



## Clinical research encounters as a focus of public engagement with science and research

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### **Abstract**

The clinical research encounter is a site of close interaction between research professionals and members of the public, as they jointly perform research, but is not normally considered as a potential site for public engagement. In this paper we adduce theoretical and empirical arguments on the potential of this site for developing a novel mode of engaging publics with science. Our empirical studies use qualitative methods, based primarily on interviews and participant observation. We find that performing in a live experiment offers participants material engagement with science through embodied experience, and generates commitment to the research and to building close working relationships with researchers. Researchers reciprocate, and acknowledge benefits from closer interactions with participants, though remaining partly constrained by their professional acculturation. We argue that the potential of clinical research as an engagement site lies in the combination of material engagement and the conscious commitment by participants to making a contribution to a specific project. Thus the clinical research encounter offers a useful alternative mode of engagement to the language-based paradigm currently dominating work in this field.

### **Keywords**

Clinical research, research encounters, public engagement, research participants, clinical research experiment, material engagement, embodied experience.

## **Encuentros de investigación clínica como foco de compromiso público con la ciencia y la investigación**

### **Resumen**

El encuentro de investigación clínica es un espacio de estrecha interacción entre los profesionales de la investigación y el público en general, ya que conjuntamente realizan una investigación, pero normalmente no se lo considera como un espacio potencial para el involucramiento público. En este artículo presentamos argumentos teóricos y empíricos sobre el potencial de este espacio para el desarrollo de una forma novedosa de involucrar a los públicos en la ciencia. Nuestros estudios empíricos utilizan métodos cualitativos, basados principalmente en entrevistas y observación participante. Encontramos que la participación en un experimento en vivo ofrece a los participantes un compromiso material con la ciencia a través de su experiencia corpórea, y genera un compromiso con la investigación y la construcción de estrechas relaciones de trabajo con los investigadores. Los investigadores intercambian y reconocen los beneficios de interacciones más estrechas con los participantes, aunque quedan parcialmente limitados por su aculturación profesional. Sostenemos que el potencial de la investigación clínica como espacio de compromiso radica en la combinación del involucramiento material y el compromiso consciente de los participantes de hacer una contribución a un proyecto específico. Por lo tanto, el encuentro de investigación clínica ofrece un útil modo alternativo de compromiso con el paradigma basado en el lenguaje que actualmente domina el trabajo en este campo.

### **Palabras clave**

Investigación clínica, encuentros de investigación clínica, involucramiento público, participantes, experimento clínico, involucramiento material, experiencia corpórea.

## 1. Introduction

In this paper we advance the general thesis that medical research involving humans has the potential to act as a site of public engagement with science and research. Our particular interest is in the involvement of those who enrol as participants in experimental or observational studies. Study of the literature suggests that this area has been overlooked by scholars and official bodies writing on public engagement. Yet clinical research with humans requires close proximity and interaction between scientists/clinical researchers and a lay public when they come together to perform clinical research.

At present, activities recognised as public engagement in clinical research are generally enacted through the mechanism of committees that involve patients and patient advocates in strategic and managerial decisions. Such activities thus take place at sites removed from the clinical encounter between researchers and research participants. We recognise the contribution made by these mechanisms, which are well established, well researched, and well-funded by national governments and charitable sources. Through such mechanisms, patients and other lay people are involved in questions of priority-setting, design and management of research and have opportunities to wield strategic influence on the politics of clinical research, as well as involvement with specific local projects (Brereton et al., 2016; Canada, 2000; National Institute for Health Research [NIHR], 2017). More recently there has been increasing evidence of patients taking or sharing the lead in these kinds of discussions (see 4.1.4. below). Some of those involved in this strategic work may also be research 'participants', but the site of activity remains the committee room or discussion forum, not the place where research is done.

In this paper we refer to how public engagement in clinical research is dominated by this kind of committee-based activity, to the apparent neglect of other, different, opportunities for clinician-researcher-public interactions. We argue that the dominant focus on patient input at the strategic and managerial level does not need to exclude the development of other routes of engagement. Clinical research with humans offers participants a lived experience of real-life science. Its potential as a site for engagement lies in the combination of material engagement and the conscious commitment by participants to contributing to a specific project. In defined circumstances, this combination can provide a fertile site for a performative kind of public engagement.

In section 2 (Defining public engagement in clinical research), we define our key terms and the kind of engagement we believe can develop in the context of clinical research. Section 3 (Empirical Data) summarises the evidence from our qualitative study of volunteers in clinical

experiments and comprises three subsections on methods, participant data, and researcher data. The Discussion (section 4) first sets our claims for clinical research as a site for public engagement in the broader institutional environment and considers the implications of that environment for alternative developments in public engagement. The second part of the section assesses what engagement might be attainable in practice in the clinical setting, its strengths and weaknesses. Section 5 (Conclusions) briefly summarises the arguments presented in relation to a distinctive mode of engagement developing within clinical research encounters.

