

# Ethical issues in neuroimaging health research: an IPA study with research participants

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# **Ethical issues in neuroimaging health research: an IPA study with research participants**

## **Abstract**

Neuroimaging is used increasingly to understand conditions like Alzheimer's disease, stroke and epilepsy. We focus on two neuroethical concerns: (1) raised anxiety prior to scanning; (2) management of incidental findings. We investigate participants' lived experiences of an MRI brain scan. Interpretative phenomenological analysis was used to analyse interview data pre- and post-scan. Findings show participants can become anxious prior to scanning and the protocol for managing incidental findings is unclear. Participants lacked a frame of reference to contextualise their expectations, thus felt ill-prepared; yet many drew on medical narratives. Results highlight the body-subject in novel encounters and its prominence in understanding experiences.

Recommendations include dialogue between researcher and participant to clarify understanding during consent. We corroborate existing research proposing a 'virtual tour' of the neuroimaging experience. The 'insider's perspective' in this research enables health psychology to develop neuroethical guidelines based on experiential accounts.

## **Keywords**

Neuroimaging, neuroethics, qualitative research, interpretative phenomenological analysis.

## **Introduction**

Understanding the structure and function of the brain has clear benefits for health psychology; neuroimaging techniques have contributed, for example, to our knowledge of the diagnosis and management of conditions such as epilepsy (Brodie & Stephen, 2007), Alzheimer's disease (Illes, Rosen, Greicius & Racine, 2007) and stroke (Lindberg, Schmidt, Forssberg, Engarat & Borg, 2004). Due to these capabilities neuroimaging health research is increasingly prevalent in both clinical and research settings (Bandettini, 2007).

Neuroimaging is an umbrella term for research involving techniques which can produce images of the brain. Historically, such studies have involved CAT (computerised axial tomography) and PET (positron emission tomography) scans and more recently MEG (magnetoencephalography), MRI (magnetic resonance imaging) and fMRI (functional magnetic resonance imaging) scanning. Neuroimaging research enables the study of both the structure and function of the brain. MRI and fMRI have become particularly popular because they are able to produce two- or three-dimensional images of the brain in fine detail, including both surface and subsurface structures, and fMRI can record which of these structures is active during the performance of different cognitive tasks. Furthermore, they can do this in a largely non-invasive way; without the need for exposure to radiation, for example.

As neuroimaging research has become more popular, a number of procedural and ethical issues have been raised, two of which are the focus of this study. Firstly, there is a growing literature investigating patient anxiety levels before undergoing MRI scanning as part of routine neurology or neuropsychiatry care. Secondly, there is increasing concern about the management of incidental findings; what happens when a neuroimage obtained for research purposes identifies a suspected pathology? These two issues are central to neuroimaging health research and are the focus of this investigation.

Although MRI scanning is defined as non-invasive in medical terms, it does impose restrictions on space and movement (Murphy & Brunberg, 1997) and the noise the scanner makes can be very intrusive (Harris, Cumming & Menzies, 2004). Some patients have commented that they felt as if they had been 'buried alive' (Grey, Price & Mathews, 2000) and others describe feeling 'scared' or 'nervous' before taking part in neuroimaging research (Cooke, Peel, Shaw & Senior, 2007). These restrictions and negative experiences can lead to claustrophobia and/or anxiety which can increase movement inside the scanner (in the form of rapid breathing, sweating or swallowing) (Grey et al., 2000) and such movements can degrade the image quality and therefore its diagnostic utility (Murphy & Brunberg, 1997). Furthermore, repeated negative experiences of scanning may lead to procedure-induced claustrophobia (Grey et al., 2000).

Grey et al's (2000) study tested whether more detailed information would reduce patient anxiety levels. They provided patients in the experimental condition with an information booklet in large print and illustrated with cartoons including details of the procedure and simple cognitive and relaxation techniques for reducing anxiety. The booklet was posted to patients in advance and on arriving for their scan patients were asked whether they understood the booklet and were given a tape-recorded demonstration of the noise made by the scanner. Patients' anxiety was measured before, during and after the scan using the Spielberger Trait Anxiety Inventory (Spielberger, 1983). Findings showed that anxiety levels of the experimental group before the scan were not significantly different but following the scan the experimental group had significantly lower anxiety than the control group. Other intervention studies attempting to reduce patient anxiety have incorporated cognitive and behavioural interventions, relaxation, information modelling and breathing techniques with varying levels of success (e.g., Byers, Soper, Miller & Springer, 1984; Weinman & Johnston, 1988; Quirk, Letendre, Ciottone & Lingley, 1989a; Quirk, Letendre, Ciottone & Lingley, 1989b; Wilson-Barnett, 1992; Horne, Vatmanidis & Careri, 1994).

