

This is a repository copy of Visualising uncertainty: examining women's views on the role of Magnetic Resonance Imaging (MRI) in late pregnancy.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/102402/

Version: Accepted Version

# Article:

Reed, K., Kotchetkova, N. and Whitby, E. (2016) Visualising uncertainty: examining women's views on the role of Magnetic Resonance Imaging (MRI) in late pregnancy. Social Science and Medicine, 164. pp. 19-26. ISSN 1873-5347

https://doi.org/10.1016/j.socscimed.2016.07.012

Article available under the terms of the CC-BY-NC-ND licence (https://creativecommons.org/licenses/by-nc-nd/4.0/)

#### Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) licence. This licence only allows you to download this work and share it with others as long as you credit the authors, but you can't change the article in any way or use it commercially. More information and the full terms of the licence here: https://creativecommons.org/licenses/

#### Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



# Visualising uncertainty: examining women's views on the role of Magnetic Resonance Imaging (MRI) in late pregnancy

Kate Reed, Inna Kochetkova and Elspeth Whitby

Accepted for publication in Social Science & Medicine (2016) Vol 164 (August 27th)

# Abstract

Prenatal screening occupies a prominent role within sociological debates on medical uncertainty. A particular issue concerns the limitations of routine screening which tends to be based on risk prediction. Computer assisted visual technologies such as Magnetic Resonance Imaging (MRI) are now starting to be applied to the prenatal realm to assist in the diagnosis of a range of fetal and maternal disorders (from problems with the fetal brain to the placenta). MRI is often perceived in popular and medical discourse as a technology of certainty and truth. However, little is known about the use of MRI as a tool to confirm or refute the diagnosis of a range of disorders in pregnancy. Drawing on qualitative research with pregnant women attending a fetal medicine clinic in the North of England this paper examines the potential role that MRI can play in mediating pregnancy uncertainty. The paper will argue that MRI can create and manage women's feelings of uncertainty during pregnancy. However, while MRI may not always provide women with unequivocal answers, the detailed information provided by MR images combined with the interpretation and communication skills of the radiologist in many ways enables women to navigate the issue. Our analysis of empirical data therefore highlights the value of this novel technological application for women and their partners. It also seeks to stress the merit of taking a productive approach to the study of diagnostic uncertainty, an approach which recognises the concepts dual nature.

Keywords: UK; Pregnancy; Magnetic Resonance Imaging (MRI); Uncertainty; Diagnosis

**Correspondence to:** Dr Kate Reed, Department of Sociological Studies, University of Sheffield, Elmfield, Northumberland Road, Sheffield, S10 2TU, UK, <u>k.reed@sheffield.ac.uk</u> +44 (0)114 22226478

# Introduction

Social scientists have often discussed the role of uncertainty in medicine (Fox 1980, 2000). Research in this field has been wide-ranging, from a focus on managing diagnostic uncertainty in doctor/patient interaction to organisational uncertainty in healthcare (Jenkins et al, 2005). As Moreira et al (2009) argue the production and management of uncertainty play a key role in the dynamics of contemporary medicine. According to Pilnick and Zayts (2014), prenatal screening offers a particularly rich site for investigating medical uncertainty as issues have often been raised about the diagnostic accuracy of screening tests. Existing research on pregnancy uncertainty has, however, tended to focus on routine blood and ultrasound screening. This paper will explore the role of fetal MRI-a new technological application- in mediating pregnancy uncertainty. Drawing on a productive approach to the concept of uncertainty, the paper seeks to offer an original contribution to sociological debates on diagnosis, uncertainty and the role of visual technology in healthcare.

Computer assisted imaging technologies such as MRI have been applied in clinical contexts across the globe since the 1970s and 1980s (Prasad 2014). These technologies have been used to scan a range of bodily elements, from brains to bones, from tumours to blood clots. In both medicine and popular culture MRI is perceived as the 'gold standard'; the epitome of what is possible in medical visualisation (Joyce 2006). As Joyce has argued, it is a tool associated with transparency, precision, certainty and neutrality 'the primary producer of knowledge, not only of a patient's condition but also of one's possibilities' (2006: 55). Despite the discourse of certainty surrounding MRI visuality, however, scans do not produce one diagnostic 'truth' (Joyce 2006, Prasad 2005). Rather, images produced by MRI are subject to different interpretations by different medical specialists who each seek to produce their own discourse of truth about the body (Joyce 2006). Furthermore, images produced by MRI do not in themselves provide diagnostic closure. They form one part of a broader assemblage of clinical materials used to home in on a diagnosis (Prasad 2005, Latimer 2013). While sociologists have been exploring the use of MRI in research and clinic for quite some time now, there is a limited focus within this work on patient experience (Joyce 2006, Prasad 2005). Furthermore, such studies have tended to confine their focus to particular specialties in medicine such as radiology, neuroscience and psychiatry (Dussauge 2008, Rapp, 2011). As this technology rapidly expands to include new areas of medicine, it is imperative that sociologists also extend their analysis to incorporate a broader range of patient experience.

