# Which young women are not being vaccinated against HPV? Cross-sectional analysis of a UK national cohort study

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# Abstract

**Objectives** HPV vaccination is highly effective in preventing HPV-associated disease, including cervical cancer, which disproportionately affects women from disadvantaged and minority ethnic backgrounds. We examined inequalities in initiation of the HPV vaccination schedule among young women in the UK and reasons given by their parents for non-initiation.

Design Cross sectional analyses of a prospective nationally representative cohort study.

Setting Four UK countries.

**Participants** 5,695 young women (39.9% from households in lowest income quintiles), 5.1% ever excluded from school, 0.5% not attending school) whose parents (14.3% from minority ethnic backgrounds; 54.1% with no stated religious faith) took part in interviews conducted when their daughters were 14 years old.

**Main outcome measures** Parent-reported initiation of HPV vaccination and reasons for non-initiation. The adjusted odds (aORs) and 95% Confidence Intervals (CI) of initiating HPV vaccination were estimated using logistic regression after mutual adjustment for household income, school exclusion, school attendance and parental ethnic background and religious faith.

**Results** 92.3% (5265) had initiated HPV vaccination at time of interview. Initiation was less likely among those living in the poorest households (aOR; 95% CI: 0.44; 0.30 to 0.64 for those in lowest household income quintile), who did not attend school (0.11; 0.04 to 0.33), had ever been excluded from school (0.47; 0.29 to 0.76), or whose parents were from Black African (0.49; 0.26 to 0.95) or Any Other (0.34; 0.17 to 0.66) ethnic backgrounds. A reason consistent with a conscious or practical decision was reported by 53.3% (219) and 24.1% (90) parents respectively.

**Conclusions** Although most young women are immunised, marked social inequalities in access to HPV vaccination initiation remain. Practical steps to address this are possible and should be implemented to reduce inequalities in primary prevention of cancers and to ensure equitable access to this important public health intervention.

Keywords: young women; HPV; vaccination; inequalities; disparities; initiation

#### Introduction

Evidence of the effectiveness of vaccination against human papillomavirus (HPV) in preventing infection, pre-invasive cervical disease, anogenital warts and, potentially, invasive HPV-associated cancers is accumulating. Vaccine programmes with high uptake have also been shown to achieve herd protection.<sup>1</sup> While high income countries have made significant progress in primary prevention of cervical cancer through vaccination, inequalities in HPV vaccine uptake remain.<sup>2</sup> These are of concern particularly given the greater risk of cervical cancer among women from more disadvantaged and ethnic minority backgrounds who are also less likely to attend cervical screening.<sup>2,3</sup> It has been suggested that ethnic inequalities in cervical cancer may widen over the next 20-50 years, should ethnic inequalities in screening coverage and HPV vaccine uptake persist.<sup>4</sup>

In the UK, HPV vaccination for young women aged 12-13 years - mainly delivered through a schoolbased programme - was introduced in 2008, initially as a three-dose and – from 2014 – as a twodose schedule. <sup>5</sup> In 2019 the HPV vaccine programme was extended to include young men aged 12-13 years. Although 87% to 93% of young women in the four UK countries are reported to receive at least one dose of the vaccine, uptake is lower among those living in the most deprived areas. <sup>6</sup> However, evidence from the UK is limited as most studies are conducted in selected areas only, and are ecological in design, employing area- or school-level measures of socioeconomic disadvantage or ethnicity which precludes adjustment for confounding of these two characteristics at the level of the individual. In addition, with some exceptions, <sup>7,8</sup> few have examined type of school attended, or uptake among those who are not in mainstream education with little or no information about uptake among young women who are or have been excluded from school.

We used data from a contemporary UK-wide cohort with individual level cross-sectional data to examine inequalities in initiation of the HPV vaccination schedule. We hypothesised that HPV vaccine initiation would be lower among young women with parents from ethnic minority backgrounds, and among those living in low income households, not attending or excluded from school. We also examined reasons given by parents for non-initiation.