Existing research has primarily focused on clinical patients' experiences of neuroimaging but with increasing research studies using this technology it is important to investigate participants' experiences in a purely research context. Anxiety and/or claustrophobia constitute ethical issues for neuroimaging researchers for several reasons. We have a duty to protect our research participants from risk of harm greater than or additional to that experienced in their everyday lives (see, for example, the British Psychological Society's *Code of ethics and conduct*; BPS, 2006). We must also take into account existing medical conditions when considering volunteers for participation; clearly, there are ethical concerns for a known sufferer of claustrophobia or someone predisposed to high anxiety levels being asked to participate in a neuroimaging study which involves being in a confined space. Other issues involve the cost of scanning and the utility of the scan should a participant's image be distorted; is it ethically sound to re-do scans which become void, given the expense of using neuroimaging equipment and the potential raised anxiety levels this may provoke?

The second issue we consider which has ethical implications for neuroimaging research is the occurrence of incidental findings. An incidental finding is the discovery of any suspicious anatomical abnormality in a neuroimage, obtained either for research or in clinical practice, which is unrelated to the purpose of the scan (Kirschen, Jaworska & Illes, 2006). Investigations of incidental findings in medical settings have formed the basis of many retrospective studies (e.g., Roof, Gregorio, Kulko & Palermino, 1999; Messersmith, Brown & Barry, 2001; Wagner, Morrison, Carrino, Schweitzer & Nothnagel, 2002) but there is limited work with healthy volunteers undergoing scans for research purposes. Kirschen et al. (2006) is an exception. It was a retrospective study in the US with healthy volunteers who had received scans purely for research purposes either at a building affiliated with a medical institution or in a university psychology building. In both settings it was made clear that researchers were not qualified to make diagnostic interpretations of scans and that their scan would not constitute a clinical examination. Reasons for taking part in the studies in order of frequency included financial compensation or course credit (62%), contribution to scientific knowledge (21%), a favour to the experimenter (16%) and being worried about a health problem (1%). About half the sample (54%) expected a brain abnormality to be identified if one existed, despite 84% of them knowing that it was very unlikely a physician would review the research scans. Kirschen et al. (2006) advise that participants should be told whether the scan and/or researchers are able to identify any existing pathology and if they are what the process is for handling incidental findings. In short, this study highlights the mismatch between participant expectations and what is described to them during the consent process. This is clearly an ethical concern for neuroimaging researchers.

Although Kirschen et al.'s (2006) study goes some way to identifying a crucial aspect of participants' expectations of neuroimaging research, more in-depth accounts of these expectations are necessary. The participants in the Kirschen study completed a retrospective survey after having had a scan at least one month prior to completing the survey. An understanding of what participants feel prior to having an fMRI/MRI scan for the first time is still not known. Furthermore, we could not identify any other published work which has obtained an in-depth account of individuals' lived experiences of an MRI brain scan. Due to this gap in our understanding we take an in-

depth qualitative approach, set within an interpretative phenomenological framework (Smith & Osborn, 2003), in order to interrogate individuals' experiences and the ways in which they make sense of their brain scan experience. The focus on participants' own meaning-making of a concrete experience together with the interpretative activity in which the analyst becomes engaged make interpretative phenomenological analysis (IPA; Smith & Osborn, 2003) a particularly appropriate method. By drawing on participants' experiences in this way we will address the ethical concerns outlined above. Our research questions are: What are research participants' expectations of having an MRI brain scan? How do participants feel prior to having an MRI brain scan? And what is the nature of participants' lived experiences of having MRI brain scanning? In asking these questions we hope to inform future ethical guidelines for neuroimaging research by exploring the nature of the scanning experience from participants' own perspectives.

## **Method**

### *Study design and participants*

Following University ethical approval, undergraduate students were recruited to participate in this in-depth study of participants' expectations and experiences of taking part in neuroimaging research. Seven volunteers agreed to a pre-scan interview (approximately one week prior to the scan), an anatomical MRI brain scan (which involves a four to five minute scan of the structure of the brain) and a post-scan interview (within one or two weeks of the scan). All participants were female undergraduate psychology students aged between 18 and 26. One described herself as Indian British while the remainder described themselves as white British. The students received course credit for participation. Informed consent was obtained prior to the pre-scan interview and all participants went through the standard protocol for neuroimaging studies (see below). Each participant was given a pseudonym to protect their anonymity and any other identifying information was removed from their data. See Table 1 for participant details.