Visual technology has often played a central role in existing studies on pregnancy however such studies have tended to focus on the role of obstetric ultrasound (Mitchell and Georgies 1997, Zechmeister 2001). These studies have tended to argue that ultrasound fulfils several roles in the prenatal realm: it provides important clinical information and can be used as a form of medical surveillance. However it also creates a sense of fetal personhood which academics have argued often enhances parental bonding (Casper 1998, Taylor 2000, Zechmeister 2001). Despite advances in screening in recent years not all abnormalities can be diagnosed using ultrasound (US) often causing significant emotional stress for parents. In

these cases a further form of examination of the fetus may be desirable (Jokhi and Whitby 2010). MRI is now starting to be offered in several fetal medicine centres across the UK to back up or provide further information to routine US screening. The initial focus of MRI was on the central nervous system (CNS). However techniques have recently evolved meaning that further evaluation of other organ systems, anatomy of the umbilical cord, amniotic fluid volumes as well as assessment of maternal structures have all become feasible and clinically useful (Jokhi and Whitby 2010). The increasing diagnostic capability and application of MRI in pregnancy poses interesting questions around prenatal technology and uncertainty. For example: to what extent does MRI offer women and their partners' diagnostic certainty? How does it compare to other visual technologies such as ultrasound or invasive technologies such as amniocentesis? The paper draws on qualitative research conducted in a fetal MRI centre in the UK in order to address these questions. In doing so the paper seeks to extend the focus of existing work on prenatal technology and uncertainty and also advances our understanding of the impact of new clinical applications of MRI technology.

The article proceeds with a brief overview of sociological literature on medical uncertainty, outlining the conceptual focus of the paper. Some background context to fetal MRI will also be provided along with a summary of the method used in the study. The main part of the article is concerned with the interview findings, presented in three sections which will explore in turn: the detection of fetal anomaly and the MRI referral process, MRI and the dual nature of diagnostic uncertainty and finally MRI visuality and the importance of the radiologist. The paper concludes by arguing that MRI cannot provide complete diagnostic closure (in fact, as others have argued, complete diagnostic certainty does not exist). Rather the detail provided by MR images combined with interpretative advice from the radiologist in this study assisted women in their navigation of uncertainty. While sociologists have consistently argued that uncertainty is a fundamental and unresolvable part of modernity, this paper seeks to argue that it can nonetheless be productively negotiated.

## The sociology of medical uncertainty

A number of attempts have been made across the social sciences to conceptualise and categorise the issue of medical uncertainty (Star 1989). Drawing on his own experience of illness, for example, Adamson (1997) identified two different types of uncertainty- existential and clinical. Existential refers to the uncertainty experienced by patients when the onset of illness presents them with an uncertain future trajectory. Clinical uncertainty refers to the

socially organised realisation that knowledge needed to diagnose a particular disease is absent. Adamson (1997) argued that these two different types of uncertainty can operate independently of one another but also mix together in all sorts of ways reinforcing or mitigating one another. Recent work has explored the ways in which these types of uncertainty are mutually constitutive, emphasising in particular the importance of doctor/patient communication in mediating uncertainty (Pilnick and Zayts 2014).

With the development of the sociology of diagnosis in recent years there has been an increasing focus on diagnostic uncertainty (Jutel 2009). Latimer (2013) for example has argued that there is always a tension between the existence of doubt and the desire for certainty in diagnosis and in clinical work. Some have argued that the pursuit of predictability that is sought through the process of diagnosis is itself an uncertain project, and that attempts to control and manage uncertainty may lead to further uncertainty (Jenkins et al 2005). The role of technology is often central to debates on uncertainty and diagnosis. As Pilnick and Zayts (2014) argue the increased integration of new medical technologies into healthcare has led to a renewed analytic focus on the issue of uncertainty. Fox (1980, 2000) suggests that as technologies increase our ability to test and measure, the lack of clarity over what such results should be taken to signify means that uncertainty is becoming the hallmark of medicine. This has led some to emphasise uncertainty as something that is managed continuously in a clinical context through evidence-based clinical judgement (Timmermans and Angell 2001).

Existing research on uncertainty in health and medicine is wide ranging and we cannot do justice to this entire field in the context of this paper. The paper is informed by literature from a range of disciplines across the social sciences including anthropology and STS, but is located more specifically within medical sociology. The paper seeks to take up the call from Jenkins et al (2005:12) to develop more work which focuses on the ways in which lay people 'encounter, experience and deal with uncertainty', focusing explicitly on women's accounts of the role of MRI in pregnancy. The paper accepts the view articulated by others that humans tend to seek order and assurance in the face of uncertainty (Whyte 1997). However, we also seek to acknowledge- as suggested more recently by STS scholars- that uncertainty may act as an interactive and practical accomplishment (Moreira et al 2009: 667). The paper will draw, therefore on what we envisage to be a productive approach to uncertainty, an approach which acknowledges the dual nature of the concept. What we mean here is the need to recognise that while uncertainty may often be viewed as something to be feared and

managed, it may at times also be actively welcomed. This approach is particularly relevant to our discussion on the role of MRI in diagnosis. For example, as will be explored in the paper a concrete prenatal diagnosis can bring with it uncertainty for the baby's future, whereas an uncertain diagnosis can sometimes offer parents hope. The paper seeks to explore the ways in which MRI has the potential to contribute to, manage and ultimately assist women in the navigation of uncertainty, drawing where appropriate on this dual notion of uncertainty. While this paper focuses on accounts from pregnant women, it does acknowledge the collective co-production of un/certainty that takes place between patients and clinicians (Adamson 1997, Pickersgill 2011). In particular the paper acknowledges the centrality of the radiologist in mediating uncertainty in this context.

