conditions among girls and their parents with uptake of HPV vaccination in Sweden.	Population-based cohort study	Used the Swedish total population Register, girls only born 1 Jan 2002 to 1 March 2004. Looked at those eligible for HPV from its inception in 2012 to March 2019. Recorded uptake of 1st dose HPV.	N=131,869. N=2211 girls had a diagnosis of any MH condition (including LD).	Uptake overall was 80.7%. Uptake was lower in girls with ID (RR 0.78; 0.73-0.83). After adjustment for potential confounders (birth year, country of birth, region, family education and income, etc) ID rate was 0.81 (0.75-0.87). LD plus autism rate was 0.63 (0.54-0.73).	

Humphrey, 2021, USA	To collect data on well-woman examinations and HPV vaccination rates in women with RTT to understand the current state of women's healthcare in individuals with RTT.	Retrospective cross-sectional chart review and prospective survey	Data collected from patients seen at the Rett Syndrome and Related Spectrum Disorders Clinic with a diagnosis of RTT. Retrospective data collection from medical records included completion of genitourinary exams, pelvic exams, breast exams and mammograms, HPV vaccination status, and reason for declining HPV vaccination, if applicable. Prospective survey carried out by phone/ email to gather further information from primary caretaker.	N=77 Aged 12-18 n=28; 19-26 n=20; 27-39 n=14; 40-55 n=15.	Of participants eligible to receive the HPV vaccination series (<26 years when HPV vaccine became available), n=48 had data on this vaccination. Only a small subset of participants received HPV vaccination as recommended (11/48, 22.9%).	Common reasons cited by guardians for patients not receiving the HPV vaccine included not feeling it was needed (11/35, 31.4%), patient not sexually active (8/35, 22.9%), unknown long-term effects (7/35, 20%), not interested with other complex health issues (5/35, 14.3%), physician has not recommended (3/35, 8.6%), and cost (1/35, 2.9%).

Klinner, 2026, Australia.	To assess whether the principles of a Person-Centred Practice Framework can improve vaccination delivery for adolescents with intellectual and developmental disability in special schools.	Qualitative.	Semi-structured in-depth interviews with 50 participants.	Adolescents with Learning disability and/or autism (n=10); parents (n=6): all female, aged 42-50. School staff (n=24): teachers or administrators or executive staff; health staff (n=10) (nurses; policy makers; managers).		The NSW Health vaccination information pack and clinical protocol are not tailored to families with special needs The policy change to HPV single dose has reduced catch-up vaccination opportunities at school Specialist vaccination services for students who cannot be vaccinated in the school programme are difficult to access for parents (only by GP referral) and referral pathways are not well known by parents and schools Alternative community vaccination options (GP, vaccination clinics, pharmacies) are less suitable for families with disability than school vaccinations due to long waiting times, noisy, crowded clinics and lack of specialist provider skills which can elevate student anxiety There is a lack of public resources available for individualised student preparation There is a lack of regulation, transparency and consistency across schools, regarding schools'

						responsibilities in facilitating the vaccination programme Nurses lack disability specific training and skills Nurses may hold assumptions about students' cognitive (in) capacity to understand and be involved. In some jurisdictions, nurses may work on pre-set time schedules with multiple schools in a day, which can make it difficult for them to take time for students, build rapport and trust with students Parental vaccination misbeliefs (e.g., vaccination causes autism; young people with disability are not sexually active and therefore don't need HPV vaccination) can, if unaddressed, lead to parents rejecting vaccination Low parental health literacy and lack of trust in healthcare providers can, if unaddressed, lead parents to reject vaccination or not submit a consent form which equals forgoing vaccination Heightened parental sensitivities, worries and health concerns for their children with disability can, if

						unaddressed, lead parents to reject vaccination.

