

TITLE: A qualitative systematic review of factors influencing parents' vaccination decision-making in the United Kingdom

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SOURCES OF SUPPORT: AF and LR are funded by a Cancer Research UK – BUPA cancer prevention Fellowship awarded to AF (C49896/A17429). JW, LM and AC are funded by a Cancer Research UK Career Development Fellowship awarded to JW (C7492/A17219). HB is funded by the Higher Education Council for England. SS is funded by a Cancer Research UK post-doctoral Fellowship (C42785/A17965).

RESEARCH HIGHLIGHTS

- This qualitative systematic review identified 2 types of vaccine decision-making
- Some parents' decision-making was non-deliberative, while others' was deliberative
- Findings will help design interventions to enhanced informed uptake of vaccines

1 **TITLE**

2 A qualitative systematic review of factors influencing parents' vaccination decision-making
3 in the United Kingdom

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ABSTRACT

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Background: High uptake of vaccinations is crucial for disease prevention. Although overall uptake of childhood immunisations is high in the United Kingdom (UK), pockets of lower uptake remain. Novel systematic methods have not been employed when reviewing the qualitative literature examining parents' vaccination decisions.

Aims: We aimed to conduct a qualitative systematic review of studies in the UK to understand factors influencing parental decisions to vaccinate a child.

Methods: On 12/2/14 we searched PsycINFO, MEDLINE, CINAHL plus, Embase, Social Policy and Practice and Web of Science for studies using qualitative methods and reporting reasons why parents in the UK had or had not immunised their child. Participant quotes and authors' interpretations of qualitative data were extracted from the results of articles. Thematic synthesis was used to develop higher-order themes (conducted in 2015).

Results: 34 papers were included. Two types of decision-making had been adopted: non-deliberative and deliberative. With non-deliberative decisions parents felt they had no choice, were happy to comply and/or relied on social norms. Deliberative decisions involved weighing up the risks and benefits, considering others' advice/experiences and social judgement. Emotions affected deliberative decision-making. Trust in information and vaccine stakeholders was integral to all decision-making. Practical issues affected those who intended to vaccinate.

29 Conclusions: Parents adopted two different approaches to decision-making about childhood
30 vaccinations. By understanding more about the mechanisms underpinning parents'
31 vaccination behaviour, in collaboration with vaccine stakeholders, we can better design
32 interventions to enhance informed uptake.

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34 **Keywords:** Thematic synthesis, Vaccination, Parents, Patient Acceptance of Health Care,
35 Review [Publication Type].

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INTRODUCTION

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Vaccination is a vital public health intervention for the prevention of communicable diseases. Its effectiveness has been demonstrated by the eradication of smallpox, the near eradication of poliomyelitis and significant reductions in the incidence of vaccine preventable diseases.^{1,2} High uptake is crucial to the success of vaccination programmes and if a sufficient proportion of a population are vaccinated, protection is also provided to those who have not been vaccinated (herd immunity). In the United Kingdom (UK), uptake of recommended childhood vaccinations is high,^{3,4} however disease outbreaks have occurred where pockets of susceptibility remain.⁵

Under most circumstances, UK parents are required to provide consent for children under the age of 16 to receive vaccinations (although individuals <16 years can provide consent if they are deemed competent to do so).⁶ Understanding why parents do or do not accept vaccinations is complex. Some parents may unquestioningly accept or reject vaccinations, while others experience uncertainty, which may delay or result in rejection of immunisation and some experience barriers that prevent immunisation.⁷⁻¹⁰

There is a pressing need for the development of interventions to address sub-optimal vaccination uptake among those experiencing uncertainty about vaccines.¹¹⁻¹⁵ Behavioural medicine has afforded researchers with the tools to develop effective interventions, but to do so it is important to understand the determinants of vaccination uptake. This is best achieved by rigorously reviewing the existing literature, much of which in this field has been qualitative (providing a rich and in-depth picture of the research area).

61 While qualitative systematic reviews have been published that explore the determinants of
62 vaccination uptake, novel approaches to systematically synthesising qualitative data have not
63 been adopted (to our knowledge one review has used such techniques to synthesise data
64 pertaining to HPV vaccination¹⁶ and one pertaining to combination vaccines¹⁷). While
65 traditional systematic reviews aim to collate and summarise existing knowledge, methods for
66 synthesising qualitative literature attempt to go beyond simple aggregation. Through
67 comparison across studies and conceptual interpretation, methods for qualitative synthesis
68 seek to generate a new and fuller understanding of the phenomenon of interest, while
maintaining rigorous and transparent methods and standards.¹⁸⁻²¹ Pa
70 decisions are context-specific,⁷ so any exploration of these decisions needs to be done by
71 country, although the decision-making processes are likely to have commonalities across
72 contexts and findings can be extrapolated to other similar countries. We present findings of a
73 qualitative systematic review that aimed to understand the factors influencing UK parents'
74 decisions to vaccinate a child.

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MATERIALS AND METHODS

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We conducted a systematic review of qualitative studies exploring factors that influence parents' decisions to vaccinate a child as part of the UK childhood immunisation programme.²² On 12/2/14 we comprehensively searched PsycINFO, MEDLINE (Ovid version of PubMed), CINAHL plus, Embase, Social Policy and Practice and Web of Science for studies conducted in the UK at any time, examining vaccination and using qualitative methods (see Supplementary Material for search terms and inclusion/exclusion criteria). Reference lists of included articles were searched for relevant articles and citation searching was performed using Web of Science.

Articles were included if they reported qualitative findings (e.g. from interviews, focus groups, free-text survey responses) and were published at any time in peer reviewed journals in English. We excluded letters, dissertation abstracts, book chapters, reviews and commentaries. Outcome data (quotes that had been reported and author interpretation of qualitative data) were extracted from the results sections of articles/abstracts.

After duplicates were removed, titles were reviewed by XX (anonymised author initials) to exclude articles that obviously did not meet inclusion criteria. All abstracts and then full text articles were reviewed by XX, XX, XX, XX and XX (anonymised author initials). 'Excluded' articles were checked by another researcher and disagreements resolved by discussion.

Thematic synthesis was used to identify important and recurrent themes (conducted in 2015).²³ This method was developed based on the qualitative analytical technique 'thematic analysis' and borrows from traditional systematic review methods. It was developed with the

102 aim that the findings of reviews using the method should be usable and accessible to policy
103 makers and researchers, and could be used to develop interventions. Firstly XX, XX and XX
104 (anonymised author initials) coded one third of the text each, line-by-line and developed
105 descriptive themes following discussion. These were applied to the data by XX, XX and XX
106 (anonymised author initials). Finally, analytical themes were generated by discussing the
107 descriptive themes at length (XX, XX, XX, XX and XX) until consensus on interpretation
108 was reached. Analysis was conducted using NVIVO.²⁴ Study quality was assessed using the
109 CASP tool.²⁵ Studies with scores of 0-4 were high risk of bias, and 5-9 low risk. Findings are
110 reported following PRISMA (Supplementary Material) and ENTREQ guidelines.^{26, 27}

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RESULTS

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114 The search identified 934 articles. Excluding duplicates (n=262), 672 titles were assessed.
115 There were 559 articles excluded based on their title, 66 based on their abstract and 25 after
116 reviewing the full text. Hand searching reference lists and citation searching identified an
117 additional 12 articles. In total 34 articles were included (Figure 1, Table 1, Supplementary
118 Material), published between 1994 and 2014 and comprising a total of 1,997 participants
119 (range: 5-950). Most (>91%) participants were mothers. The majority of articles focused on
120 MMR (n=17) or immunisation in general (n=11) (HPV 5, influenza 1, DTaP/IPV/Hib 1).
121 Most used interviews (n=18) or focus groups (n=9) (free text questionnaire responses 3,
122 participant observation 1). Where described, data were frequently analysed using thematic
123 analysis (n=7), grounded theory (n=6), constant comparison (n=6) or framework analysis
124 (n=3) techniques (5 other articles each used a different analytic technique). Thirty articles
125 were low risk of bias and four high risk of bias.

