



# “I want to chat with a person”: a qualitative longitudinal cohort study in England exploring drivers of sub-optimal childhood vaccination uptake

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## ABSTRACT

**Background:** Childhood vaccination rates in the UK have declined for the thirteenth year in a row. This study explores parents' vaccination experiences to identify key barriers affecting uptake, helping stakeholders better understand and support families.

**Methods:** A qualitative longitudinal study following a cohort ( $n = 22$ ) of parents from birth to age one. Three waves of data collection took place in line with key vaccination due dates at approximately two (July 2023–February 2024), four (October 2023–May 2024), and twelve months of age (May 2024–December 2024). In total, the dataset comprises 63 interviews and 98 diary entries (including 119 picture submissions) across all waves of data collection. Data were analysed using temporal thematic analysis.

**Results:** Information provision was a critical temporal theme accounting for divergences in parents' experiences and, in some instances, the outcome of their vaccination journeys. Parents received minimal information in the lead up to vaccination and during the appointment itself. Parents had different relationships with vaccination (confident, curious, or concerned), however, this was subject to change between waves of data collection. In addition to a lack of proactive information provision, there was nowhere for parents to turn to having developed vaccine-related concerns leaving some stuck “on the fence”. Parents were further nudged towards vaccine deferral or refusal based on a breakdown of trust with their General Practice, search engine results, and content on social media.

**Conclusion:** To address declining vaccination coverage in England, it is essential that parents have opportunities to meaningfully discuss their questions with healthcare providers. For many, information provision is too little, too late, and there is no opportunity for dialogue. This study deepens our understanding of parents' experiences of information provision regarding childhood vaccinations and provides recommendations for policy and practice.

## 1. Introduction

Uptake of the childhood vaccination programme in the United Kingdom (UK) is consistently below the 95 % target which has contributed to increases in disease outbreaks [1]. In addition to sub-optimal coverage, vaccination deferral or delay is a cause for concern – a phenomenon which is more pervasive in vaccine doses scheduled later into childhood [2]. In the UK vaccinations are available via General Practices (GenPrs) to protect against nine serious infectious diseases during the first year of life [3]. Despite being offered free of charge with the National Health Service (NHS) uptake has declined for a thirteenth

consecutive year [4]. Uptake of the rotavirus vaccine by 12 months of age decreased by 0.7 % down to 88.4 % in the last annual quarter [5]. This is consistent with annual trends, as observed in coverage of the 6-in-1 vaccine (a combination vaccine that protects against six diseases: Diphtheria, Tetanus, Pertussis, Poliomyelitis, *Haemophilus influenzae* b, and Hepatitis B) where there was a decrease of 0.6 % (down to 91.2 %) from 2022 to 23 to 2023–24 [6].

Resultantly, in recent years there have been several national incidents declared in relation to disease outbreaks such as measles and pertussis [7]. In 2024, there was the largest number of laboratory confirmed cases of measles ( $n = 2911$ ) since 2012 with one acute

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measles-related death [8,9]. For pertussis, laboratory confirmed cases rose to 14,894 in 2024 – a 59 % increase compared to the previous major outbreak in 2012 ( $n = 9367$ ) – resulting in 11 infant deaths [10]. Key vaccination stakeholders have voiced increasing concern and calls to action, but research reveals that 46 % of those who commission or manage vaccination services are not confident in their ability to address poor performance [11].

Accurately identifying the factors driving poor vaccination uptake is critical in informing appropriate interventions to increase coverage [12]. Most of the literature on vaccine attitudes in the UK presents substantial confidence in childhood vaccination and research is increasingly acknowledging the role of accessibility in accounting for poor uptake [7,13]. A landmark national survey conducted in 2017 ( $n = 1792$ ) found that among the 10 % of parents who did not take their children for vaccination when due, only 2 % cited refusal as the cause [14]. This is corroborated by a more recent survey ( $n = 2001$ ) conducted in 2023 [15], which found that only 1 % claimed that they would never get their child vaccinated; both studies reported that 75 % of respondents cited automatically taking their children for vaccination when due [14,15].

Notably, the more recent survey was conducted after the Covid-19 pandemic, contradicting global trends of increasing hesitancy towards childhood vaccinations [16]. A UK-based study ( $n = 518$ ) exploring the impact of Covid-19 concluded that accessibility remained a more prevalent issue than vaccine-related concerns, with 90 % of parents citing childhood vaccinations as important [17]; some parents felt that vaccinations were even more important with only a ‘small minority’ citing distrust of the childhood vaccination programme as a result of the pandemic. Nevertheless, 38 % of parents reported increased questions about childhood vaccinations relative to the pre-pandemic period [17].

While vaccines may still be seen as important following the pandemic, a potential rise in questions, concerns, or selective vaccination was also alluded to in the aforementioned 2023 attitudinal survey: only 83 % reported having all vaccines offered and 11 % were not happy with the safety of vaccines for babies and young children [15]. More than a third of parents were concerned about vaccine ingredients (42 %), the number of diseases vaccinated against per appointment (47 %), with the majority believing that vaccines weaken a child’s natural immune system (60 %) [15]. A smaller, but important, proportion of parents did not think that vaccines worked (3 %), were safe (5 %), properly tested (5 %), or to be trusted (6 %). Amid increasing questions and safety concerns regarding the childhood vaccination programme, sustained efforts to support vaccine confidence are essential. With this study, we aimed to take a broad account of parents’ vaccination journeys and identify points of tension which undermine vaccination uptake. Findings will enable vaccination stakeholders to have a greater appreciation for the lived reality of parents and take action with greater confidence.

## 2. Methods

### 2.1. Research question

What are the driving forces and lived experiences associated with different vaccination outcomes (i.e., on time, after delay, not received) during infancy?

### 2.2. Study design

This study followed a group of parents from their child’s birth to age one. A qualitative longitudinal (QL) cohort study design was selected due to its ability to reveal ‘the wholesale movement of study populations from one circumstance to another’ [18 ,p.14]. The phenomenon of interest, however, is not simply the changes or continuities (i.e., vaccination outcomes) but the *trigger points* or *pivotal moments* which precipitates them and how these are interpreted, managed, and responded to. In other words, the overriding focus is on ‘*how and why things emerge,*

*develop, grow or terminate over time*’ [18 ,p.47]. The study scope and methods, including appropriate theoretical framework selection, was informed by a preparatory systematic scoping review [13].

This is the second analysis to emerge from the QL cohort study. The initial analysis revealed four vaccination trajectories within the cohort collectively referred to as the 4S Vaccination Trajectory Framework [19]:

1. *Supported*: GenPrs assume a proactive role in ensuring vaccination takes place (on time) - parents feel that vaccination is a smooth and easy process.
2. *Struggled*: parents assume a (burdensome) driving role in ensuring their child receives their vaccinations (on time).
3. *Stalled*: parents face challenges securing appropriate appointments which results in delayed vaccination.
4. *Shunned*: information provision from the NHS does not meet parents’ needs, which alongside other factors (e.g., negative experiences with the NHS, social media exposure, search engine results), leads to vaccination deferral or refusal.

Three temporal themes associated with these trajectories were identified within the dataset: booking systems; the unexpected (i.e., how GenPrs handled parents who were late or missed their appointments); and information provision. The prior two temporal themes (i.e., booking systems and the unexpected) were analysed and published in a preceding manuscript as both pertained to the logistics of securing and attending vaccination appointments [19]. The other temporal theme (i.e., information provision) was deemed distinct and that it would benefit from an additional wave of data collection to observe how information provision (or lack thereof) went on to shape vaccine uptake at age one. This manuscript presents the third temporal thematic finding, information provision, based on three waves of data collection (from birth to age one).

### 2.3. Setting

Greater Manchester was purposively selected as the site of this investigation due to its sub-optimal vaccination uptake and high rates of deprivation as per the English Indices of Deprivation 2019 report (IoD2019) published by the Ministry of Housing, Communities and Local Government [20,21]. The IoD2019 report combined seven domains of deprivation: income, employment, health deprivation and disability, education and skills training, crime, barriers to housing and services, and living environment. This made it an appropriate site to explore declining vaccination uptake within a socioeconomically diverse cohort.

### 2.4. Patient and public involvement

Socioeconomically disadvantaged parents ( $n = 10$ ) were invited to consult and co-design elements of the study through participation in two workshops delivered in partnership with a local community centre. Socioeconomic status was inferred from the mode of workshop recruitment which took place via the community centre’s food bank service for low-income residents. Participants were aware that workshops were for lower-income families. Involving socioeconomically disadvantaged parents in the co-design of the study was a deliberate strategy to enhance inclusivity, address potential barriers to participation among lower-income groups, and achieve a more diverse study cohort.