#### The unfolding application of MRI in obstetrics

In the UK all pregnant women are currently offered a range of prenatal screening tests during the first and second trimester of pregnancy (NHS Choices 2015). This includes blood screening to detect inherited blood disorders and provide a risk prediction of chromosomal anomalies. It also includes ultrasound scans to ascertain the gestational age of the fetus, estimate risks for Down's syndrome and locate medical problems such as structural abnormalities of the developing central nervous system (Reed 2012). These tests are not diagnostic and in many cases offer only an informed prediction of risk. This has led sociologists such as Pilnick and Zayts (2014) to argue that pregnant women and clinical personnel face a double uncertainty: screening tests produce uncertain answers expressed in the form of probabilities and those results are themselves of uncertain reliability. Greater diagnostic certainty for a range of conditions from chromosomal conditions to musculoskeletal disorders can be obtained through amniocentesis. However amniocentesis carries a 1% risk of miscarriage (NHS Choices 2015). MRI is now starting to be used as an adjunct in some clinics across the UK to routine ultrasound. It can be used to inform the diagnosis of a range of prenatal anomalies and may in some cases diminish the need for invasive testing such as amniocentesis.

MRI was first introduced into the obstetric realm in the early 1980s. Initially the sequences used low field strength magnets that could take between 1 and 10 minutes to acquire images (Bekker and Von Vugt, 2001). Financial cost and risks associated with sedating the fetus constituted an argument for the continued use of routine screening techniques at that time. However, in recent years we have witnessed the development of fast sequencing making

sedation no longer necessary- leading to the increased use of fetal MRI (Jokhi and Whitby 2010). Currently women may be referred for an MRI scan by an obstetrician if anomalies show up on the 20 week ultrasound. Women are almost always offered MRI when problems with the fetal brain are shown, but are also referred for problems in other fetal or maternal organs where MRI can offer more detailed information and measurement. In clinical research MRI has been positioned as offering several advantages over ultrasound: the scan is less affected by maternal and fetal position, it is deemed safer for mother and baby than invasive tests such as amniocentesis or tests involving exposure to ionised radiation (for example, CT). Furthermore, MR images are dynamic, and superior tissue contrast can be achieved using this type of scan (Pugash et al. 2008). The enhanced capability of MR imaging over routine ultrasound coupled with the limited safety concerns have contributed to the recent advance of MRI use in pregnancy (Mailath-Pokorny et al. 2010).

While clinical studies have emphasized the diagnostic potential of MRI, we know little about how women feel about its use in pregnancy. The small number of studies which have explored women's feelings show mixed results. For example, while Leithner et al (2009) highlight the potential for MRI to reduce pregnancy uncertainty, data from their study suggested that only '66% of women were able to provide detailed information about the purpose of fetal MRI' (185). Other factors have also been cited as potentially contributing to patient feelings of uncertainty: the size of the machines, the duration of scans (generally around 20 minutes), and the difficulty patients may experience getting comfortable within them, especially in the third trimester of pregnancy (Levine, 2006; Pugash et al., 2008). Leithner et al., (2009) argue however that more research is needed which focuses on exploring women's subjective experiences of fetal MRI. This paper seeks to contribute to this emerging literature by providing an in-depth sociological analysis of women's experiences of fetal MRI from the process of referral to diagnosis.

#### Methods

This paper explores the role of MRI in mediating pregnancy uncertainty. It does so by drawing on a sub-section of the findings from an ethnographic study funded by the British Academy on the role of MRI in obstetrics. Our study was informed by a naturalistic approach to ethnography (Arber 2006). We sought to develop an understanding of fetal MRI as it was being used in practice. Ethical approval for this project was granted by the UK National Research Ethics Service in February 2013. The study included semi-structured interviews

with 17 pregnant women who had undergone MRI and 14 health professionals. Respondents were recruited via a National Health Service (NHS) fetal medicine unit in the North of England between March and August 2013. In order to understand the wider social and cultural context in which fetal MRI is being developed and applied we also interviewed 2 representatives from 2 different manufacturers of MRI systems. We also conducted observational work during the study attending clinics, observing patients in the scanner and observing the radiographers and radiologists at work. In a small number of cases we observed the radiologists' consultation with parents after the scan. Two members of the research team also attended one of the monthly team meetings where all the professionals met to discuss individual cases. Fieldnotes were taken by hand during all observations which were typed up into fuller reports shortly afterwards. Due to the scope and focus of this paper only data relating to patient interviews will be explored. Accounts from professionals and representatives from industry are explored elsewhere (Reed et al, 2016).

Respondents participating in the study were aged between 21 and 36. Although all respondents were over 20 weeks pregnant, the sample included women in both the second and third trimesters of pregnancy. It included women experiencing their 1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup> and 4<sup>th</sup> pregnancies. The conditions women were being scanned for were diverse and ranged from problems with the developing fetal brain or digestive system to maternal problems such as placental abruption. Respondents included women from a range of occupations, those who were unemployed or currently not looking for employment. Some differences were less well represented in the study for example almost all the women in the study identified as ethnically white. Furthermore, women who volunteered to participate in the study included only those seeking to continue with the pregnancy after indication of (and despite) possible fetal abnormality through routine ultrasound. Some respondents decided against termination prior to fetal MRI and were seeking clarification regarding potential treatment options and others hoped that fetal MRI would inform further decision-making. The paper does not seek however to offer a generalizable account of women's experiences of MRI but rather to offer insights into an emerging technological application as it unfolds.

