

How do beliefs and attitudes in the GRT community affect decision making in and experience of care in pregnancy and postnatally? 2018

Background

Gypsy, Roma and Traveller (GRT) communities are among the most disadvantaged minority groups in Europe, experiencing significantly poorer health outcomes, when compared to majority populations.

¹ Specifically, there is poorer infant and child health² among GRT populations, and increased maternal and child mortality^{3 4 5}. A systematic review, undertaken by McFadden et al.¹, found that GRT people face barriers to health service usage related to the organisation of health systems, discrimination, culture and language, health literacy, service-user attributes, and economic barriers. As well as being less likely to access health services⁶, Gypsies, Roma and Travellers are also less likely to access immunisation⁷. Although data is poor, some research has identified that uptake of immunisations⁸ as well as breastfeeding⁹ is potentially lower than in the general population, significantly increasing the risk of infections and preventable disease among children and families.

It is estimated that there are 150,000 – 300,000 people with a GRT background in the UK, although this is widely recognised to be an underestimate.¹⁰ There are conflicting definitions and beliefs as to what it means to be a member of the Gypsy Roma Traveller community, as this range of communities holds different histories, cultures and beliefs. A widely used definition from The Traveller Movement states that ‘Irish Travellers and Romany Gypsies.....distinctive way of life, values, culture and traditions manifest themselves in Traveller ‘nomadism’, the centrality of the extended family, their own language and the entrepreneurial nature of their economy.’ Travellers traditionally travelled to seek work to survive. According to the European Commission, Roma is the term commonly used in EU policy documents and discussions, although it encompasses diverse groups that include Roma, Gypsies, Travellers, Manouches, Ashkali, Sinti and Boyash, all of which are very

¹ McFadden et al. Gypsy, Roma and Traveller access to and engagement with health services: a systematic review

² Smart H, Titterton M, Clark C. A literature review of the health of Gypsy/Traveller families in Scotland: the challenges for health promotion. *Health Education* 2003;103:156-165.

³ Aspinall P. Hidden needs: identifying key vulnerable groups in data collections. Vulnerable migrants, Gypsies and Travellers, homeless people, and sex workers. London: National Inclusion Health Board; 2014.

⁴ Parry G, Van Cleemput P, Peters J, Walters S, Thomas K, Cooper C. Health status of Gypsies and Travellers in England. *J Epidemiol Community Health*. 2007;61:198–204.

⁵ Aspinall P. A review of the literature on the health beliefs, health status, and use of services in the Gypsy Traveller population, and of appropriate health care interventions. Cardiff: Office of the Chief Medical Officer, Welsh Assembly Government; 2005.

⁶ Siebelt et al. Use of UK health services by Gypsies, Roma, and Travellers: triangulation of two mixed methods studies. *The Lancet*. 2017. Meeting Abstract.

⁷ Jackson et al. Understanding uptake of immunisations in travelling and gypsy communities: Protocol for an exploratory, qualitative study. *BMJ Open*. 2015: 5

⁸ Dar O et al. Mapping the Gypsy Traveller community in England: what we know about their health service provision and childhood immunisation uptake. *Journal of Public Health*. 2013. Vol 35 (3): 404-412

⁹ Pinkney K. The practice and attitudes of Gypsy and Traveller women towards early infant feeding. *Community Practitioner*. 2012; 85: 26-29

¹⁰ <https://equityhealthj.biomedcentral.com/track/pdf/10.1186/s12939-016-0475-9>

different groups. Varied definitions can be found in the Cambridge or English Oxford Dictionary and Current Planning Policy or London Plan Policy - the main difference being if the individual no longer physically travellers they cannot be classed as a Traveller. This variation and inconsistency is often contested in various professional settings and can mean that health needs and views will vary. For the purpose of this paper we will be using the definition giving by The Traveller Movement.