### 2.5. Study cohort

The cohort comprises 22 parents whose child was born between May–Nov 2023. Eligibility criteria included: residing within Greater Manchester; speaking proficiency in English; being over the age of 18; and

not anticipating support from a neonatal unit after birth. In the first instance, priority was given to lower-income households to ensure a socioeconomically diverse sample. Guiding household income figures were provided (equivalized for family size) and participants self-allocated into higher- or lower-income study spaces. Participants were recruited via NHS maternity services and community outreach through dissemination of a study flyer, interested parties contacted GC and were provided information sheets ahead of study enrolment. The cohort was evenly divided between higher and lower income status and diverse in terms of ethnicity, migrant status, number of children, and socioeconomic status. A full cohort overview is provided in Chisnall et al. (2025) [19].

## 2.6. The dataset

Data collection comprised a combination of life journey interviews (see supplementary material 1) and diary keeping (see supplementary material 2). Data collection tools were informed by Levesque's accessibility framework which examines the interface between individual and system-level factors across the healthcare pathway [22]. This analysis draws on data from three waves of data collection conducted in line with key vaccination due dates as presented in Fig. 1. In total, the dataset comprises 63 interviews and 98 diary entries (including 119 picture submissions) across all waves of data collection. Interviews lasted 50 min on average. Attrition between data collection waves was minimal, with only two participants not participating in all three waves.

## 2.7. Data analysis

Before patterns in *trigger points* and *pivotal moments* can be observed across the cohort these need to be identified at the case-level. Thus, QL analysis is a multi-stage process progressing from case-led to cross-case analysis utilizing the traditional skills and principles from thematic analysis. This approach is termed *temporal thematic analysis* [18]. An overview of the analytical process is presented in Fig. 2, with further methodological detail available in the preceding publication [19]. Data analysis was led by GC; temporal themes were reviewed by all authors for internal homogeneity (consistency) and external heterogeneity (distinctness).

## 2.8. Recommendation development

The discussion presents a set of policy and practice recommendations designed to address the specific barriers to childhood vaccination reported by parents in our study. These recommendations were informed by a systematic scoping review and supplementary handsearching of recent empirical and policy literature. We mapped each recommendation against existing policies, identifying where action is already endorsed but unimplemented, where adaptation is needed, and where new policy attention is warranted. This mapping process was guided by the expertise of HB, an expert advisor in immunisation policy. To ensure the relevance and feasibility of our recommendations, we conducted both internal cross-author review and external consultation with two NHS vaccination stakeholders. This process ensured that the recommendations are both evidence-based and grounded in current policy realities.

## 2.9. Ethical considerations

Ethical approval was issued by the NHS (no. 22/PR/1465) and the London School of Hygiene and Tropical Medicine (no. 28158). All ethical principles were adhered to including informed consent procedures and right to withdraw throughout the duration of the study. Participants received a £20 voucher per interview, with an additional £20 for diary entries per wave of data collection. Participants who completed the study were given a £30 voucher. This compensation strategy was deemed commensurate with the ongoing efforts required of study involvement. Pseudonyms have been assigned to each participant to ensure confidentiality.

## 3. Results

### 3.1. Vaccination trajectories

Many ( $n = 12/22$ ) of those within the cohort had changed trajectory (at age one) since the last vaccination interaction (at four months of age). All but one of these shifts were towards worse vaccination trajectories (i.e., struggled, stalled, or shunned). The change in prevalence of each trajectory between waves 2 and 3 of data collection is presented

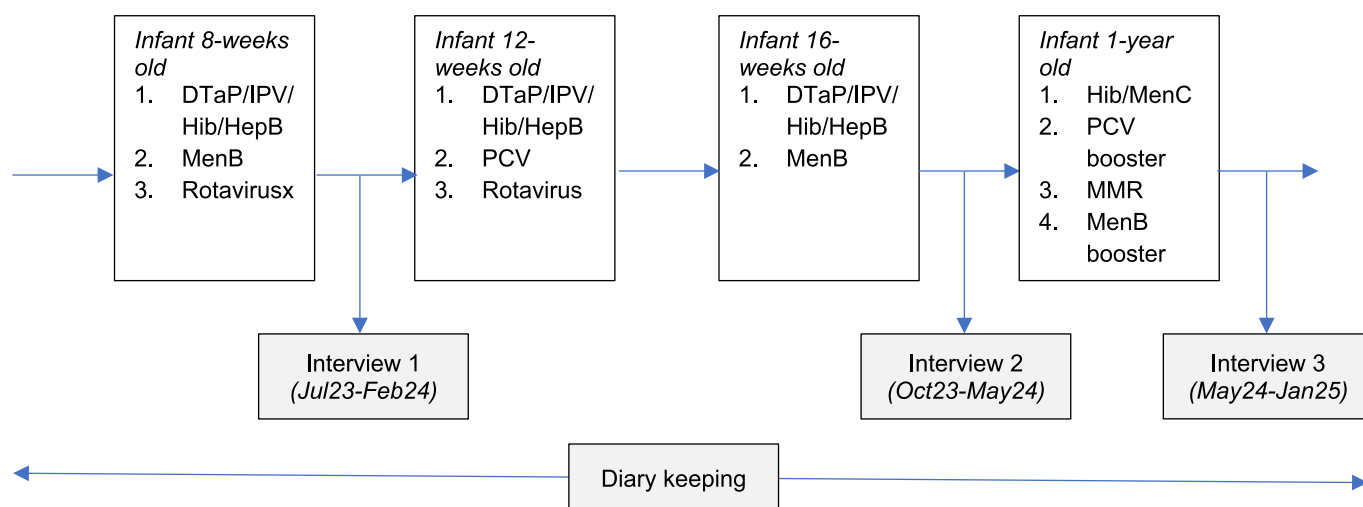


Fig. 1. Data collection.

Note.

- 1) Following enrolment into the study (during pregnancy or shortly following birth) parents were asked to start making diary entries. The dairy keeping tool listed topic prompts for diary entries and provided an email address or WhatsApp number where entries could be submitted in-real-time.
- 2) Interviews were scheduled once the parent had either: (a) made a diary entry specifying that a vaccine appointment has been attended/declined; (b) 4-weeks post the vaccinations being due. This was to avoid influencing parental vaccination decisions during the period which is considered 'on time' [23,24]. Interviews took place in-person or online based on participant preference.

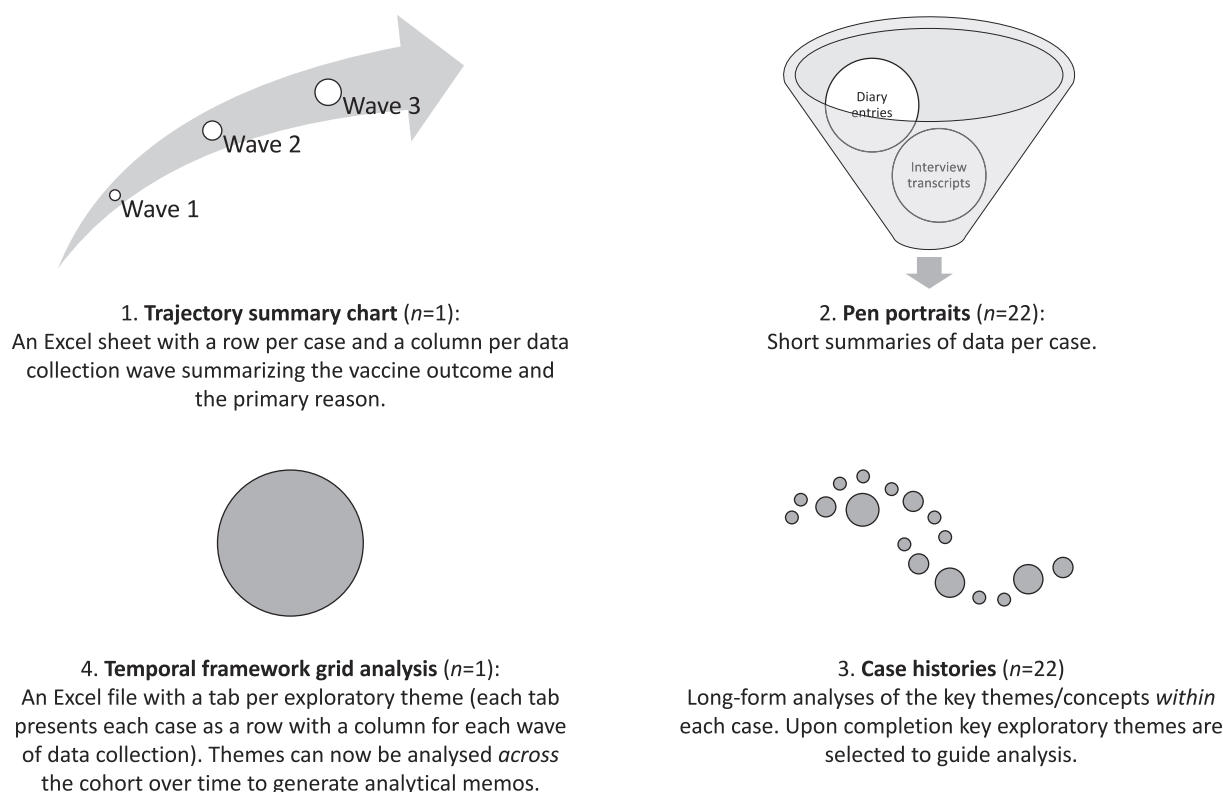


Fig. 2. Data analysis.

in Table 1, and shifts in trajectory status are presented visually in Fig. 3. A full case-by-case, wave-by-wave overview is presented in supplementary material 3.

