***Title:***
Motherhood and vaccine refusal in the UK: a new examination of gender, identity and the journey to contemporary non-vaccination.

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***Ethical Statement***
This study was approved by the University College London's Research Ethics Committee, reference number 18749/001.

The key ethical issue of this study related to the recruitment and interviewing of a group of women who may have had previous negative experiences of vaccine conversations. It was for this reason that study invitations giving a full description of the research were posted to forums and social media groups where interested participants could then approach the researchers. At every stage of the study, participants were given the opportunity to ask questions or to withdraw from the study. Participants signed consent forms prior to being interviewed and were given information sheets detailing what kind of information would be collected, how it would be used, who to contact with concerns and how to withdraw from the study.

It was also mentioned in the study that one of the interviewees was a 'personal contact', this individual was an acquaintance of the primary researcher and was given the same information and opportunities to withdraw from the research as every other participant. The researchers acknowledge that the recruitment of a personal contact is not without ethical issues given possibility coercion to participate in the study, however every attempt was made to mitigate this by communicating in the same way as with all other participants and clearly communicating the interviewee's freedom to withdraw at any time.

***Declaration of competing interest***
The Authors have no interests to declare.

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***Title:***
Motherhood and vaccine refusal in the UK: a new examination of gender, identity, and the journey to contemporary non-vaccination.

***Abstract:***
*Introduction*
Contemporary research into non-vaccination has highlighted some of the attitudes, beliefs and characteristics of non-vaccinating parents with recent research also beginning to examine the journey to non-vaccination. However, the interaction between gender, identity and non-vaccination is less well understood, as well as the non-vaccination journey for parents in the UK.
*Methods*
Using purposive sampling we recruited mothers who have rejected some or all of their child's routine vaccinations in the last 5-10 years. Semi- structured interviews were conducted by phone in late 2020 and analysed using thematic analysis.
*Results*
Ten mothers were interviewed. They differed in socioeconomic, educational, and cultural backgrounds yet all wanted the same thing: to have happy and healthy children, a goal which they saw as their responsibility and within their control and did not include vaccination. Within this shared parenting priority, identities varied considerably. Most mothers strongly rejected the label or identity of 'anti-vaxxer', preferring alternative terms with less negative social connotations. The decision not to vaccinate was predominantly made by mothers, describing a dynamic where mothers (rather than fathers/partners) were clearly responsible for their children's health, but this largely appeared to be internalised as the mother's role.
*Conclusions*
The heterogeneity of mother's identities within the non-vaccination movement and the pressures on mothers to raise children with 'optimum health' explored in this study, suggest that non-vaccination is a largely individual choice which requires nuanced and compassionate engagement to understand the root causes behind this decision.

***Keywords:***
United Kingdom; vaccine refusal; qualitative research; childhood vaccination; immunization; vaccination; COVID-19; public health.

## *Introduction*
Within the medical community and media, vaccine refusal is viewed as a global threat and whilst concerning, it's also hyperbolic to suggest that a movement is sweeping the nation. Studies have shown that only ~2% of UK parents refuse all vaccinations with the vast majority vaccinating automatically in line with the schedule (Campbell et al., 2017) and reported vaccine uptake among young children exceeding 90% (NHS Digital, 2020). While encouraging, non-vaccinating parents or those with doubts about vaccination may not be fully represented in studies of vaccine attitudes, giving a more positive picture of parents' views. Dubé et al. (2013) suggested that a significant and potentially growing number of parents in developed countries have concerns about vaccines, which can become refusal (MacDonald, 2015).

Whilst some studies (Jackson et al., 2017) focus on parental knowledge and understanding of vaccinations, in most cases insufficient information is not an issue (Campbell et al., 2017; Yaqub et al., 2014). Several studies also focus on parental risk perceptions, indicating that parents are predominantly concerned with individual risks to their children (Karafillakis and Larson, 2017; Poltorak et al., 2005). However, Western culture advocates for informed health consumerism (Sobo, 2015) where parents are responsible for researching and making educated decisions for their child's health as well as emphasising freedom and empowerment in healthcare. This shift towards individualism undermines vaccination as a social contract and in this context, Hobson-West (2003) argues that vaccine refusal is rational, the assumption being that others will vaccinate. By operating on an information-deficit model and continuing to deliver one-way information, policymakers and health professionals do not effectively or empathetically engage with concerned parents, overlooking that how parents react to and understand information is as important as the information itself.