## Data collection and Analysis

Pregnant women received an invitation to participate in the study, along with an information sheet and consent form at the point of referral for fetal MRI. Women were asked by a member of the research team upon arrival to the MRI suite whether they would consider

participating in the study where they were given the opportunity to ask questions. Respondents were often anxious before and after the scan and therefore a number of them opted to talk to us at a later date via phone or skype. The interviews were conducted by the PI and RA who are both social scientists. An interview schedule acted as a guide but we sought to encourage women to tell their own pregnancy story as appropriate to them. Interviews were organised around several topics including: experience of pregnancy, screening, MRI referral, the scanner, diagnosis and decision-making. We took a cumulative approach to data collection which ceased when we felt our overall research aims were addressed (Denscombe 2014). Arber (2006) suggests that the credibility and reliability of data can be improved by identifying the status and position of the researcher (Arber 2006). We attempted to reflect on our position as social scientists throughout data collection and analysis evaluating the potential effects this might have on the research process. The interviews were digitally recorded, transcribed and anonymised (all respondent's names have been changed). Both members of the research team read the transcripts independently and identified shared themes. We took an inductive approach to thematic analysis focusing on the themes which emerged most prevalently in the data (Braun and Clarke, 2006). Themes emerging from patient accounts included: experience of MRI, diagnosis, comparison between MRI and other technologies, role of the radiologist, importance of images, role of technology in mediating pregnancy uncertainty. Identified themes were then used to reflect back on the literature and conceptual framework. This paper will reflect in particular on one of the most prominent themes in women's accounts, the role of MRI in mediating pregnancy uncertainty.

#### **Research Site**

In the United Kingdom there are currently fewer than 20 fetal medicine centres providing specialist services such as fetal MRI (National Health Service England 2013). This study took place in one such clinic. Pregnant women are referred for an MRI scan mostly from different and cities across the county. However, due to the limited number of services across the UK some women are referred from other parts of the UK. In some cases women may travel for up to three hours to attend clinic. Through the observation work we were able to see MRI being used to inform the diagnosis of a range of fetal and maternal conditions from tumours, to missing kidneys, to problems with the placenta. As the conditions women were being scanned for were diverse they all involved different options and potential outcomes. After the scan women were offered non-directive counselling to discuss their options. Options could range from changes to birthing plans to neonatal surgery. In some cases termination may be offered

as an option both before and after MRI. It is important to note that no women opted for termination in this study and therefore we cannot comment on this process. MRI however does not always lead to further medical intervention in pregnancy. It can also be used as a reassurance tool for parents who have experienced problems in a previous pregnancy. Furthermore, in some cases it can lead to less intervention (for example, a potential tumour identified by ultrasound could turn out to be a harmless cyst on MRI). This paper will not focus on a particular condition but will discuss various issues as they emerge in women's accounts.

The fetal MRI clinic was run by a fetal and neonatal specialist radiologist who was also assisted in the clinic by a paediatric radiologist (a third radiologist is currently in training). Radiographers (allied health professionals) would conduct the MR scan which normally lasted around 20 minutes. The radiologist (physician) was present and sat in the back room interpreting images on a computer. The radiologist would be in constant conversation with the radiographer asking for different images in order to home in on various pathologies. Once the scan was complete, the radiologist would take pregnant women (and their partners/supporters) into a separate room and discuss the images and potential diagnoses with them. It is not common practice for radiologists to speak directly to pregnant women after the scan. However, this is something which is being encouraged in this particular sub-specialty in the UK context. As data showed, women greatly valued this communication and it played a significant role in enabling them to manage uncertainty. Once the scan was complete images were uploaded on to the central hospital system so that other professionals such as obstetricians, neonatologists, paediatricians and pathologists could see them. After the radiologist had discussed a potential diagnosis with women and their partners, she would refer them back to the obstetrician to discuss and plan how to proceed with their pregnancy.

# **Findings and Discussion**

Having given some background context to the study this paper now turns to an exploration of our main research findings drawing on data from respondents. In the following two sections we seek to focus on detailing women's MRI journey from referral through to diagnosis moving on to examine the role of images and the radiologist in the final data section. We seek to explore the role of MRI in mediating pregnancy uncertainty, and in doing so give further analytical consideration to the concept of uncertainty itself.

#### Fear and uncertainty: the process of MRI referral

Women in this study had been through standard prenatal tests including blood screening, nuchal fold scan at 12 weeks and 20 week ultrasound. According to clinical need women may also have been offered a CVS test or amniocentesis. All women with an anomaly identified on the 20 week ultrasound are referred for a fetal medicine consultation. The fetal medicine specialist then decides whether an MRI scan would be helpful. Overall 2-3 % of pregnant women are referred for MRI in this particular jurisdiction. Women are informed that MRI will help work towards a diagnosis but that it is the combination of test results - ultrasound and blood tests- that will provide more information and a possible answer. Waiting time between ultrasound and MRI is less than 7 days but in urgent cases it can be conducted sooner. Occasionally, (for example where there is a family history of disease) women may be referred before 20 weeks. While MRI tends to be offered once women have been through routine tests, there is currently no direct alternative to MRI. Respondents in this study were all happy to consent to a scan. They hoped MRI would provide them with some diagnostic certainty but also worried about the potential difficult decisions they may have to make afterwards. Colette for example had been referred for a fetal MRI during her fourth pregnancy after ultrasound had indicated a potential problem with the fetal brain:

### Interviewer: How did you feel when the doctor mentioned fetal MRI scan?

**Colette:** Nervous, worried about what they'd find. I'd prepared myself for the worst case scenario, so I was convinced that she was going to have something really wrong with her. So I was thinking I was going to have to have an abortion, and then I was imagining having to go into labour with her, and everything. And that's all I kept thinking, so I was just really scared, but at the same time I just wanted it over and done with, just to know what I was faced with.