126
127 -FIGURE 1-

Overview

130 The thematic synthesis identified two types of decision-making used by parents: non-
131 deliberative and deliberative (Figure 2). These two approaches were not mutually exclusive
132 and there was evidence that some parents adopted both approaches at different times. Non-
133 deliberative decisions were those in which parents were happy to comply (theme 1), where
134 parents did not think they had a choice (theme 2) and/or relied on social norms (copying
135 others' behaviour) (theme 3). Deliberative decisions involved parents weighing up the risks
136 and benefits of vaccinating (theme 4), making an assessment of the appropriateness of
137 vaccinating their child based on others' advice/experiences (theme 5) and social judgement

138 (feeling responsible and fearing judgement by others) (theme 6). Parents' emotions (theme 7)
139 affected the themes within deliberative decision-making, and the media sometimes influenced
140 this. Trust (theme 8) (in information and vaccine stakeholders) was affected by the media and
141 influenced Themes 2-5. Finally, (regardless of whether decisions were non-deliberative or
142 deliberative) practical issues influenced whether those who intended to vaccinate their
143 children actually did so (theme 9). Quotes are presented within the text (with first author
144 name and whether it is an author/participant comment). Additional quotes are provided in
145 Supplementary Material.

146 -FIGURE 2-

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148 **Non-deliberative decision-making**

149 Most articles suggested parents spent much time considering their immunisation decisions;
150 however, some made non-deliberative decisions.

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152 **Theme 1: Compliant.**

153 For some, vaccination was seen as routine and this was positive. However, for others,
154 vaccinating their child was an act of compliance, although not necessarily perceived as
155 undesirable. Parents described being 'guided' to immunise and had accepted that complying
156 with recommendations was appropriate.

157 "Immunisation... was something you were prompted to do by the system as part of
158 the routine of having a baby, and you don't really think about" Johnson, author
159 comment.

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163 **Theme 2: Don't have a choice.**

164 Parents described feeling that they were under pressure to immunise, sometimes specifically
165 mentioning that they felt they had no choice (including incorrectly believing that vaccination
166 was a mandatory requirement for school-entry and fear of being removed from GP patient
167 lists).

168 "I think you just feel pressurized anyway by health visitor and doctors: 'this is the
169 thing to do, we are doctors, we know what's best'" Marlow, participant comment.

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171 **Theme 3: Social norms**

172 Social norms were used by parents as a heuristic (cognitive shortcut) for their decision-
173 making. Parents rationalised their decision because others they knew also did or did not
174 vaccinate or it was not the 'done' thing in their culture. Some parents suggested that they did
175 not do research before making a decision because they felt other parents had done this for
176 them.

177 "Women's risk perceptions were largely influenced by their cultural norms and these
178 made an important contribution to their decision not to accept HPV vaccination when
179 it was offered to them" Gordon, author comment.

180

181 **Deliberative decision-making**

182 **Theme 4: Weighing up the risks and benefits of vaccination**

183 One aspect of deliberative decision-making was weighing up the risks and benefits of
184 vaccination, balancing the risks of contracting the disease, the severity of the disease, the
185 effectiveness of vaccines and the risk of side-effects (Supplementary Material). This theme
186 has been discussed extensively in the vaccination literature, so findings are summarised and

187 presented fully in Supplementary Material. For most parents, vaccination decisions were a
188 balancing act, however, some felt that no level of risk was acceptable.

189 “Although it might be a very, very small percentage risk, it’s your child and if it gets
190 that, you have to deal with that for the rest of your life.” Brownlie, participant
191 comment.

192

193 Parents considered whether vaccination was necessary to prevent the disease in question,
194 based on their assessments of the severity of the disease (sometimes in relation to other
195 diseases or the child’s sex) and whether the child would be exposed to the disease. One
196 parent explained, “I su I was at home with him, for the first... year of life, I
197 knew that he wouldn’t be exposed to anything, he wasn’t going to a nursery or a child
198 minder... I knew that to some extent I had some degree of control over the people he was
199 exposed to and the germs he was exposed to” (Sporton, participant comment). Many diseases
200 were perceived not to be a particular threat in the UK. Some parents believed their
201 lifestyles/environment protected their child sufficiently without the need for vaccination or
202 alternatively provided reason to immunise. One mother explained “coming from a Muslim
203 background... we don’t have sex before marriage ... because of that reason I’d probably say
204 no...” (Marlow, participant comment about human papillomavirus (HPV) vaccination).

205

206 Knowledge of scientific reports, historical changes in disease prevalence, or a general trust in
207 medicine informed parents’ assessments of whether vaccines are an effective way to prevent
208 disease. Some parents held models of how the immune system works that were inconsistent
209 with the current medical model of immunology and for others their beliefs in God or fate
210 influenced their perceptions of vaccine efficacy.

211 “If children get measles, mumps, and rubella it helps build up their natural immunity,
212 and that’s better than the immunity built up by vaccines.” McMurray, participant
213 comment.

214

215 Parents carefully considered potential side-effects of a vaccine. Concerns about the safety of
216 particular vaccines were either extrapolated to other vaccines or caused parents to perceive
217 that some were lower risk than others.

218 “I’ve never heard anything adverse about the five-in-one ..., not like MMR is
219 constantly in the press. I never really hear about the five-in-one being bad, so erm I
220 don’t have an issue.” Tickner, participant comment.

221

222 Concern that vaccinations might cause side-effects made parents assess the level of risk to
their own child, considering fa

224 birth.

225 “the second one had lots of colds, he had allergies and eczema, and em, it just seemed
226 to be too much on his wee [little] immune system and I just felt it was too risky,
227 whereas the third one is a much more robust child...” Hilton, participant comment.

228

229 Parents conceptualised the mechanisms by which vaccines cause harm in three ways: 1) by
230 weakening the immune system or sending it into ‘over-drive’; 2) vaccine ingredients causing
231 harm; and 3) vaccines causing an increase in high-risk behaviour (relevant for viruses with a
232 ‘behavioural’ mode of transmission such as HPV).

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236 **Theme 5: Others' experiences and advice** (Supplementary Material)

237 Others' experiences shaped parents' vaccination decisions. Knowing other families who had
238 positive vaccination experiences encouraged parents to accept vaccination for their own
239 child. Some knew others who had negative experiences of the disease that vaccination was
240 aiming to prevent, which raised their perceptions of their own child's vulnerability.

241 "Debbie... recounted how two of her friends had young sons who had had MMR and
242 were 'fine'" Petts, author and participant comment.

243

244 Conversely, some parents had been influenced by others' experiences of vaccine side-effects,
245 which in some instances were considered severe. Although this did not always result in
246 parents deciding not to vaccinate their child, it caused anxiety. Specific to MMR vaccine,
247 parents who knew of children with autism were dissuaded from vaccination, presumably
248 through fear of their child developing the condition.

249 "...a bloke I work with, his brother had it and his brother has got autism. He swears it
250 was something to do with it." Petts, participant comment.

251

252 When parents knew of children who had not been vaccinated but remained healthy, they
253 sometimes perceived their own child as being less vulnerable to that disease and less in need
254 of vaccination. Similarly, parents who knew of others who had experienced the disease that
255 the vaccine was aiming to prevent, but who had not suffered long-term side-effects, did not
256 perceive the disease to be severe.