Contrary to the commonly held view that vaccine refusal is a single decision, Poltorak et al. (2005), Helps et al. (2019) and Wiley et al. (2020) explore vaccine refusal as a continual process rather than a pre-existing stance. These studies move the narrative away from stereotypes of vaccine refusers, showing that not all parents adhere to an "alternative" lifestyle (ibid) and challenging the notion that it's a straightforward decision (Helps et al., 2019; Poltorak et al., 2005).

The pandemic has brought vaccines to the forefront in a way not seen in living memory, with the development of a COVID-19 vaccine having the potential to both change opinions and heighten divisions (Vanderslott, 2020). As Larson suggests (Henley, 2020) some non-vaccinating individuals may change their behaviour to accept a vaccine, whilst 'extremists' may deepen their beliefs, potentially gaining from the increased attention.

Qualitative research on non-vaccinating parents remains sparse, warranting further investigation. To our knowledge this is the only contemporary investigation of non-vaccinating mothers' beliefs in the UK in relation to routine childhood vaccinations. Previous studies have tended to focus on acceptance of specific vaccines (e.g. Smailbegovic et al., 2003; Brown et al., 2012) however as this study shows, mothers often consider vaccines as a single entity highlighting the importance of understanding perceptions of childhood vaccinations as a whole.

Furthermore, we explore the gendering of vaccine conversations, including expectations of motherhood and the burden of maternal health responsibility (Hays, 1996; Wolf, 2011; Kukla, 2006;2008), where a disproportionate responsibility for children's health rests on mothers. In particular, the enormous pressure of modern motherhood (Hays, 1996; Kukla,2006;2008), to raise a child with 'optimum health' may lead to questioning or losing trust in authority.

This study sets out to understand the origin of non-vaccination beliefs, exploring themes such as maternal health responsibility, relationships, and interaction with healthcare professionals.

## *Methods*

### Sampling and Recruitment

Initial recruitment was through a personal contact[1] and by posting a written invitation on online parenting forums detailing the research and providing contact details for the researcher. This invitation was extended to other online groups and some participants were recruited through snowballing.

Once potential participants responded to the study invitation, they were supplied with further details of the study via a participant information sheet and a form to gain informed consent. Given the sensitive nature of this study, it was particularly important to reassure mothers of their privacy and confidentiality. A resource providing mothers with reliable information sources was prepared in case vaccine questions arose during the interviews (e.g. Public Health England; Vaccine Knowledge Project and selected publications). A table with participant characteristics is provided (Appendix B).

### Data Collection

Using a qualitative approach, semi-structured interviews were conducted. An interview topic guide was developed taking a chronological approach to explore past, present, and future thoughts concerning vaccinations. Questions were informed by the literature but allowed for flexibility during the interview, adjusting to participants' responses. This allowed for a conversation that felt natural and enabled a detailed, complex discussion. Ten interviews were conducted lasting between 30-50 minutes. Due to COVID-19, interviews were conducted telephonically, audio recorded and transcribed afterwards. Telephone interviewing removed geographic constraints, and so mothers were recruited from across the country.

### Data Analysis

Interviews were recorded and transcribed verbatim. Once all the interviews had been conducted, the transcripts were coded line-by-line with descriptive preliminary codes, attempting to remain open-minded about potential theoretical directions, as advocated by grounded theory (Charmaz, 2006) whilst also being aware of the current literature in this field. All codes were derived directly from the data rather than themes identified in advance, the coding was done using NVivo 12 and due to the nature of the project as an undergraduate dissertation, only the primary researcher was responsible for the coding. Once all interviews had been coded, these codes were grouped, analysed, and synthesised to look for patterns and theoretical insights (thematic analysis). At this point, we could have continued recruitment but were satisfied that a sufficient degree of saturation was met with the sample at hand.

## *Results*

[1] It's important to note that one participant was an acquaintance of the primary researcher, this was carefully considered prior to recruiting and has been reflected in the ethical statement, reflexivity statement (Appendix A) and limitations of this paper.

The following sections chronologically explore mothers' attitudes to childhood vaccines, from their journey to non-vaccination through to present experiences and future expectations, examining the non-vaccination trajectory.