Most of the transitions from ‘supported to struggled’ and ‘struggled to stalled’ were driven by booking system challenges which required parents to proactively reach out to their GenPr and navigate difficult booking systems – a challenge identified during the preceding analysis [19]. In a limited number of cases the shift towards a stalled trajectory was caused by rescheduling the appointment due to infant illness or parental choice (e.g., difficult to schedule around return to work). In one instance, the shift from ‘supported to struggled’ was driven by how ‘the unexpected’ was handled, as presented in the preceding publication [19].

Information provision and associated factors accounted for three additional ‘shunned’ trajectories by the third wave of data collection. As a QL study prevalence is not used to infer patterns at the wider population level, but additional cases are valuable in providing rich explanatory accounts regarding the driving factors and lived experiences associated with a given trajectory. Unlike the preceding temporal

themes (e.g., forgetting an appointment) information provision is a phenomenon experienced by the whole cohort, even if it takes a less dominant role in shaping their vaccination journey. Resultantly, this temporal theme represents data from all parents within the cohort reflecting how information provision shaped their experience of the vaccination service.

### 3.2. Information provision

Information provision was a critical temporal theme accounting for divergences in parents’ experiences and, in some instances, the outcome of their vaccination journeys. Most parents received minimal information, not only in the lead up to vaccination, but also across all four individual vaccination appointments. Parents had different relationships with vaccination (confident, curious, or concerned), however, this was subject to change between waves of data collection with a number of parents developing doubts during the course of the study. With a backdrop of insufficient information, parents were nudged towards vaccine deferral or refusal in response to events which undermined trust in their GenPr, search engine results (e.g., Google), and content on social media. In the absence of proactive information provision from the NHS, there was nowhere for parents to talk about their vaccine-related concerns leaving some stuck “on the fence” [Hailey, wave 3 interview].

#### 3.2.1. The ‘when’ and ‘what’ of information provision: too little, too late

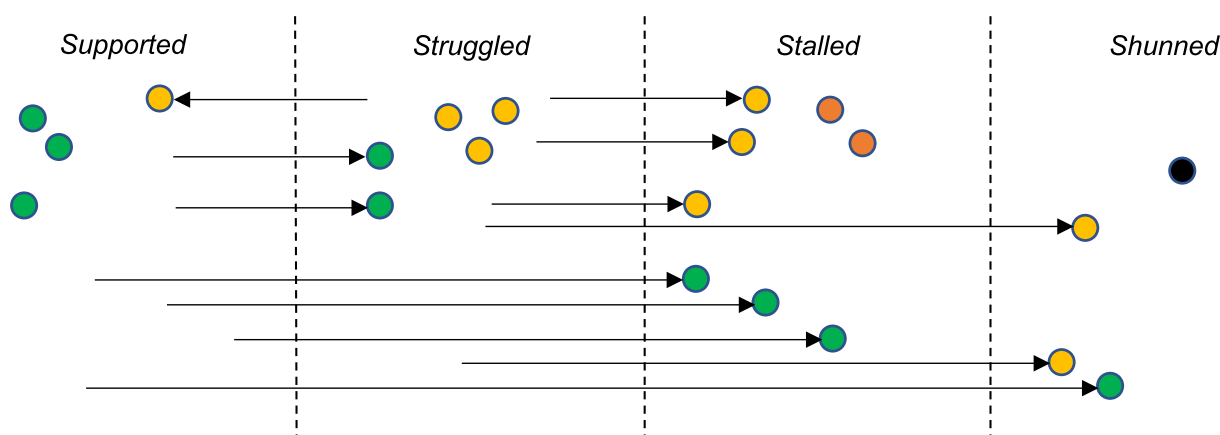
Only a handful of parents reported that childhood vaccination had been mentioned during the antenatal period, and this was often in passing. One participant shared a screenshot of their MyMFT portal (a patient portal and app provided by Manchester University NHS Foundation Trust) which listed the discussion topics scheduled over the antenatal and postnatal period. A total of 39 topics were listed on this schedule, however childhood vaccination was not listed in any of the antenatal or postnatal discussion points. This may be discussed postnatally within the topic ‘Register baby/babies with GP’ but vaccination is not independently presented, nor would this include vaccination

Table 1

Prevalence of vaccine trajectories (as per the 4S Vaccination Trajectory Framework) at 4-months of age vs 1 year old.

Trajectory	Prevalence at 4 months old (wave 2)		Prevalence at 1 year old (wave 3)	
Supported	n = 9	Eloise, Emilia, Hailey, Holly, Ifra, Kimberly, Parvana, Reema, Ruth	n = 4	Eloise, Emilia, Holly, Safa
Struggled	n = 10	Anna, Bahia, Emily*, Evie, Jade, Jane, Kafya, Safa, Silvia, Vanessa	n = 5	Jane, Pravana, Ruth, Silvia, Vanessa
Stalled	n = 2	Chloe, Paula	n = 9	Anna, Bahia, Chloe, Evie, Ifra, Kimberly, Paula, Reema
Shunned	n = 1	Nathen	n = 4	Hailey, Jade, Kafya, Nathen

Note, \*Emily not represented in wave 3 as she was unavailable for interview.



**Fig. 3.** Case-level shifts in vaccination trajectories.

Note, each dot represents a participant, showing their vaccination trajectory by the end of data collection (wave 3). The dot's colour reflects their status at the end of the previous wave (wave 2): Green (supported); Yellow (struggled); Orange (stalled); and Black (shunned). Arrows indicate how participants moved between trajectories over time. Emily is not represented as she was unavailable for interview during wave 3 of data collection.

discussions during the antenatal period. Furthermore, parents often reported that items which were on the scheduled discussion list were not explained to them despite being ticked in the 'after visit summaries' written by their midwife or health visitor. Many felt that this was a missed opportunity to discuss and make decisions about vaccination before a busy and emotional period following childbirth.

*"But, certainly, in those I had boxes ticked that, as far as I was aware, hadn't been discussed with me. I mean, I may be mistaken but, yeah, things like, for example, bottle versus breastfeeding discussed, tick, and I've certainly never discussed that..."* [Holly, wave 2 interview].

*"...[antenatal health visitors] were really friendly and nice...you can build up a bit more of a relationship where you're seeing them regularly, you probably have a bit more trust in having a conversation with them there anyway. So it'd be good to bring that [information provision] in there. So one appointment, they'll say, 'OK, these are your options available to you. These are the vaccines. Maybe just have a quick look into them and we can discuss at the next appointment,' because if you bring it up in the appointment, people might just not want to engage at the time or just not have thought about it that deeply. But yeah, it's just making sure that we're having those conversations earlier, to be honest, and then it gives people time to think of questions as well."* [Nathen, wave 3 interview].

For the majority, vaccination was first mentioned (in passing) by their midwives or health visitors in the postnatal period. Some handed out leaflets on vaccination among other flyers (e.g., breastfeeding), but parents within the cohort shared that they had not had time to read them and limited capacity in the postnatal period. For some the vaccination letter was the first time they received any communication regarding childhood vaccinations. Given the limited information received in the lead up to the vaccination appointment, parents felt that the letter being packaged as a reminder and the use of acronyms was not appropriate.

*"It was one of the last few ones and she said once the baby's born, there'll be a few vaccinations that we'll have to go through. She didn't give that much information."* [Chloe, wave 1 interview].

*"...to me, a reminder is, well, I've already been told when this is, but I hadn't. So all the letters you get from child health are 'your reminder, your appointment is on X date'. So to me, it's as though they're missing the first step, which is the information given about the vaccine...it's not a reminder because you've not told me to remind me."* [Emilia, wave 2 interview].

*"But, again, on that letter, it doesn't explain...It's got them [the vaccinations] all in short form, but I don't understand what that means."* [Emily, wave 1 interview].

Parents felt that the information provided on vaccination appointment letters could be more informative. For most parents understanding what to expect during the appointment, how to prepare, and aftercare was the primary concern. This was not provided, so some parents turned to friends or social media for advice. There was some confusion regarding whether paracetamol was needed after all appointments and first-time parents were often not aware it was needed for the first appointment. Some parents were scolded by the GenPr for administering paracetamol prior to the appointment as this could mask a fever which could contradict vaccination.