[insert table 1]

### *Neuroimaging protocol*

In order to clarify the routine procedure for neuroimaging research participants at this institution we provide a detailed description of the protocol and the screening form (see Box 1). The MRI scanner is housed in a University building which functions both as a clinic (with members of the public as patients) and centre for research. Protocol for an anatomical scan (as well as fMRI scans which look at brain function) is that participants receive an information sheet, screening form and consent form to help them decide whether to take part. The information sheet states that MRI scanning “poses no direct health risks” but that certain people should not be scanned: individuals with a pacemaker, clips or other metal implants and those with “body-piercing items”. It also describes metallic items which will need to be removed: dental plates containing metal (normal fillings are okay), coins, keys, metal fasteners and most jewellery. It then goes on to describe appropriate clothing (“jogging trousers and sweatshirt”), and states: “Ladies may be asked to remove bras (in the provided changing room) that contain a metal fastener”. We previously observed that under-wired bras also needed to be removed, but that women were not always aware of this when arriving for their scan (Peel, Shaw, Senior & Cooke, 2006). At the time we recommended the reference to “ladies” be changed to “women” and the recommendation become “any underwear with metal fittings, such as underwired bras, should not be worn”. Reference to incidental findings is made asking participants to provide the name of their GP (whom by consenting participants authorise the researchers to contact): “there is a very small chance that the scan could reveal something which required investigation by a doctor. If that happened, we would contact your doctor directly”. The information sheet describes the procedure (e.g., participants lay on their back, wear ear-plugs to protect them from “intermittent loud noises”, and have their head partially restrained). It also warns those likely to feel “very uneasy in this relatively confined space (suffer from claustrophobia)” not to take part. However, it goes on to say that if a volunteer should feel uneasy they can talk to the researchers, activate an alarm and be removed from the scanner.

[insert box 1]

The screening form (see Box 1) asks volunteers to state whether they have certain items in their body, if they are pregnant and/or if they suffer from certain conditions.

Definitions of the more technical terms are provided and volunteers are urged to ask the researcher should they have any questions.

This protocol involves detailed information and a stringent screening process. However, as previous research has indicated research participants do not always digest the information they receive in ways anticipated by researchers (Block & Williams, 2002; Cooke et al., 2007; Kiviniemi & Rothman, 2006; Millar, 2006). For example, Kiviniemi & Rothman (2006) found that participants showed selective memory for health-related information; they were better at recalling information that was consistent with their own attitude rather than information that was attitude-inconsistent. In our study it is possible that participants may recall information from the protocol more effectively when it coincides with their expectations (or attitudes toward neuroimaging) rather than that which does not. On a related note, in a systematic review of interventions to achieve better informed consent, Flory & Emanuel (2004) concluded that dedicated one-to-one and face-to-face time with a member of the research team (or a neutral educator) was the most effective way of improving understanding of the activity to which patients/participants are consenting. The protocol for neuroimaging research followed here does specify that a researcher is present during the consent and screening process.

#### *Data collection*

Interviews were guided by a semi-structured schedule but the interviewer (LD and EP) took a flexible approach so that participants could speak freely about their experience and introduce unexpected phenomena should they so wish (Kvale, 1996). Questions were framed in an open-ended manner (e.g., Can you tell me about your reasons for taking part in this study? What do you think the scan will involve? Tell me about your experience in the scanner.). Prompts were used where necessary. Interviews were transcribed verbatim for subsequent analysis.

#### *Analysis*

The interview data were analysed using interpretative phenomenological analysis (IPA; Smith & Osborn, 2003), a method which has been used particularly effectively within health psychology (e.g. Turner, Barlow & Ilbery, 2002; Bramley & Eatough, 2005; Smith & Osborn, 2007). Transcripts were read initially by the lead analyst (RS)



and interviewers (LD and EP) to achieve a broad understanding of participants' pre- and post-scan accounts. The lead analyst then proceeded with an in-depth reading of the first case pre-scan interview. Notes were made to summarise what the participant was saying and to highlight anything which seemed significant. On subsequent readings tentative interpretations were made about the essence of the participant's experience which started to form a set of emerging themes. The analyst then moved on to the pre-scan interview of the second case and repeated these steps. All pre-scan interviews were examined in the same way before moving on to the post-scan interviews. This produced two sets of themes, one derived from the analysis of participants' expectations of the MRI scan and one from the analysis of their reflections on the experience. At this stage the lead analyst consulted the rest of the team to discuss the emergent themes and to ensure that they adequately portrayed participants' accounts. Finally, in order to engage fully with the idiographic approach of IPA, individual participant's pre- and post-scan transcripts were re-examined separately in order to consolidate any idiosyncrasies within the sample. Any further observations at this stage were again discussed within the research team. In order to assess the quality of the study we used a series of prompts to appraise qualitative research devised by Dixon-Woods, Shaw, Agarwal & Smith (2004), including: Are the research questions clear? Are the claims made supported by sufficient evidence? Are the data, interpretations and conclusions clearly integrated? These questions act as prompts to ensure methods are appropriate and the reporting of them is transparent.