## 2. Defining public engagement in clinical research

### 2.1. USE OF THE TERM 'PUBLIC ENGAGEMENT'

Public engagement is a contested term among practitioners and the definitions of what constitutes 'public engagement' in the literature cover a wide range of interactions and aims. In these circumstances, we have found it helpful to refer to the framework set out by Rowe and Frewer (2005, p. 253) in their typology of public engagement mechanisms. They define 'public engagement' as the general term referring to a wide spectrum of activities. These activities are classified by the information flows between publics and researchers. Three main types emerge, namely Communication, Consultation, and Participation (see Rowe and Frewer, 2005, p. 275-282).

We shall argue that the type of engagement possible in clinical research encounters stands outside the Rowe and Frewer framework in some important ways. One characteristic of the clinical situation is that it does not assume any prior commitment to engage with research *subjects*, though activists or expert patients may have been involved at earlier stages. Those participating as research subjects simply take part in a research project: but they have to be players, not bystanders. They are bodily engaged, and the mode of their engagement is not so much cerebral as material and performative.

## **2.2. DEFINING 'CLINICAL RESEARCH'**

While the scope of public engagement potentially includes all public policy and fields of learning, we limit our attention here to how it may apply to clinical research, and more particularly to 'live' interactions with participants in experimental work. To develop this theme we need to define further what we mean by clinical research and the kind of participative public engagement we believe is possible.

The term 'clinical research' is seldom defined, with one notable exception. Levine (2008) gives the following definition: 'research involving human subjects that is designed to advance the goals of the medicine (and other health-care professions)'. In accordance with this definition we use the term 'clinical research' to cover all forms of medical research involving humans. That is, it includes observational and measurement studies requiring no physical intervention, as well as the better known 'clinical trials' testing new therapies and practices, often under strictly controlled conditions. This point is important for our work and the question of how far the type of study, as well as the type of participant (healthy volunteer, terminally ill patient, patients with non-life-threatening conditions, and so on), will influence the scope for their engagement with science.

By 'clinical research encounter' we mean the occasion(s) when research participants (a.k.a., 'research subjects' as formerly known) interact directly with professionals conducting research. This is most usually face-to-face, in the clinic or the laboratory, but some kinds of interaction may also take place over the telephone or through electronic media.

## **2.3. THE KIND OF PARTICIPATIVE PUBLIC ENGAGEMENT POSSIBLE: PARALLELS WITH INFORMAL SCIENCE EDUCATION AND LIVED EXPERIENCE**

### **2.3.1. Informal science education**

To characterise the range of interactions that are possible in clinical research encounters we needed to turn from the dominant interests of the academic and policy-oriented literature that focuses on broad issues and policies. We found alternative approaches more relevant to our narrower focus in this paper in some of the scholarly work originating from 'museums' or informal science education perspectives (Bonney et al., 2009). Davies and colleagues (Davies, McCallie, Simonsson, Lehr, and Duensing, 2009), for example, defend 'dialogue events' that do not inform

policy, arguing that they create an environment for social and cultural exchange far removed from the much-criticised one-way information transmission or management of public attitudes. Such events are conducted on the principles of equality of all participants and symmetrical learning (though it is acknowledged that this may not always be achieved in practice). This suggests a format likely to be transferable to the clinical experiment.

Other educationally –and politically- motivated work focuses on the use of communicative media other than dialogue, notably the experiment or object-centred experience. A high level of interest in the potential of the experiment as a vehicle of public participation and engagement has been particularly evident in programmes undertaken in museums and science centres since the pioneering work of Frank Oppenheimer in establishing the Exploratorium in San Francisco in 1969. Oppenheimer’s vision was to create a space for interaction with scientific objects and practices:

‘...an environment in which people can become familiar with the details of science and technology and begin to gain some understanding by controlling and watching the behavior of laboratory apparatus and machinery’ (Oppenheimer, 1968).

### **2.3.2. Lived experience**

Interactive and object-oriented forms of communication have continued to be discussed and developed, particularly in the context of museum and exhibition displays (Barry, 1998; Soderqvist, Bencard, and Mordhorst, 2009), and like the Oppenheimer concept above have relevance for the clinical research situation. The similarities include participants doing science, and participation often taking a material form –interacting with measuring devices or scanning equipment, giving samples, among others.

The immediacy of the lived experience of science and technology (through experiment or exposure to scientific objects) has been claimed to be superior as a model of communication to the traditionally privileged culture of interpretation via language (Gumbrecht, 2004). This has resonances with other recent work ranging from renewed philosophical interest in the development of an ‘object-oriented ontology’ (arguing for an understanding of objects as entities and actants independent of human mediation) (Harman, 2007; 2011) to empirical and theoretical studies of the significant role of material objects in environmental engagement projects (Marres, 2009). Soderqvist and colleagues (Soderqvist and Bencard, 2010; Soderqvist et al., 2009) argue ‘that we appropriate with our bodily faculties prior to and irrespective of any linguistic appropriation of the world’, and that this provides a fruitful way to explore the relationship

between humans and objects (Soderqvist and Bencard, 2010, p. 100). Given the significance of sophisticated technology and specialised environments in today's clinical research, we speculate that the exposure of research participants to the materialities of science could add to their knowledge and perceptions of science in fruitful ways. Of interest here is Marres' understanding of 'material forms of engagement' as a performative phenomenon, and a particular modality of participation, which seems likewise relevant to the research encounter (Marres, 2012).