#### Methods

## Study design

We used cross-sectional data from the Millennium Cohort Study (MCS), a prospective UK-wide cohort of children born between September 2000 and January 2002 in the UK. A stratified clustered sampling design was employed to over-represent children born in disadvantaged areas, from ethnic minority groups and from Northern Ireland, Scotland and Wales.<sup>9</sup>

#### Study population

When the cohort child was aged nine months, 18,552 (68.1%) of 27,257 families contacted were interviewed at home and demographic, social and health information obtained. At the sixth interview, carried out when the cohort members were aged 14 years, 11,726 (76.3%) of 15,369 potentially eligible families were interviewed comprising 11,884 young people (supplementary Figure 1). After excluding 308 twins or triplets and 5,881 boys (hereafter referred to as young men) we included information reported by parents for 5,695 14 year old singleton girls (hereafter referred to as young women) comprising 96.0% of all young women taking part and whose parents were interviewed. These young women were eligible to have received a first dose of HPV vaccine at age 12-13 years between 2012 and 2015. Young men were not included as they were not eligible for the vaccine until 2019.

# Outcomes

We defined the primary outcome for this study - initiation of HPV vaccination – as an affirmative response by the interviewed parent to the following question: *"Since the last interview when [^name] was [^age of cohort member at last interview], has she had the HPV (Human Papilloma virus) vaccination?"* The parent interviewed was the natural mother in the majority (92.1%) of interviews.

Parents reporting no HPV vaccination initiation were asked: "Why did she not have the HPV vaccination?" Interviewers recorded their responses verbatim. These responses were initially coded into one of 16 reasons by the MCS study team, and subsequently recoded by the authors into three mutually exclusive categories: active decisions; practical reasons; and other reasons based on previous MCS immunisation studies and on evidence for reasons for non uptake of HPV vaccine. <sup>10, 11</sup>

#### Explanatory variables

At the age 14 interview, parents were asked to select their own ethnic background from a list of 2011 Census categories. For this analysis, we created eight mutually exclusive groups: Any White, Any Mixed, Indian, Pakistani, Bangladeshi, Black Caribbean, Black African, and Any Other ethnic groups (Other Black, Other Asian, Chinese and Other). Parents were also classified as having any religious faith (yes, no) based on self-report.

We categorised young women as attending a state-maintained or fee-paying school, or as not attending school (including those not in school at all or home schooled). We classified young women as ever or never permanently or temporarily excluded from school based on parental report. We used household income quintiles created by the MCS study team from parentally reported information at the age 14 interview and using Organisation for Economic Co-operation and Development equivalised household income quintiles, based upon the UK income distribution. <sup>12</sup>

## Statistical methods

We described HPV vaccination initiation status for the study population by parental ethnic background and religious faith, school type, and history of school exclusion and reported reasons given for non-initiation. We conducted logistic regression to estimate the log odds and 95% confidence intervals of having initiated HPV vaccination by parental ethnic background, parental religious faith, type of school attended, school exclusion history, and household income for children with complete data. All analyses were adjusted for cohort member's age (in years) at interview. Analyses were weighted to take account of survey design and attrition of the cohort between successive interviews, using the 'svyset' command and were performed using Stata/SE 15 (Stata Corporation, Texas, USA).

## Ethics approval

Approval for the sixth MCS interview was granted by the National Research Ethics Service Research Ethics Committee London - Central (ref: 13/LO/1786). No further approval was required for this analysis.

### Results

## Characteristics of the sample

Most parents were from any White background, with parents from Pakistani background being the second most frequently reported group (Table 1), with the proportion of parents reporting all other ethnic groups lower than 3%. Over 90% of young women attended a state-maintained school at the time of interview, with a small number (n=23) receiving home schooling or not in school. Parents of 197 young women (5.1%) reported that their daughter had ever been temporarily or permanently excluded from school. Under half of parents reported any religious faith (supplementary Table 1). As expected, the sample was distributed evenly across household income quintiles. At the time of interview carried out at a median age of 14 years, most young women (n=5265, 92.3%) were reported to have initiated HPV vaccination.

(Table 1).

#### Associations with initiation of HPV vaccination

In unadjusted analyses, young women living in poorer households or with parents from ethnic minority backgrounds or with parents reporting any religious faith were less likely to have initiated HPV vaccination, as were those not attending school, or with a history of school exclusion (Table 2). Specifically, those whose parents were from Bangladeshi, Pakistani, Black African and 'Any Other' ethnic backgrounds were less likely to have initiated HPV vaccination than those with parents from any White ethnic background, as were those whose parents reported any religious faith. Young women living in households in the lowest two income quintiles were less likely to have initiated HPV vaccination than those in the highest-income quintile, and those not attending school or with a history of ever having been excluded from school, were less likely to have initiated HPV vaccination compared to those attending a state-maintained school.