Qualitative research studies have been conducted to understand more about GRT families' attitudes towards breastfeeding¹¹ and immunisations¹² specifically and have found that culturally sensitive health promotion and trusting relationships with health professionals are key. The aim of this project is to take a timeline approach to explore GRT women's experiences of and attitudes towards antenatal and postnatal care and how these influence decision making regarding care of themselves and their babies, in order to develop strategies to improve quality of care for GRT women.

Methods

Qualitative research methods were selected to understand the factors influencing decision making and care experiences in pregnancy and postnatally in the GRT community, as such methods are suited to exploring beliefs, values, feelings and reasoning. One focus group, with 4 participants, and 3 1:1 semi-structured interviews were conducted with female members of the GRT community in the Royal Borough of Kingston, London in March-April 2018. The criteria for inclusion were mothers from any GRT background based on the nine groups recognised (Roma Gypsy, Romany Gypsy, Irish Traveller, New Age Traveller, Circus, Bargees, Show People and "Housed") who had delivered a baby at hospitals within Kingston or neighbouring local authority areas in the last 10 years. Grandmothers with children who had delivered a baby at these hospitals in the last 10 years were also included, as they were considered to have an influence on mothers' decision making. In total, 7 participated and they identified as Irish Travellers, English Gypsies or "English Travellers" aged 15-54 years.

Women were recruited opportunistically for the research by one of the researchers using their existing contacts and links in the GRT community. This researcher identified potential participants and checked that they met the inclusion criteria (described above). The interviews and focus group were conducted by three female researchers; one from Maternity Voices, one from NHS England, and one from the local authority Public Health department. The interviews and focus group were conducted in the participant's own home, and this included both council and privately owned sites.

Consent to participate in the research was obtained prior to the commencement of interviews and focus groups. Participants were given a copy of the information sheet and consent form and this was also read aloud to them. The interviews and focus group were recorded using a Dictaphone and transcribed, with the participants permission.

Both the semi-structured interviews and the focus groups followed a topic guide which took a chronological approach, covering care and decision making in pregnancy, childbirth and postnatally.

¹¹ Condon et al 'You likes your way, we got our own way'...

¹² Jackson et al Needles jabs and jags

Thematic coding was undertaken by two researchers independently of one another, and then the coding was shared and themes agreed.

Findings

Three main themes were identified which describe women's experience of care and decision making in pregnancy and postnatally.

1. Antenatal and postnatal timeline

For most appointments and decision making in pregnancy, GRT women described following the routine antenatal schedule and attending all appointments necessary; *"she never missed out on any appointments like that"*.

Most participants reported that they contact their GP as soon as they find out they are pregnant and the timings ranged from between 6 and 10 weeks gestation. No women reported self-referring themselves to maternity services, instead visiting the GP was seen as the first port of call. One other individual was unaware that she was pregnant until she was more than 20 weeks pregnant.

This was with the exception of one individual who reported that she chooses not to tell anyone about her pregnancy (including her partner) until about 12 weeks gestation; *"three months, I don't tell anyone until I'm three months.....so I knew, but because....I'll go later, I'll go later....I don't tell anyone when I'm having a baby...I don't even think my husband knew"*

Most of the women had limited knowledge of screening programmes in pregnancy, and had few comments on the tests and scans received. The majority did not immediately connect the Downs Syndrome testing at the dating scan and foetal anomaly scan as being screening programmes, but they seemed content with the care they received and the information that they were given. They were assumed to be routine parts of the schedule of antenatal care and there was limited knowledge of the risks associated with screening.

"Well, you'd like to know beforehand, wouldn't you, prepared, you wouldn't get rid of it, that's one thing that you wouldn't...it's to be prepared"

"They said there could be something wrong with her heart. "we don't know until she's born", serious things, she told me, there's something wrong with baby's heart, you had me in there an hour scanning her heart and now you're telling me, "We don't know until it's born". It's a horrible thing to say to someone, isn't it?"