257 "no parents mentioned that they knew of anyone who had suffered long-term damage
258 [of contracting measles]. Indeed, their experiences of measles often rendered it a less
259 threatening disease." Hilton, author comment.

260

261 Others' advice influenced parents' vaccination decision-making, including their families,
262 particularly their mothers, as well as friends with older children.

263 "One described how her mother said 'Oh you know, whooping cough is not so bad,
264 you had whooping cough, you know. If there's any risk with the injections, don't get
265 it because whooping cough's fine'" Hilton, author and participant comment.

266

267 **Theme 6: Social judgement** (Supplementary Material)

268 Regardless of parents' decisions, many reasoned that their choice was part of being a 'good
269 parent'. Parents were sometimes aware that others (parents or health professionals) would
270 judge them according to this principle, and themselves judged others who made decisions
271 opposite to their own. Further pressure to accept vaccination was created through discourses
272 of the social responsibility to contribute to herd immunity. Parents often mentioned this as
273 secondary to protecting their child, but protecting the community was also reported as
274 influencing the decision to vaccinate. Non-immunising parents used a second discourse of
275 being a good parent, placing the wellbeing of their child above others to mitigate social
276 pressures.

277 "My own children's health and safety is more important than the impact on the
278 population." Casiday, participant comment.

279

280 Relatedly, in the context of the HPV vaccine (which protects against a sexually transmitted
281 infection) parents reasoned that vaccination could invoke social judgement and preferred
282 their child to remain unvaccinated over being stigmatised. One mother discussing the HPV
283 vaccine stated that she did not feel a social responsibility to contribute to herd immunity
284 because HPV is only transmitted through skin-to-skin contact.

285

286 **Theme 7: Emotions affecting decision-making** (Supplementary Material)

287 The role of others' advice/experiences, social judgement and weighing the risks and benefits
288 were all influenced by emotional responses that affected decision-making. Emotions were
289 only related to the act of making a deliberative decision. The media triggered emotional
290 responses, particularly regarding side-effects. Fear, worry and guilt surrounding vaccination
291 led some parents to decide against it or to defer the decision, whereas it motivated others to
292 vaccinate. Parents described anticipating that they would regret vaccinating, while others
293 anticipated regretting not vaccinating and some felt torn between the two.

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295 **Theme 8: Trust in vaccine information and stakeholders affects non-deliberative and**
296 **deliberative decisions** (Supplementary Material)

297 Parents discussed the issue of trust in relation to various key stakeholders and the information
298 they provide. Trust was crucial to whether parents were happy to comply (theme 1) and
299 whether to act in accordance with social norms (theme 3), or how parents interpreted the
300 'evidence' of the risks and benefits (t) and valued others' advice/experience (t).
301 As with Theme 4, this theme has been discussed extensively in the vaccination literature, so
302 findings are summarised and presented fully in Supplementary Material.

303

304 Parents' distrust in the government originated from historic health scares that remained in
305 their memories, believing that the government conceals information. One author stated that
306 "generally parents did not have confidence in statements issued by the government about the
307 safety of MMR and analogies were made with the BSE [Bovine Spongiform Encephalopathy]
308 crisis" (Evans, author comment). There was a perception that the government's motive for
309 promoting vaccination was a cost-saving activity. Parents who distrusted vaccination research

310 and drug development saw their children as being used as “guinea pigs” and disliked the
311 uncertainty of scientific research.

312 “I think, well how can they just say that and just, so confidently, you know, think the
313 atom is the smallest thing until they split it open and then it’s not and they can just so
quickly just change and I t

315 .” (Johnson, participant comment).

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Paren

318 financially rewarded for vaccine uptake, with one parent expressing “you're meant to trust
319 your doctor implicitly and yet... they're getting paid for having so many people vaccinated...,
320 and you start thinking 'well... who's got my wee [little] boy's best interests at heart?" (Hilton,
321 participant comment). Issues arising in the GP consultation, including rushed appointments,
322 lack of discussion and feelings of being pressurised also fostered distrust. However, some
323 parents trusted health professionals and more generally the NHS. Disclosure from health
324 professionals regarding their own child’s vaccination status facilitated vaccination and those
325 with a friend who worked as a health professional felt a deeper level of reassurance.

326

327 Information presented in the media attenuated parents’ trust in key vaccination stakeholders
328 and often dissuaded them from vaccinating. Parents in some articles had an attentional bias
329 towards negative information, dismissing scientific information.

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331 **Theme 9: Practical issues influence vaccination receipt post-decision** (Supplementary
332 Material)

333 Practical issues made vaccination difficult for parents who decided to obtain a vaccination for
334 their child. Difficulties included: travelling to the clinic, arranging childcare for other

335 children during the vaccination appointment, not receiving reminders about appointments,
336 lack of time (particularly for mothers who had returned to work), and practical features of
337 general practice (for example, being unable to get an appointment). For other parents, having
338 sufficient time to vaccinate and practical steps taken by healthcare providers facilitated
339 vaccination.
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DISCUSSION

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This qualitative systematic review identified two distinct types of decision-making about vaccination among parents in the UK: non-deliberative and deliberative. Non-deliberative decisions were those in which parents were happy to comply, felt they did not have a choice or followed social norms. These decisions were characterised by being quick, and not involving an explicit weighing up of the pros and cons of vaccination. By contrast, parents making deliberative decisions weighed up the risks and benefits of vaccination, considered others' advice/experiences and were affected by beliefs about social judgement. Parents making deliberative decisions were influenced by their emotions, in which the media also played a role. The review identified that trust was integral to non-deliberative and deliberative decisions, with trust in information and those offering vaccination influenced by portrayals of vaccinations in the media. Practical issues affected some parents who intended to vaccinate their children.

Kahneman's Two Systems approach and Fuzzy Trace Theory (separate, but closely aligned approaches) also suggest that individuals' decision-making occurs in two similar ways.^{28, 29} Individuals make effortful and conscious decisions (similar to deliberative decision-making), as well as automatic or gist-based decisions (akin to non-deliberative decision-making). In this review, some parents were seen to adopt both deliberative and non-deliberative decision-making at different times, suggesting that decision-making does not fall cleanly into an effortful/conscious approach versus an automatic approach. Use of each approach might be modulated by how familiar each vaccine context feels to parents (for example, does a vaccine 'feel' like a routine one, or is there something different for parents to consider?). Automatic decisions are driven in part by emotions²⁸, although this was not evident in the present review. Heuristics (or cognitive shortcuts) are used in automatic or gist-based decision-

366 making and have helped us to understand that decision-making is affected by how messages
367 about vaccination are presented (or ‘framed’). Individuals have a preference for avoiding
368 losses (e.g. mild vaccine side-effects) over gains (e.g. disease protection) for frequent
369 behaviours, but a preference for the reverse for one-off behaviours and this was reflected in
370 the present review.³⁰⁻³² However, determining whether and/or under what circumstances
371 framing increases vaccination uptake may be complex. A recent review of interventions to
372 increase intentions to receive HPV vaccination found no study to report a main effect of gain
373 versus loss framing, but interaction effects were reported.³³ In our review most data referred
374 to parents making deliberative decisions, which may be explained by the fact that the
375 majority of articles were published after the publication of a now retracted article in the
376 Lancet in 1998 that linked MMR to autism and bowel disease.³⁴ This may have biased our
377 results towards a focus on deliberative decision-making.