## THE JOURNEY TO NON-VACCINATION

### THE TRIGGER

For most mothers, the 'journey' to non-vaccination begins with an event or interaction triggering their search for more information. This 'trigger' can be a primary experience, e.g., a perceived vaccine reaction, or secondary information, e.g., speaking to a friend or a comment from a stranger. Whilst some mothers already had a family history of non-vaccination or existing vaccine concerns, it was the 'trigger' that mothers were able to identify, and which led them to research.

*"the big deciding moment was meeting a friend at an antenatal group...I started talking to her about it and she lent me a book...it was full of studies about issues around vaccines and…from there I started doing my own research." (Interviewee 9).*

*"I thought I gave birth to a healthy son…but after his 4 months vaccinations, a day or two after the vaccinations, my son started having seizures. So that's how I kind of realised and started digging" (Interviewee 4).*

Mothers subsequently described their research. There was a repeated emphasis on being informed and most were eager to describe their research process as looking to experts and reliable sources, rather than social media, potentially a reaction to criticism of non-vaccinating parents as being uninformed or anti-science. Recurring information sources included books, conferences, documentaries, and scientific papers, with public health and NHS information sometimes perceived as unclear or biased. The research phase was enormously important for these mothers, giving them a sense of ownership and empowerment, whilst for others also being hugely conflicting and confusing.

*"nobody's ever paid me for the work I've done researching vaccines and probably gosh over the years spent hundreds of thousands of hours researching them because my children's lives depend on that to some degree, and you just do that out of love and concern and responsibility." (Interviewee 9).*

### SOCIAL NETWORKS

Following, or sometimes during, their research many mothers sought social support through online groups, local groups or existing friends. They described how these social networks supported them in their decision but didn't force or influence them, describing groups as neutral spaces to share experiences, information and connect with other mums.

*"people share stories, share information and then really it sort of snowballs from there and you get quite a community...of people that think alike, and you actually feel a lot stronger for it." (Interviewee 5).*

Other mothers spoke of feeling isolated by their decision and unable to tell those around them, highlighting the differing experiences of non-vaccinating mothers: some felt supported and able to build a network whilst others were alone with their decision.

*“I felt really, really uncomfortable telling people that I hadn't vaccinated because it wasn't a very common thing, and it did lead me to struggling to...build relationships with other mums” (Interviewee 7).*

*“it's not socially acceptable to not vaccinate…friends don't know about the decision that I've made because I don't want to become a social outcast” (Interviewee 8).*

## MAKING THE DECISION

### THE DECISION

Following their research, which often continues after the decision is made, mothers began to make the decision not to vaccinate. Many expressed this as a process of weighing up the risks and focussing on their child’s individual needs, acknowledging the social norm and pressure to vaccinate.

*“it's your children that you've got to make the right decision for and weigh up your own risk factors. You’ve got to make a decision for you and your children, not necessarily think about others” (Interviewee 10).*

*“I didn’t feel any guilt that I wasn’t vaccinating my sons, because of society or to protect other people, I was just concentrating on how to protect my sons and it was the best thing for them.” (Interviewee 4).*

When weighing up the risks of vaccinating, vaccine concerns and perceptions of vaccine preventable diseases played a significant role in the thought process of mothers. Recurring concerns included worries over vaccine ingredients, safety testing, the vaccine schedule, vaccine efficacy and interference with the immune system and the body’s “natural” processes. These concerns were often accompanied by perceptions of vaccine preventable diseases as “historic” illnesses, with participants perceiving them to pose a low risk to their child. Only one of the mothers considered each separate vaccination individually, suggesting that generally, they’re viewed as a single entity.
Another factor for several mothers was a perceived lack of transparency and informed consent, not vaccinating wasn’t presented as a viable option. Again, there was a strong emphasis on autonomy and freedom of choice for the health of their family.

*“we should have a choice - we do have a choice, but it's made out that it's mandatory. I just assumed it was mandatory... it's kind of like this is what you do, rather than you have a choice.” (Interviewee 7).*

*“give them the manufacturers leaflet rather than the sanitised version of a patient information leaflet...it doesn't give the full picture...it’s hiding some of the truth, isn't it?” (Interviewee 5).*

These vaccine concerns along with the desire to make the best choice for their child manifested in different ways, for some mothers the decision was “very easy”, and they were confident in their decision, making it quickly. For others, it was a difficult, emotionally heavy decision which left them feeling isolated and overwhelmed. For some, there was also an element of following “your gut” highlighting the complexities of vaccine decision-making as more than just a rational choice based on cost-benefit.