Some women were aware that flu and whooping cough vaccinations are offered in pregnancy, but some women were not aware. Of those that were offered vaccinations a small number accepted these. In the focus group discussion, one participant commented *"I had a flu jab, but that's it"*, and others in the group were surprised at this, commenting:

“No, I didn’t have it, no, I just chose not to..I just didn’t want to, I didn’t like the thought of it really...yes, if I wasn’t pregnant I would have had it, but I don’t know, I didn’t like the thought of it when I was having the baby, no”

Postnatally, one woman reported being vaccinated as well; *“after I had my girl, straight away, just before I left hospital with you, they gave me an injection, but I can’t remember what it was for....I did know, but I can’t remember, I think it was just a jab, you know one of them you have to have every so many years, I was due it and that’s what they gave me. I can’t remember what they’re called”*

For childhood vaccinations some mothers reported ensuring that their babies and children receive all of these on schedule, and were familiar with the immunisation schedule reporting that “the age” was how they knew when these should be given.

“Yes mine had all of those straightaway”

“Yes, she got them, all mine got them, all my grandkids getting them”

“The way I look at it, if you don’t have it, if they did get something, it’s your fault not getting this for saving this baby, that’s the way I look at it, one way or the other. It’s like measles, everything can be dangerous, can’t it?”

However, some families reported a preference for delaying certain vaccinations such as the MMR, due to concerns about the link between the MMR vaccine and autism risk. This indicates that GRT families who have concerns about the MMR vaccine will not avoid the vaccination altogether and remain unvaccinated all their lives, rather, they choose to delay the time at which they take their children to be vaccinated, thus creating their own amended version of the immunisation schedule.

“Is it when they start talking they give them the MMR? They always say wait until they start talking, don’t they?”

“Yes, wait until a little bit later when they’re on their feet a bit more, but they have the first lot”

“My plan is to wait until he’s gone over the....”

“My oldest daughter has had it, but no, the other two haven’t had it yet, because obviously they haven’t started talking”

One parent who has a child with autism spoke in detail about her attitudes towards and beliefs about the MMR vaccine. She explained that she chooses to delay giving the MMR vaccine to her children, despite experience of an unvaccinated child in the community dying from measles:

“Because we say it can be caused by the MMR vaccine, typically, in the travelling community as well, never give your baby MMR...I even had a doctors appointment, just to talk about it to the doctor and they reassured me that there was no link...but even if there is a slight 1% chance that it’s going to do it, I took it very serious...because I was told that, obviously, you’re supposed to have it when they’re little because they could catch it and I know there’s a big risk if they do and they haven’t, but they can have it at any point.

I had my MMR when I was 12, because my mum put it off completely over the same reason we've all got in the travelling community, it causes disabilities and what not....then there was this huge outburst of measles where we lived and it ended up in a child dying that was unvaccinated who we knew and my mum was like, 'right', and she went and got us all done. I was 12, so I was, like, he can have it at any point in life, so let's get over the curve that I went through with development. When he's three or four and he's up doing everything he's meant to be and I can literally sit there and say, "okay, he's not autistic", let's go for it then"

Postnatally, most participants reported attending health visitor appointments and weighing clinics for babies, describing the importance of this, especially with their first babies, but admitting that as their baby gets older and with subsequent babies that they attended less.

"Every time they needed to go, I never missed out on clinics"

"I think the first one, you do it loads, don't you"

"Yes, you know they're alright, so it gets less and less"

The use of antenatal clinics and the respect for Health Visitors was clear from many participants but they also expressed a desire for more visits post birth:

"They should come out a bit more though, I think."

"She came out once, to be honest, didn't she, when you were pregnant, didn't she? Then she came out just after you were having the baby and I didn't see her again."