In fully adjusted analyses, socioeconomic status, as assessed by household income, showed a marked and strong gradient with initiation of HPV vaccination, with young women living in the poorest households less likely to have initiated vaccination (Figure 1; Table 2). Young women whose parents were from Black African or Any Other ethnic backgrounds, and those who did not attend school or who had a history of school exclusion were also less likely to have been vaccinated.

# Reasons for HPV vaccine non-initiation

More than half (n=219; 53.3%) of parents reporting a reason for non-initiation of HPV vaccination in their daughters gave reasons consistent with having made an active decision: most commonly this was either because the young woman, or her parent, did not want to have the vaccination (Table 3). Practical reasons were reported by around one quarter (n=90, 22.6%), predominantly because their daughter had not been at school at the time of vaccination or – to their knowledge - had not received an offer to be vaccinated.

## Discussion

#### Main findings

Our findings from this large, UK-wide, contemporary cohort confirm that – while most 14-year-old young women had initiated HPV vaccination – significant socio-economic and ethnic inequalities in initiation remain. Notably, those living in the poorest households and with parents from Black African and 'Other' ethnic backgrounds were most at risk of being unvaccinated, as were those not attending mainstream school. Our finding that risk of non-initiation is increased among those temporarily or permanently excluded from school has not been previously reported. We found no differences according to whether parents did, or did not, report a religious faith. Of those parents reporting a reason for non-initiation of HPV vaccination, just over half reported a conscious decision, with a significant proportion of the remainder citing practical reasons.

These findings are of public health concern given the higher incidence of cervical cancer and the lower use of screening by socially disadvantaged women. They, also have implications for the expanded school HPV vaccination programme given the reported gender and ethnic differences in permanent and fixed period exclusions from schools. <sup>13</sup>

#### Strengths and Limitations

This is, to our knowledge, the first UK-wide study to examine inequalities in initiation of HPV vaccination using individual-level data on socioeconomic status, parental ethnic background and religious faith, school setting and school exclusion. We were able to use this rich data to mutually adjust for socioeconomic and demographic variables at the individual level and to include young women who were not attending, or were previously or currently excluded from, school. In particular, we avoided some of the limitations of area-based measures of deprivation employed in most other UK studies by using a measure of household poverty, derived from direct parental report. We were also able to examine parental ethnic background using specific ethnic groups selected by parents themselves, rather than broad ethnic categories, or area or school-level measures of ethnic density, and to adjust for parent-reported religious faith. Measures of active religious observance were lacking, the small sample sizes across different faiths did not permit analysis of specific religions, and information on whether the school attended was a faith school was not available. While our finding of lower initiation in young women who were not in school is based on a small sample, it is consistent with findings from a previous regional study reporting lower vaccine uptake among those not in mainstream education.<sup>7</sup>

HPV vaccination status was reported by the parent and could not be compared directly with health records; however we have previously found very good agreement between parental report and routine health records for childhood vaccinations in this cohort.<sup>14</sup> While parents were not asked about completion of the HPV vaccine course, similar patterns of inequalities in initiation and completion have been reported.<sup>15, 16</sup>

## Comparison with other studies

Direct comparison with other UK based studies reporting inequalities is limited as these have usually been ecological in design using area- or school-based measures of socioeconomic status and ethnic background. Our findings suggest that, with the exception of parents from Black African or 'Other' backgrounds, associations of lower HPV vaccine initiation with other parental ethnic backgrounds and with parental religious faith reflect socioeconomic disadvantage.