378

379 While there has been a move from encouraging patients to unquestioningly comply with
380 health professionals, towards making informed decisions,³⁵⁻³⁷ evidence suggests that
381 conscious/effortful thinking might not result in good decision-making²⁸ and our review
382 suggests that some people find this difficult. Furthermore, some parents are happy to go along
383 with the recommendations of vaccination experts without considering the decision further
384 and we know that the use of ‘presumptive’ communication (for example, ‘your child is due
385 for the HPV vaccine’) is associated with greater vaccine acceptance compared with
386 ‘participatory’ communication (for example, ‘what do you want to do about the HPV
387 vaccine?’).³⁸ Presumptive communication may shift parents into making a non-deliberative
388 decision, which although it may increase vaccine uptake, may not be the best way to promote
389 informed decision-making.³⁸ The ‘consider an offer’ approach, put forward to facilitate
390 patients making decisions about attending screening, might suit parents’ needs better.³⁹ In this

391 approach, communicators would recommend vaccination, discuss why it is being offered,
392 help parents assess the appropriateness of vaccination for their child and provide additional
393 information where needed. Parents can then respond to the recommendation in a manner that
394 suits them; some may accept the recommendation from a health professional, while others
395 may want further discussion. There may be a need for interventions to facilitate this
396 discussion, based on the findings of this review, so that health professionals can anticipate
397 and appropriately respond to parents' queries. Such interventions need to be developed in
398 collaborative partnership between parents, policy makers and health professionals. The
399 'consider an offer' approach will work best in settings involving parents and individual health
400 professionals (rather than community / school-based programmes). It must also be
401 acknowledged that health professionals will not always be a trusted source of advice and, as
402 suggested in our review, parents might defer to the media or other parents.

403

404 The findings of this review provide an understanding of the factors underlying parents'
405 vaccination behaviour and highlight targets that will help us to better design interventions to
406 enhance informed uptake. Of particular interest is the social aspect of vaccine decision-
407 making. Many parents who discussed making non-deliberative decisions had opted to
408 vaccinate their child, although some did so because they felt pressure to. However, others had
409 copied other parents and had not vaccinated their child. Some parents had involved others in
410 their deliberative decision-making. These findings highlight the importance of understanding
411 vaccination decision-making at a social level; the impact of one child being unvaccinated
412 may go beyond just that child being unprotected.

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415

416 **Limitations**

417 This study had limitations, particularly in relation to our method. Study quality was assessed
418 for the whole article, however some articles reported quantitative and qualitative findings so
419 our assessment may not truly reflect the qualitative aspects of the studies. The review focuses
420 on UK studies, and, while our findings might apply to other countries that have similar
421 programmes, decision-making among parents in different contexts may differ (such as in
422 countries where vaccines are not free-at-the-point-of-receipt and with different historical
423 vaccination experiences, for example, parents in the UK were largely unexposed to the
424 thimerosal scare in the USA about mercury content in multi-dose vials of vaccines).
425 However, the social psychology of non-vaccination decisions is likely to be comparable
426 between countries. Even within the UK, parents' attitudes differ across vaccines and will vary
427 by socio-demographic factors, which was not considered in this review. Relatedly, most
428 articles focused on MMR immunisation, which limits the extent to which we can generalise
429 our findings to other immunisations. The focus of papers on MMR in the UK is likely due to
430 the publication of the 1998 Lancet paper,³⁴ which resulted in a decrease in MMR uptake in
431 the UK and has been followed by outbreaks of measles.⁵ All but one of the included studies
432 were conducted after the publication of that paper, so our paper must be considered as an
433 appraisal of vaccination decisions in this era. A difficulty with any review is that researchers
434 do not have access to the raw data, so our interpretation is reliant on the original authors'
435 analyses and decisions about which quotes to report. Finally, our qualitative method does not
436 allow us to determine the frequency of each type of decision-making at a population level.

437

438 **Conclusions**

439 Our review identified two very different approaches to decision-making about childhood
440 vaccinations: deliberative and non-deliberative. Parents' balancing of the risks and benefits of

441 vaccination and their trust in immunisation providers are influential in their decision-making.
442 Some parents express concern about social judgement of not immunising and some parents'
443 decisions are bespoke to their perceptions of their child's vulnerability to infection and
vaccine side-effects. By understanding more about the mechanisms underlying pa
445 vaccination behaviour, in collaborative partnership with vaccination stakeholders, we can
446 better design interventions to enhance informed uptake.
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448 **Conflicts of interest:** None declared.

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TABLES

Table 1 - Characteristics of included studies

Lead author	Aim	Population of interest	Participants	Data collection period	Study design	Analysis	Vaccination of interest	Risk of bias
Anderson (2002)	To study the context of child care decision making by inner city and suburban mothers	Inner city and suburban mothers of new-borns	131; Female	Not described	Free text questionnaire responses	Not detailed but analytical process described	Childhood vaccination in general	High
Austin (2001)	To understand parents' experiences of deciding to have their child immunised	Parents of children aged 7-18 months who had recently been immunised	13; Male (2) and Female (11)	Not described	Semi-structured interviews	Staged process	MMR (other vaccines considered that are not part of UK programme)	Low
Austin (2008)	To hear parents' stories about immunising their children and to compare the views of parents of completely and incompletely immunised children	Parents of children aged 5-6 years	25; Male (1) and Female (24)	Not described	Focus groups	Spiral analysis	Childhood vaccination in general	Low
Brown (2012)	To explore parents' MMR decision-making	Mothers planning to accept, postpone or decline the first MMR dose for their 11-36 month old children	24; Female	June 2008 to March 2009	Semi-structured interviews	Modified grounded theory	MMR	Low

Table 1 Characteristics of included studies (continued)

			1998 & 2001	Focus groups	Not described	MMR	Low
Brownlie (2005)	To explore the role of trust in parents' vaccination decisions	Parents from different deprivation backgrounds and with children (aged 2-18 months) of different MMR invitation stages (pre/post)	85; Male (7) and Female (78)	Focus groups	Not described	MMR	Low
Casiday (2007)	To explore parents' decision-making about the MMR vaccination	Parents of young UK children	87; Male (10) and Female (77)	Focus groups and interviews	Not detailed but analytical process described	MMR	Low
Condon (2002)	To explore attitudes of ethnic minority parents to preschool immunisations, particularly first MMR vaccination	Mothers of children aged 16 months to 3 years of Pakistani, Somali and African-Caribbean ethnicity	21; Female	Semi-structured interviews and focus groups	Thematic analysis	Childhood vaccination in general	Low
Cunningham (1994)	To survey reasons for non-uptake and attitudes to immunisation and immunisation services within the orthodox Jewish community in London, UK	Parents from the orthodox Jewish community	67; Gender not described	Interviews	Not described	Childhood vaccination in general	High

Table 1 Characteristics of included studies (continued)

		Parents with children aged between 14 months and 3 years of age	48; Male (5) and Female (43)	Not described	Focus groups	Modified grounded theory and constant comparison	MMR	Low
Evans (2001)	To investigate what influences parents' decision-making regarding MMR immunisation and the impact of the controversy over its safety	Parents with children aged between 14 months and 3 years of age	48; Male (5) and Female (43)	Not described	Focus groups	Modified grounded theory and constant comparison	MMR	Low
Gardner (2010)	To extract underlying beliefs towards MMR vaccination from UK parents' views towards potential motivational and organisational interventions	Parents living in London	28; Male (8) and Female (20)	Summer 2008	Focus groups	Thematic analysis	MMR	Low
Gordon (2011)	To explore attitudes to human papillomavirus (HPV) vaccination and reasons for accepting or declining the vaccine in the British Jewish community	Jewish mothers of girls offered the HPV vaccination	20; Female	June 2010 to September 2010	Interviews	Framework analysis	HPV	Low
Guillaume (2004)	To examine the MMR vaccination scare, its impact on parents of young children, and its effect on their need for information	Parents of children <5 years of age	17; Male (1) and Female (16)	February 2002	Semi-structured interviews	Not detailed but analytical process described	MMR	Low