Lyons, 2026, USA	To test whether HPV vaccination status differed for male and female students classified as having Autism, ID, or other conditions requiring learning support compared to students with no Individual Educational Plan (IEP) classification.	Cross-sectional study	All New York City (NYC) public school students ages 13 to 21 enrolled in the 2022–23 academic school year as of June 30th, 2023, with data obtained from the Student Population Health Registry.	Total N = 365,167 Autism n = 9,284 Intellectual disability n= 3,367 Other Individualised education plan = 70,000 Sex (total%) = 47.8f, 52.2m Sex (autism%) = 18.6f, 81.4m Sex (ID%) = 41.3f, 58.7m Ethnicity(total) = 12.8% white, 25.5% black, 43.3% Hispanic, 15.8% Asian/Pacific Islander Nationality: 79.2% born in USA, 20.7% born elsewhere Neighbourhood poverty level: Low 25.2%, Med 32.3%,	At least 1 dose HPV vaccine: No IEP (79.9%), Autism (70.3%), ID (83.6%), Other IEP (84.1%) Up to date HPV vaccine: No IEP (68.5%), Autism (60.0%), ID (73.9%) Adjusted Prevalence ratios for at least one HPV vaccine dose No IEP 1.00, Autism 0.89 (0.88,0.91), ID 1.02 (1.00 to 1.04), Other IEP 1.04 (1.03,1.04)	

				High 21.1%, Very high 21.3%		
MacLeod, 2014, UK	To report 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	Cross-sectional study	Girls attending schools for pupils with moderate or severe LD in 2010-11 in one UK local authority.	Not stated. Sample sizes not stated.	Vaccination rate in LD 77%; rate in local mainstream school in same area: 93%. Socio-economic status and ethnicity not controlled for in the analysis.	
O'Neill, 2019(a), Australia	To measure the HPV vaccine uptake in a cohort of adolescents with disabilities who attend a paediatric developmental medicine clinic at a tertiary hospital.	Retrospective audit.	Data obtained from adolescents aged 14 attending a developmental medicine clinic in 2014.	N=72, females n=34 (47%). Range of impairments (physical and intellectual).	HPV uptake (3 doses): Intellectual impairment 12/33 (36%); probable intellectual impairment 4/14 (29%); no or probable not impaired 14/25 (56%). Comparable rate in general state population (aged 15): received 1 dose 87.2% females; 80.9% males. Received 2 doses 84.3% females; 77.8% males. Received 3 doses: 78.6% females; 71.3% males.	

O'Neill, 2019(b), Australia	To measure the uptake of school-based immunisations for young people with disabilities in the specialist school setting in Victoria, Australia, and to identify barriers and enablers to vaccine delivery.	Prospective cohort study	Principals of all eligible schools (n=73) sent information about the study.	N=374 students (98.7% had intellectual disability).	Uptake rate for HPV (dose 1) 66% for females and 67% for males; HPV (dose 3) recorded for 40% of females and 43% of males.	Reasons for missed doses included absence from school on immunisation day (30%); lack of consent card returned (25%); declining immunisation (13%); inability to vaccinate due to student anxiety/distress (9%).
Rager, 2025, USA	To assess if there is a discrepancy in HPV vaccination between AWD and their non-disabled peers.	Retrospective cohort study	Data collected from females (aged 16-21) in academic health system for any reason 2021-2024.	N=7.801, all female, of whom 1,132 (14.5%) had a disability. N=178 with ID.	HPV vaccination (any doses) in all patients was 74.2% (n=5,785). HPV vaccination in people with ID OR 0.71 (0.50-1.03); p=0.07. Unclear if these are adjusted or unadjusted ORs.	

Remes, 2014, Canada	To identify the individual- and health unit-level determinants of HPV vaccine refusal.	Population-based retrospective cohort study	Collected data from girls in Ontario born in 1994-1997 and collected data in 2011. Excluded girls whose vaccination records were unavailable. Looked at rates of HPV vaccine non-receipt (ie 0 doses), classified by researchers as 'refusal'.	N=144,047, females (including n=639, 0.4%, with Down's Syndrome)	Down's syndrome refusals 60.6%. Without Down's syndrome refusals 49.3%. Unadjusted OR 1.58 (1.35, 1.85). Adjusted OR (for all other factors, including other conditions and previous vaccination refusal and deprivation 1.37 (1.16, 1.63).	
Roden, 2019, USA	To assess care provider adherence to preventative sexual and reproductive health guidelines in adolescents and young adults with disabilities.	Retrospective matched cohort study	Data collected from clinic records 2011-2016 on children with complex neuro-developmental conditions, matched by age and sex with children receiving care at paediatric clinic at same institution.	N=42 patient with disability (females 17; 36/42 85.7% had intellectual disability. Matched with n=42 patients (females 17).	Starting HPV (at least 1 dose): disabled 17/42 (41.5%); non-disabled 25/42 (59.5%); p=0.10. Completed HPV doses: disabled 11/42 (27.5%); non-disabled 19/42 (45.2%); p=0.54.	