IPA is a naturally reflexive method and throughout this study we have engaged in a process of hermeneutic reflection (Finlay, 2003). This is a particular implementation of reflexivity suited to interpretative phenomenological approaches because it focuses on interrogating one's interpretative activity throughout the data collection and analysis stages. We engaged in reflexive strategies therefore by discussing our reflections on the interview process and analysis within the research team (and between interviewers and lead analyst in particular).

## **Findings**

The themes presented reflect participants' expectations of an MRI brain scan and their post-scan reflections on the nature of their experience. The super-ordinate themes presented are: *anticipating the MRI experience, expectations of a diagnosis/clean bill*

*of health, submitting to a medicalised context and MRI scanning as a bodily encounter.*

### *Anticipating the MRI experience*

This theme describes the mixed emotions participants recounted in their pre-scan interview. As ‘naïve subjects’ some participants were simply eager to have a novel experience. The extract from Helen’s account demonstrates her excitement at having a firsthand experience of something out of the ordinary:

Interviewer: So how do you feel about taking part in this experiment, about being scanned?

Helen: I’m really excited about it [laughs] sort of like something I don’t know why but, it’s like one of those crazy things that you always want to do as a child [laughs]. I don’t know why [laughs] guess it’s from TV and stuff but I think it’ll just be quite interesting like to just experience something like that first hand and see the brain. (pre-scan)

Karen also describes being excited about experiencing something new, but her excitement is mixed with nerves:

Interviewer: You’ve got approximately a week until your MRI scan so how are you feeling about it at this moment?

Karen: I suppose I’m feeling quite nervous because I don’t know what to expect but on the other hand I’m quite excited because I’ve never seen one of these scanners so it’s quite exciting in that aspect, but yeah I’ll be fine. I’m happy with it. (pre-scan)

Becky and Jo’s accounts illustrate possible reasons why participants feel nervous prior to their scan. Becky expects to feel claustrophobic inside the scanner and Jo is unsure how she would exit the scanner should she start to panic:

Interviewer: When you’re actually in the scanner, how do you think you’ll feel?

Becky: Isn’t it quite claustrophobic? (pre-scan)

Interviewer: How are you feeling about having the scan at the moment?

Jo: I am a little bit worried because I don’t know whether I’d like panic when I was inside or something because obviously once you’re inside you’re – there’s not really a lot you can do [laughs], you’re stuck [laughs]. (pre-scan)

When asked why they volunteered for the study, several participants said they wanted to see a ‘picture’ of their brain, for example:

I think it'll just be quite interesting if I can actually see my brain on a scanner I think, the image of it. (Becky; pre-scan)

I'm just interested in finding out what my brain looks like and stuff like that, so I'm more interested and sort of curious. (Helen; pre-scan)

These extracts give a flavour of how participants anticipated feeling prior to and while having the scan. They also reveal a curiosity to see a scan (or 'picture') of their brain indicating a desire to find out more about their own health and brain function.

### *Expectations of a diagnosis/clean bill of health*

Following on from the curiosity revealed above, participants expected the scan itself, and the researchers, to be able to identify anatomical abnormalities should they exist.

This made Helen nervous:

Interviewer: Do you think that might change as the scan date comes closer?  
[Helen had previously said she wasn't very nervous]

Helen: Probably, I'll probably get panicked sort of 'what are they going to find?' I'll probably get nervous like just before an exam, but just quite intrigued about what it involves and stuff. (pre-scan)

Nina believed the researchers would be able to identify pathology while the scan was being conducted which indicates either that she had not read the information provided or had not taken in its content:

Interviewer: You said earlier you were interested in MRI scanning, but do you feel nervous or anything?

Nina: I'm not so, I think I might be a bit, not now but in my post scan [interview] I might be if I hear them whispering 'oh there's something wrong there' or something like that [laughs]. Then I might be but other than that no I'm not. (pre-scan)

Dawn also assumed the researchers would have the skills to diagnostically interpret the scan whilst it was happening:

I was a bit nervous because I said 'if you find anything abnormal you have to tell me' and I was a bit nervous in case they said, in case like they found anything and then [the scanner] said 'we do pass it on if we find anything' so now I'm thinking I hope no-one contacts me. (Dawn; pre-scan)

When asked during the scanning procedure the researcher did inform Dawn that incidental findings would be referred for further examination but it is unclear from Dawn's account whether s/he reminded Dawn that any communication would be via

her GP. It also begs the question of whether researchers should be given a time limit within which any abnormalities should be identified (if they exist) and reported to research participants' GP.