Table 1 Characteristics of included studies (continued)

Henderson (2008)	To assess reasons for low uptake of immunisation among orthodox Jewish families	Mothers from the orthodox Jewish community	25; Female	May 2003	Interviews	Modified grounded theory	MMR (and two vaccines not included in UK programme)	Low
Henderson (2011)	To explore parents' and girls' understandings of the protection offered by the HPV vaccine, or the need for future screening	Parents of 12 and 13 year old daughters who had been offered HPV vaccination	26; Male and Female	July 2009 to June 2010	Semi-structured interviews	Thematic analysis and constant comparison	HPV	Low
Hill (2013)	To ascertain factors influencing parental immunisation decision making	Parents of children who have received the MMR vaccination	5; Male (1) and Female (4)	July 2010	Semi-structured interviews	Modified grounded theory	MMR	Low
Hilton (2006a)	To examine how British parents conceptualise the notion of 'immune-overload' and how they relate this concept to their own children	Parents with a range of ages, socio-economic circumstances, and family circumstances	72; Male (8) and Female (64)	November 2002 to March 2003	Focus groups	Constant comparison	Childhood vaccination in general	Low
Hilton (2006b)	To explore parents' understandings of the diseases included in the current UK Childhood Immunization Programme	Parents with a range of ages, socio-economic circumstances, and family circumstances	72; Male (8) and Female (64)	November 2002 to March 2003	Focus groups	Constant comparison	Childhood vaccination in general	Low

Table 1 Characteristics of included studies (continued)

Hilton (2007)	To examine parents' views on the role the media, politicians and health professionals have played in providing credible evidence about MMR safety	Parents with a range of ages, socio-economic circumstances, and family circumstances	72; Male (8) and Female (64)	November 2002 to March 2003	Focus groups	Constant comparison	MMR	Low			
Johnson (2014)	To explore mothers' engagement with advice around the combined MMR vaccine	Mothers of children aged 12-18 months	5; Female	2011	Focus group	Thematic analysis	MMR	Low			
Kennedy (2014)	To explore vaccination views in Scotland among parents across three vaccines	Mothers resident in Scotland	15; Female	2008 to 2010	Interviews	Thematic analysis	MMR and HPV (also H1N1, not included in review)	Low			
Lewendon (2002)	To identify local factors contributing to poor immunisation uptake	Parents in areas of low vaccine uptake in South Devon, UK	Not described	1998 to 1999	Focus groups	Not described	Childhood vaccination in general	High			
Marlow (2009a)	To assess HPV awareness and HPV vaccine acceptability in a sample of women representing the major UK ethnic minority groups	Women from various ethnic backgrounds	950; Female	July 2008 to August 2008	Structured questionnaire interviews	Not detailed but analytical process described	HPV	Low			

Table 1 Characteristics of included studies (continued)

		Parents of nursery aged children	15; Male (1) and Female (14)	Not described	In-depth interviews	Interpretive phenomenological analysis	Childhood vaccination in general	Low
Raithatha (2003)	To assess vaccine risk perception among parents who have their children immunised	Parents of nursery aged children	15; Male (1) and Female (14)	Not described	In-depth interviews	Interpretive phenomenological analysis	Childhood vaccination in general	Low
Sampson (2011)	To explore parental reasons for non-uptake of influenza vaccination in young at-risk groups	Parents of children identified as being at risk for influenza vaccination but who had not received vaccination	16; Gender not described	November 2008	Interviews and free text responses from questionnaires	Not detailed but analytical process described	Influenza	Low
Smailbegovic (2003)	To explore the knowledge, attitudes and concerns regarding immunisation and vaccine-preventable infections in parents whose children have not completed the recommended course	Parents of children resident in the London, UK	Female (10)	Not described	Interviews	Not described	Childhood vaccination in general	Low
Sporton (2001)	To explore the decision-making process of parents who have chosen not to have their children immunised	Parents of children aged between 7.5 months and 20 years	13; Male (1) and Female (12)	Not described	Semi-structured interviews	Consistent and systematic review	Childhood vaccination in general	Low

Table 1 Characteristics of included studies (continued)

Tickner (2007)	To explore parental decision-making about the DTaP/IPV/Hib 'five-in-one' vaccine	Parents of children aged 4-13 weeks	22; Male (1) and Female (21)	November 2005 to November 2006	Semi-structured interviews	Modified grounded theory	'Five-in-one' Dtap/IPV/Hib	Low
Tickner (2010)	To explore parents' views about pre-school immunization and to identify reasons for lower pre-school uptake compared with the primary course	Parents of children aged 2-5 years	21; Male (2) and Female (19)	April 2006 to December 2006	Semi-structured interviews	Modified grounded theory	MMR (and another vaccine no longer offered in UK)	Low
Tomlinson (2013)	To explore the health beliefs of Somali women resident in the UK	Somali women resident in the UK with one child <5 years of age	23; Female	February 2012 to April 2012	Semi-structured interviews	Thematic analysis	Childhood vaccination in general	Low

FIGURES

Figure 1: Flow diagram of included studies, adapted from ²⁶ (single column fitting)

Figure 2: Themes identified and relationships between themes (2-column fitting)