*"...I was a bit surprised. I think it's they don't give you enough information, for example, about administering Calpol for temperatures. I think they should give more information about when to do that, because I gave a Calpol in the waiting room and then got told off because she said that it can drop her temperature. So I think there needs to be more information about the aftercare for vaccinations..."* [Anna, wave 1 interview].

Information provision typically occurred at the appointment itself. Some parents reported receiving leaflets about paracetamol administration, although some had already administered paracetamol or would have picked it up at a more convenient time. Many participants found the vaccination appointments "brusque" and even "standoffish" [Holly, wave 1 interview]. Not everyone within the cohort felt comfortable asking questions at the appointment. For some this was precipitated by negative experiences at previous appointments. Resultantly, many participants had unaddressed information needs even after their baby had been vaccinated.

*"...the way that she went through information about the vaccine was very, very quick. It just, like, ticked the box. But it was very brief. Like, I don't know; 20 seconds, or less than a minute, anyway."* [Bahia, wave 2 interview].

*'She didn't tell me which vaccines she was getting or any side effects.'* [Ruth, wave 3 diary entry].

This effect was reversible following positive interactions with their GenPr which could have a transformative impact on parents' experience of taking their children for vaccination. Those with positive experiences reported that nurses were responsive to questions and took their time. An emblematic case is presented in Table 2.



**Table 2**

Emblematic case of a parent who went from a negative to a positive information provision experience.

Jade expressed disappointment at the information she received prior to and during the 8-week vaccination appointment. She had anticipated that the vaccines would be discussed over a period of 7–10 min during the vaccine appointment and was surprised that this took place in a matter of seconds. Her mother who attended with her went to ask questions, but Jade intervened and said to her “I don’t think you are going to get the answers”.

*“I expect that the doctor should be able to at least just explain it out of the appointment time. I feel 10 min, or even seven minutes out of the appointment time is just enough time to talk about this. But when I got there he already had everything set, “Oh you’re having three vaccinations, this and this, this and that, you’re going to get this first, she’s going to get this, you have got a lot of flyers, you can go through the flyers, they help you.””*

At the second interview a few months later Jade was feeling much more comfortable and a lot less nervous about vaccination following a positive information provision experience at the next set of vaccinations. She felt that the nurse took her time in explaining the vaccinations to her and engaged in discussion regarding her questions.

*“...she explained, we asked questions, we had discussions around it, how to manage it, what to do, what not to do...She didn’t make us feel rushed...She was very, very nice, quite patient. It just felt really different, I have to be honest. I have nothing bad to say about it. It was really nice...It was good, it was good. Seriously it was. Even my mum noticed the difference...the previous one I was just like, “What have I done...oh god, what’s happening...it makes a lot of difference to be honest. [Laughs] It put me so much at ease, it made a lot of difference honestly.”*

Parents described hand-outs as desirable given information was easy to forget, however this was not seen as something that should replace information provision during appointments. Those who did receive leaflets at the appointment found them informative and easy to understand. A minority were satisfied with information provision and felt that leaflets were unnecessary. When asked about the information printed in the personal child record (i.e., the Red Book), many parents cited that they did not have time around parenting to read it and that it was not user friendly. This was on account of it being overwhelming, complicated, and difficult to navigate (e.g., having parent and medical sections integrated). An online version where you could click on different sections was reported as a preferable format.

*“...prompts and written down information are needed because forgetfulness still really is a thing and brain fog is really thick still. It’s very easy forgotten even now that I’ve already forgotten what everything was. So just more written down information before and after the vaccines would be such a huge, huge help.”* [Chloe, wave 2 interview].

*“I find the Red Book quite overwhelming, actually, there’s so many pages to it, and so many – it just feels like there’s just so much to look through...”* [Jane, wave 1 interview].

The gap between parents’ information needs and provision, in tandem with poor timeliness, was further highlighted at the final wave of interviews. Participants were invited to reflect on their vaccination journey as a whole and point out key events, moments, or experiences. Many felt that the start of the vaccination programme was a pivotal moment in determining their ongoing behaviour as this essentially represented the start of the pathway. Given its significance they felt that the lack of information provision by the NHS during the antenatal and postpartum period was alarming. Participants wanted more information during the antenatal period and a slightly longer slot for the first vaccination appointment with someone who could meaningfully engage with their questions.

*“...you’re on a schedule with vaccinations from eight weeks to the next dose to the next dose...So, for me, the most important time is the starting the programme. Starting the system. You know, that first eight weeks was the critical eight weeks to either get us on board with the vaccination, not get us on board with the vaccination...”* [Jane, wave 3 interview].

*“...you’re still a bit worried ‘cause it’s your first time. You still have questions. So, I don’t know if the initial appointment they could give you a*

*bit more time so that, in the first vaccination, you’re well aware...I think the first one would be the initial one would be the best time to give us all detailed explanations.”* [Parvana, wave 3 interview].

### 3.2.2. The ‘who’ of information provision: confident, curious, concerned

For most parents’ information provision (or lack thereof) was a key experience throughout their vaccination journey. For many, however, this was just ‘one of those things’ and did not deter them from attending vaccination appointments. Some reported supplementing information provision with their own research (typically the NHS website) which was able to resolve any unanswered questions or concerns. These parents were *confident* in vaccination. Vaccination was seen as simply “the right thing to do” [Emilia, wave 2 interview] and there was an implicit trust in the healthcare system. Many within this group still found vaccination very unpleasant, for some unbearably so, yet this did not deter them as it was seen as an important priority.

*“I haven’t got time to sit and Google, what’s this vaccination, and look into it myself. I could, if I wanted to, but I just don’t. You just get the letter and you just go, right, that’s that.”* [Vanessa, wave 2 interview].

*“Yeah, I think we definitely wouldn’t have questioned having it or not. It was more the kind of what is this acronym, why has it not got pneumonia, I’m not familiar with the acronym, what is it and you know – that was more of the issue really more than are we going to give it or not.”* [Hailey, wave 2 interview].

Most of these parents did not know, nor distinguish, between the different vaccines in the schedule instead viewing the programme as a whole. Although, a minority within this group expressed a desire to know more were it conveniently provided. Often, *confident* parents expressed shame that they did not know more about the vaccines their children were receiving and believed that personal research was a social norm. A minority of parents within the *confident* parent group were aware that there was material online which could deter them from vaccination (e.g., MMR and autism) but had made an active decision to not entertain or investigate such things.

*“It was just, that’s the programme that he’s on that we follow as his parents.”* [Emilia, wave 3 interview].

*“Yeah, I feel a bit of shame... you know, other mums are like, educated about it, they read about it. They know what they give to their children*

and what's the disease name? Well, no, not me..." [Safa, wave 3 interview].

"...if I talked with my friend, she would have poisoned my mind with so many, I don't know, things about them. And TikTok; of course, if I typed 'vaccines in the UK' there will be some poisoned information. So I've done it on purpose. I didn't want – I only focused on the NHS website and that's it. So I truly isolated myself from all the voices." [Bahia, wave 2 interview].

For most parents who went ahead with vaccination, a delay of a few weeks was acceptable, but anything more would have caused stress while for a minority, even a small delay was deemed unacceptable. Those who were less stressed about vaccination timeliness often had inferred and read between the lines of their GenPr's behaviour.

"...there's one nurse who does the vaccines and then she was off sick, so the vaccines then couldn't happen for a week or two...then I was thinking, 'Well, if it's a matter of life and death, they'd make sure that someone was there to do them.'" [Emily, wave 1 interview].

Alternatively, some parents within the cohort were curious about vaccination, even when coming from a positive vaccination stance. They wanted it to feel like an informed choice even if they strongly anticipated vaccination would be the outcome of this process. For this group, having information in advance of the appointment was therefore very important. The lack of information provision was a more notable event in this group's vaccination journey.

"But for me I feel like information before the appointment means that you care about me and you are interested in whatever concerns I might have. But information with the appointment means that you've decided for me, show up, read what you need to read, but show up. That's how I see it." [Jade, wave 3 interview].

"... 'Oh, just jab him up because that's what you recommend,' I don't think I would've been just comfortable with that...you do have a responsibility for your own healthcare and for your own wellbeing, at the same respect, so yes, they gave us some information, and this is what they recommend, and I'm 90 % there, and yes, they're doing it for our own good, but I also think we do have liability of our own care...and so it's your responsibility just to have a little bit of a head in the game of what's expected, and why, why we're having this, why they recommended it, and to make your own decisions." [Jane, wave 1 interview].

In some cases, curious parents became concerned parents who felt that the risks of vaccination may outweigh the benefits to their child. At the point of study enrolment, no parents were concerned by vaccination, but by the first interview a couple of months later and the one-year mark some parents had made this transition. Parents did not think that they were conspiracy theorists. They felt that their concerns were valid and that these were insufficiently addressed by NHS information provision. Often, they felt dismissed by the NHS and treated as 'extreme' despite being willing to engage in conversation. For this group, a lack of information provision represented a critical turning point in their vaccination trajectory.