*"we do tend to know what's right for our children...the conflict I felt whilst I was pregnant was really emotive, I think I remember [partner] coming home and I'd actually be in tears" (Interviewee 1).*

*"it's a huge deal and overwhelming, I was extremely emotional, on top of you know sleep deprivation, hormonal stuff" (Interviewee 8).*

**THE ROLE OF THE MOTHER**

The internal conflict described by participants and our cultural understanding of maternal health responsibility clearly translates into vaccination decisions. In an analysis of anti-vaccination Facebook groups Smith and Graham (2019) found that 75% of users are female, a skew increasing for the most active group members. We can deduce that vaccination is a gendered issue across the spectrum, from vaccine acceptance through to hesitancy and strong anti-vaccine convictions.

When discussing this with mothers, they mostly described an arrangement where the mother researched and took responsibility for the decision, sharing their findings with their partner and sometimes acting as their partner's sole source of information.

*"the more information...that I shared with him, obviously I wouldn't say it was biased information, but – I was a source of information, so it was natural I felt whatever was making me lean towards [not] vaccinating is probably what I was conveying to him. And so, that's what he took confidence in" (Interviewee 1).*

In most cases, whilst their partner wasn't proactive, they did support the decision. For some this wasn't the case and their partner disagreed strongly, yet still the decision fell to the mother, highlighting the expected and internalised roles of motherhood regarding their children's health and wellbeing.

*"there's no chance that I would ever have gone with the full schedule even if my partner had said he wanted the children to be vaccinated, the compromise would have been that they will get some but not all" (Interviewee 1).*

*"he was at work…she had been in my care and he felt that if one of us was going to - he disagreed - but if one of us was going to make the decision it would be me." (Interviewee 8).*

This also plays into wider parenting pressures, many mothers felt that the choice of vaccination was a matter of "life or death" for their child. Simultaneously, mothers seemed not to notice or question this gender dynamic, accepting and embracing this role as part of their identity.

*"it can be overwhelming because…I feel like that's what I'm here for, if I can't do that for my family...then what can I do?" (Interviewee 3).*

**HEALTHCARE PROFESSIONALS**

Before, during and after the decision-making process, interactions with healthcare professionals and health institutions were important for non-vaccinating mothers.

Experiences were mixed, described as mostly negative with some positive interactions. Positive experiences were largely when interacting with health visitors[2] rather than doctors, when mothers felt listened to, spoken to and where an attempt was made to understand their concerns. Negative experiences included: being confronted publicly in the waiting room by a doctor, being called a 'disgusting parent', not feeling able to receive appropriate medical care, switching GPs due to repeated challenges and their child potentially being removed from a hospital ward due to non-vaccination. The unpredictability of medical interactions adds a layer of anxiety, the uncertainty and possibility of a negative experience having the potential to push mothers even further from the medical establishment.
*"I think they're very alienating, very unhelpful and they really make you feel like you're not making the right decision and you don't know what you're doing…and you're trying to harm your child." (Interviewee 3).*

*"she gave me a lot of information as to why I was making a bad decision. Even though…I was there for my own reasons, nothing to do with my daughter...I changed my doctor in the end because every time I went to see her, she would put pressure on me and remind me about vaccinating." (Interviewee 7).*

For some mothers, their choice became a barrier to healthcare, describing experiences where they or their child were unable to get the medical attention they required due to vaccinations being brought up in what they perceived to be unrelated contexts.

*"for us it's like if anything were to happen to a child who was unvaccinated...that would be the first thing that they mention. We're all waiting for that y'know?" (Interviewee 3).*

*"I took him to the doctor, and she just absolutely laid into me about what a terrible mother I was, how irresponsible I was...and that…made me see, in my eyes anyway, that they were more interested in getting my child vaccinated than my child himself, in his wellbeing" (Interviewee 9).*

**TRUST**

Trust is an important component of relationships with healthcare professionals and more widely with institutions and government. For some mothers a lack of trust manifests itself as lying or hiding their decision for fear of repercussions. Whilst this wasn't always expressed as distrust in establishments per se, the inability to be honest about their vaccine stance potentially suggests wider concerns about establishments and their power. Dishonesty was also seen as a way to avoid confrontation or having to justify their choice.