Our finding that young women who had been temporarily or permanently excluded from school were at increased risk of being unvaccinated adds significantly to the limited literature on this factor. Fisher et al reported lower HPV vaccine uptake among young women receiving education in non-mainstream settings in the south west of England, however this study did not include those with temporary or permanent exclusions. <sup>7</sup> Although a relatively small group in our study, this finding is important given concerns about the increasing use of exclusion in UK secondary schools, particularly of young men who are now included in the HPV vaccine programme, and those from ethnic minority backgrounds. <sup>13</sup>

In our study, active decision-making played the larger role in reasons given for non-initiation. Although the MCS study design precluded a more in-depth investigation of these reasons, similar findings have been reported from other studies of HPV vaccine acceptance as well as of childhood vaccines more generally, with concerns about the safety or perceptions of the necessity of vaccination cited<sup>-16-18</sup> Importantly, practical reasons, specifically difficulties with access, accounted for one quarter of the reasons for non-initiation. Reasons given for non-initiation in this study are potentially modifiable. There is evidence of the value of a strong recommendation from a health professional for increasing acceptance<sup>19</sup>, and GP-endorsement of the vaccine invitation letter might be one way to achieve this in school-based programmes where there is usually no opportunity for a face-to-face conversation prior to giving consent. Health promotion messages should emphasise the importance of timely and complete vaccination for optimal protection against infection with HPV.<sup>20</sup> Parents and their daughters need ready access to service providers who are equipped to effectively respond to vaccine questions and concerns (e.g. about safety and side-effects).<sup>21</sup>

#### Implications for policy and practice

Understanding the reasons for non-initiation of HPV vaccination and developing interventions to engage parents and young women from groups at risk of low HPV vaccine uptake is central to reducing inequalities. It is therefore important that policy makers, commissioners and practitioners are aware of these inequalities and the groups at higher risk of non-initiation. In one interview study, school nurses reported that - despite being aware of evidence from population studies – they did not consider ethnic background or social disadvantage to be important factors for not vaccinating, although they were aware that non-attendance at school was.<sup>22</sup>

Practical steps to reduce inequalities include interventions to optimise communications with parents, and alternative approaches to consent. The introduction of a local policy for verbal consent by parents and self-consent by young women shows promise as an effective intervention to reduce social inequalities in uptake.<sup>23</sup> Ensuring equity of access to protection against HPV infection for all requires timely and systematic identification and proactive contact with young women who have not been vaccinated, ensuring that those educated outside mainstream settings are included in the vaccination offer. This could be facilitated with near real-time data sharing between schools and general practitioner or community health services to enable follow up with further offers of discussion and vaccination. Such information sharing would also create an enduring primary care health record of their immunisation status which can be accessed by young women for their future health care, enabling fully informed decisions about cervical cancer screening and awareness of immunisation status throughout the life course.

Research among school nurses has reported their efforts to reduce inequalities in HPV vaccine uptake. These include persistently chasing young women to complete the vaccine course, opportunistic vaccination and holding 'mop-up' clinics at times and places to suit the convenience of young women, which for those out of education, includes in off-school premises or outside school hours. <sup>24</sup> However, such approaches require extra resource and that staff involved in school vaccination programmes understand the population needs of the local area.

## Unanswered questions and future research

Future research is needed to define and test approaches for improving uptake among young women who have not received HPV vaccine, including those who are not being educated in mainstream settings or have been excluded from school. This will also be important in order to minimise inequalities for boys who are now being offered HPV vaccine in the UK. Further work is needed to

examine the role of attendance at faith schools given a recent report of lower rates of vaccination among those attending certain faith schools.<sup>8</sup>

# Summary

Although most young women are immunised, marked inequalities in HPV vaccination initiation remain, with those living in poor households, not in mainstream education, or excluded from school at higher risk of being unvaccinated. Practical steps to address this are possible and should be implemented to reduce inequalities in primary prevention of cancers and to ensure equitable access to this important public health intervention.