"Honestly, beforehand, I was one of the people who thought – because you know anti-vaxxer has that negative connotation, I was one of those people thinking, 'Oh, if you're anti-vax, then you're just a bit of a conspiracy theorist,' blah, blah, blah..." [Nathen, wave 3 interview].

### 3.2.3. 'Who' as a fluid entity: enduring confidence vs. emerging curiosity and concern

Many participants reported consistency in their attitudes towards vaccination over the duration of the study but had become more lenient

with vaccine timeliness. Some expressed emerging curiosity, while they still took their child for vaccination for some this came with heightened doubt and anxiety. A notable minority experienced significant shifts resulting in vaccination deferral or rejection at the point of interview. For some this represented a radical shift having endured confrontation or burden to ensure their child was vaccinated on time months prior, while for others it was a more gradual shift towards doubts that they had previously acknowledged but tried to ignore.

"I feel like it's absolutely essential for her to receive them still. It's not even something I would question." [Evie, wave 3 interview].

"I'm probably going to look up what rotavirus is now. But also that just makes me feel a bit like, 'Oh why have I had him vaccinated against it? I don't even know what it is.'" [Emilia, wave 2 interview].

"This vaccine was so stressful. But I was like, 'You always had that position that I'm going to trust what other science is saying in 2024.'...I was trying to just stay logical but doubts were there. And stress also was there, anxiety was there. But in the first vaccine I didn't have them... And this is coming from a person, you know me, who trusts science a lot. I'm a researcher myself. But when you're a mother it's different. You doubt every single thing...You don't want to be the cause of the harm of your baby. So you just become, you become this...But I'm really satisfied with my decisions. I was brave and courageous and tried to be really logical. But I didn't know. It kind of surprised me that I had felt all of this...I was so ignorant. It's something that I will put in my boy's body that will stay forever in his body. So it's not that simple. I need to know what he's getting. And it's a decision that I'm taking for him. So it needs to be really informed. It's not that simple." [Bahia, wave 3 interview].

"Because we didn't go into the process thinking we're highly suspicious of vaccines, or anything. We've always got everything done so far. It's just I think we're happy to be talked into it if it's talked into it with evidence..." [Nathen, wave 1 interview].

Many of those who rejected vaccination at the point of interview were either still actively considering their decision or open minded to vaccination in the future. To support them in their decision-making however, they wanted the opportunity to discuss their concerns with a nurse, health visitor, or midwife. They did not believe that any such opportunity existed and that if they did turn up for the appointment, they would be judged and pressured into vaccination without discussion. Furthermore, they were not confident that healthcare workers would be equipped to meet their information needs or answer their questions in sufficient detail (e.g., the difference between 'vaccines don't cause autism' and the lengthier response detailing where this rumour originated and why this is no longer a cause for concern). Formats which championed discussion such as focus groups, round tables, and support sessions like those seen for other postnatal health issues (e.g., breastfeeding) were seen as highly desirable.

"They'll want me to have it because I'm there and if I refuse to I will be seen as, 'Oh she doesn't want what's best for her child.' So I also do not want that narrative because that's not what the case is. So I don't think if I go into the practice for questions I will get it... back home, normally you get focus group discussions of pregnant women. So everyone comes together, they have like a round table or whatever sitting arrangements. You ask questions, they answer, the nurses answer." [Jade, wave 3 interview].

"I definitely feel very unsure of how to proceed because I really am on the fence. I'm not against childhood vaccinations but I guess I'm just questioning them a bit more...I think that the information hasn't been available to me in the way that I feel like I needed it...They had a thing in the playground the other day with people there from children's service, legal

advice. There were some dieticians there about eating and cost of living advice and independent organisations...Manchester Library had a thing on for breastfeeding awareness...There was nothing there about childhood immunisations... I want to chat with a person. I don't want to chat with a computer or read on the computer. I want to chat with a person and have an honest conversation. These are my reservations. These are the questions that I have..." [Hailey, wave 3 interview].

Feeling unable to access information as desired from the NHS and being judged for harbouring vaccination questions was not only experienced by *concerned* vaccinators, but also those who were *curious*. Many felt that vaccination was a taboo topic, not only with healthcare providers, but also wider society (i.e., family, friends, community acquaintances) leaving them isolated and unable to get the information they needed in response to emerging questions. One parent turned to ChatGPT, while they found the response provided reassuring, they would have preferred to discuss their concerns with a healthcare provider.

"Because I get it, like if you think of it if they make such a big fuss regarding vaccines it may just make it worse. But the thing is the struggle is there. It's just hidden. It is there. Everyone is struggling to make decisions. So just let's speak about it. Stop treating it as a taboo. Let's just speak about it. There are concerns with all the vaccines whether we want it or not. It has nothing to do about the level of education. It has nothing to do about your level of intelligence or whatever. It has nothing to do about your religious beliefs. These are valid doubts that need to be addressed. Otherwise people are just making their own decisions without being informed." [Bahia, wave 3 interview].

Some parents experienced appointments or home visits being booked on their behalf after non-vaccination. These often came 'out of the blue' [Nathen, wave 3 diary entry] and were experienced as an administrative service that did not meet their information needs. Diary entries included pictures of outreach letters which specified that appointments had been booked on the parents' behalf but did not comment on, or offer to address, any concerns which may have contributed to vaccine deferral or refusal. A vaccination team, commissioned by a local NHS foundation trust, who visited Bahia (her son was incorrectly on the system as unvaccinated) did not introduce themselves and started immediately prepping the vaccines upon entering her home which she found both abrupt and alarming.

"What surprised me is that when they came in they were ready with their needles and everything. They started getting ready and I'm like, 'Whoa, whoa, whoa, stop.' It wasn't as if I was against vaccination and I didn't want my boy to get vaccinated. They weren't like, 'OK, we understand that you didn't vaccinate your boy. Is there a reason for it?' It was like they just came in with their needles. I was like, 'Whoa. Stop. First, my boy's fully vaccinated.' It was quite shocking to be honest...But I would get, if I was another parent I imagine that was against vaccination that would have been quite shocking for them. And they might even get into an argument by the way they entered. That's what I really didn't like. And I'm the sort of person who's not against vaccination. But you need some introductions...I didn't like it...It was a bizarre experience. I will remember it my whole life with them coming in with the needles." [Bahia, wave 3 interview].

### 3.2.4. Drivers of change: triggers of curiosity and concern

While there was no singular relationship between cause and effect, three main factors associated with *curiosity* or *concern* were identified which are presented below: negative prior experience, social media, and surfing the web. These often interacted with one another and were supported by other contextual drivers including perceptions of disease severity or likelihood. For instance, while the main trigger for Kafia was her negative prior experience, the impact of this was reinforced by other

secondary exposures (e.g., social media). All of these, however, exist within the backdrop of insufficient (or negative experiences with) information provision within the vaccination service.

#### a. Negative experiences with GenPrs and a breakdown of trust

Many parents reported high dissatisfaction with the NHS and examples of poor care during the antenatal, labour, and postnatal period. This, however, did not impact their confidence in the childhood vaccination service or their comfort in utilizing this programme as it was seen as a separate entity. Despite negative vaccination appointment experiences (e.g., rushed, rude, poor vaccination skills) at the start of the study, many remained *confident* in vaccination.

"I guess with the vaccination... it's a bit more separate... it's separate to the whole system as to pregnancy... the first [vaccination appointment] was awful. She went in really bad, and just went in whilst we were talking, and baby ended up getting a really bad bruise, and a lot of blood coming out, so obviously she'd gone into a vein or gone into something that – it was just too quick. I know that sometimes they just want to be quick, but I felt the first one was really bad. They didn't do it properly. But the others after that, it was the same lady the last two, so it was much better" [Parvana, wave 2 interview].

For others however, experiences of poor care diminished the relationship and the degree of implicit trust with their GenPr. Poor care was experienced in the form of: perceived mismanagement of their child's health (outside of vaccination) or their health; negative experiences of information provision which undermined credibility and left parents' feeling alienated; and adversarial or confrontational events. Detailed, chronological emblematic cases detailing a breakdown of trust from negative information provision experiences and confrontation is presented in supplementary material 4 and 5 respectively.

"But these things, they should be more open about chatting the side effects of whatever medicine, whatever vaccine it is...They have never chatted with me or never listened about my experience with steroids and same with the vaccine." [Kafia, wave 3 interview].

"I still remember when I talked about the flat head, do you remember? When I told you about the flat head and it was like, "You watch a lot of TikTok don't you." I don't want to hear that. I want to be reassured. I don't want you to tell me that I'm being stupid and I'm just watching a lot of TikTok...I mean if the first experience was good I would have considered booking and asking these questions. But because the answer was so rude I don't want that. That was about flat head, imagine I talked about vaccines with them, "You want your child to die." [Bahia, wave 3 interview].