*"I actually have not told them the truth, I told them I'd got them all done privately and that continues now if I ever pop in, I say "…she's had the boosters so if you can just log her in as having the boosters". I sometimes even research what would she have had...I lie about it so that they have not got me on a list" (Interviewee 2).*

Distrust of pharmaceutical companies was also expressed, particularly in connection with perceived financial motives and incentives. By doubting large pharmaceutical corporations,

[2]In the UK healthcare system a 'health visitor' is a qualified nurse or midwife that works in the community to support children aged 0-5 and their families, this often yields more trusting relationships as parents are supported through milestones of their child's life and often receive this support within their own homes.

questioning authority such as government or medical professionals, mothers were potentially able to outsource some of their parenting concerns and anxieties.

*"that…was a turning point for me where it's just like well I really don't believe that these experts, that I've built up in my head...I'm not comfortable with placing my decisions in their hands because I feel like I'm looking at the data and I'm now more informed to make better decisions than they are. I've lost faith in the system" (Interviewee 8).*

A further dimension of trust is the paradox of mothers often looking to experts and credible sources, e.g., by condemning social media information, whilst also not wholly trusting official government or medical bodies. This raises questions about the nature of perceived expertise and how to rebuild trust in establishments. Schools were mentioned negatively due to nasal flu mists and checking vaccination statuses, for these mothers it may seem that the institutions they interact with act together to encourage or even force vaccination.

## THE PRESENT

### HOW THEY FEEL NOW

When reflecting on the present, most mothers insist they are very firm and happy with their decision, have no regrets and would never 'go back'. Several of the mothers were careful to point out how healthy their children are, using this as evidence to support their choice and even describing their children as "poster children" for their decision. They are arguably so familiar with being criticised that the majority repeatedly gave this information unprompted or when answering unrelated questions.

### LIFESTYLE

It's evident that non-vaccinating mothers have the same parenting priorities as any mother, to first and foremost have safe, healthy, and happy children. For many of the mothers, non-vaccination is therefore not an isolated behaviour but reflects wider lifestyle and parenting choices. These lifestyle choices included long-term breastfeeding, avoiding formula milk, eating raw and/or organic food and following a vegan lifestyle. This often also included an avoidance of 'western medicine' and medical intervention where possible, with many of the mothers emphasising 'natural immunity' and lifestyle.

*"I didn't even let them give him Vitamin K shots...I was so anti-intervention by the time [he] came that I didn't even let them do that nor did I let them clamp his cord" (Interviewee 1).*

Several mothers described their parenting style as "informed" or "conscious" emphasising the need to be aware of everything that goes into their children's bodies, taking sometimes unconventional measures such as detoxes to maintain their health.
There was a definite leaning towards 'alternative' practices in this sample, but it must be reiterated that lifestyles and parenting styles are as diverse amongst non-vaccinating mothers as within the wider parenting population.

### IDENTITY

When discussing the term "anti-vaxxer" with mothers, only one identified as such and was happy with the term. The vast majority of interviewees didn't like the word, referring to

themselves instead as “non-vaxx”, “informed vaxxer” or “pro-choice”. These alternatives were chosen by the mothers due to their perception of the term anti-vaxxer as derogatory and its social connotations. Anti-vaxxers were described as “extremists” or “activists, a term contributing to negative public perceptions of non-vaccinating parents.

*“it immediately makes me think of these groups online and these extremists that don’t just make a decision based on their research and their beliefs but seem determined to tear down people that aren’t with them. I associate Anti-Vaxxers with almost activists...whereas I feel quite strongly about not influencing other mothers…I feel like Anti-Vaxxers is a title that doesn’t resonate or that I don’t identify with because I don’t want to influence anybody…I see them as extremists, and I don’t feel extreme about it.” (Interviewee 1).*

## THE FUTURE

### CHANGING THEIR MINDS

When looking to the future, mothers had mixed thoughts. Some were completely firm in their stance and said they would never change their minds, whilst others had a more nuanced approach, admitting that they would be open to new information and potentially accepting future vaccines depending on the context and the individual needs of their child.

*“I don't think anything would change my mind, I think if I had to, I would go and live in the countryside and lead a completely alternative, self-sufficient lifestyle rather than comply with a government regulation” (Interviewee 7).*

*“we were confident in the decision that we'd made - and are making...it's not set in stone and we'll see, we can re-evaluate at any point” (Interviewee 10).*

### COVID-19 VACCINATIONS

At the time of interviewing (October-November 2020) no COVID-19 vaccine had yet been approved but was a clear focus of public attention, with vaccines strongly emphasised as a way out of the pandemic. Participants were asked their thoughts on a vaccine and whether they would accept it for themselves or their children. None of the mothers were willing to accept a vaccine, listing numerous concerns including the speed of vaccine development, safety testing, side effects and conspiracy theories regarding the nature of the pandemic.