	n	%⁵ (95% Cl⁵)	
Age at interview in years		78 (9578 CF)	
13	1349	22.7 (21.1,24.3)	
14	4346	77.3 (75.7,78.9)	
HPV vaccination initiation status <sup>1</sup>	13 10	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	
Yes	5265	92.3 (91.2,93.2)	
No	399	7.2 (6.4,8.1)	
Don't know	26	0.5 (0.3,0.9)	
Parental ethnic background <sup>2</sup>		( / /	
Any White background	4736	85.7 (82.4,88.5)	
Any Mixed background	56	0.9 (0.7,1.3)	
Indian	148	1.8 (1.3,2.7)	
Pakistani	311	3.8 (2.3,6.2)	
Bangladeshi	135	1.4 (0.8,2.5)	
Black Caribbean	65	1.4 (0.9,2.1)	
Black African	117	2.4 (1.6,3.7)	
Any Other background	119	2.1 (1.5,3.1)	
Parental religious faith <sup>3</sup>			
No religious faith	2643	54.1 (51.2,56.9)	
Any religious faith	3051	45.9 (43.0,48.7)	
Household income quintile <sup>4</sup>			
Lowest	958	19.1 (16.8,21.8)	
2	998	20.6 (18.9,22.3)	
3	1154	20.4 (19.0,21.8)	
4	1277	19.3 (17.9,20.8)	
Highest	1303	20.6 (18.8,22.6)	
History of school exclusion			
No	5498	94.9 (93.9,95.8)	
Yes	197 5.1 (4.2,6.1)		
School type			
State-maintained school	5299	93.9 (92.4,95.1)	
Fee-paying school	373	5.6 (4.4,7.1)	
No school	23	0.5 (0.3,0.9)	

Table 1 – Characteristics of 5695 young women participating in the age 14 interview

<sup>1</sup>HPV vaccination initiation status missing for 5 young women.
 <sup>2</sup>Ethnic background missing for 8 parents.
 <sup>3</sup>Parental religious faith was missing for one parent.
 <sup>4</sup>Household income quintile missing for 5 young women.
 <sup>5</sup>Weighted proportions.
 <sup>6</sup>95% confidence interval

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	HPV va	HPV vaccination initiatedHPV vaccination not initiatedN=5265N=399		Unadjusted OR	Adjusted OR <sup>1</sup>	
	n	% (95% Cl <sup>2</sup> )	n	% (95% Cl <sup>2</sup> )	OR (95% Cl <sup>2</sup> )	OR (95% Cl <sup>2</sup> )
Parental ethnic background						
Any White background (ref.)	4438	93.6 (92.5,94.5)	280	6.4 (5.5,7.5)	1	1
Any Mixed background	50	93.2 (83.6,97.3)	6	6.8 (2.7,16.4)	0.94 (0.35,2.51)	1.03 (0.37,2.87)
Indian	136	92.3 (84.2,96.5)	12	7.7 (3.5,15.8)	0.83 (0.36,1.92)	0.87 (0.37,2.04)
Pakistani	269	90.7 (87.4,93.1)	35	9.3 (6.9,12.6)	0.67 (0.45,0.98)	1.09 (0.67,1.75)
Bangladeshi	112	86.1 (80.3,90.4)	21	13.9 (9.6,19.7)	0.42 (0.27,0.67)	0.66 (0.39,1.13)
Black Caribbean	55	85.5 (71.4,93.3)	10	14.5 (6.7,28.6)	0.41 (0.16,1.01)	0.54 (0.20,1.44)
Black African	98	84.9 (75.7,91.0)	18	15.1 (9.0,24.3)	0.39 (0.21,0.72)	0.49 (0.26,0.95)
Any Other background	99	81.0 (70.4,88.4)	17	19.0 (11.6,29.6)	0.29 (0.16,0.55)	0.34 (0.17,0.66)
Missing	8		0			
Parental religious faith						
No religious faith (ref.)	2466	93.6 (92.4,94.7)	165	6.4 (5.3,7.6)	1	1
Any religious faith	2798	91.7 (90.4,92.9)	234	8.3 (7.1,9.6)	0.76 (0.59,0.97)	0.80 (0.60,1.06)
Missing	1		0			
Household income quintile						
Highest (ref.)	1239	95.5 (93.8,96.7)	106	4.5 (3.3,6.2)	1	1
4	1208	94.9 (93.4,96.1)	95	5.1 (3.9,6.6)	0.89 (0.60,1.33)	0.89 (0.61,1.30)
3	1074	93.6 (91.5,95.2)	71	6.4 (4.8,8.5)	0.70 (0.46,1.06)	0.72 (0.47,1.10)
2	901	90.7 (88.4,92.6)	66	9.3 (7.4,11.6)	0.46 (0.31,0.70)	0.49 (0.33,0.73)
Lowest	841	89.0 (86.4,91.1)	61	11.0 (8.9,13.6)	0.38 (0.27,0.55)	0.44 (0.30,0.64)
Missing	2		0			
History of school exclusion						
No (ref.)	5099	93.2 (92.3,94.0)	368	6.8 (6.0,7.7)	1	1
Yes	166	85.2 (78.9 <i>,</i> 89.9)	31	14.8 (10.1,21.1)	0.42 (0.27,0.66)	0.47 (0.29,0.76)
School type						
State-maintained (ref.)	4914	93.0 (92.1,93.8)	359	7.0 (6.2,7.9)	1	1
Fee-paying	339	92.0 (88.0,94.8)	33	8.0 (5.2,12.0)	0.87 (0.55,1.37)	0.65 (0.40,1.04)
Not attending school	12	61.1 (32.5,83.7)	7	38.9 (16.3,67.5)	0.12 (0.04,0.39)	0.11 (0.04,0.33)