More fundamentally, these extracts indicate flaws in the consent process. Despite detailed provision of screening information and the advocacy of caution throughout the consent process, these participants did not fully understand the protocol for dealing with incidental findings. Firstly, despite having consented to take part in a scan purely for research, participants' perceptions of the purpose of the scan were coloured by their expectations of being in a clinical context. Participants in this study believed the anatomical scan they had (for research purposes only) would involve a clinical examination (or diagnosis). They believed that researchers are trained to perform such an examination and that they can do it while the scan is happening. Secondly, the information provided does not state whether efforts are usually made to interpret scans in such a way or whether there is the capability to do so within the research team. Consequently, participants are led to believe that having a scan for research is equitable to having a scan for medical purposes, if only in terms of its diagnostic capabilities.

#### *Submitting to a medicalised context*

As a development of the previous theme, *submitting to a medical context* illustrates the pervasiveness of a medical narrative in participants' understanding of the MRI experience. It is clear from the above that volunteers expected a medical diagnosis and therefore did not fully appreciate that this research procedure did not constitute medical treatment. However, here we see that the physical experience and the surroundings in which the scan takes place also invoke a medicalised context:

It portrays the image of you going into hospital and going into the scan to see if something is wrong with you, and then they could turn around and say 'oh yeah there is something wrong'. And then I think it's just, I just think it's that. It's that whole image it portrays. (Nina; post-scan)

Here Nina is drawing on the wider cultural code of medicalisation; tests are conducted to determine illness which then requires treatment. The possibility of incidental findings, however, emphasises to Nina the connection between the research scan for

which she volunteered and its clinical equivalent. Invoking a medicalised narrative brings with it the power dynamic of the authoritative clinician (or in this case, researcher) and the submissive patient (participant). Indeed, being a participant in research which involves physical testing of any kind arguably demands that a participant submits to the researcher (the historical term, 'subject', is potentially more descriptively accurate in this instance). In both her pre- and post-scan interviews, Jo demonstrates this submissiveness; as we saw earlier she anticipated feeling "stuck" and following the scan she compared this feeling to the experience of being in a dentist's chair:

It was a little strange. It's a bit like being at the dentist when you're, you're in the same sort of, although you're lying down it's like being in a [dentist's] chair. You're just sort of stuck there. (Jo; post-scan)

Elizabeth also refers to this analogy:

It's the whole lowering back I suppose and being flat isn't it really, flat out, and it's the smell, and the chair and whole... 'cause I'm assuming 'cause it's obviously got to be very um... clinical hasn't it so it's gonna be in that sort of situation. (Elizabeth; pre-scan)

Both Jo and Elizabeth conjure a classic anxiety provoking activity. For Elizabeth it is possible that drawing on this experience in her pre-scan interview had a derogatory effect on her MRI encounter. While waiting for the scan Elizabeth started to panic:

I think it's just the whole unknown which is even worse and then I was panicking thinking what if I panic when I'm in there and like I said before and I can't get out fast enough and then I'm stuck inside and I couldn't believe it I was panicking for the panic. I mean it is crazy. Absolutely mental. (Elizabeth; post-scan)

Despite these feelings Elizabeth did go into the scanner but her expectation of panic was realised:

Well I was laying there and obviously they were there behind the screen at this point filling out the questionnaire [participant details] and stuff and erm I think

I'd just made myself worked up so badly that I just wanted to sit up. So I just said to them 'look please', course they come back into the room and said 'is everything okay?' and I was like 'no not really can I just sit up?' and they were showing me - it was like in a dentist - they were showing me how this chair works and stuff they were showing me it's only a little bit and everything like that but then I just physically could not have got back into that thing. It's just I can't explain it the fact that, it's just that thing that holds your head in. I think if you didn't have that it wouldn't be so bad. Because then you've got the feeling that you can move. But even the earphones restricts movement obviously which is the whole point of it anyway but you know. (Elizabeth; post-scan)