*“COVID-19 is a minor illness, it’s common flu, it’s like over 99% survival rate…I just don’t think that COVID-19 vaccine is for COVID-19, it’s much more than that.” (Interviewee 4).*

Even those who had been directly impacted by the pandemic, e.g., family members catching the virus, were still not comfortable with taking the vaccine. Many of the mothers acknowledged its importance and described it as “right for some people” - elderly individuals or those with underlying health conditions - whilst still questioning the need for a vaccine or feeling suspicious of the monetary gains to be made. This potentially indicates that during the pandemic a cognitive dissonance manifests in some individuals, they can both acknowledge the importance and value of a COVID-19 vaccine without trusting or accepting the vaccine itself. The interviews suggested that participants haven’t changed their vaccine opinions during COVID-19. For some the overwhelming attention on vaccines has been stressful, whilst for others this focus appears to have deepened their opposition.

*"I would be dead before I take that and obviously my kids as well because that's not happening. No way, it doesn't work! I don't understand?! Other than the fact that it probably will give you covid! I don't understand how else it will benefit you. So, no. Not happening." (Interviewee 3).*

**THE FUTURE FOR THEIR CHILDREN**

When considering their children's futures, mothers were aware that the decision not to vaccinate wasn't a 'one-off' decision but rather a 'lifelong commitment'. It was also important to some of the mothers to involve their children in the decision once they were older.

*"I've always said, and I say this to the children as well, when they're older and they want to make decisions about their own bodies…I want them to understand how vaccines work, I want them to understand how their immune system works so that they can make those educated decisions for themselves." (Interviewee 9)*

Generally, mothers didn't look too far into the future, considering mainly the next few years for their children. Overwhelmingly, there was a sense of fear for the future, concerns that vaccines would become mandatory in schools or that they would be forced into vaccinating their children. This fear was potentially heightened by the pandemic, reflecting some of the mothers' anxieties or feelings of being targeted for holding a minority opinion.

*"it's scary...I find it really scary, I'm so scared that...someone will find out or someone will force something" (Interviewee 2).*

*"That's my worry in the UK, if this becomes mandatory [sighs]...My child won't be able to go to school. It's scary, it's really scary. Freedom of choice, your body, your choice, that will go away if that happens...I would home school, I just cannot vaccinate them, it's not safe...The world is going mad." (Interviewee 4).*

## *Discussion*

In examining the journey of these ten mothers to non-vaccination, their beliefs were triggered by an experience which prompted further research, a quest for the 'truth'. These mothers are by no means uninformed placing a great deal of emphasis on 'research' and what they perceive to be credible information. Whilst mothers described pro-actively searching for information, the definition of 'research' will differ between individuals and perhaps warrants cautious interpretation, although most importantly for practitioners, mothers *feel* informed. This process of research requires further exploration, examining in-depth and characterising how mothers carry out this research which appears to ultimately inform their views on vaccination.

As discussed by Benin (2006) it would appear that the role of the healthcare professional is important in vaccine behaviour but perhaps not as a direct influence on the decision. Mothers rarely cited the interactions with healthcare professionals as catalysing their decision, however for some, negative experiences potentially strengthened their disconnect with medical institutions, making them feel less supported or able to ask for help. Whilst healthcare professionals cannot, and shouldn't, proactively try to change mothers' minds, the experiences described highlight the important role of health professionals in vaccination

behaviour. By building trust with new or expectant mothers, and approaching vaccine hesitancy with empathy and understanding, healthcare workers can attempt to engage with mothers, helping them feel able to change their minds or accept new information. These findings echo the principles of effective vaccination conversations (Bedford and Elliman, 2020) which guide healthcare professionals to listen to parents' concerns with empathy and understanding, tailor information to the individual and most importantly to build trust with parents for future conversations. These principles need to be implemented throughout the NHS to have the maximum positive impact on non-vaccination and to foster an environment where parents are not afraid to ask questions or to reconsider their decision.