### 2.3.3. Material engagement

A distinctive feature of the clinical research encounter is that those members of the public enrolled as participants are taking part in a live experiment. Research is assimilated as a lived experience, and depending on the specific research, often is literally an embodied experience. In clinical research, as to a lesser extent in health care, the participants are likely to be brought into close proximity with novel equipment and practices.

We suggest therefore that engagement in clinical research may be mediated by that bodily appropriation or experience of the material paraphernalia of science discussed in the previous section. The lived experience is a contributor to –and constituent part of– the relationship forged with science (or a particular piece of science) by people taking part in experiments. Our empirical data indicates that clinical research participants react emotionally and physically to the sounds, smells, flashing lights and vibrations of people and equipment they encounter in giving their 'live' performance. This has some features in common with the work on 'shared immersion' - involving lay people joining a team of professionals to perform simulated surgery (Tang, Marrothynaden, Bello, and Kneebone, 2013) though there are fundamental differences in setting and type of relationship. Both constitute a different type of engagement from –for example– a focus group mediated almost solely through language. Further development of this area appears both feasible and worthwhile.

In the next section of the paper we adduce empirical evidence about the engagements occurring between researchers and members of the public acting as research participants. While interactions through dialogue are of course present and important, these take place within the framework of a performance and a particular material environment. We have called this 'material public engagement' but it might equally be described as 'public engagement as public performance' – a phrase kindly brought to our attention by an anonymous referee, to whom we offer thanks.

### 3. Empirical data

In the absence of any definitive indicators from the literature on the potential of routine clinical research as a site for public engagement, we decided to undertake a secondary analysis of data collected for a broader empirical study of participant experience of research on a new health technology. This study, funded by the Economic and Social Research Council (ESRC), aimed to gauge the scope for research participants –in the course of a biomedical experiment led by scientists- to engage as a public with the science they encounter and with the staff involved. As with most clinical research, the lay participants had no prior input to study design and planning. Thus, we were a long way away from 'participative research', since conventional power structures remained unchanged. This did not however necessarily inhibit participants from seizing their window of opportunity to influence the action (as noted in a different context by Davies, 2013).

#### 3.1. METHODS

The biomedical study forming the site for our research was non-therapeutic and low risk. It concerned the first tests in humans of a new high-tech optics-based diagnostic technology with potential for application in early recognition of breast disease. It offered no hope of direct medical benefit to the participants, who included healthy volunteers as well as women with benign or cancerous breast conditions. Participants were normally seen only once by the research team.

The social scientists (including two of the present authors) worked in collaboration with a team of medical physicists of the United Kingdom (UK) about to start *in-vivo* clinical testing of their prototype imaging system. We added to the original test protocol to allow collection of feedback and views on their experiences from test subjects. The data would be used to help in development of the instrument and test procedures and to explore the feasibility of engaging participants in discussion about issues addressed or raised by the research. Separate ethical approval was obtained for the social science arm of the study. The qualitative methods used comprised observation of test scans, and in-depth interviews with participants and researchers by two experienced sociologists. The same methods were later used for a smaller study in the United States of America (USA) where tests of a related optical technology, developed by another team, were in progress. Observations and interviews were carried out with 65 women in the UK, and a



further 15 in the USA. Participants for both sites were recruited by collaborating clinicians (for patients) and personal or institutional networks (for healthy volunteers). All interviews, and scan sessions when feasible, were audio-recorded and transcribed verbatim. Analysis was by standard sociological methods, with assistance from N-vivo software for coding, analysis and data management. In this paper individual participants are identified by a code specifying their location (UK or US), their cohort (I or II) where applicable, their status as patient (PV) or healthy volunteer (HV) and an individual number. We also conducted 12 interviews with 10 different researchers, as a necessary complement to the participant data, and held informal group discussions with the research teams. In addition, we took part as observers or participant-observers in many of the experimental sessions so could observe interactions at first hand. Researchers are identified by a code that consists of the country in which they are located (UK, US, or NL) and a number.

The project was not selected as being representative of a major tranche of clinical research but chosen for its simplicity. By being non-therapeutic, it avoided the difficulties of exploring research participation when the line between research and treatment (normal care) is blurred (Whong-Barr and Haimes, 2004). In such circumstances patients may feel driven to join the study as 'a lifeline' (Agrawal et al., 2006), or choose participation as offering them a superior standard of health care (McCann, Campbell, and Entwistle, 2013; Timmermans and McKay, 2009; Townsend and Cox, 2013). Nor was the study a randomised controlled clinical trial (RCT). Though we are aware that the RCT is often taken as the epitome or 'gold standard' of clinical studies, it has a number of structural disadvantages for studying the scope for more active participation. These include the relatively inflexible structure (particularly of multi-site trials) and inherent ethical issues (for example, around understandings of randomisation and equipoise).