 Table 2 Unadjusted and adjusted odds ratios for HPV vaccination initiation by age 14 interview (n=5654)

<sup>1</sup>Mutually adjusted for parental ethnic background, parental religious faith, household income quintile, history of school exclusion, school type, and young women's age at interview in whole years. <sup>2</sup>95% confidence interval.

Table 3: Reasons given for not initiating HPV vaccination (N=399)

	n¹	Weighted % <sup>2</sup> (95% Cl <sup>3</sup> )
Conscious decisions	219	53.3 (46.7,59.8)
Young person did not want to have it	39	11.8 (8.2,16.6)
Parent doesn't want young person to vaccinate for unspecified reasons	51	11.1 (8.2,14.9)
Fear of needles/injections/pain <sup>4</sup>	32	10.0 (6.4,15.1)
Doesn't believe in vaccinations	38	7.5 (5.1,10.8)
Concern about side effects	20	4.5 (2.7,7.3)
Considered unnecessary	7	2.1 (0.8,5.2)
Thinks better done when older	10	1.7 (0.8,3.5)
Wanted more info on pros/cons	9	1.7 (0.8,3.7)
Perceived vaccine contraindication	6	1.4 (0.5,3.7)
Religious beliefs	4	1.1 (0.4,2.8)
Refused for unspecified reasons	3	0.5 (0.1,2.3)
Practical reasons	90	24.1 (19.5,29.4)
School awaiting/not give vaccinations	51	12.5 (9.0,17.1)
Away from school that day and missed it	39	11.6 (8.2,16.1)
Other	90	22.6 (17.8,28.2)
Don't know	44	9.8 (6.6,14.2)
Vague irrelevant answer	31	8.0 (5.3,11.9)
Other reason	15	4.8 (2.5,8.9)

<sup>1</sup>Total number who had not initiated HPV vaccination at the age 14 interview=399. <sup>2</sup>Weighted percentages. <sup>3</sup>95% confidence interval. <sup>4</sup>Two respondents were coded as giving more than one reason for non-initiation of HPV vaccination (fear of needles and young person did not want it; fear of needles and other reason) and these were coded as 'fear of needles, injections and pain'.

# Figure 1: Adjusted odds of HPV vaccination initiation



Mutually adjusted for parental ethnic background, parental religious faith, household income quintile, history of school exclusion, school type and young women's age at interview in years.



<sup>1</sup>Due to death, emigration, permanent refusal or sensitive family circumstances. <sup>2</sup> 5,953 young men; 5,931 young women. Data for individual young people not available prior to the point of productive interview.

Parental religious faith	n	Weighted % <sup>1</sup>
Christian	2306	35.9
Muslim	566	7.4
Hindu	93	1.1
Sikh	51	0.7
Jewish	10	0.2
Buddhist	11	0.2
Other	14	0.4
None	2643	54.1

<sup>1</sup>Weighted proportions.

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# Contributors

HB, CD and NF designed the study and analysis which was conducted by NF. Analysis was critically reviewed by all authors. HB and CD led the writing of the manuscript which was critically reviewed by all authors. The corresponding authors (HB and CD) attest that all listed authors meet authorship criteria. HB and CD are the guarantors.

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# **Declaration of Interests**

Professor Dezateux, Ms Firman, Drs Waller, Forster and Marlow declare they have no competing interests. Professor Bedford declares she is a member of the National Institute for Health and Care Excellence vaccine uptake in the general population guideline committee.

# **Data Sharing Statement**

All MCS data used in this analysis are available from UK Data Service, University of Essex: http://doi.org/10.5255/UKDA-SN-8156-4