#### b. Social media

Parents were divided as to whether they had come across negative vaccination content on social media, however a notable portion reported either being aware of negative vaccination content online, it spontaneously appearing on their 'for you' page, or in some cases actively using it as an information tool. This included Instagram, TikTok, and MumsNet. Some parents were unphased by the presence of negative vaccination content online, or at most were concerned about how this may be shaping other parents' vaccination choices. One parent reported only seeing a normative post about vaccination online.

For others, the content they were exposed to online was sufficient to shift their attitude to *curious* or *concerned*. Notably, it was not necessary for the social media posters to be people they respected or knew well to be influential. In some cases, it was not the post itself that was influential (or even vaccination related) but the number of people discussing vaccination risks within the comments and the number of likes they received. One parent felt like it was the only forum where vaccination was openly discussed. An emblematic case with diary entries of social media content is presented in supplementary material 6.



*"I watched a video where someone was trying to give her baby something to eat, baby is not having it and someone say, "Baby would have eaten that if you didn't give them vaccines." And some people are like, "Yes, don't give them vaccine, they kill them." [Jane, wave 2 interview].*

*"...a girl I know whose baby is a month older...she put something on her Instagram about how she'd felt pressured to have vaccines...so she didn't take her baby for them...she's a bit whacky...but 12/18 months ago, she's posting on Instagram about 'just got my COVID vaccine' and it's like, well...She's obviously not anti-vax, or anything like that. I don't know. It just made me think she's got a fair point in the fact that I actually don't probably know what this is that they're saying you've got to have this..." [Emilia, wave 2 interview].*

*"Social media, definitely. That definitely plays a big role. Like if it wasn't social media I wouldn't have become this stressed about it. Like social media played a huge part... No [I don't search for it]. It comes up [on my recommended]. If you have baby concerns it comes. And my TikTok is all baby concerns. It comes up. And also if you follow a lot of naturalistic people. For example, I have a lot of pages regarding natural baby food and recipes. People who have that mindset they also have the same position regarding heavy metals and vaccines and all of that...TikTok makes the world more like a village you come across that. But in the real world maybe you won't come across that at all because the majority is talking about the benefits of vaccines. But then once you come across that and because it is quite interesting you stop. And then other content starts coming and you just see that all the concerns...And then TikTok will start showing you more videos about that. And then you stopped receiving videos that are talking about the benefits of vaccines and then every day you hear the same thing. And slowly, slowly it starts getting a bit bigger. So it is the system TikTok, especially TikTok and Instagram works. Is that once they see that you are interested they start bombarding you with content." [Bahia, wave 3 interview].*

*"I'm not really distracted by – I know there are these things on social media, etc, particularly with the COVID jab and whatnot. But I'm just happy to follow the science." [Kimberly, wave 3 interview].*

#### c. Searching the web

Unlike social media, which has the potential to spontaneously show negative vaccination content and presents support in the form of comments and likes, search engine searches are more self-directed. Parents frequently cited supplementing the lack of information provision with search engine results. While most parents used the NHS website, this didn't always answer their questions. Parents were surprised by the range of alternative websites on vaccination to the NHS, including one run by a doctor discouraging combined vaccination and offering single dose vaccinations on a private basis.

One parent clicked on the manufacturer's leaflet listed on the NHS website and found the information "*disturbing*" [Nathen, wave 1 interview]. Namely, the frequency of seizures for some vaccines which, unlike the other potential side effects, seemed more intimidating. They also shared three empirical bodies of work commenting on the benefits and risks of vaccination (refer to supplementary material 4). As discussed under the negative experiences sub-section, Nathen tried to discuss these concerns with his GenPr but felt dismissed. Some explicitly acknowledged the risks of self-directed research. An emblematic case of search engine results is presented in supplementary material 7.

*'We have still stalled [baby's name] 1year jabs. I've been doing more reading and having 2nd thoughts. I am half way through an interesting podcast from Dr [name redacted] who set up [name redacted] company.'* [Hailey, wave 3 diary entry].

*"...it is like a conveyor belt sometimes, isn't it? But, yeah you don't get loads and loads of information but I guess in some ways if that is*

*something that parents would like to know more about, a lot of people just do it themselves don't they, they get on the internet and go what is that injection? But, then that can have its negatives can't it, if you go down a rabbit hole and read all these scary things."* [Vanessa, wave 3 interview].

*"The point of having misinformation online isn't that it screams this has been misinformation. It's well written and it's hard to tell what's true and what's not, and it's hard to be able to take the conclusion away. So that's why I think the NHS needs to step in and just be like, "Well, you people can rely on this as the resource. We will provide all the information you need.""* [Nathen, wave 3 interview].

## 4. Discussion

Information provision is a central factor accounting for parents' experiences of the vaccination service in England. The findings reported in this paper need to be contextualised within the preceding analysis which reported access challenges due to inadequate booking systems and punitive approaches towards parents who were late (or forgot) vaccination appointments [19]. Eight months on, at approximately one year of age, it is clear these issues continue to undermine vaccination uptake accounting for sizable shifts towards *struggled* and *stalled* vaccination trajectories.

Focusing on information provision in isolation is inadvisable, but opportunities for improvement need to be actioned. While a *shunned* trajectory (i.e., vaccine refusal) is less prevalent within the cohort this analysis sheds important light on the mechanisms which can lead towards vaccination *curiosity* and *concern*. The classifications (confident, curious, and concerned) produced during analysis are similar to those presented by Leask et al. which includes additional typologies based on vaccination outcome (i.e., late or selective vaccinators, and refusers), which in this instance is further interrogated using the 4S Vaccination Trajectory Framework (supported, struggled, stalled, shunned) [25].

While information provision and vaccine hesitancy have been a dominant focus in childhood vaccination uptake research within the UK, this study is the first to follow parents prospectively as they progress through the vaccination programme, documenting information encountered and its impact in real-time. By introducing temporality into the analysis, and seeing what information is offered to parents and when, we have been able to observe notable deficiencies in parents' opportunity to access information in a way which meets their needs.

Building on the initial eight recommendations for policy and practice [19], eight more are included focused on appropriate and accessible information provision. As discussed by McMurray et al. [26], we include these recommendations in the knowledge that simply providing more information (leaflets, television campaigns) is unlikely to be an effective strategy. Instead, the NHS should seek to embed opportunities for meaningful and collaborative knowledge exchange [7,26,27].

Our findings, and indeed the wider qualitative literature, suggests that parent satisfaction with information provision by the NHS prior to appointment attendance is lower than that reported in an annual survey conducted by UKHSA which specifies satisfaction rates of 76 % [15]. This is likely to be due to methodological differences: retrospective vs prospective; 15-min survey vs in-depth interviewing; 'non-nationally representative' vs socioeconomically diverse. Given the prospective nature of this study the risk of selection bias is diminished but not eradicated as further discussed within the strengths and limitations section. This discrepancy is a point of interest and warrants further investigation.

### 4.1. Policy and practice: implementation fidelity, amendments, and innovations

Data from our research suggests that childhood vaccinations were

not discussed in the antenatal period, although they were often mentioned in passing postnatally. We echo recommendations for more timely information provision [7,26,28]. Appointment letters should not be the first point of contact (as noted in our findings), instead should be viewed as a health promotion opportunity for providing key information about vaccines. The Red Book is also arguably under-utilised as an information provision tool because parents find it difficult to navigate. This may be geographically unique to Manchester on account of the region using their own version of the Red Book which is more extensive than its national counterpart. A national survey ( $n = 1454$ ) found that 21 % of parents reported using the Red Book as a source of information; this is notable but still comes second to alternative sources such as online (67 %) and Facebook (24 %) [15].

**Recommendation 1:** The role health visitors play in promoting childhood vaccinations within the antenatal and postnatal period should be strengthened. Within the UK context health visitors are only mandated to 'ensure' vaccinations are booked at the 6-to-8-week review [29]. Health 'promotion' (i.e., encouraging conversations and using motivational interviewing) is limited to selective vaccinations in relation to maternal hepatitis B and rubella status. This contradicts the Healthy Child Programme which specifies that health promotion applies to the full routine programme [30]. Commissioning guidance should be aligned with the Healthy Child Programme and the intervention should be brought forward to the antenatal period given parents' desire to receive information and make decisions about vaccination earlier. This policy variation may account for why some parents (30 %) report receiving information from health visitors or midwives while others do not [15]. Implementation fidelity may suffer due to the erosion of the health visitor workforce (down 40 % from 2015) with a shortfall of 5000 across England [31].