In reporting our findings, we accept that the expectations and priorities of patients enrolled in a therapeutic clinical drug trial are likely to be different from those in our study (Catt, Langridge, Fallowfield, Talbot, and Jenkins, 2011; Locock and Smith, 2011). The interests of paid 'professional guinea-pigs' (Almeida, Azevedo, Nunes, Vaz-da-Silva, and Soares-da-Silva, 2007; Weinstein, 2001) would be different again. Nevertheless, some of the issues addressed by participants –and which seem to drive them to engage– appear to be generic to clinical research participation. Namely, resisting or re-defining the 'guinea-pig' label; dealing with intimidating surroundings; dealing with social challenges like being undressed in front of strangers; uncertainty about what is going to happen; being patronised; and fulfilling their personal need to perform creditably (Goffman, 1971).

## **3.2. FINDINGS: PARTICIPANTS**

### **3.2.1. Feasibility**

Participants in the biomedical study were highly cooperative regarding participation in our qualitative study. It seemed to generate satisfaction that they were not being regarded as 'just bodies', but asked to comment on their experience (see 'guinea pigs' below). The collaborating researchers too were positive, reporting positive effects on their work and relations with the participants. We interpret this as 'soft' evidence of a general willingness to engage beyond the limits of the formally defined research project, and to enter into a closer working relationship between lay participants and researchers.

### **3.2.2. Sensational science: entry to a hidden world**

In his critique of dialogue-based communications, Irwin (2008) concludes that something more may be needed (probably still with dialogue in mind): 'forms of communication that do not simply trade in the unreflexive language of deficit and dialogue, but that open up fresh interconnections' (p. 210). Indeed, participants' accounts suggest that, for them, engagement was less about dialogue or technical content, but experience of an embodied or material engagement. Accepting an invitation to participate in an experiment seems to have an element of 'sensation-seeking' in the popular sense, like a traveller venturing into a foreign culture. Participants often appeared to relish the opportunity of a novel experience and visiting behind the scenes (this is not dissimilar to reported reactions of visitors to a science festival) (Jensen and Buckley, 2014). Even those with some scientific background expressed fascination in viewing the work from a different, 'research subject' perspective, which, in the words of two different interviewees, made the experience 'strange' or 'surreal'. While for some, reactions were dominated by personal background (for example, recent medical history), many expressed curiosity about this largely hidden world or commented on the mental or physical sensation they felt there: 'I was in there among the engineers' (UKIPV8), or 'to see what they are doing, and have a chat with them, and feel that energy' (UKIPV15).

In some cases, entry into the physical world of the study as participants was a visible (though transient) surprise. For example, one healthy volunteer on entry to the laboratory where the experimental scan would take place exclaimed 'Wow! It's like Frankenstein's lab' (UKIIHV5). Or, as another participant, a patient, tells it:

'...all of a sudden, there's this lab, gosh, this really is a lab... I suppose that when you, when you come in, you actually see, my goodness, this really is an experiment.' (UKIIPV33)

This mixture of practical, emotional and self-mocking reaction on being exposed to the material world of science demonstrates its impact on the participants, and how they shape or reshape their behaviour and opinions to make themselves at ease with these phenomena. It seems thereby to constitute a key point where understandings of science might likewise be shaped, and an opportunity for scientists and lay participants to collaborate in that process. As we now discuss, this general notion of 'sensational' science appears to frame a range of more specific types of engagement that, far from being abstract, cerebral or dialogic, are instead material and embodied.

### 3.2.3. Participants reconstructing themselves for engagement

*Managing personal fears and aspirations.* As volunteers, participants in our study first had to organise themselves and construct identities to help them deal with the often novel, always unscripted, situation of being a research participant (Goffman, 1971; Morris and Balmer, 2006). Though this is likely to be a process all participants have to go through irrespective of any engagement agenda, its shape and articulation may depend on interactions with researchers, as rationales and self-image are stimulated by context and others' expectations (Mills, 1940). One key task for our participants was confronting the guinea-pig stigma. Some participants professed a breezy acceptance of the passive role of guinea pig with such comments as 'we are just bodies basically' (UKIIV4), or 'I'm just someone who's willing to, to be a guinea pig for helping people carry out research. It's nothing special' (UKIIPV10).

But there was evidence of underlying reservations. The second participant quoted above later revealed some of the tensions inherent in the guinea pig role:

'Like I can express my feelings afterwards [in the interview] and it's not just like, oh, I'm this guinea pig and that's, that's it, I'm just used and then off I go. You can actually attempt to contribute something which might be helpful.' (UKIIPV10)

Thus not only was the reassurance of being treated like a thinking human appreciated, but so was the perceived opportunity to open up her role and become an active contributor. Good researcher-participant relations are needed to provide reassurance regarding 'guinea-pig' apprehensions, and constitute an essential baseline condition for further engagement: as one of the US participants commented:

'I felt very special... I don't feel like a guinea pig, a little rat or anything... You just, I just felt really welcomed, you know, and real special for doing this.' (USHV296)

*Defining a role and focus.* Participants often mentioned 'curiosity about the research' as one of their motivations for participation (Almeida et al., 2007; Locock and Smith, 2011). We noted that for some participants the interest stayed at a generalised, quite abstract level: 'Interesting... the idea of future developments from that research... it makes me happy that I've been part of it' (UKIIPV2). Whereas others wanted to explore the technicalities of how it is done: 'I'm not a medical person at all but I can understand the concept – I'm interested... in how they graph it out' (US288).