Collette's need for diagnostic confirmation on the one hand whilst also fearing what this confirmation might indicate on the other is perhaps not unusual and chimes with the findings of other studies on prenatal screening and diagnosis (Rapp 2000). However, respondents did articulate concerns which related specifically to MRI technology. For example, in contrast to ultrasound and amniocentesis women tended to view MRI as a technology primarily used to detect serious medical conditions such as cancer. This often made women more nervous and

uncertain of their referral as articulated by Nasra who was pregnant for the first time and whose baby had suspected spina bifida:

I was very nervous and very scared because MRI scans, I had that mindset it is usually done for very serious problems in the body, like people who have cancers or something like that. Only those people needed MRI scans and stuff. So obviously, I was very shocked that I needed an MRI scan to be done. If it helped me or my baby, it's better to do it.

Women were also concerned about the scanner itself which was large, noisy and uncomfortable (Levine 2006). Although pregnant women are placed in the scanner feet-first and their head is kept outside, a number of respondents still articulated fears around claustrophobia. This was articulated by Karen who was referred for an MRI scan during her second pregnancy because her first child had been diagnosed with cerebral palsy:

I don't like being in small spaces [....] in that little tunnel thing (MRI scanner), I just got all panicky but I was alright, I didn't cry or anything, I was just a bit hot and I was thinking; just hurry up because I want to get out.

Overall, while women were concerned about being referred for an MRI scan they tended to minimise these concerns, focusing instead on what they perceived to be the best actions for the baby. Women hoped that the MRI would give them important diagnostic information about the baby's health. This is illustrated in the quote from Alice who was pregnant for the second time and whose baby had a suspected duplex kidney anomaly:

I just wanted to know in my own mind I think that he (the baby) was going to be okay, and at least know what to expect if there was going to be a problem really. I don't like them [MRI], I've had one before and I absolutely hated it, but it needed to be done and if it helped then that's fine [....] I think at the end of the day if it's something that's necessary and that's going to help in the future then you've got to put your own fears aside and you've got to do what's best for the baby.

While respondents all sought reassurance through their MRI referral they did articulate some concerns about this process. Their concerns tended to relate to popular understandings of MRI- as a potentially claustrophobic machine used primarily to detect cancer. As other

sociologists have argued, medical technologies are not value-neutral. Rather technologies become inscribed with particular socio-cultural meanings through different types of clinical practice (Timmermans and Berg 2003). In this study respondents' associations of MRI with certain forms of clinical practice (not with obstetrics) played a key role in mediating their experience of pregnancy uncertainty.

#### Diagnosis and the dual nature of uncertainty

Sociologists have argued that biomedical attempts to manage diagnostic uncertainty often have the reverse effect to the one intended. Rather than managing diagnostic uncertainty they may create further uncertainty (Jenkins et al 2005: 17). In this study the radiologist would interpret images after the scan and then discuss the findings and a possible diagnosis with parents. While MRI provided women with important diagnostic information which could assist them with decision-making and post-pregnancy planning, it did not always offer them diagnostic certainty. Women's accounts in this context however, appeared to highlight the potentially dual nature of un/certainty. In some cases, a lack of diagnostic certainty could actually be reassuring. In Nasra's case ultrasound had indicated the baby had spina bifida whereas MRI suggested a cyst on the bladder. Although she was uncertain about the potential change in diagnosis Nasra felt reassured after the scan:

> It was explained by the radiologist, that there was no problem at all with the spine. That was a very good thing for me to know. [....] I was, like, relieved after listening to that. Then she had told me that there is a cyst kind of thing which is causing the problem with the bladder. Yeah, so that was a little bit of concern because obviously it's the baby.

Despite a very tentative MRI diagnosis another respondent Danielle also felt reassured. MRI is good at diagnosing problems with the brain, soft tissues, and chest. However even in cases such as these, diagnostic certainty and reliability may remain contingent on other factors. Danielle was told after her 20 week ultrasound that the right ventricle in her baby's developing brain was small. Although the MRI indicated that the brain was developing normally, the baby appeared small for its gestational age thus making it difficult for the radiologist to confirm a diagnosis. Danielle still felt relieved after the MRI scan:

**Interviewer:** But do you think, that MRI has been very important in being sort of reassuring?

**Danielle:** We just didn't know what we were dealing with up until that point, now we know we're dealing with a small baby, probably, you know, not growing as much as she should but from a brain point of view, a development point of view as much as they can tell before birth, they know that she's okay.

While women could feel reassured by a slightly uncertain diagnosis they could also continue to feel uncertain after a clear diagnosis. Studies on prenatal testing for chromosomal anomalies such as Down's syndrome have sometimes found that women remain uncertain even after receiving 'normal' diagnostic results (Statham and Green 1993, Baillie et al, 2000). In this study Collette's baby was diagnosed with ventriculomegaly (enlarged ventricles of the brain). MRI is used to measure the ventricles in order to evaluate the extent of the potential problem and what the implications might be (Glenn 2010). Fetal MRI is routinely used to assess ventriculomegaly and clinicians are often confident about diagnosis. In Collette's case the MRI showed a very minor enlargement and the radiologist felt there was no problem. Despite this diagnostic certainty Collette still felt uncertain about the future:

I was talking to a lady the other day that I know, and her niece went through exactly the same, got told her daughter had enlarged ventricles, and went for an MRI, and her results were totally fine yet she never enjoyed any of the pregnancy after that, and was so nervous, which I know I'll be like that now, until the day she's here in my arms, I won't feel happy. And I think even after she's been born, I'll still be wondering, is she going to have any mild learning difficulties. I won't feel settled at all.