**Recommendation 2:** Appointment letters should spell out vaccinations, including the diseases they protect against, in full and should invite discussion as recommended by The National Institute for Health and Care Excellence (NICE) [32]. They should assume that this may be the first time a parent has been contacted about vaccination and provide QR codes which link to further information [32]. This should include links to tips on how to prepare for appointments and what to expect post-vaccination as seen on the NHS website and in the red book [32,33]. Linking information rather than embedding it in the letter keeps them short and simple while improving information accessibility. As appointment invitations become increasingly digital embedded links will become easier for parents to use [34], although a clear invitation to discuss should not be lost in shorter text-based invitations. Movement towards digital communication may reduce information accessibility based on digital literacy and smart phone status – this warrants monitoring and mitigation as a potential unintended consequence.

**Recommendation 3:** Our findings reiterate the need to assess the feasibility and acceptability of an online version of the Personal Child Health Record (known as the Red Book in the UK) which presents topics in discrete, digestible formats so that more parents choose to use it as a source of information. This is necessary given the scale of reform required for digital roll-out. Ideally, the Red Book would be housed within the main NHS App to create a one-stop shop for all health information and appointments. This, however, is only available in England with other nations having different systems. Furthermore, this would require parents to have their child's account linked to their own via proxy access which is currently only being piloted in certain GenPrs. Plans are underway to expand the proxy offering within the NHS App [35]. Furthermore, parents would require support to set up proxy access via the NHS App which could be laid out by the GenPr following registration and during subsequent appointments. Long-term this may enhance communication between NHS and families, and offer financial savings as notifications are free-of charge. For some, a digital Red Book may not be accessible, and a paper copy should still be made available. The Red Book is currently under-review by the Royal College of Paediatrics and Child Health (RCPCH) [36].

Due to deficiencies in information provision during the antenatal and postnatal period, and administrative style appointment letters, many parents had not received any information prior to appointment attendance. With this context we can see why attendance being viewed as informed consent is problematic and off-putting for parents [26], or why they may find appointments brusque and depart feeling uninformed [26,37–39]. Resultantly, many parents were dissatisfied with the information provided at the appointment and the limited scope for discussing their questions. We build upon recommendations previously made in the literature for: sufficient time to discuss vaccination [27,28,40–43]; training staff to ensure they can meet parents' information needs (including incidence of side-effects as reported in manufacturers leaflets linked on the NHS website) [27,42,44–46]; and actively encouraging empathetic communication with empathy [25,27,28,39,47–49]. This may require addressing low vaccine uptake and hesitancy within the healthcare workforce itself [50].

**Recommendation 4:** Appointment attendance should not be viewed as implied informed consent [25]. In addition to health professionals making it clear which vaccines are to be administered, parents should be encouraged to share any questions or concerns they may have [32,51]. This acknowledges that not all parents may feel comfortable asking questions without invitation, particularly if they have previously had negative experiences. NHS leaflets are important and valued by parents but should be an adjunct not a replacement for face-to-face discussion. Sufficient time should be allocated to discuss vaccination [32]. The Royal College of Nursing recommends a minimum of 20 min for vaccination appointments [52], while most parents reported vaccination appointments to be just a few minutes long. Implementation of this recommendation will require expanding staff capacity. Given the context of severe understaffing, implementation of this recommendation should be prioritised for the 8-week appointment given its significance in opting in or out of the programme. Even allocation of 10 min would represent a significant improvement and align with parents' expectations.

**Recommendation 5:** To support the implementation of recommendations 1 and 4, midwives, health visitors, and vaccinators should be sufficiently trained to provide personalised evidence-informed answers to a range of potential concerns held by parents [32,51]. Advice should be given on how to handle unexpected, or new, concerns voiced by parents and how to engage with parents in a way which is compassionate. Respectful communication training should challenge negative conceptions of parents with vaccination concerns and reflect on their duty of health promotion. Informing staff why this is important, and the potential impact of negative experiences may motivate implementation.

There are many toolkits to support vaccination conversations [25,43,53,54], but ensuring staff are adequately trained on their implementation and that they are kept up to date requires attention. National training outlines minimum standards and core curriculum for vaccination training [55]. Furthermore, the online training portal run by NHS England offers a session on '*communicating with patients, parents and carers*' which was last updated in February 2023 [56]. Several providers offer enhanced (face-to-face) vaccine conversation training at an additional cost [57,58]. JITSUVAX offer such a course which utilises a train-the-trainer format to build capacity [57]. These courses are vital in improving skills and confidence but raise questions regarding variability in healthcare providers ability to engage in conversations about vaccination and by extension their accessibility to parents.

Not all parents may be comfortable using vaccination appointments as a forum to discuss their concerns due to (a real or perceived) pressure to vaccinate within the scheduled visit and a belief that staff will be unable to meet their information needs. In part, this could be addressed with the implementation of recommendations 3 and 4, whereby attendance is not viewed as implied consent and discussion is encouraged. This said, alternative information provision sessions in the format of focus groups or round tables may still prove valuable in encouraging attendance by parents or alleviating information provision pressures on

staff across individual appointments. Drop-in community sessions were also recommended by Tickner et al. [39].

**Recommendation 6:** Parents who are *curious* or *concerned* about vaccination would benefit from community round tables, but open group formats risk being disrupted by others seeking to use them as a misinformation platform. To mitigate this, while still promoting dialogue, one-to-one information stalls or drop-in clinics could be piloted. These settings lower the chance of disruption, but staff should still be prepared to handle disruptive members of the public seeking to use sessions as a platform to dissuade other parents. Therefore, these sessions should be run by public health specialists who have the required skillset. Sessions should be offered in a range of community settings. Given resource constraints this intervention could be reserved for low coverage areas and may have to be delivered as part of a catch-up initiative rather than prospectively being offered to all parents.

Given challenges booking and accessing appointments it is promising to see appointments being scheduled on parents' behalf and the provision of home visits. However, the way these appointments are communicated and provided does not acknowledge that vaccine deferral may be due to ongoing *concerns* regarding vaccination. Resultantly, these efforts may be received as abrupt or alarming by parents.

**Recommendation 7:** Outreach efforts to parents of under-vaccinated children (through booking appointments on their behalf or arranging home visits) should specify that as part of the offer they are welcome to discuss concerns or questions, and that vaccination is not a pre-requisite of the appointment. Staff running such services should be particularly confident compassionately engaging with parents' concerns.

The factors associated with a *shunned* vaccination trajectory (negative experiences, social media, and internet search results) were ultimately driven or exacerbated by inadequate information provision. As such, the preceding recommendations should heavily mitigate against these factors. For example, prior negative experiences with a GenPr are, in part, addressed by building relationships with trusted vaccination advocates outside of the GenPr such as midwives, health visitors, and community-based round tables. While negative experiences in terms of rushed appointments or needle phobia have been discussed in the literature [6], experiencing conflict, embarrassment, or unsatisfactory medical care (beyond vaccination) and documenting the impact this can have on vaccine confidence over time is a unique contribution of this study. Other studies have, however, retrospectively considered the potential impact of negative interactions [49].

Similarly, by improving information provision parents are less likely to search for, or be impacted by, (negative) vaccination materials online. Should these materials still bear an impact on parents' confidence, the preceding recommendations ensure that there are appropriate avenues to discuss their concerns in a non-judgemental environment and that outreach efforts are appropriate. Nonetheless, spontaneous exposure to negative vaccination content on social media is concerning. Whether this be posted directly from popular naturalist accounts with large followings, or comments on posts unrelated to vaccination (e.g., eczema).

The influence of social media is increasingly being reported in the literature and warrants further attention [25,43,44,47,48,59]. Reassuringly, one survey found only 5 % of parents ranked social media in first to third place in terms of level of trust [15] and in another interview-based study ( $n = 10$ ) parents cited only turning to 'reliable' sources [49]. This seems to conflict with the accounts of parents within this cohort; perhaps this is due to the wording of these studies which focused on whether sources were 'trusted' as opposed to whether they were 'influential' (i.e., parents do not appear to necessarily need to trust the information sources on social media to be affected or concerned by them). Furthermore, being impacted by social media content may be seen as taboo and result in reporting bias. Notably, within the same survey study, the number of parents reporting that they had not been exposed to concerning information dropped from 79 % to 59 %; social media played a significant role accounting for 67 % of those reporting

exposure to worrying information [15].

**Recommendation 8:** During the pandemic social media platforms issued warnings on videos spreading misinformation and blocked certain hashtags including those regarding Covid-19 vaccination, however, policing of content remains controversial and difficult to enforce [60–62]. Instead, the NHS should invest in providing counter-narratives across their national, regional, and local social media platforms and encourage parents to reach out to their GenPr to discuss their concerns.