'I wish that there was a way that you could (...) have some kind of explanation as to what each of those light frequencies would mean, what kind of tissue they're really looking at, you know.' (USHV278)

Others might question the researchers about potential further applications, for instance: 'Can you use it on men's bits?' (UKIPV2).

This curiosity, like that of an interested guest, was thus quite a relaxed affair, but appeared to add to overall satisfaction. Going beyond that however, other participants –perhaps driven by the exigencies of the interview situation (Callon and Rabeharisoa, 2003)- were more inclined to articulate a vision of themselves as partners in knowledge creation and translation to practice. They might see their body as being the informant: 'I've got three, three different areas of infection [in the breast]... So I would say that I would be a good candidate for seeing if this machine works' (UKIIPV3). Others claimed a status for themselves within the research team as active contributors: 'I suppose it's I see myself as kind of helping move on breast imaging' (UKIIPV4), 'I felt I was part of the team' (UKIIV2), or '[we are] pioneers, not victims' (UKIIPV1).

Another participant –a woman with active breast cancer- highlighted the significance for her of *not* being a patient in this context. She was not a supplicant, but a donor: 'It's not like going to a medical appointment, because it's research. (...) You want something from me more than I want something from you. That's the point' (UKIPV16).

Status was important. It was acceptable to be a 'data point', 'a statistic', on the understanding that they were nonetheless both individually and collectively essential to the R&D process, as the following quotations indicate:

'If you don't have people like myself you can't move forward. (...) You need volunteers: without volunteers you can't progress.' (UKIIPV5)

'You obviously need to have people to try this thing out on... I mean it would just be theory unless you could actually try it out on somebody.' (UKIIPV19)

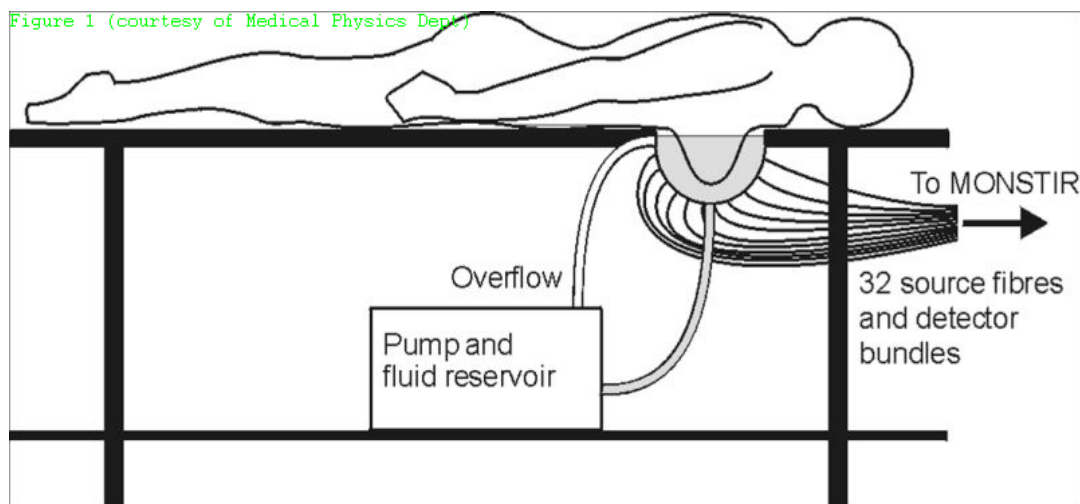
'You need to get the numbers up, the 'n' equal number up so, again, and as a scientist, you know, you gotta do the epidemiology. (...) Everyone counts'. (USHV2)

To adapt a phrase from Michael, the participants are actively engaging themselves in 'doing being a research participant' (Michael, 2009). This may constitute a necessary preliminary before progressing to the more sophisticated and self-conscious participation that Michael describes, where lay participants in public engagement develop and redefine their role over the course of an engagement exercise, and which he calls: 'doing being a member of the public'.