Weaning is another example where some mothers chose to move away from and adapt the recommended timelines given by health professionals based on their beliefs and knowledge shared within in the community. Some parents reported feeding their children at 3 months of age as this is what they are used to doing, and another explained how her children were weaned at different ages, based on their hunger:

"I didn't feed x until she was nine months old, I fed her, she was perfectly happy, she didn't want it. All my kids were different, x, he was a greedy cow, three months old"

"The health visitor wrote down for me, "what you're doing is wrong, you should feed children at four months", I said, I know, but he's the only one I fed at two months because he was hungry and he was happy"

2. Beliefs and knowledge

The interviews and focus group discussions highlighted that the strong belief system in the GRT community influence decision making in pregnancy and postnatally. This was apparent in the way that some women described their attitudes towards newborn screening, infant feeding and food choices through the use of the words "believe" and phrases such as "that's the way I feel":

"Yes, of course I always believe in that....only for that heel prick, they would not have known that, that's how they find out"

"I imagine the baby wouldn't be getting....you wouldn't see the milk going in there, that's the way I feel...just to know how much the baby is getting, that's what you want to know, isn't it?"

"I believe that when a child is give good food at a young age, it builds them up and it helps them"

For one participant, her experience of the way she was treated by health professionals when in childbirth were also shaped and influenced by her beliefs about how others view the GRT community:

"I think she treated me differently because I was a traveller, that's being honest with you, that's what I think, I was treated differently because I was a traveller. That's the way I felt anyway, I do believe they treated me different because I was a traveller....but I could sense it. I think a human being can sense.." [beliefs about how they were treated]

The GRT women also described having strong and powerful connections to their own body. The extent to which health professionals respected this knowledge, understanding and connection to their bodies in pregnancy, strongly influenced their experiences of and perceptions of the quality of care they received. Some women described negative experiences in pregnancy and labour which were worsened by health professionals not listening to the women's own experiences and knowledge of their bodies:

"I was in so much pain with my little girl, they didn't realise. I was telling them what was wrong, I was telling the nurses..."Okay, let me explain to you, I have a scar" and I was trying to explain to them about the pain"

"So I just said to them, "I think maybe you should look into it a little bit, because he's feeling massive in there"....and then I was like, "No, he's growing big, something is going on". They agreed with me and they did some testing and then it came back that I had diabetes".

"I kept telling the doctors, it's the epidural, "No, you're depressed", they drove me mad....And they kept telling me I was depressed, that I needed to be on depression tablets, I used to go for them to take the pain away....I was never the same woman" [after the epidural]

The participants knowledge of and connection with their own body was more important to them than the knowledge, training and experience of qualified health professionals, and a couple of women commented that whether or not a nurse or midwife had had a baby themselves was a greater indication of their knowledge, than their clinical training and experience.

"They listened to me and, obviously, I know my body, I know, like, textbooks and everything, they've got to go by books, but a woman knows her body doesn't she? And literally, I got in there at 12 and had her at three"

"They're like, "we know more than you", but no, when you've been through it, you know more than them, unless they've been through it themselves"

They also described and compared their own knowledge of pregnancy, childbirth and caring for children to the training given to and knowledge held by midwives and doctors. For several of the

participants the knowledge gained from having had several children, and from being surrounded by young children and babies in the GRT community, has given them expertise and knowledge that is equivalent or superior to professional training:

“Literally, if people come to me, I know I’m not a doctor, I don’t go to medical school, I’m far from that, but I just definitely know about my body, I go to the doctor and I’m always right. I know, I can’t help it, I just know things, even with children.”

“I know everything in the book now about pregnancies and labours and what, I should be a midwife, like literally”.

“I think we’ve done it, our whole lives with everybody, I think when you have them, you just know what you’re doing, don’t you?” [bottle feeding]

“They gave me a big list of things she couldn’t eat, I just knew what to do myself, and how she’s a bit okay now with the....she doesn’t really like milk or stuff, but I know what to do”

“Yes, I weigh my kids myself, I have weighing scales so I weigh myself, so if the kids don’t eat, I think they must have a sore belly.”

Participants described using this knowledge and understanding of their own bodies to inform their decision making in pregnancy and in childcare. One GRT woman described how her knowledge of hygiene and infection control helps her to make decisions about immunisations and caring for her children. She discussed the importance of cleanliness in the home and linked this to infection control and immunity within her children, herself and her partner. She made a clear connection between keeping the home clean, diet and the level of health her family experiences.