Echoing findings by Helps (Helps et al., 2019) it was concerning to hear about the negative interactions which some non-vaccinating mothers had experienced with certain healthcare professionals regarding their vaccination decisions. These negative experiences influenced their view of healthcare services as a whole and could undoubtedly affect their willingness to accept other routine contacts. The language used to describe non-vaccinating parents is also important with most parents rejecting the term "anti-vaxxer" and reacting negatively to being identified as such, a finding also reported by Helps et al. (ibid). Healthcare professionals need to be aware not only of how they interact with parents but also the implications of these interactions. All parents should be treated with respect, even if their beliefs are hard to understand. It was striking that, mothers particularly reported positive experiences when interacting with health visitors, feeling that they were listened to, and their concerns understood. Through their work supporting families, health visitors are often able to build strong, trusting relationships with parents which facilitate such positive experiences.
Given these mothers' views about vaccination generally, echoing a recent UK survey suggesting widespread complacency and misunderstanding of the re-emergence of vaccine preventable diseases (Luyten, 2019), it was no surprise that they were opposed to accepting a COVID-19 vaccine. Indeed, the recent almost constant public discussion about vaccination had been a cause for stress for some mothers, while for others only served to reinforce their views.

In relation to gender, this study and previous parenting literature, have shown that non-vaccination is a highly feminised phenomenon, borne out of internalised expectations of motherhood and the maternal responsibility for their child's health. This 'burden' is often accompanied by fear or anxiety and can prevent open vaccine discussions with healthcare providers. Maternal health responsibility, specifically in relation to vaccine decisions, warrants further research, examining how the pressures of modern motherhood may interact with a desire to seek out alternative health practices or to refuse vaccinations for their children. In policy and practice, these findings highlight the importance of tailoring vaccine messaging towards mothers, creating a non-judgemental space for mothers to discuss their concerns and as discussed earlier, utilising the role of health visitors as an integral factor to a mother's future relationship with the healthcare system.

As a result of the controversy over its safety, much of the research on vaccine acceptance in the past 20 years has focussed on MMR vaccine (Smailbegovic et al., 2003; Poltorak et al., 2005; Brown et al., 2012). Our study takes a wider view of non-vaccination in a contemporary context, but this limits comparability with others' findings. Studies from

Australia and USA have noted the challenges of recruiting non-vaccinating parents to such studies. As only a small proportion of parents decline vaccines, the pool of potential participants is relatively small and, as highlighted in this study, there can be issues of trust and of not wanting to come forward. The sensitive and potentially challenging nature of conversations concerning vaccines can discourage parents from participating in research of this nature, fearing a confrontational conversation. Due to these recruitment challenges and the time constraints placed upon this study, the sample size is relatively small. Whilst the ten interviews conducted were deemed sufficient to reach thematic saturation reflecting a range of typical attitudes held by non-vaccinating mothers, it is of course possible that the smaller sample size means that some views have not been covered within these interviews. In addition, the research quality is potentially impacted by the interviewee who was a personal contact of the primary researcher. The researchers acknowledge that this may impact the quality of the data collected, for example through social desirability bias on the part of the researcher or the interviewee.

## *Conclusion*

This study builds on existing literature, exploring the journey to non-vaccination, the dimension of maternal health responsibility and how these beliefs shift in a global pandemic. To our knowledge this is the only contemporary UK study of non-vaccinating mothers not focussing on a specific vaccine, filling an important gap in understanding how mothers perceive childhood vaccines and their identity within this discourse. Additionally, this is the first study to discuss COVID-19 vaccines with non-vaccinating mothers during the early stages of the pandemic, gaining valuable insight into their concerns and fears.

The overwhelming majority of parents in the UK continue to vaccinate automatically and in line with the NHS schedule, with vaccination seen as a normal part of parenting. For the mothers in this study this is not the case, the decision not to vaccinate can be challenging, emotionally difficult and disruptive to relationships.

Examining the journey to non-vaccination in the UK provides an insight into the burden which mothers can feel for their child's health, highlighting the need for greater trust in the institutions which deliver vaccine information and more open, compassionate conversations between healthcare professionals and parents about their vaccine concerns. These findings will be useful to inform healthcare practice and policy which should focus on training to equip healthcare practitioners to openly and empathetically hold vaccination discussions which build trust with parents; compulsory vaccine programmes are best avoided. Furthermore, greater transparency may be required on financial structures, vaccine testing and ingredients, helping to reduce suspicion and distrust amongst parents.