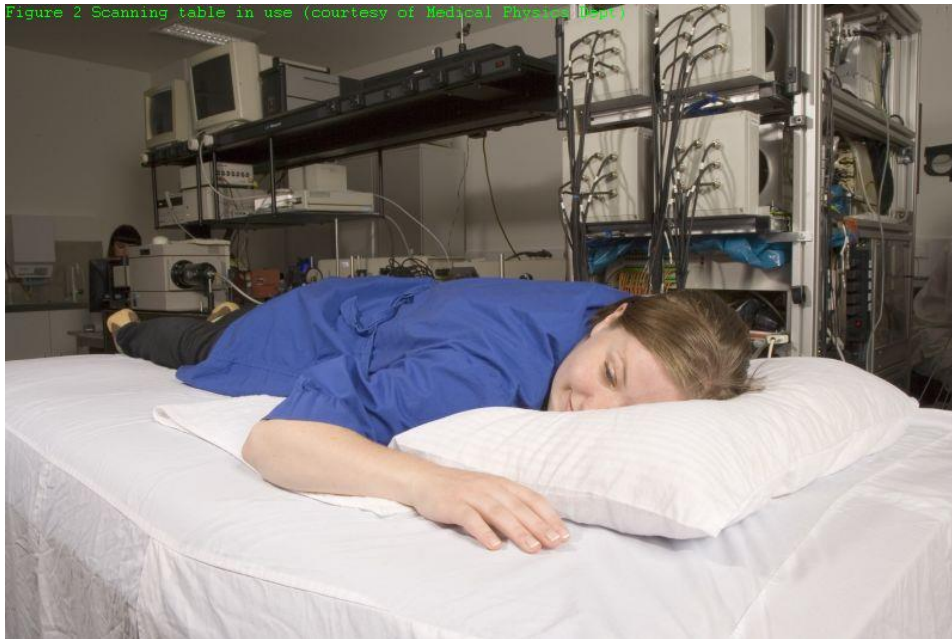
### 3.2.4. Engaging with the material processes of science

Physical contact with the instrumentation and exposure to a research environment were integral to these participants' task (see Figures 1 and 2). The confrontation with the material culture of science and 'science-in-the-making' was a completely novel experience for some, but they took on the challenge of shaping their relationship to it. We identified a number of facets to this embodied engagement.

**Figure 1.** Diagrammatic view of scanning bed.



**Figure 2.** Scanning bed in use.



First, *making the experiment work* by doing it right, not 'messing up':

'...at first I was like, oh no, I'm moving too much because I can feel myself breathing and I'm, you know, mortified I'm going to mess up because I'm breathing too fast or too heavily.'  
(UKIIPV10)

'I was worried before I came, that I would start coughing, which I did, and would spoil it.'  
(UKIPV12)

The participants here identified themselves with the research endeavour, and with playing a small, but crucial, role in the experimental procedure. They took pride in, and avoided damage to self-esteem by giving a good performance.

Secondly, *appropriating and demystifying the technology*, for example, by taking the initiative, to ensure they were optimally positioned for the scan (e.g. breast fully in the coupling liquid):

Researcher: 'So, I'll turn the lights off now.'

PV: 'I don't feel I'm completely in. Is that as high as it [the liquid] goes?'

Researcher: 'Um, I'll top the liquid up a bit.'

PV: 'Well, yeah, because it's - can you see? There's sort of an inch not [...] [Researcher: yeah]  
I think I'll just move [the pillow]' (UKIIPV37).

In this instance the participant was rewriting the rules, and enlarging her role, by temporarily taking over the management of a detail of the project from the researcher, albeit with due deference. She was also demonstrating that she felt at ease with the technology.

A further common participant strategy to demonstrate or bolster their ease with the 'props' of science (Oppenheimer, 1968), and thus work on equalising the relationship with the researcher, was through humour. Participants domesticated the technology by means of down-to-earth analogies. Thus the inset, liquid-filled bowl into which the breast had to be lowered for imaging, provoked comments of 'You gotta put it in a bucket?' (UKIIPV39) or 'That looks like a loo, doesn't it?' (UKIIPV30). Likewise the rather cluttered laboratory provoked jokey comments of the kind 'it looks like my living room'. As well as being part of negotiating an easy relationship with the researchers, and enjoying a kind of 'backstage chat' with them (Goffman, 1971, p. 114), this also helped adjustment to a strange environment.

Thus the comments and behaviour of the research participants show them as committed to performing their research role to the best of their ability and engaging both physically and mentally with the technology and the research environment. Overall, we see them working to create a secure platform from which they can build a more active engagement with the researchers and with those aspects of the research they feel are within their grasp. How far they can take this nevertheless depends a great deal on the receptiveness of the research team.

### **3.3. FINDINGS: RESEARCHERS**

#### **3.3.1. Researcher priorities**

The researchers' approach to the research encounter operated on a different scale from that of participants. They were focused on their project as a whole; comprising many experiments and many participants as well as ongoing analytical, computing and engineering development. Participants were normally involved only for a couple of hours so their attention was on the single experiment and how they performed or reacted to it. For some researchers interacting with participants was a new task to assimilate, for example:

'I'm saying this completely in terms of physical, almost thinking about these volunteers as a piece of instrumentation I suppose.' (UK2)

'The most important thing for us is the quality of the data. (...) Having said that if people come to us we want them to be comfortable and we're going to get better quality data if they are comfortable.' (UK1)

Researcher anxieties, as well as the expectation of practical benefits voiced above, acted as an incentive to interactions with participants. Non-clinical scientists not accustomed to dealing with human participants acknowledged anxieties about finding the right approach and whether their technology was sufficiently optimised for the purpose. Talking and listening to participants provided reassurance, as explained by two researchers from different research environments:

'So I think we can always keep on, you know, listening (...) you never know, someone might mention something that you haven't thought about.' (UK3)

'I don't know, maybe we just forget about something, something important. We cannot finish; we are learning always.' (NL2)

### **3.3.2. Professional distance**

A further incentive to interactive dialogue was researchers' concern about discharging the responsibility they felt for ensuring that participants were sufficiently informed about technicalities to give a valid consent. The ethical and technical talk that took place during scan sessions (reported in Morris et al., 2009) fulfilled these purposes and also served other ends, such as reassuring participants on safety and establishing their own professional standing and experience.