“I’ve got a very good immune system, my immune system is great, it fights off all infections, I won’t even go to the doctor if I’ve got an infection, I fight it off myself....but my husband, he’s got a weak immune system,he was born that way so he’s got a weak immune system, so the flu can kill him..he gets the flu jab because the flu can kill him, and my other little boy he’s got a weak immune system.....So, him, any kind of infection at all, anything that goes around, Eddie catches it, so I’m glad, since ‘X’ has been out of school, he hasn’t been sick, not once, not once has he been sick. So, that’s one bonus, to be honest with you, so I don’t have to deal with children being not well. “

“Because if you have a car and you put faulty diesel in it, it isn’t going to work very good, is it? If you put good diesel in it, your car is going to run fine. If you’ve got oil in it, keep fixing it up ... I believe that when a child is given good food at a young age, it builds them up and it helps them. My kids don’t like junk food.”

The participant discussed how the physical environment affects one's ability to have infections and how she prevents this for her family:

“Even in the snow, I let the kids out, because I know the snow kills all the bacteria and everything, so I let them out...before you came, my windows were opened, when you go, I’ll open them again, we’re all going to freeze in here. Because it’s, like, I smell bacteria bad, it’s got to go out, so when you go, I’ll open those two doors and I’ll open everything up to air it out, I like to air my home. “

In contrast to the experiences in pregnancy and labour, several of the GRT women described having positive relationships with midwives in the community and with health visitors, especially where these health professionals had recognised and valued their knowledge of childcare:

“Yes, she [midwife] was really lovely, she let me do what I know how to do, she was very good”

“The midwife was very surprised by me because I knew more than her, I literally knew more than her, because travellers are brought up with kids so even though I was 16, I knew everything about children. I knew about temperatures, I knew about rashes....”

However, there were also some less positive experiences postnatally as well, and these were often considered by women to be linked to health professionals not listening to or understanding their point of view:

“She [midwife] said ‘well we’re not coming out’, I said, ‘but you have to come out, I’m ringing you to come out’, and she did once I put pressure on that they have to come out, then they did come out, but you don’t get it a lot anymore do you?”

“We took him to the doctor, he had his injections, we took him to the Doctor and he [the Doctor] said, “No, just give him calpol”....So anyway I said, “Let’s just go, just take him to the hospital to be sure”. His temperature was so high, you know.....I know it’s over the needles, I knew it was the needles”

“It was the first baby, but you know, don’t you, and I was, like, you’re still not playing, you’re still not speaking...and I remember saying to the health visitor, “I’m really worried about his development”...I know you keep telling me “it’s premature, it’s premature”, but he doesn’t respond....I was screaming like ‘I need help....right there’s got to be somebody who can help me, I need help, I know something is wrong’. Nobody agreed with me, not even family, “he has to catch up”, and I was, like, “I know something is not right””.

“Because, like, with him, I kept giving him little bits and she was, “Alright, I think you need...in there because he’s still hungry.” She went, “Listen to me, his little stomach is like that,” I said, “Yes, but you want to stretch it, because he’s hungry, look, he’s starving.”

3. Role of family and community

It was evident from all participants that family played a large role in the birthing process and few went through birth independently from other female family members. Family members play a key role as birthing partners, providing knowledge and advice as well as caring for the baby once born.

“Because, like, me and her mum were sitting outside and they knew we were there all night until the next day and they came in and got us in, and that was really nice. She said, “We shouldn’t really, because she’s still in the delivery suite, but you can come in.”

“Everybody is just sharing care with the baby, yes.”

“My aunt grabbed her off me at one o’clock in the morning, because we don’t believe in doing

anything on our own. So, mum and dad weren't there and my husband wasn't there, so I went into early labour, I had to have her and my aunt lived up the road and my aunt came straight down, thank God she did."

Two women expressed a need for medical professionals to understand this desire for family to be present during and post birth as a part of their culture.