***Key points of practice, policy and research:***

· Non-vaccinating mothers largely do not identify with the term 'Anti-vaxxer', preferring to self-describe with other terms.

· COVID-19 has not greatly changed non-vaccinating mothers' attitudes to vaccines, except in some cases to increase the negativity and stigma which non-vaccinating mothers experience around their decision.

· Motherhood and expected gender roles are bound up with vaccine decision-making, policy and practice needs to reflect the highly feminised nature of vaccine decision-making.

· Further research is needed to explore and characterise the research process which non-vaccinating parents go through to reach their decision. Further research is also needed to examine maternal health responsibility and how this impacts vaccine decision-making.

· Public health strategies and practice should place greater emphasis on the relationships they can build with new and expectant mothers, particularly through healthcare visitors, to foster more open and trusting conversations around the topic of vaccines.

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## APPENDIX A: REFLEXIVITY STATEMENT

### *Reflexivity Statement*

This study accepts that whilst we strive to achieve wholly neutral and unbiased research, this can never be fully achieved due to our inherent unconscious biases we hold, the circumstances we find ourselves in and the experiences which we, as researchers, have had. The primary researcher (LS) who conducted the interviews and coding is a young, female university student who conducted this research as her undergraduate dissertation. This researcher is fully vaccinated and has grown up in a setting where vaccinations are wholly accepted, trusted, and encouraged. The secondary researcher (HB) has been studying childhood immunisations and attitudes to these for several decades, following a background in nursing and health visiting. This researcher also acts as a vaccine communicator to advice on childhood vaccinations and vaccine related issues. It is therefore possible that both researchers hold implicit assumptions and biases regarding those that vaccinate and those that don't, though every effort has been made to remain neutral and grounded in the literature.

## APPENDIX B: SUMMARY OF PARTICIPANT CHARACTERISTICS

| # | Personal Characteristics* | Vaccine Characteristics** |
|---|---|---|
| 1 | - 36 years old<br>- Lives in a city.<br>- Single<br>- White British and Black Afro-Caribbean | - 2 children.<br>- Child 1: 5 years old, has not received any vaccinations<br>- Child 2: 4 years old, has not received any vaccinations. |
| 2 | - 33 years old<br>- Lives in a city.<br>- Single<br>- Mixed ethnicity (didn't specify) | - 1 child.<br>- Child 1: 5 years old, has not received any vaccinations. |
| 3 | - 30 years old<br>- Lives in a town.<br>- Married<br>- Black Caribbean | - 2 children.<br>- Child 1: 4 years old, fully vaccinated up to 12 months.<br>- Child 2: 3 years old, has not received any vaccinations. |
| 4 | - 31 years old<br>- Lives in a town.<br>- Married<br>- White European | - 2 children.<br>- Child 1: 3 years old, fully vaccinated up to 4 months.<br>- Child 2: 11 months old, has not received any vaccinations. |
| 5 | - 39 years old<br>- Lives in a town.<br>- Married<br>- White British | - 2 children.<br>- Child 1: 7 years old, has not received any vaccinations<br>- Child 2: 3 years old, has not received any vaccinations |
| 6 | - 40 years old<br>- Lives in suburbs.<br>- In a relationship, co-habiting<br>- White British | - 6 children.<br>- Child 1 & 2: both 16 years old, fully vaccinated up to 12 weeks.<br>- Child 3-6: 10, 8, 4 and 1 year(s) old. |
| 7 | - 38 years old<br>- Lives in a city.<br>- Single<br>- White British | - 1 child.<br>- Child 1: 7 years old, has not received any vaccinations |
| 8 | - 41 years old<br>- Lives in a village.<br>- Married<br>- White British | - 1 child<br>- Child 1: 4.5 years old, has received only the 5-in-1 vaccination |
| 9 | - 43 years old<br>- Lives in a town.<br>- White British. | - 2 children<br>- Child 1: 13 years old, has not received any vaccinations<br>- Child 2: 8 years old, has not received any vaccinations |
| 10 | - 31 years old<br>- Lives in a rural area.<br>- Married<br>- White British | - 3 children<br>- Child 1: 8 years old, all recommended vaccines inc. pre-school boosters.<br>- Child 2: 6 years old, all recommended vaccines exc. pre-school boosters.<br>- Child 3: 6 months old, has not received any vaccinations |

*Personal details (e.g. ethnicity) are based on self-identification.

**Ages of children are correct at the time of interview.