Elizabeth's reaction meant that she was removed from the scanner without the scan being conducted. We can learn from her experience in several ways. In her pre-scan interview Elizabeth expected to feel claustrophobic ("just lay down and they put you in the scanner and hope for the best and just [laughs] and just be extremely claustrophobic") but this did not prevent her consenting to participate. Perhaps the phrase "suffers from claustrophobia" in parentheses on the information sheet was not stressed enough or perhaps it is stated too formally thereby seeming to require a medical diagnosis of claustrophobia. Furthermore, Elizabeth may not have felt she was 'claustrophobic' when completing the screening form, yet she still experienced an adverse reaction. This may suggest a reference to claustrophobia is too specific. Secondly, it is clear in her account that Elizabeth felt a degree of obligation to make good her consensual agreement ("I got so frustrated with myself 'cause I couldn't do it and I'd let people down which made it even worse"). This reminds us how crucial it is to emphasise that participants may withdraw at any point during the research activity without prejudice, and more significantly, without feeling responsible for any disruption or loss of data. Her last sentence in the extract above indicates that Elizabeth is aware that her emotional response is in spite of her rational judgment; she knows why the restraints are in place but this does not prevent her physical reaction to panic. This suggests that 'informed consent' is not always achieved despite the

cautionary steps taken in this case. The final theme goes some way to explaining this phenomenon, once again starting with Elizabeth's experience.

### *MRI scanning as a bodily encounter*

In her pre-scan interview Elizabeth had described being nervous, and together with what was discussed above, we can see that difficulties conceptualising the physical experience worked to exacerbate those feelings:

Interviewer: What about when you're actually there being taken into the scanning room itself?

Elizabeth: I think it'll be once you see it, [the nervousness] might change a bit obviously but I don't know, you can't really say until you're in there and in that situation. (pre-scan)

Similarly, in her post-scan interview Dawn discusses the almost impossibility of having tangible expectations of what will happen in a novel encounter:

Interviewer: You said you were a little bit nervous but mainly excited. What was the nervousness about?

Dawn: I think it's just the unknown really, not knowing exactly what I was going to expect because nobody said – gave me a full overview of what exactly would be happening. I mean I was told I would have to lie down and I'd be going into this machine thing and there'd be loud noise but I didn't actually know anything. I just didn't know what to expect actually being in there. That was all really. I think if I'd done it loads of times before then I wouldn't have felt that, but you know. (post-scan)

This is reminiscent of Elizabeth's account in the previous theme; Dawn struggles to imagine what will physically happen despite having received information in advance ("I didn't actually *know* anything"). We know that information is sometimes insufficient but these data stress the physical nature of what is demanded of participants in this particular type of study. The written description of the noise, the confinement and so on, with the benefit of hindsight, does not adequately describe to these participants what actually happened to their body. Even though this study involved a brain scan (as opposed to a full/part body scan), it is a physical procedure which involves bodily consent. However, participants were required to consent to the procedure based on a written description and were then expected to physically submit their body to the researcher in order for the scan to be conducted. This represents the embodied nature of the self; participants need (as far as possible) a bodily experience in order to understand and therefore be prepared for a physical procedure. Extracts in

this theme and throughout the data corpus indicate the significance of embodied information, such as audiovisual and physical cues, as a means of fully preparing participants for their bodily encounter in the MRI scanner.

### *Summary of findings*

The overriding concern we can take from these women's accounts is that it is difficult to anticipate what experiencing an MRI brain scan will entail, which leads to several ethical issues for neuroimagers in both research and clinical practice. Firstly, there is naïve curiosity and excitement about a novel experience; and second, participants developed somewhat misguided expectations of the capability and/or function of the scan. Participants believed that the scan was capable of identifying pathology and that researchers would be able to make a diagnostic interpretation. The medicalised context in which the scans took place meant participants drew upon comparable experiences in clinical settings which invoked the narrative of illness, treatment and practitioner-patient relationships. This made participants nervous because they expected to be told whether their brain was healthy. Furthermore, the physical nature of the MRI scan necessitated participants to submit their body to researchers, again emphasising the medicalised context of clinical testing in which scans are conducted, even if their sole purpose is research. Finally, we see that participants faltered in forming expectations of the scan because they lacked embodied knowledge of the essence of the experience. This meant that despite having received detailed written information and the opportunity for verbal clarification from the researchers, after the event participants felt they had been ill prepared for their MRI experience.

## **Discussion**

This study explored participants' expectations and lived experiences of an MRI brain scan, firstly, in order to address the ethical issues evoked by using neuroimaging technology in research and secondly, to understand the protocol for dealing with incidental findings occurring in scans conducted purely for research. Our current findings confirm Cooke et al.'s (2007) observation that research participants, as well as clinical patients, may become anxious prior to having an MRI scan. Furthermore, the level of anxiety Elizabeth experienced would have necessitated sedation if the scan were required for medical purposes (Murphy & Brunberg, 1997). Consequently



our study re-emphasises the need for research which aims to identify in advance of their scans those who are predisposed to anxiety or claustrophobia (Grey et al., 2000) and those who require sedation in order to tolerate the procedure (Murphy & Brunberg, 1997).