The researchers' traditional understanding of their professional responsibilities includes always being in charge and being protective of participants. Their role (as formulated in codes of ethics) comprises leadership, and giving reassurance to the vulnerable (Weindling, 2001; World Medical Association [WMA], 2013). In the research encounter, as when dealing with the public generally they felt, as one said, a responsibility to be 'an ambassador for science'. The effects of this culture tended to maintain a certain professional distance between themselves and participants. This has implications for engagement when engagement should be on equal terms. They nonetheless appreciated the benefits of a good and cooperative working relationship with participants, because it not only served their instrumental ends but also engendered mutual satisfaction, as shown in the following quotation from the lead UK researcher: 'The perfect patient



would be one that did everything I asked them. But at the same time gave me complete feedback the whole time about how it was going' (UK1).

### 3.3.3. Asymmetrical relations

Asymmetries in the relationship nevertheless remained: for example receptiveness to input from participants was generally limited to matters of physical comfort, and action on participants' suggestions confined to short-term, low-cost re-arrangement and amelioration. Participant comments on possibilities for re-design were unlikely to get serious discussion because these were seen as 'outweighed by technical considerations' (UK4), and therefore viewed as exclusively the province of the research team:

'We do everything that we can immediately that's pretty quick and (...) more for comfort (...). Whereas the more technical side is more geared towards what we're trying to do ourselves.'  
(UK4)

Discussion was likewise ruled out on the issue of the uses to which the technology might be put. Participants were strongly in favour of its eventually replacing the mammogram, but all the research teams ruled this out as self-evidently not feasible (in terms of costs and vested interests), and not a matter for discussion with participants. This closed off a potential avenue to discussion of public policy, science politics and science-society relations. Such discussion would not of course help to progress the immediate research project, which was always the researchers' main focus. With regard to involving participants in decision-making, the situation is a little more fluid. On the one hand, both the EU researchers interviewed initially asked for clarification of 'decision-making' and then did not engage with the issue:

'I really don't [worry] about it [*the fact that the breast needs to be slightly compressed*] because I am sure it is going to be really gentle. (...) You need to compress breast only to have good contact. (...) This I think will be no problem at all.' (NL2)

On the other hand, another researcher said he was open to the idea of discussing strategies but nonetheless could not see a way forward. He commented that participants were involved:

'...on a very short term basis... On the longer term basis, the strategic basis, in terms of how we redesign our system, perhaps kind of passively. [*Pause*] In fact, that's a difficult one. I would like to think that they were involved but I really don't know how.' (UK2)

Basically the position is to leave the technical decisions to the technical people. The borders of the technical and the techno-social are shifting but working cultures may be slower to change (see Caron-Flinterman, Broerse, and Bunders, 2005 for parallels).

## 4. Discussion

In the preceding sections we have set out the basis from which we see the clinical research encounter developing its capacity to foster 'engagement', *i.e.* developing a mutual understanding between 'publics' and scientists about matters of science and research. Such an understanding could have ramifications beyond completion of the immediate task. We shall go on to explore further how such beginnings might be developed (section 4.2.). Before that, however, we need to take stock of the academic and socio-political institutional environment in which this new development must grow, and how elements there may help or hinder such development.

### 4.1. INSTITUTIONAL ENVIRONMENT

#### 4.1.1. Public engagement policy

Governments' policies for advocating and funding public engagement generally give prominence to encouraging dialogue between citizens and government to increase mutual understanding. Thereby they hope to exert a positive influence on public attitudes to national policies for change and innovation (European Commission, 2013; House of Lords, 2000; Zerhouni, 2003). Likewise the public engagement literature has ranged widely over issues of the democratisation of scientific decision-making, scientific citizenship and power structures along with critical discussion of engagement mechanisms and policy dialogue (Elam and Bertilsson, 2003; Irwin, 2001; Irwin, Jensen, and Jones, 2013; Laurent, 2011; Lehoux, Daudelin, and Abelson, 2012; Lengwiler, 2008; Rowe and Frewer, 2005; Stirling, 2008). Particular criticism has been levelled at the take-up and execution of 'dialogue' by scientific and political institutions (Powell and Colin, 2008; Stilgoe, Lock, and Wilsdon, 2014; Stirling, 2008; Wynne, 2006). Critics claim that much of the policy drive for this work has been based on 'imaginary publics', supposedly anti-science, low trust, etc. The

processes themselves may be viewed as a means to manage these and/or create new informed and attitudinally correct publics (Gregory and Lock, 2008; Stilgoe et al., 2014). This critical vein we read as indicating a continuing need for developing variant forms of engagement. Such variants might enable some gentle loosening of the power structures that limit exchanges between 'publics' and policy practitioners, giving mutual benefits.