FIGURE 1

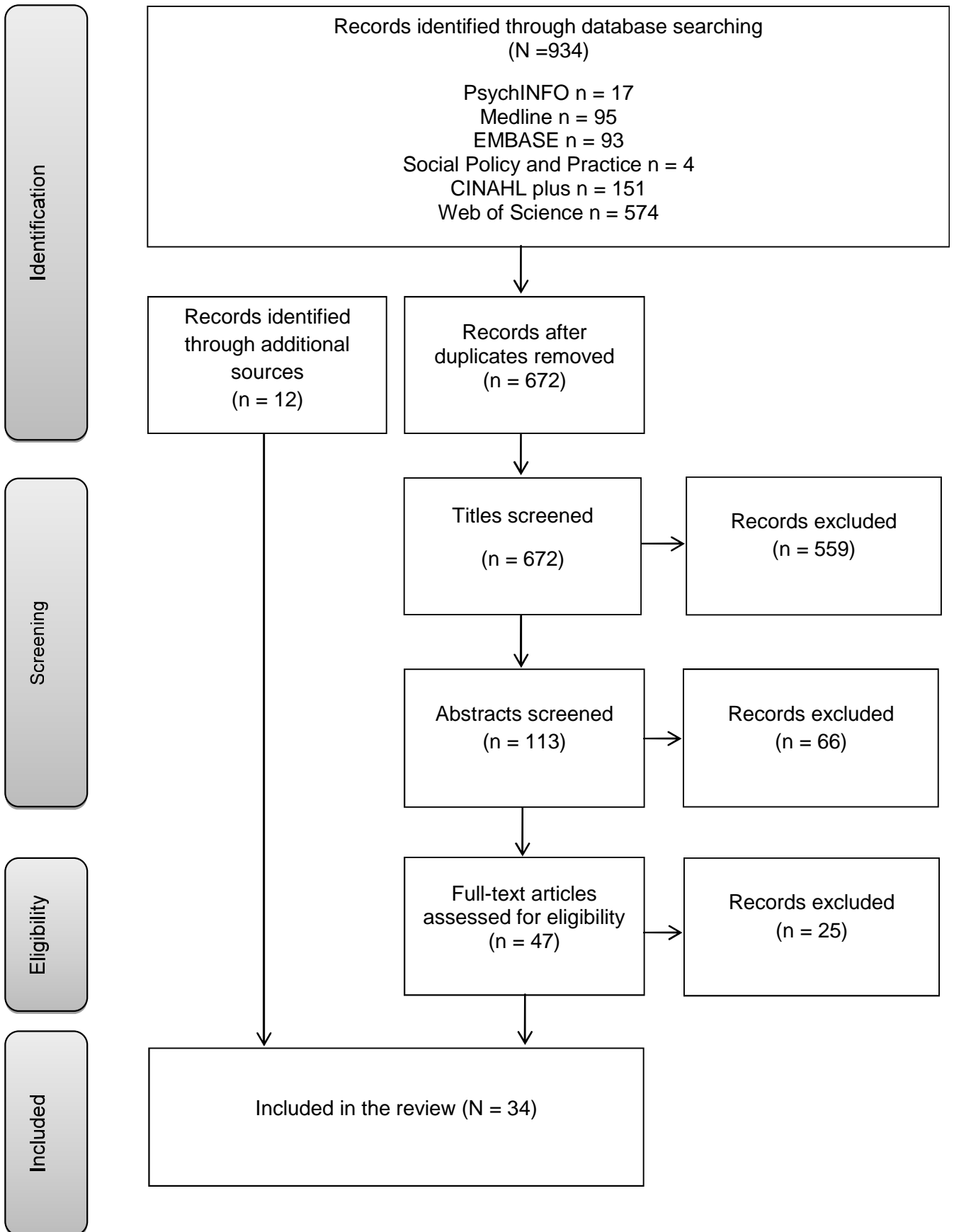
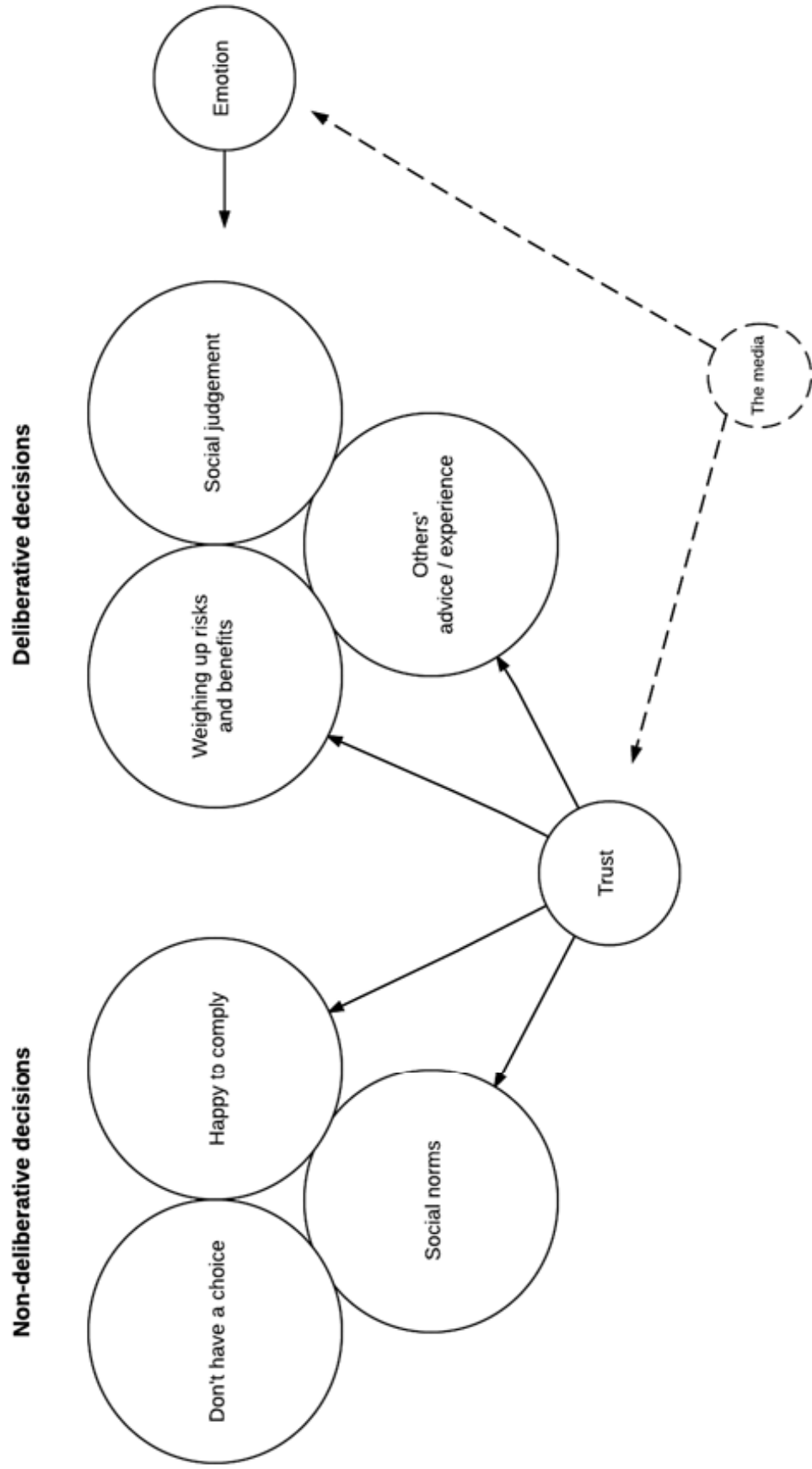


FIGURE 2



SUPPLEMENTARY MATERIAL

SEARCH TERMS BY DATABASE

	PsycINFO	MEDLINE	Embase	Social Policy and Practice	CINAHL plus	Web of science
Vaccination	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	Exp Immunization/ "Immunization*" .ab,ti. "Vaccination*" .ab,ti.	"Immunization*" .ab,ti. "Vaccination*" .ab,ti.
Qualitative	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnog*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnog*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnog*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnog*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Studies/ exp Anthropology, Cultural/ exp Ethnographic Research/ exp Interviews/ exp Semi-structured Interview/ exp Structured Interview/ exp Focus Group/ exp Nonexperimental Studies/ exp Content Analysis/ exp Thematic Analysis/ exp Grounded Theory/ Qualitative* Anthropology* Ethnog* Interview* "Focus group" .ab,ti. Observation* "Content analysis" "Thematic analysis" "Grounded theory"	Qualitative* Interview* "Focus group" .ab,ti. Observat* Ethnog* Anthrop* "Content analysis" "Framework analysis" "Interpretative phenomenological analysis" "Grounded theory"
United Kingdom	"United Kingdom" .ab,ti. "Great Britain" .ab,ti. England .ab,ti. Scotland .ab,ti. Wales .ab,ti. "Northern Ireland" .ab,ti.	"United Kingdom" .ab,ti. "Great Britain" .ab,ti. England .ab,ti. Scotland .ab,ti. Wales .ab,ti. "Northern Ireland" .ab,ti.	"United Kingdom" .ab,ti. "Great Britain" .ab,ti. England .ab,ti. Scotland .ab,ti. Wales .ab,ti. "Northern Ireland" .ab,ti.	"United Kingdom" .ab,ti. "Great Britain" .ab,ti. England .ab,ti. Scotland .ab,ti. Wales .ab,ti. "Northern Ireland" .ab,ti.	United Kingdom/ England/ Great Britain/ Scotland/ Wales/ Northern Ireland/ "United Kingdom" "Great Britain" "England" "Northern Ireland" "Wales" "Scotland"	"United Kingdom" "Great Britain" "England" "Northern Ireland" "Wales" "Scotland"

PRISMA CHECKLIST

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2/3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4/5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	n/a
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6 and supplementary material
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary material
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6/7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	n/a
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2 for each meta-analysis).	7
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8 and figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	8 and table 1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Supplementary material
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	n/a
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	8
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	18
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	21

Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	18-22
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Title page

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“... mumps was often a source of humour, and participants often laughed while holding their breath, puffing out their cheeks, or (men) crossing their legs and clasping their hands over their groins as if in pain. Some queried the need for girls to receive the mumps vaccine as they perceived mumps to be a disease that affected boys.” Hilton, author comment.