MRI didn't necessarily appear to lead to the straightforward creation or management of diagnostic uncertainty. Rather data on diagnosis appears to emphasise the potentially dualedged nature of un/certainty. Despite a clear MRI diagnosis some women continued to feel uncertain about their baby's future whereas for other women uncertainty offered reassurance. Respondents accounts- particularly Danielle's- also raise a further issue, the importance of recognising technology as only one part of a broader journey of diagnosis (Jutel 2009, Latimer 2013, Prasad 2005). MRI offered women important information but as illustrated here this was one part of a broader process of diagnosis which might not be resolved until birth. The findings also illustrate a final point, the centrality of the radiologist in mediating technological uncertainty. This is something that will be explored in more depth in the final data section of this paper.

## MRI visuality and the navigation of uncertainty

In contrast to X-ray and ultrasound MR images are not based on the reflection or absorption of light or other electromagnetic waves (Prasad 2005). They involve 'seeing' in a different way. Diverse sets of MR images are produced by converting physical data such as relaxation times into spatial maps of internal parts of the body with the help of computers (Joyce 2006; Prasad 2005). MRI images are then interpreted by radiologists who compare them with other anatomical 'facts' - statistics on disease, and brain and body atlases (Dussauge 2008). In this study women were keen to highlight the value of MR images along with the professional skills of the fetal radiologist. The radiologist used images to explain potential diagnoses giving women a guided tour of their baby's brain and body. The images combined with the explanation from the radiologist appeared to help women navigate an often uncertain diagnosis. In the case of Alice, for example, MRI offered no more diagnostic confirmation over her baby's suspected kidney anomaly than ultrasound. However, Alice still found the MRI scan and the radiologists' explanation reassuring:

Alice: I found it all fascinating actually!

**Interviewer:** Why is that, what in particular was fascinating?

Alice: I think because you actually got to see the pictures as well. So you get a better understanding of what it is they're looking for, how it actually works. (...) to actually be sat down at the end of it and spoken to, and have things explained and be shown the pictures and to be shown the problem area that they're looking at, and what they can see from that, I think that's really reassuring.

Women's ability to deal with difficult or uncertain screening results is often contingent on the way information is communicated to them by health professionals (Baillie et al 2000, Statham and Green 1993). In this study women's expectations about the baby's long term prognosis were managed through non-directive counselling by the radiologist and other health professionals involved in the women's healthcare pathway. Because of this women appeared to understand that MRI may not offer complete guarantees as to what would happen once the baby was born. For example one of the twins that Jenny was carrying had a suspected cyst on an ovary and could potentially need further scans after birth. Jenny knew MRI could offer no guarantees about the baby's future. It did, however, help her to feel more comfortable about diagnostic uncertainty:

Yes, I suppose nothing is 100 percent, but, I feel a lot more sure after having those two scans and talking to people that are experts in obviously what they do. I feel a lot more comfortable about what I was told.

Women are made aware of the limitations of MRI and understood, for example, that for certain conditions (relating to the heart and limbs) ultrasound is better. They still however, tended to favour MRI in comparison to ultrasound. This may relate to the fact that by the time women have an MRI scan they already know something could be wrong with their pregnancy. Even when the MRI scan confirmed or highlighted a poor outcome, however, respondents remained positive about MRI. For example, although the MRI scan confirmed that Susie's baby would need surgery after birth because its bowel and stomach were growing outside the fetal body, she found the MR images and professional support gave her a really positive experience of pregnancy:

I think it (MRI) was a lot more thorough. [....] I think I've had about four ultrasounds now and out of all those four I've always come out feeling sad, feeling negative, feeling down. And the MRI scan was the first scan we've been able to come out of and I'd just got a smile on my face and I felt a bit more positive and a lot happier with what was happening. It just seemed so clear. [....] At the end of the day even when we're having the ultrasound I know they're there to detect stuff and to see what's wrong with the baby, but it would be nice to actually have a look at the baby itself and listen to the heartbeat and maybe take away some pictures. Because normal pregnancies are getting that and just because this is not a normal pregnancy, it doesn't mean we can't still get those nice things as well. So it was nice to go to MRI.

Research on ultrasound has often emphasised the positive role that images play in creating a sense of fetal personhood and enhancing parental bonding. In the US context authors have related this to broader debates on the commodification of pregnancy, and in some cases shown how the creation of fetal personhood can feed into debates on pro-life (Casper 1998,

Taylor 2000, Rapp 2000, Zechmeister 2001). MRI images in this particular UK clinic however were used primarily to counsel parents about potential fetal anomalies. The radiologist also often emailed images to parents after the scan so that they could have a keepsake of the baby. The flexibility and detail provided by MRI visuality combined with significant skill of the radiologist (both interpretative and communicative) gave women a much more positive experience of a potentially problematic pregnancy. While MRI could not offer women absolute diagnostic certainty it did perhaps enable them to negotiate the issue of uncertainty. This is something which will be reflected on in more detail in the conclusion.