As we saw earlier, a number of interventions have been tested to reduce patient anxiety prior to scanning, including combinations of music, relaxation techniques, cognitive and behavioural techniques and information modelling (e.g., Byers et al., 1984; Weinman & Johnston, 1988; Quirk et al., 1989a; Quirk et al., 1989b; Wilson-Barnett, 1992; Horne et al., 1994). Our findings concur with the utility of such interventions but we question their practicability; is it feasible, especially in a clinical context, for anxiety levels to be measured prior to scanning? Furthermore, Grey et al. (2000) did not find a significant difference between experimental and control groups until the post-scan anxiety levels were measured. The implication of this is that it may not be possible to identify those predisposed to high anxiety before their first scan.

Our findings support Flory & Emanuel's (2004) proposal of the need for further face-to-face discussion between researcher and participant to clarify the meaning of statements made in the consent and screening forms. For instance, what constitutes claustrophobic reactions or anxiety levels that would be detrimental both in terms of the participants' exposure to unnecessary risk and the utility of the scan for research or diagnostic purposes? Time spent with Elizabeth discussing whether she had experienced problematic levels of anxiety in the past would have revealed that she had experienced panic attacks prior to academic examinations. This would have warned researchers of her potential to become overly anxious and may have prevented her from going through an unpleasant experience. We advise therefore that a routine exchange between researcher and participant focusing on definitions and clarifying what sort of reaction may be problematic or unpleasant become part of the standard protocol for neuroimaging research. The focus should be on an interaction rather than a researcher being present in a passive sense to answer any questions participants may have; our results show that 'naïve subjects' lack a frame of reference for this novel experience and may not therefore know what questions to ask. This simple shift in the dynamic during the consent process may prevent future misapprehensions on behalf of participants.

Another issue highlighted by Grey et al. (2000) was the possibility of procedure-induced claustrophobia following repeated scans. Our analysis of participants' experiences raised doubts about this. As far as we are aware our study is unique because it explores in-depth lived experiences of research participants' expectations and experiences of having an MRI brain scan for the first time and the novelty of the experience was significant to participants. However, the fact that participants lacked embodied knowledge of the MRI procedure left them feeling ill-equipped and uncertain what to expect. Drawing on Merleau Ponty's ([1945] 1962) notion of the body-subject, this finding illustrates how we experience things primarily through our body; we speak with our body and understand with our body. Thus, when our body lacks a frame of reference in which to place a novel experience, it is unable to attach meaning to it. In other words, when participants are told they will be asked to lie down and moved backwards into the scanner – a novel bodily encounter – their body has no contextual information with which to furnish their expectations. The body is inextricably linked to our social world and our understanding of encounters with and within this world, are embedded within our physical (or embodied) experience of it. In terms of understanding the potential for procedure-induced claustrophobia, our results indicate that it is unlikely. This theorised analysis demonstrates that once an individual has undergone the physical process of having an MRI scan they will possess embodied knowledge of it which will be drawn upon to inform future encounters with the same technology. In terms of preparing participants for their MRI experience this finding corroborates previous suggestions for a 'virtual tour' of an MRI scanner which includes sensory information (Bryers et al., 1984; Grey et al., 2000; Cooke et al., 2007).

The second substantive issue is the protocol for dealing with incidental findings. Our participants were similar to those in Kirschen et al.'s (2006) study in two ways: many of them took part in the research to gain course credit and many of them believed researchers would be able to identify anatomical abnormalities in the brain. A key difference is that we obtained accounts in anticipation of the scan and more immediately following their scan (within one or two weeks compared to waiting over a month). A second major difference is that, although we identified the same mismatch between protocol and participant expectations, we were able to rationalise

this through having access to detailed experiential accounts of both expectations and subsequent experiences. As detailed above, the MRI scanner is located in a medical environment which functions to highlight the already prominent clinical connotations the technology invokes. Helen mentioned television as an indicator of her limited previous exposure to MRI technology; the television news, medical dramas and documentaries are likely to act as key cultural reference points for those with no prior experience of MRI scanning. This ready association with hospitals, illness and treatment strongly influenced participants' expectations of what it means to have an MRI scan. Most significantly, participants believed researchers could interpret scans diagnostically and would inform them if anything was wrong. It is clear from this finding that researchers need to state and stress to participants both their capability and intention to conduct clinical examinations of scans conducted purely for research. Indeed, this information should be written into any standardised protocol for neuroimaging research. Researchers are responsible for protecting participants from any unnecessary harm, which includes inducing raised anxiety by not correcting participants' misapprehension that following the scan they will automatically know whether their brain is healthy. Another common misapprehension was that participants expected to receive a 'picture' of their brain following participation. This was stated nowhere in the information participants received and does not happen ordinarily. One explanation may be that as students in an institution which is very active in neuroimaging research, they are familiar with seeing images of MRI scan results in lectures and poster presentations; hence, they expect to see the results of their own scan.