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“I just don’t want them to think they can go out there and have sex and they’re protected against everything, when they’re not in actual fact.” Marlow, participant comment.

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Theme 5: Others' experiences and advice

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“A friend of mine who I worked with lost her baby erm at about eight weeks from meningitis, which was just awful. So I mean that may have been something that's influenced me to make sure that they get the Hib and stuff 'cos it was just so tragic.” Tickner, participant comment.

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“Well, to be honest with you, had I not been, dare I use the word, alerted by friends, who said have you thought about your views on immunization? I thought it was compulsory until people told me it wasn't” Sporton, participant comment.

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“I'd feel really uncomfortable having to go into hospital and think that there are people looking at me thinking, my God, why didn't she get him vaccinated? Let her baby become ill and potentially die or whatever.” Brown, participant comment.

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“Although it might be a very, very small percentage risk, it's your child and if it gets that, you have to deal with that for the rest of your life, I mean would you ever forgive yourself?” Brownlie, participant comment.

“Although parents recognized serious side effects to be rare, these often provoked feelings of 'dread'”. Raithatha, author comment.

“I suppose if anything does happen to them and you had a choice to immunise them and you didn't you could only blame yourself really.” Petts, participant comment.

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“...[the health professionals] gave me a lot of stuff which basically I couldn't understand most of it, it was all really medical obviously and a lot of it went over my head...” Sporton, participant comment.

“Although parents recognised that information in the media can be sensationalised, reassurances about the safety of the vaccine issued by the Department of Health were treated with scepticism as parents felt that their concerns had not been adequately addressed”. Evans, author comment

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Parents also assessed whether they believed their child would be exposed to a disease. Many diseases were perceived to not be a particular threat within the UK and some believed that their lifestyles and environment protected their child sufficiently or provided reason to immunise.

“I su I was at home with him, for the first, his first year of life, I knew that he wouldn’t be exposed to anything, he wasn’t going to a nursery or a child minder... I knew that to some extent I had some degree of control over the people he was exposed to and the germs he was exposed to.” Sporton, participant comment.

Diseases which were seen to be transmitted just through ‘being around someone’ were considered more important to protect against than those which are seen to have ‘behavioural’ modes of transmission such as sexual intercourse.

“Coming from a Muslim background... we don’t have sex before marriage for example, so your first experiences of these things are when you’re married and you stay in a relationship... because of that reason I’d probably say no, I wouldn’t bother with it with my two girls.” Marlow, participant comment.

Is vaccination an effective way of doing this?

Some parents expressed that they were also only likely to vaccinate their child if they believed that vaccination works. Knowledge of scientific reports, historical changes in disease prevalence, or a general trust in medicine informed parents’ assessments.

When parents doubted vaccination efficacy, they were concerned that vaccines do not cover all strains of viruses that cause a disease or believed that efficacy was short-lived. Some pa

vaccination. Other parents believed that regardless of the efficacy of vaccination, it may be overridden by more powerful forces, such as God or fate.

“If children get measles, mumps, and rubella it helps build up their natural immunity, and that’s better than the immunity built up by vaccines.” McMurray, participant comment.

Risks of vaccinating

Parents took into account whether there were any potential serious (i.e. fatal, or life-altering) side-effects. Parents recognised that there were short-term, minor side effects of vaccination, but these were not sufficient to outweigh the benefits of vaccinating (although they did have emotional effects on the parent, discussed below).

One of the common concerns evoked was that the MMR may cause autism, or more general developmental problems, despite awareness that the study that raised this concern had been discredited. Some parents extrapolated this concern to other vaccines, whereas others evaluated the risk of other vaccines in relation to the 'higher risk' MMR, which made them more confident in those vaccination decisions.

“I know that the research that Andrew Wakefield has done and his findings. I know that it is not categorically proven but to me there is enough evidence to be questioned.” Guillaume, participant comment.

How likely are these risks?

Some parents who believed that vaccinations have the potential to cause side-effects assessed the level of risk to their own child, based on how common side-effects are in the general population using their experiential knowledge and instinct. Parents also considered their fa (e.g. colds and ear infections), chronic conditions or premature birth.

“the second one had lots of colds, he had allergies and eczema, and em, it just seemed to be too much on his wee immune system and I just felt it was too risky, whereas the third one is a much more robust child...” Hilton, participant comment.

Mechanisms of harm and individualised vulnerability

Parents conceptualised the mechanisms by which vaccines cause harm in three ways: 1) by weakening the immune system or sending it into ‘over-drive’ (particularly a concern when a child is ill); 2) vaccine ingredients causing harm; 3) vaccines causing an increase in high risk behaviour (relevant for viruses with a ‘behavioural’ mode of transmission).

Theme 8: Trust in vaccine information and stakeholders affects non-deliberative and deliberative decisions

Trust in key stakeholders and the information they provide

Lack of trust in government confused parents’ decision-making. The sense of distrust originated from various issues including historic health scares that remained in parents’ memories, believing that the government conceals information, lack transparency in the information they publish and questioning the validity of official statistics. Parents queried the government’s motives for promoting vaccination, suggesting that it is a cost-saving activity.

“Generally parents did not have confidence in statements issued by the government about the safety of MMR and analogies were made with the BSE crisis”. Evans, author comment.

Similarly, lack of trust in healthcare professionals was frequently discussed, particularly pa

Concerns were heightened for parents who had previous negative experiences. Specific issues arising in the GP consultation, such as rushed appointments, lack of discussion and feelings of being pressurised into vaccinating also fostered distrust.

“...you're meant to trust your doctor implicitly and yet ... they're getting paid for having so many people vaccinated..., and you start thinking 'well... who's got my wee boy's best interests at heart" Hilton, participant comment.

Conversely, some parents also trusted health professionals and more generally the NHS, which was considered as distinct from the government. Disclosure from health professionals regarding their own child's vaccination status was rated as important and those with a friend who worked as a health professional offered a deeper level of reassurance.

“When doctors ... shared their own stories about making such decisions as a parent ... parents were reassured that their concerns had been taken seriously.” Casiday, author comment.

Distrust in vaccination research and drug development was commonly mentioned. Parents
sa uncertainty of scientific
research.

“It makes me slightly untrusting [...] I think well how can they just say that and just, so confidently, you know, think the atom is the smallest thing until they split it open and then it's not and they can just so quickly just change and I t

, participant
comment.

Provision of information assisted in the decision-making process. However, often articles reported that parents were dissatisfied with the information they received, particularly because of their distrust in the information source. Parents perceived the information to be unclear, unengaging, lacking in quantity and delivered through an inappropriate medium.

Media influence

Information presented in the media attenuated the trust that parents held for official bodies' research and development of the vaccines. Parents in some articles had an attentional bias towards negative information, dismissing scientific information that could counter sensationalised media stories. In general, the media's influence tended to put parents off vaccinating their children.

“Although parents recognised that information in the media can be sensationalised, reassurances about the safety of the vaccine issued by the Department of Health were treated with scepticism as parents felt that their concerns had not been adequately addressed”. Evans, author comment.

INCLUSION AND EXCLUSION CRITERIA

Types of studies

Primary research studies meeting the following criteria:

- reporting qualitative analysis of textual data (collected using focus groups, interviews, participant observation, free-text questionnaire responses);
- and indexed at any time in online databases and published in peer reviewed journals in English.