# **Conclusion:**

By examining the role of MRI in mediating pregnancy uncertainty this paper has sought to offer an original contribution to existing work on prenatal screening, medical uncertainty and the sociology of diagnosis. It is important to note that this paper is based on an ethnographic study of one fetal medicine clinic at one point in time. Fetal MRI is currently an unfolding technology-in-practice in the UK. It is unlikely- given the cost- that this technology will become fully routinized in obstetrics in the same way perhaps that ultrasound has been (Leithner et al. 2009, Levine, 2006). However, the diagnostic capacity of MRI is rapidly expanding to include new aspects of both fetal and maternal health. Furthermore, fetal medicine clinics offering MRI continue to develop. In fact the fetal radiologist in this study is currently involved in training specialists to set up clinics in other parts of the UK. The findings of this paper, therefore, do offer some interesting insights into this expanding technology.

Pilnick and Zayts (2014) have argued that prenatal screening offers fertile ground for debates on uncertainty because the tests themselves produce probabilities which also are of uncertain reliability. This uncertainty is often reflected in women's dual-edged attitudes towards screening results and referral for further diagnostic tests (Rapp 2000). While respondents in this study all sought diagnostic assurance through their MRI referral they did articulate some feelings of uncertainty. These feelings often appeared to relate to popular understandings of MRI. Respondents often associated MRI with the detection of serious illness. This perception- although likely to change as the technology becomes more widely adopted in the prenatal realm- emphasises an important point: that technologies become imbued with particular socio-cultural meanings through different types of practice (Timmermans and Berg

2003). In order to fully appreciate the role technology plays in mediating clinical uncertainty therefore, future research must examine the ways in which the socio-cultural context in which technology is applied affects patient and professional experience of uncertainty.

Existing research on clinical uncertainty has tended to concentrate on the extent to which uncertainty can and should be managed. While the focus on managing uncertainty is important, data from this study emphasised the importance of also acknowledging the potentially productive aspects of uncertainty (Moreira et al 2009). This is illustrated particularly by data on the role of MRI in diagnosis. MRI could refine, confirm or refute an initial diagnosis. It could also highlight different anomalies from those identified by routine ultrasound. Un/certainty created during this process however was often two-sided and could in some cases be embraced by respondents. The potentially dual nature of diagnostic uncertainty could therefore be something worthy of exploration in future research. Respondents' accounts also illustrate a further important point about diagnosis and the role of technology. MRI informs diagnosis but often cannot provide diagnostic closure or predict with any certainty what a baby's long-term prognosis might be. This reinforces a point made by others that technology forms only one part of a much broader, multifaceted and ongoing process of diagnosis, prognosis and treatment (Prasad 2005, Latimer 2013).

Visual technologies such as ultrasound have come to occupy a particularly significant position within the prenatal context. This has been related by many to the powerful position held by the 'visual' in western culture (Zechmeister 2001). By focusing on fetal MRI, this paper offers a novel contribution to this existing focus. Although MRI could not always offer more diagnostic certainty than other prenatal technologies, respondents did find the detailed nature of MRI visuality particularly useful. MR images can be taken on different axes to illuminate particular pathologies. These images can also be reconfigured to produce a picture of a whole baby. This has led STS scholars such as Prasad (2005) to argue that technologies such as MRI offer a new visual regime in medicine- a cyborg visuality- which produces multiple visions of the internal workings of the body. While one could argue that this has the potential to enhance medical surveillance, in this study such detailed visuality appeared to enable women to navigate the issue of uncertainty. In emphasising the importance of the technology itself, however, it is important to recognise that the technology does not operate in a vacuum but is embedded in other tools and social relationships (Timmermans and Berg 2003). In this context the radiologiest played a crucial role in mediating parents' experience of

MRI. Parents felt that the clinical ability and communication skills of the radiologist were crucial to their positive evaluation of MRI, enabling them to cope with uncertainty and move forward with decision making and planning. Parents particularly valued the immediacy of diagnostic discussions after the scan. This is something that should be considered further in other prenatal care contexts (Reed et al, 2016).

Sociologists often view uncertainty as the hallmark of contemporary medicine and a fundamental and unresolvable part of modernity (Fox 1980, 2000; Zinn 2006). However, as articulated in this paper on fetal MRI, while technologies such as MRI may not provide unequivocal certainty, they can (when combined with the professional skills of radiologists) assist parents in successfully navigating the issue. Furthermore, data here suggests that clinical uncertainty can in some cases be positively and productively employed by patients and health professionals, rather than simply being something to overcome.

# References

Adamson, C. (1997) Existential and clinical uncertainty in the medical encounter: an idiographic account of an illness trajectory defined by inflammatory bowel disease and avascular necrosis, Sociology of Health and Illness 19(2): 133-59 Arber, A. (2006) Reflexivity: A challenge for the researcher as practitioner? Journal of Research in Nursing 11(2): 147-157 Baillie, C., Smith, J., Hewison, J., and Mason, G. (2000) Ultrasound screening for chromosomal abnormality: women's reactions to false positive results, British Journal of Health Psychology, 5: 377-394 Bekker, M. and Van Vugt, J. (2001) The role of magnetic resonance imaging in prenatal diagnosis of fetal anomalies, European Journal of Obstetrics and Gynaecology and Reproductive Biology 96(2):173-178 Braun, V., and Clarke, V. (2006) Using thematic analysis in psychology, Qualitative Research in Psychology, 3(2): 77-101 Casper, M. (1998) The Making of the Unborn Patient: Social Anatomy of Fetal Surgery New Brunswick, NJ: Rutgers University Press Denscombe, M. (2014) The Good Research Guide: For Small-Scale Social Research Projects, Berkshire: Open University Press.