While we present a series of recommendations, commissioners and providers are encouraged to engage with their local communities and involve them in identifying and resolving barriers to vaccination as per guidelines issued by NICE [32]. While some of these recommendations sit outside mainstream policy and practice (recommendations 6–8), others expand upon pre-existing recommendations (recommendations 1, 3), provide added context (recommendations 4, 5), or simply demonstrate the need to improve implementation fidelity (recommendation 2). As stated in the preceding publication [19], considering severe staffing and resourcing pressures across the NHS, adoption of recommendations is likely to require strong leadership at the practice level and additional financial support [63,64]. As of 1st April 2026, commissioning of all vaccination services will become the responsibility of Integrated Care Boards (ICBs) [65]; this period of reform may provide an opportunity to integrate new recommendations.

## 4.2. Closing reflections

### 4.2.1. Unaddressed risks: the confident vaccinator

These recommendations are not only to serve *curious* and *concerned* parents. The lack of accessible information leaves even *confident* vaccinators vulnerable to negative vaccination material propagated on social media and internet pages. Relying on a parent's status as a *confident* vaccinator with an implicit trust in the NHS fails to acknowledge that their relationship with vaccination is malleable. Without a strong grasp of why vaccination is important and deemed safe, parents are vulnerable to feeling embarrassed or concerned in the face of material promoting vaccination-related risks.

Parents should be supported to know more about the vaccination programme, to become familiar with the individual vaccinations within the programme and the diseases they protect against. While for many their confidence in vaccination will endure, it is not possible to identify and target those who will transition in the future, meaning a cohort-wide approach is needed. Given resource constraints, short-term there may need to be a focus on reactive (as opposed to proactive) interventions which seeks to improve the information offer at the point of *curiosity* or *concern*.

### 4.2.2. Unseized opportunities: shunned parents

While the fluid nature of vaccination relationships poses a risk for *confident* vaccinators, there is also opportunity for re-directing parents on a *shunned* trajectory. Most parents who had refused vaccination considered themselves still on the 'fence' or open to vaccination in the future. While we do not condone pressuring, or coercing parents into vaccination, we support the provision of accessible information which enables parents to choose vaccination with greater confidence. Increasingly, vaccination refusal is being seen as a "continual process rather than a pre-existing stance" [49, p.980].

Currently, the vaccination service is built for *confident* vaccinators with very little support for those who are *curious* or *concerned* about vaccination. To address falling vaccination coverage it is essential that the vaccination service provides space for open discussion, otherwise this gap is increasingly filled by social media and internet searches. Given the taboo nature of vaccination concerns [49], directly inviting parents to share concerns whether that be during appointments or in scheduled drop-ins is vital. In a large-scale US survey study ( $n = 3924$ ) the biggest trigger for parents changing their mind and opting into vaccination was information or reassurance from a healthcare provider



[66]. This demonstrates the potential impact of improving information provision.

The NHS and health professionals remain highly trusted by parents with 66 % reporting feeling more confident about vaccination after a discussion; 14 % reported changing their mind to have vaccines following discussion [15]. This could be better utilised to support parents make decisions about vaccination. Currently, passive sources such as the NHS website and leaflets are the most common information sources reported by parents [15].

#### 4.2.3. Vaccine hesitancy and information accessibility: the chicken or the egg

Shifts in terminology and their application have powerful implications for how the problem of vaccine uptake is defined and by extension the design of interventions which seek to improve coverage [19]. Recent efforts were made to move away from the term ‘anti-vaccine’ due to its negative connotations and the implication that people could only conform to one of two binary positions (i.e., ‘anti’ or ‘pro’). Instead, to acknowledge the full spectrum of vaccine attitudes (and that concerns could be legitimate instead of radical) ‘vaccine hesitancy’ was proposed [48]. Often vaccine hesitancy is referred to as the problem, with trust building and information provision the solution.

Through utilization of a qualitative longitudinal cohort study, we have observed severe deficiencies in information provision in which a position of vaccine acceptance is assumed but not earned. This raises the question, which comes first, vaccine hesitancy or (inadequate) information accessibility? In reality, some parents may enter the system with pre-existing concerns about childhood vaccination, but it is important to recognise that others may develop doubts as a result of their experience with the vaccination service. This resonates with Gardner et al. [40], who attributes misinformation as a result of poor access to information, and with Skirrow et al. [7] who positions parents’ desire for information as ‘normal’. This blurs the lines between attitudes and accessibility further demonstrating the need for them to be considered in tandem.

#### 4.3. Strengths and limitations

Due to the prospective nature of the study, the potential impact of selection bias due to parents having particularly strong experiences is lessened, as parents were yet to experience the phenomenon of interest at the point of study enrolment. Notably, none of the parents anticipated refusing vaccination when they joined the study. A strength of this approach is its prospective nature rather than relying on retrospective reporting. Furthermore, significant efforts through community outreach were taken to recruit a sample which was not dependent on ease of access through extensive community outreach.

We aimed to mitigate observation bias by reassuring participants of their autonomy in vaccination decisions, acknowledging concerns about vaccines without judgement, and timing interview invitations to occur no earlier than four weeks after the child’s vaccination due date. Having built rapport during previous interactions, participants who became curious or concerned about vaccination continued to participate in the study; this was critical in gaining access to thoughts and behaviours which participants had internalised as “taboo”. This demonstrates the strengths of longitudinal enquiry in enabling rich experiential findings which may otherwise be under-represented in research. During the final interview parents were asked to reflect on their involvement in the study. For a small number of participants, involvement in the study prompted greater reflection on their reasons for vaccinating their children and a desire to be better informed; however, they did not perceive this to have influenced their actual vaccination behaviour.

For this analysis we would like to stress that while QL research presents results which are causal these are to be interpreted and understood in ways which acknowledge that an outcome cannot be traced back to any specific event and that to do so would be reductive. Instead, QL research seeks to acknowledge the multiplicity of causal processes

and celebrate its ability to capture a world in ‘flux’ even if understandings are inevitably ‘partial, plural and unfinished’ [18, p.334]. Thus, causality is conceptualised differently in qualitative investigations compared to their quantitative counterparts. Quantitative studies aim to answer positivist questions with objective truths (e.g., does smoking cause cancer?), while qualitative studies aim to answer constructivist questions where there may be multiple ‘truths’ within and between cases (e.g., what *can* cause someone to abstain, start, quit, or re-start smoking?). While the sample size was in line with best practice, there may be further triggers or pivotal moments within the wider population which were not captured within this cohort. This is a limitation of the study. Nonetheless, due to its explanatory power, QL research is increasingly being used as an exploratory or evaluative tool in policy and applied research settings and represents a strength of our approach [18].

Given the aim of the analysis, to identify themes in drivers across the cohort, some key events relevant to individual cases were not presented as part of the results. Given the small sample size these events may be ‘thematic’ within the wider population and warrant further investigation. Namely, the potential impact of differences between the UK schedule and that of a parents’ home country, and integration with communities that have vaccine concerns at a higher rate than the general population. While the study was based in Greater Manchester commissioning guidelines are provided nationally (i.e., the expectations of health visitors to promote vaccination). Resultantly, generalisability to other areas of the UK is likely although there may be a degree of variation in service provision; parental triggers (e.g., online search engines or social media) are not deemed unique to the study setting. Lessons learnt and associated recommendations may point to areas of interest for other countries seeking to improve their vaccination coverage.

By requiring speaking proficiency in English this study cannot speak to the experiences or needs of those with language-related barriers to access. This was an intentional sampling choice as English literacy and migrant status have been explored as barriers to childhood vaccination elsewhere [44,45,47,67,68].

#### 5. Conclusion

To address declining vaccination coverage in England, it is essential that parents have opportunities to discuss their questions with health-care providers who treat their concerns with respect and offer evidence-based information. Often the need for ‘more’ information is discussed, but this fails to accurately reflect the dearth of opportunities for information exchange within the current system as experienced by parents. Missed opportunities for information provision are observable across the vaccination pathway from the antenatal period, in vaccination appointment letters, during appointment attendance, and within the wider community. For many, information provision is too little, too late, and there is no opportunity for discussion. This leaves an information vacuum in which parents are vulnerable to online search engines and social media which often harbour negative vaccination sentiment. This study deepens our understanding of parents’ experiences of information provision regarding childhood vaccinations and provides eight recommendations for policy and practice.

#### Ethics Declarations

Ethics approval was granted by the NHS (no. 22/PR/1465) and LSHTM (no.28158). Participants were informed of the purpose of the study, their right to confidentiality, and that any data would be appropriately handled. Written consent was obtained during enrolment to the study and verbal consent was obtained during each subsequent wave of data collection.

## CRediT authorship contribution statement

**Georgia Chisnall:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Louise Letley:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Sandra Mounier-Jack:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Helen Bedford:** Writing – review & editing, Supervision. **Tracey Chantler:** Writing – review & editing, Supervision, Methodology, Conceptualization.

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## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Data availability

The dataset generated and/or analysed during the current study are not publicly available due to their containing information that could compromise the privacy of research participants. Plans are in place to archive anonymised copies of transcripts and analysis materials which will be available from the corresponding author on reasonable request.

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