We excluded dissertation abstracts, book chapters, review articles and commentaries.

Types of participants

Parents or caregivers of children/adolescents living in the United Kingdom. Participants must have been making decisions about vaccinating a child (under 18 years old).

SUPPLEMENTARY MATERIAL

SEARCH TERMS BY DATABASE

	PsycINFO	MEDLINE	Embase	Social Policy and Practice	CINAHL plus	Web of science
Vaccination	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	exp Immunization/ "vaccination*" .ab,ti. "immunization*" .ab,ti.	Exp Immunization/ "Immunization*" .ab,ti. "Vaccination*" .ab,ti.	"Immunization*" .ab,ti. "Vaccination*" .ab,ti.
Qualitative	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnogr*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnogr*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnogr*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Research/ exp Interviews/ exp Observation Methods/ "interview*" .ab,ti. "focus group*" .ab,ti. "ethnogr*" .ab,ti. exp Ethnography/ "thematic analysis" .ab,ti. "grounded theory" .ab,ti. "interpretative phenomenological analysis" .ab,ti. "content analysis" .ab,ti. "framework analysis" .ab,ti.	exp Qualitative Studies/ exp Anthropology, Cultural/ exp Ethnographic Research/ exp Interviews/ exp Semi-structured Interview/ exp Structured Interview/ exp Focus Group/ exp Nonexperimental Studies/ exp Content Analysis/ exp Thematic Analysis/ exp Grounded Theory/ Qualitative* Anthropology* Ethnogr* Interview* "Focus group" .ab,ti. Observation* "Content analysis" "Thematic analysis" "Grounded theory"	Qualitative* Interview* "Focus group" .ab,ti. Observat* Ethnogr* Anthropol* "Content analysis" "Framework analysis" "Interpretative phenomenological analysis" "Grounded theory"
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Parents considered whether their child having a disease was a negative thing that they wanted to avoid. This was based on whether a disease was potentially fatal, or could cause serious lifelong effects. This assessment was sometimes made in relation to other diseases or the sex of the child. Public health campaigns caused parents to perceive that diseases focused on in the campaign were more serious, but the absence of similar campaigns for other diseases was taken as a sign that these diseases are not a threat.

Parents also assessed whether they believed their child would be exposed to a disease. Many diseases were perceived to not be a particular threat within the UK and some believed that their lifestyles and environment protected their child sufficiently or provided reason to immunise.

“I su I was at home with him, for the first, his first year of life, I knew that he wouldn’t be exposed to anything, he wasn’t going to a nursery or a child minder... I knew that to some extent I had some degree of control over the people he was exposed to and the germs he was exposed to.” Sporton, participant comment.

Diseases which were seen to be transmitted just through ‘being around someone’ were considered more important to protect against than those which are seen to have ‘behavioural’ modes of transmission such as sexual intercourse.

“Coming from a Muslim background... we don’t have sex before marriage for example, so your first experiences of these things are when you’re married and you stay in a relationship... because of that reason I’d probably say no, I wouldn’t bother with it with my two girls.” Marlow, participant comment.

Is vaccination an effective way of doing this?

Some parents expressed that they were also only likely to vaccinate their child if they believed that vaccination works. Knowledge of scientific reports, historical changes in disease prevalence, or a general trust in medicine informed parents’ assessments.

When parents doubted vaccination efficacy, they were concerned that vaccines do not cover all strains of viruses that cause a disease or believed that efficacy was short-lived. Some pa

vaccination. Other parents believed that regardless of the efficacy of vaccination, it may be overridden by more powerful forces, such as God or fate.

“If children get measles, mumps, and rubella it helps build up their natural immunity, and that’s better than the immunity built up by vaccines.” McMurray, participant comment.

Risks of vaccinating

Parents took into account whether there were any potential serious (i.e. fatal, or life-altering) side-effects. Parents recognised that there were short-term, minor side effects of vaccination, but these were not sufficient to outweigh the benefits of vaccinating (although they did have emotional effects on the parent, discussed below).

One of the common concerns evoked was that the MMR may cause autism, or more general developmental problems, despite awareness that the study that raised this concern had been discredited. Some parents extrapolated this concern to other vaccines, whereas others evaluated the risk of other vaccines in relation to the 'higher risk' MMR, which made them more confident in those vaccination decisions.

“I know that the research that Andrew Wakefield has done and his findings. I know that it is not categorically proven but to me there is enough evidence to be questioned.” Guillaume, participant comment.

How likely are these risks?

Some parents who believed that vaccinations have the potential to cause side-effects assessed the level of risk to their own child, based on how common side-effects are in the general population using their experiential knowledge and instinct. Parents also considered their fa past history of minor illnesses (e.g. colds and ear infections), chronic conditions or premature birth.

“the second one had lots of colds, he had allergies and eczema, and em, it just seemed to be too much on his wee immune system and I just felt it was too risky, whereas the third one is a much more robust child...” Hilton, participant comment.

Mechanisms of harm and individualised vulnerability

Parents conceptualised the mechanisms by which vaccines cause harm in three ways: 1) by weakening the immune system or sending it into ‘over-drive’ (particularly a concern when a child is ill); 2) vaccine ingredients causing harm; 3) vaccines causing an increase in high risk behaviour (relevant for viruses with a ‘behavioural’ mode of transmission).

Theme 8: Trust in vaccine information and stakeholders affects non-deliberative and deliberative decisions

Trust in key stakeholders and the information they provide

Lack of trust in government confused parents’ decision-making. The sense of distrust originated from various issues including historic health scares that remained in parents’ memories, believing that the government conceals information, lack transparency in the information they publish and questioning the validity of official statistics. Parents queried the government’s motives for promoting vaccination, suggesting that it is a cost-saving activity.

“Generally parents did not have confidence in statements issued by the government about the safety of MMR and analogies were made with the BSE crisis”. Evans, author comment.

Similarly, lack of trust in healthcare professionals was frequently discussed, particularly pa . These concerns were heightened for parents who had previous negative experiences. Specific issues arising in the GP consultation, such as rushed appointments, lack of discussion and feelings of being pressurised into vaccinating also fostered distrust.

“...you're meant to trust your doctor implicitly and yet ... they're getting paid for
 ha .. who's got my wee
 boy's best interests at heart" Hilton, participant comment.

Conversely, some parents also trusted health professionals and more generally the NHS, which was considered as distinct from the government. Disclosure from health professionals regarding their own child's vaccination status was rated as important and those with a friend who worked as a health professional offered a deeper level of reassurance.

“When doctors ... shared their own stories about making such decisions as a parent ... parents were reassured that their concerns had been taken seriously.” Casiday, author comment.

Distrust in vaccination research and drug development was commonly mentioned. Parents
 sa
 research.

“It makes me slightly untrusting [...] I think well how can they just say that and just, so confidently, you know, think the atom is the smallest thing until they split it open and then it's not and they can just so quickly just change and I think that's, that's hard when you're trusting these people with your child's health.” Johnson, participant comment.

Provision of information assisted in the decision-making process. However, often articles reported that parents were dissatisfied with the information they received, particularly because of their distrust in the information source. Parents perceived the information to be unclear, unengaging, lacking in quantity and delivered through an inappropriate medium.

Media influence

Information presented in the media attenuated the trust that parents held for official bodies' research and development of the vaccines. Parents in some articles had an attentional bias towards negative information, dismissing scientific information that could counter sensationalised media stories. In general, the media's influence tended to put parents off vaccinating their children.

“Although parents recognised that information in the media can be sensationalised, reassurances about the safety of the vaccine issued by the Department of Health were treated with scepticism as parents felt that their concerns had not been adequately addressed”. Evans, author comment.