Dussauge, I. (2008) Technomedical Visions: Magnetic Resonance Imaging in 1980s Sweden Division of History of Science and Technology Royal Institute of Technology, KTH, Stockholm papers in the History and Philosophy of Technology, pp1-258. Fox, R. (2000). Medical uncertainty revisited. In P. and F. Bird, C., Conrad & A. (Eds.), Handbook of Medical Sociology (5th ed.) New Jersey: Prentice Hall. Fox, R. (1980) The evolution of medical uncertainty, Milbank Memorial Fund Quarterly/Health and Society, 58: 1-49 Glenn, O.A. (2010) MR imaging of the fetal brain Pediatric Radiolology. 40(1): 68–81. Jenkins, R., Jessen, H and Steffen, V. (2005) Matters of life and death: the control of uncertainty and the uncertainty of control, in Jenkins, P., Jessen., and Steffen, V. (eds) Managing Uncertainty: Ethnographic Studies of Illness, Risk and the Struggle for Control, Copenhagen: Museum Tusculanum Press, pp9-29. Jokhi, R.P. and Whitby, E.H. (2010) Magnetic resonance imaging of the fetus, Developmental Medicine and Child Neurology, 53(1): 18-28 Joyce, J. (2006) Magnetic Appeal: MRI and the Myth of Transparency, New York: Cornell **University Press** Jutel, A. (2009) Sociology of diagnosis: a preliminary review, Sociology of Health and Illness 31(2): 278-299 Latimer, J. (2013) The Gene, the Clinic and the Family: Diagnosing Dysmorphology, Reviving Medical Dominance London: Routledge Leithner, K., Pornbacher, S., Assem-Hilger, E., Krample-Bettelheim, E. and Prayer, D. (2009) Prenatal magnetic resonance imaging: Towards optimized patient information Ultrasound and Obstetrics in Gynecology 34(2):182-187 Levine, D. (2006) Obstetric MRI Journal of Magnetic Resonance Imaging 24(1):1-15 Mailath-Pokorny, M., Worda, C., Krample-Bettelheim, E., Watzinger, F., Brugger, P. and Prayer, D. (2010) What does magnetic resonance imaging add to the prenatal ultrasound diagnosis of facial clefts? Ultrasound Obstetrics and Gynecology 36(4): 445-451 Mitchell, L.M and Georgies, E. (1997) Cross-cultural cyborgs: Greek and Canadian women's discourses on fetal ultrasound, Feminist Studies 23(2): 373-401. Moreira, T., May, C. & Bond, J. (2009). Regulatory objectivity in action: mild cognitive

impairment and the collective production of uncertainty. Social Studies of Science 39(5): 665-690.

NHS Choices, screening tests in pregnancy <u>http://www.nhs.uk/conditions/pregnancy-and-baby/pages/screening-tests-abnormality-pregnant.aspx</u> (accessed May 2016)

Pickersgill, M. (2011) Ordering disorder: knowledge production and uncertainty in neuroscience research, Science as Culture 20(1): 71-87

Pilnick, A and Zayts, O. (2014) "It's just a likelihood": uncertainty as topic and resource in conveying "positive" results in an antenatal screening clinic, Symbolic Interaction, 37(2): 187-208

Prasad, A. (2014) Imperial Technoscience: Transnational Histories of MRI in the United States, Britain and India, Cambridge Massachusetts, London England: MIT press Prasad, A. (2005) Making Images/making bodies: visualising and disciplining through Magnetic resonance Imaging (MRI), Science, Technology and Human Values 30(2): 291-316 Pugash, D., Brugger, P., Bettelheim, D. and Prayer, D. (2008) Prenatal ultrasound and fetal MRI: The comparative value of each modality in prenatal diagnosis European Journal of Radiology 68(2): 214-226

Reed. K., Kochetkova, I and Molyneux-Hodgson, S. (2016) 'You're looking for different parts in a jigsaw': Fetal MRI (Magnetic Resonance Imaging) as an emerging technology in professional practice Sociology of Health and Illness 38(5): 736-752

Reed, K. (2012) Gender and Genetics: Sociology of the Prenatal, London: Routledge Rapp, R. (2011) A child surrounds this brain: the future of neurological difference according to scientists, parents and diagnosed young adults. In Pickersgill, M. and Van Keulen, I. (eds) Sociological Reflections on the Neurosciences. Bingley: Emerald, 3-26

Rapp, R. (2000) Testing Women, Testing the Fetus London: Routledge.

Statham, H and Green, J. (1993) Serum screening for Down's syndrome: some women's experiences, British Medical Journal, 307: 174-6

Star, S.L. (1985) Scientific work and uncertainty, Social Studies of Science 15: 391-427Taylor, J.S. Of sonograms and baby prams: prenatal diagnosis, pregnancy and consumption,Feminist Studies 26(2): 391-418

Timmermans, S and Angell, A. (2001) Evidence based medicine, clinical uncertainty, and learning to be a doctor, Journal of Health and Social Behavior, 42(4): 342-350.

Timmermans, S and Berg, M. (2003) The practice of medical technology, Sociology of Health and Illness, 25, anniversary issue: 97-114

Zechmeister, I. (2001) Foetal Images: the power of visual technology in antenatal care and the implications for women's reproductive freedom, Health Care Analysis, 9 (4): 387-400. Zinn, J.O. (2006) Recent developments in sociology of risk and uncertainty, Historical Social Research 31(2): 275-286 Whyte, S.R. (1997) Questioning Misfortune: The Pragmatics of Uncertainty in Eastern Uganda, Cambridge: Cambridge University Press.