Roggendorf, 2009, Germany	To investigate the acceptance of the vaccine among 15-year-old girls across all secondary schools in Essen one year after the March 2007 STIKO recommendation.	Cross-sectional study	Vaccination certificates were collected via schools from all girls in Essen within one school year cohort.	N=2,301 girls were asked to provide data. N=1711 (74%) participated in the certificate review.	N=760 (44%) girls had initiated HPV vaccinations. Girls in special schools 25% (27/72) were vaccinated. Girls in mainstream schools 45.7% (733/1603) were vaccinated. OR = 1.40 (0.86 to 2.23), p=.17.	
Sisnowski, 2021, Australia	To identify school-level correlates of low vaccination course initiation and completion in New South Wales, Tasmania, and Western Australia to inform initiatives to increase uptake.	Ecological study	All secondary schools in NSW, Tasmania, and Western Australia for which student enrolment numbers and delivered HPV vaccination doses were available for 2015 and 2016.	N=1,286 schools in 2016; N=1,295 schools in 2015.	Low initiation (defined as <75% uptake) was associated with schools catering for special educational needs compared to mainstream schools (females: OR=4.1, 95% CI = 2.5-6.6; males: OR = 3.8, 95% CI = 2.5-5.8). Low vaccine completion rates: special education school educated females OR 2.5 (1.5-4.1), special education school educated males OR 3.1 (2.0-4.7). Both p<0.001.	

Tiley, 2019, UK	To describe the school-level and area-level factors that influence coverage of the school-delivered HPV and MenACWY programmes among adolescents.	Ecological study	14 screening and immunisation teams asked to voluntarily submit school-level vaccination coverage data for 2016/2017 for all schools in their area.	N=1,407 schools for HPV (n=1,432 schools for MenACWY).	HPV vaccine coverage was >80% in 67.1% of state-funded secondary school, 40.4% of independent schools, 33.5% of special schools, and 19.5% of PRUs. Crude vaccine coverage: state-funded secondary 83.1%; independent school 72.8%; special school 56.7%; PRU 42%.	

Tuckerman, 2024, Australia	To identify and improve understanding of the facilitators and barriers of HPV vaccination among adolescents with intellectual disabilities or autism in Victorian specialist schools to inform strategies to increase vaccination acceptance and uptake.	Qualitative study	Semi-structured interviews with stakeholders at 6 participating specialist schools.	N=32 school and council staff, parents, and adolescents; 27 female, 5 male		Barriers- lack of understanding of the importance of the HPV vaccine, seen as not needed for boys or adolescents with a disability; HPV vaccination thought to be 'just for cervical cancer'; parents may decline HPV vaccination based on child's disability 'I don't believe she's ever going to have sex, so I don't think there's a need for her to have the HPV vaccine'; providing accessible information to parents seen to be challenging. Facilitators- few differences in attitudes between HPV and other vaccines .

Tuckerman, 2025, Australia	To co-design strategies to improve school-based immunisation service delivery for adolescents with disability in Victoria, Australia.	Co-design study	Co-design workshops with stakeholders from 6 Victorian specialist schools.	N=15		The advisory group recommended better integration of adolescents with disabilities into mainstream health services. Suggestion to promote the HPV vaccine by balancing varying levels of disability and parent expectations, particularly concerning sexual activity. Emphasis on the importance of providing accessible information to parents.
Voss, 2023, Denmark	To identify girls in Denmark with lower first dose HPV vaccination coverage than girls in general.	Population-based retrospective cohort study	Four birth cohorts covering girls born in 2001-2004, residing in Denmark in September 2019. Data from the Danish Vaccination Register linked to sociodemographic data from the Danish Civil Registration System and Statistics Denmark.	N=127,661 N=302 attending special need education	HPV vaccine coverage at 14 years of age for study population= 72%. Groups with particularly low vaccination uptake included girls living with neither of their parents (53%), girls attending special needs education (50%), and immigrant girls (43%). Girls attending special need education had a 50% lower risk of being vaccinated compared to girls attending public schools (HR 0.50; 95% CI 0.42-0.59, p <.001).	