"Only me and my husband, so our kids come and see the baby, it was either I go in or my husband goes in or my mother-in-law would take the kids. We don't believe in our kids staying away from us, we like our kids being with us at all times, we don't like kids staying away. I would be there every day, I used to, like, feed her, because I want the baby to get close to me, not close to the doctors, so I used to be there all the time and with the other kids as well."

"Yes, because they even let me in and her mum in, because after Sherin, she bled a lot and needed to clot."

The theme of family members and the community playing a large role in the experience of being a mother continued with discussions around the family members and communities influence on immunisation and infant feeding decisions. When referring to the MMR vaccination multiple women expressed that their independent vaccination timeline was passed down from their mothers.

"My mum always said, "Leave them until they're talking,""

"Well, I was just always was told to do that so I just did it."

In terms of breastfeeding, the women we spoke to were clear that this was not something they or their community do. For some participants it was the belief they had done what was necessary for the baby during birth or they had concerns around experiencing further pain from childbirth through breastfeeding.

"Because, to be truthful, I think you do enough."

"I think the end is the end and then that's it, I can't do anymore."

"Yes, even though you should do, because it's natural for a mother to breastfeed, but, it's just I had no time. So really and truly, I would never have enough time to do that, I went through all that suffering having her, then really, as well, another thing, I didn't really want go through any more pain, that's another thing..... So yes, I formula-fed her and then I don't do ready dinners, I don't like them, I just blend it myself, I cook, I blend it myself."

Knowledge about bottle feeding is also something which is passed down through the generations and shared amongst the community.

"I think we've done it, our whole lives with everybody, I think when you have them, you just know what you're doing, don't you?"

The majority of women we engaged with showed a level of respect for what their older family members taught them and these other community members opinions were valued when it came to birthing locations.

"I was happy to get to Hospital X because my sister had a bad experience in Hospital Y, they'd run out of gas and air and the women were screaming. I was pregnant at the same time while my sister was having the baby and I was booked for Hospital Y. I transferred my papers straight to Hospital X, I said, "No, I'm not chancing this hospital." They ran out of gas and air."

"I said, "Excuse me, that's the experience she's had, I would never, never let her come back to this hospital and have another child. I've had four children and where I live, there's always a woman on there pregnant, always ..."

However, one woman we spoke with showed that within her family they were breaking generational cycles of beliefs in regards to weaning and focusing on the professional opinions given from doctors or health visitors.

"No, she wouldn't start [weaning], she listened to them...No, so she just went by the book with the baby, because she's a very big worrier about the kids.....I said, "The baby is screaming with the bottle, no good, just give him a few spoons," "No, three months."

"No, I respect them that way because they're being told by a doctor."

All the participants we spoke with were clear about the role men play as they become fathers and showed a strong sense of independence from their partners. This meant that it would be uncommon for travelling families to have a home birth, where men could be around.

"It's mainly because of the way that we are in ourselves, so we don't really, typically, believe in having men there in the delivery. We, sort of, don't have it as the big open ... it's a very personal, private female thing."

"Yes, from the family, a grandma, something like that [birthing partner]. So, to do it at home is just a no, you have the baby in hospital, in privacy, you know, it's not something you do at home, at all, that's, like, no."

"Typical travelling community women don't have their babies at home, it's, like, no."

However, one woman's reasons for not considering a home birth were related to concerns regarding safety and complications.

"No, I wouldn't chance a home birth, some complications with woman or baby, you know, I would be frightened in things like that."

This independence from their partners, for some women, linked with their feelings of dignity during the birthing process:

"They brought her back to the room and they left her and not to be horrible, if she was married to a travelling man, her travelling man will have done it, but because she's, like, married to your kind of people, they don't sort of take notice as a travelling man would, would they? And that's what she said."

"He had to go in and wash her and dress her and to her, that was so embarrassing and degrading, do you understand what I mean? And she wouldn't have another baby in there"

and she had three after that.”

The role of family and community was clear in relation to childbirth more generally, with women’s perceptions of the quality of care heavily influenced by the experience of other women within the community, sometimes rather than their own.