While this study may be criticised for its small and homogeneous sample, this is exactly the kind of sample most appropriate for IPA research (Smith & Eatough, 2006). The purpose of IPA research is not to generalise in the traditional sense, i.e., 'vertically' to the rest of the population via a representative sample, but to generate concepts and theoretical understanding which may be transferred to different settings 'horizontally' (Guba & Lincoln, 1985; Yardley, 2000). It is clear that similar studies with different groups - particularly men, non-students, older and younger individuals, and importantly clinical patients - would benefit the knowledge base. In attending to the cues to appraise the quality of this study (Dixon-Woods et al., 2004) the research team concluded that the research question was clear and that the methodology was

appropriate. We endeavoured to be transparent about research process and have provided detailed data extracts to support the claims made. Our engagement with reflexive strategies enabled collaborative discussion of interpretations during the analysis which also strengthens the rigour of the analysis.

In summary, this research confirms that more needs to be done to clarify the protocol for dealing with incidental findings. Furthermore, participants need to understand that their scan does not constitute medical treatment and they need to be made aware of the research team's capability and intention of clinically examining their scan. Secondly, we support existing evidence that written and verbal information is not sufficient to fully prepare participants/patients for an MRI scan. This finding alone is not a new but our study offers invaluable insight about why this is the case. We must embrace the body-subject first, when designing information provision and second, when designing interventions to identify those predisposed to anxiety or who suffer from claustrophobia. This means we must endeavour to offer participants an embodied 'taster' of what will happen inside the scanner, in the form a virtual tour or similar (Bryers et al., 1984; Grey et al., 2000; Cooke et al., 2007); and this must be accompanied by a discussion with participants to clarify the meaning of terms used on the screening form (Flory & Emanuel, 2004). In short, this research adds weight to previous recommendations and emphasises the importance of dealing with ethical concerns proactively. Furthermore, this in-depth experiential analysis of participants' own meaning-making of their neuroimaging encounter has given us insight into how it feels to be a neuroimaging research participant or patient. This 'insider's perspective' (Conrad, 1987) enables us as health psychologists to develop an informed process for dealing with the ethics of neuroimaging research and practice that will adequately address the needs of those being scanned because it was derived from their own first-hand experiential accounts.

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**Table 1: Participant details**

Pseudonym	Age	Sex	Ethnicity	Occupation	Self-defined class
Becky	20	Female	White British	Student & barperson	Working class
Dawn	20	Female	White British	Student	Middle class
Elizabeth	26	Female	White British	Student & part-time administrator	Working/middle class
Helen	19	Female	White British	Student	Middle class
Jo	18	Female	White British	Student & part-time tutor	Working class
Karen	20	Female	White British	Student	Middle class
Nina	18	Female	Indian British	Student	Middle class

**Box 1: Extract from Initial Screening Form used in the Magnetic Resonance Imaging Unit**

<i>Please answer all questions</i>	<i>Circle your answer</i>
1. Have you been fitted with a pacemaker, artificial heart valve, cochlear implant or any other implanted device?	YES/NO
2. Have you any surgical clips, aneurysm clips, shunts or stents in your body?	YES/NO
3. Have you ever had any metal fragments in your eyes?	YES/NO
4. Do you wear a hearing aid?	YES/NO
5. Have you ever had any metal fragments, e.g. shrapnel in any other part of your body?	YES/NO
6. Have you any surgically implanted metal in any part of your body (e.g. joint replacement or bone reconstruction)?	YES/NO
7. Have you ever had any surgery that might have involved metal implants of which you are not aware?	YES/NO
8. Is there any possibility that you might be pregnant?	YES/NO
9. Have you been sterilised using clips?	YES/NO
10. Do you have a contraceptive coil (UCD) installed?	YES/NO

11. Do you have <b>any</b> dental work (including dentures, crowns, bridgework, braces) in your mouth, other than simple fillings?	YES/NO
12. Have you ever suffered from any of: epilepsy, diabetes or thermoregulatory problems?	YES/NO
13. Have you ever suffered from any heart disease?	YES/NO
14. Do you have any permanent eye make-up?	YES/NO
15. Do you have any Tattoos?	YES/NO