Zaina, 2025, Australia	To investigate the perceptions and support of school-based delivery of vaccines for adolescents (boys and girls) with Intellectual and Developmental Disabilities in special schools in New South Wales, Australia.	Qualitative study	Focus groups and interviews were conducted with 50 individuals across four groups of stakeholders (adolescents with intellectual disability, parents, nurses, vaccination coordinators, school vaccination facilitators) in Special schools in New South Wales, Australia.	N=50 from four groups of stakeholders: students with IDD aged between 12 and 16 years (*n* = 10), parents of adolescent children with IDD (*n* = 6), education staff (special school principals, administrative staff, teachers, and school learning support officers) (*n* = 24), and health professionals (nurses, team leaders, program coordinators, and policy managers) (*n* = 10).		*Convenience and accessibility*: Parent participants expressed high satisfaction with the school vaccination program, citing its convenience and accessibility. Parents' preference for schools as vaccination settings was explained by parents experiencing challenges with private vaccination appointments, including long wait times, complex referral pathways, and a lack of specialized care processes for their child with IDD. These difficulties were echoed by nurse participants who talked about high patient volumes, time pressures and limited staff who could address adolescents with IDDs' needs in general practices (IS8) (Q1b), which may have led some parents to resign from vaccinating their child. Students valued the support they received when getting vaccinated at school, noting the comfort of being surrounded by people they knew and trusted. Some parent participants appreciated having their child vaccinated at school, as this spared them from experiencing distress by watching and

						emotionally supporting their child undergo a painful and/or anxiety-provoking medical procedure. *Lack of clarity and conflicting opinions about schools' responsibilities*: While school staff participants recognized that schools serve as an important "*bridge*" between families and vaccination providers, they were unclear about how to define their responsibilities in the program. They distanced themselves from giving parents health advice and from persuading parents to get their children vaccinated. Referring to a new Restrictive Practices Policy issued by the Education Department that prevented school staff from holding or restraining students, school staff also described uncertainty around and conflicting opinions on the appropriateness of holding and/or restraining students for physical support and safety during vaccination.

Table 2. Quality Appraisal of cross-sectional and cohort studies

	Chen, 2026, USA.	Cody, 2010, USA.	Dufour, 2026, France	Emerson, 2019, UK	Hu, 2024, Sweden	Hoyle, 2025, USA	Humphrey, 2021, USA	Lyons, 2026, USA	MacLeod, 2014, UK	O'Neill, 2019, Australia	O'Neill, 2019, Australia	Sisnowski, 2021, Australia	Tiley, 2019, UK	Rager, 2025, USA	Remes, 2014, Canada	Roden, 2019, USA	Rogendorf, 2009, Germany	Voss, 2023, Denmark
JBI Item 1	yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
JBI Item 2	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
JBI Item 3	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	yes	Unclear	Yes	Yes	Unclear	Unclear	Unclear	Yes	Yes
JBI Item 4	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes
JBI Item 5	Yes	No	Yes	yes	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	No	Yes	Yes	No	Unclear
JBI Item 6	Yes	No	Yes	Yes	Yes	Yes	No	Yes	No	No	No	Yes	Yes	No	Yes	Yes	No	No

JBI Item 7	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes
JBI Item 8	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
JBI total	8	2	8	7	8	7	6	8	2	5	6	8	6	3	7	7	4	6

Table 3. Quality appraisal of qualitative studies

	Bouza, 2021, USA	**(PK) Carnegie, 2025, UK.**	**(PK) Carter, 2024, Australia.**	**Klinner, 2026, Australia**	**Tuckerman, 2025, Australia**	**Tuckerman, 2024, Australia**	**Zaina, 2025, Australia**
JBI Item 1	Unclear	Unclear	Unclear	Yes	Unclear	Unclear	Unclear
Item 2	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 3	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 4	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 5	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 6	No	No	No	Yes	No	No	No
Item 7	No	Yes	No	No	No	No	No
Item 8	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 9	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 10	Yes	Yes	Yes	Yes	Yes	Yes	Yes
JBI Total	7	8	7	9	7	7	7

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryFigureS1.ExamplesearchstrategyEmbase.docx
- SupplementaryFigureS2.HPVinitiationgirlswithoutDufour2026.pdf
- SupplementaryFigureS3.HPVinitiationboyswithoutDufour2026.pdf