“It’s what they did to her, do you know what I mean? I said, “You have really, really treated her like ... to me, the experience I’ve had at my hospital, to me, you’ve treated her like a guinea pig.”

“The maternity, I do think they were horrible to me and you will find many travellers will tell you the same thing, we do have a horrible experience. Because we’ve had this, we’ve had things happen to us, we’ve had family members die in hospital, we do know because we’re taught at a young age, when we’re pregnant or if my kid was having a baby, she was fairly young, I would tell her, okay, if you get a hard time when you get to hospital, if you get this kind of pain, that kind of pain, “I’ve got a pain in my belly,” What side of your belly is it on?” “This side,” I’d say, “You’re probably constipated, take this, do this, do that,” and I’m always right. Of courses, doctors ... nurses, not doctors, doctors are worse in hospital, it’s the nurses, they don’t like to listen, they don’t like to listen to you. “

This desire for privacy continued as we spoke with more GRT women in regards to breastfeeding, highlighting the need not to be seen by any males, not just their partners, within the community or outside of it:

“Now, you see, I wouldn’t do that [breastfeeding].”

“The thing is, when it’s our family, I mean how can you sit there feeding the baby and then, like, your brother is walking in or your dad is coming in?”

“I mean, when I’m out and about, I wouldn’t judge anyone, because that’s what she said, I said.... you know, in front of all the people, keep pulling your top down in front of people.” “No,” she said, “I won’t, I won’t, I won’t.””

“Not to be horrible, she knew not to do it front of ... [Men and things, yes.] well, she wouldn’t anyway.”

One participant talked about a rare occasion she witnessed a GRT woman breastfeed and how this was still kept as a private act from all other community members:

“Yes....a lady doing it and then she just went at the end of the trailer and shut the shutters over and things like that.”

Discussion

This research with a small sample of GRT women in Kingston has identified three key themes related to women’s decision making and experience of care in pregnancy and postnatally; adherence to and adaptations of recommended timelines; the influence of beliefs and knowledge of their bodies and childcare on decision making; and the role of family and community and the effect of this on choices and decisions.

Across these themes, the women we spoke with highlighted differences in gender roles relating to responsibilities in childbirth and childcare as well as the great importance held around personal privacy and dignity. The theme of privacy, as a woman, was common and the majority tended to focus on and favour the involvement of female family members in the journey to motherhood, rather than their partners.

Privacy was also an important factor in relation to breastfeeding, with some women choosing not to breastfeed because of the lack of privacy within their homes as well as a sense that they had 'done enough already'. Condon et al. also found that English Gypsy and Irish Traveller were less likely to view breastfeeding as something done by women in their community, and limited privacy was a factor in this.^{ix} They also found the centrality of the family to be an important factor in infant feeding decisions, as family members could share the task of bottle feeding babies. However, it was unclear from our research if decisions around breastfeeding were the woman's independent choice or a cultural expectation, and there was a lack of evidence indicating how much educational communication around the benefits of breastfeeding women had received from healthcare professionals. This is something health services should explore further, looking at what conversations they are having with new mums and what options are being provided. For example, for GRT women, it might be beneficial to focus on discussing more flexible options such as expressing milk for their babies which they can then bottle feed with to remove the issue of dignity and privacy, but introduce the use of breast milk rather than formula.

We also found that women had a strong sense of their own bodies, their own health needs and were confident to challenge and move away from professionals' advice, for example, in relation to the vaccination and weaning timelines they have adopted. In relation to immunisations, this research found that the majority of women followed recommended guidelines for the majority of vaccinations and there was broad acceptance of vaccinations, a theme also found by Jackson et al.^{xii}. However, a few women had concerns about the MMR vaccine, resulting in them choosing to delay, rather than withhold completely, vaccination against measles, mumps and rubella. This was despite knowledge about the risks of measles and experience of previous outbreaks within the community. Vaccine delay is also known to be an issue in the Charedi Jewish community, with some families preferring to hold all vaccines until their child reaches around two years of age¹³. Health professionals need to consider this in their messaging to GRT families, for example, discussing the risks of delaying vaccinations and addressing them in a culturally appropriate way.

There was a struggle for the GRT women we spoke with between their desire to be independent from medical professionals, using their own knowledge and experience of raising family members versus their dependence on beliefs passed down and advice from family members and from women in the community from older generations. This lack of reliance on health professionals was also referenced by many of the participants as a lack of trust built up through other community members' their experiences and their own family member's specific experiences in specific hospitals, limiting where they would go for delivery. Within the child birth and weaning process it is evident

¹³ <https://www.gov.uk/government/publications/tailoring-immunisation-programmes-charedi-community-north-london>

that health professionals need to treat people with dignity and respect, taking into account their own beliefs and knowledge of their own bodies as this is something GRT women respond positively to and have a strong opinion on.

There is also evidence from this research that some GRT women are beginning to break generational ties, be less reliant on advice from within the community, and to follow more closely what health professionals advise. This appears to be a slow process, but increased contact with Health Visitors would be positive to aid this transition from reliance on their own independent knowledge vs professional's knowledge.

This research provides insight into the decision making of women from Gypsy or Traveller backgrounds settled within Kingston. The researchers had access to GRT women via a trusted professional, which enabled us to engage with women who otherwise may not have and the women were at ease and more willing to share their thoughts and opinions. This is community who do not often have their voices heard, therefore this research acted as a gateway and platform for these community members and they were proactive in voicing their appreciation in being consulted about their experiences on this level.

However, there were some limitations with this research, such as the small number of women spoken with. We used different formats, such as 1:1 interviews versus a focus group which can change the dynamic between the interviewers and interviewees as well as what the women felt comfortable to share and discuss in front of their peers. A further limitation was we didn't discuss relevant education given by professionals to the women or what they had had access too. We were unable to engage with GRT women from Roma Gypsy backgrounds, as well as Bargees, Circus or Show People, as these groups are not present within the local borough and these communities tend to populate areas outside of Kingston.

Conclusion

This research with a small number of GRT women in one London borough has highlighted the centrality of beliefs and knowledge about their own bodies and babies, and of family and community to decision making in pregnancy and in relation to choices made about caring for babies such as vaccinations, infant feeding and weaning. This has an impact on the extent to which women follow recommended guidelines and timelines provided by health professionals. Where women choose to divert from health professionals advice it is important that they are given information and treated with dignity and respect in order to build trust. This is important as women within the GRT community share their experiences of healthcare professionals with other families and this too, has an impact on future decision making.

It is important that further research is carried out in this area to explore further what impacts on decision making, and the best ways to address this in the care and support delivered by health professionals.

Recommendations (Royal Borough of Kingston)

1. Generations of GRT women are changing their attitudes and beginning to follow more closely what Health Visitors are advising. This appears to be a slow process but increased contact with Health Visitors would be positive to aid this transition of reliance on their own independent knowledge vs a professional's knowledge.
2. There was a lack of evidence to assess whether GRT women maintain not breastfeeding due to cultural expectations or a lack of knowledge or flexible options of how to breastfeed. This is something health services should explore more, looking at what conversations they are having with new mums and what options are being provided. For example, for GRT women, it might be worth discussing more flexible options such as expressing milk for their babies which they can then bottle feed with to remove the issue of dignity and privacy but introduce the use of breast milk rather than formula.
3. It is clear the vaccination and screening timeline need to be re-addressed within the community but the approach will need to be explore by health professionals based on research carried out elsewhere and case studies demonstrating what has and has not worked. It is important to note that they do not refuse vaccinations/immunisations completely, instead they chose to delay such prevention methods. Based on this health professionals need to consider this in their messaging, such as including discussions around the risks of delaying and addressing them in a culturally appropriate way.
4. Within the child birth and weaning process it is evident that health professionals need to treat people with dignity and respect, taking into account their own beliefs and knowledge of their own bodies as this is something GRT women respond positively to have a strong opinion on.
5. Cary out more research to explore further whether these themes are common among a wider source of the community and that they apply more generally.