#### **4.1.2. Public engagement with clinical research**

Here policy focuses on promoting dialogue to help formulate policies for health and well-being, both generally and in relation to particular projects. In the UK (where most of our own research has been done), the close coupling of clinical research with health care, due to the National Health Service (NHS), has influenced the way the institutions of public engagement have developed. Thus, the government-funded institutions set up within the NHS to foster public engagement (the Public and Patient Involvement initiative [PPI]) have a strong focus on patient care (research being blended into care). They typically work through committee structures modelled on those for health-care delivery. Consequently public engagement in medical research becomes conceptualised as an activity taking place quite separately from the research encounter.

The locus for public participation in clinical research is thus the committee room –within a management board or advisory panel- not in the laboratory or clinic. Similar practices may be observed in studies of patient associations working to strengthen the patient voice (Rabeharisoa, Moreira, and Akrich, 2014). Such interactions are important, but need not preclude developing a complementary stream of work at the site of the experiment or intervention, where research participants and front-line research scientists/health professionals regularly meet and interact.

#### **4.1.3. Institutional rulings on clinical codes of practice and ethics**

Our focus on *participant*-researcher interactions raises the question whether, given current conventions governing clinical research practice, research participants can rightly be regarded as a 'public' for engagement. Participants are often also patients and may participate in research primarily for expected health care benefits (Agrawal et al., 2006; Easter, Henderson, Davis, Churchill, and King, 2006; Locock and Smith, 2011; Timmermans and McKay, 2009). As discussed earlier, matters are further complicated where a terminally ill patient views volunteering as a last resort treatment, though this can sometimes lead to an ultimately productive public engagement (Epstein, 1996). Furthermore, where doctor and researcher are the same person, distinctions between the doctor's and the researcher's obligations may likewise be blurred, presenting difficult

practical and ethical dilemmas (Abma, Nierse, and Widdershoven, 2009; Fisher, 2008; Sariola and Simpson, 2011; Timmermans, 2011).

Current codes of medical ethics are the prime influences in framing research participants' identities. These codes reflect their origin in the abuses revealed in the Nuremberg trials (Moreno, 2001; Weindling, 2004) and within a then largely paternalistic medical profession. Consequently, despite regular revisions, internationally agreed ethical frameworks still enshrine a perception of the research participant as essentially passive and vulnerable. Though still a valuable safeguard, arguably and with some exceptions the current framework accords less well with the totality of today's better informed, better protected and organised patients and volunteers, at least in industrialised countries (Cooper, 2012; Moreira and Palladino, 2005; Weinstein, 2001). In the UK, recent activity by the Health Research Authority, which governs research on NHS staff and patients, indicates a greater openness to the capabilities of patients and research participants. Thus, what could have been a hindrance to development of engagement within the clinical research encounter may lighten in the future.

#### 4.1.4. Where next?

Although there is an extensive body of work in both the social sciences and the medical literatures about *research participants*, we have not yet found studies that consider possibilities for lay public engagement with science as an ancillary or complement to their participation in the research. That said, Epstein's seminal study of AIDS activists and the politics of knowledge did demonstrate how the experiences of the activists, many as research participants, had epistemic effects on the design of clinical trials and the regulatory process (Epstein, 1996). There is also a significant literature on emergent health movements and patient associations' involvement in promoting and prioritising research in their field of interest (Brown et al., 2004; Callon and Rabearisoa, 2008; Panofsky, 2011; Rabearisoa et al., 2014). These activities illustrate new ways of effecting strategic engagement with policy, often facilitated by new developments in information technology.

In summary, the current institutional environment, while not intrinsically hostile to the development of another stream of public engagement with clinical research, is deeply pre-occupied with other modes of engagement. These modes are policy-oriented, dialogue-based, and promote public involvement in management-type decisions. It would be over-optimistic to expect much support for novelty from these settled institutions, unless the new strengths given to activism by developments in information technology stimulate some re-thinking.

## **4.2. WHAT KIND OF ENGAGEMENT MAY BE DEVELOPED IN THE CLINICAL RESEARCH ENCOUNTER?**

### **4.2.1. What kind of partnership?**

While both researchers and participants in our study engaged with each other to help in building a good working relationship, they had different conceptions of how far this might constitute a partnership. For participants a temporary recognition of them as team members and a will to engage with the scientific objectives of the research could enable them to feel socially comfortable in a strange situation, to feel enriched by new experiences and satisfied with their contribution. As the empirical data shows, they achieved this endpoint in a variety of ways –often tentative, experimental and instinctive.

As already pointed out, researchers' interactions with participants can be constrained by demarcation of the scientist-researcher role and traditional expectations about passive patient-participants. They committed to listening and responding thoughtfully to conversational overtures, knowing this was good for both participants and research, but were selective about which issues raised by participants they engaged with –a situation these participants appeared to accept. It could be a relatively easy step towards a more serious engagement to lift this embargo on discussion in the expectation more of increasing mutual understanding rather than changing views.

We acknowledge that we are using the terms 'engage' and 'engagement' loosely in applying them to the drive shown by participants in the empirical studies to involve themselves in the aims of the research and to make themselves useful contributors to the outcomes. Our commentary may demonstrate that both participants and researchers are working actively to build a social relationship, but where (apart from the small step towards opening up broader issues identified above) is the link to 'public engagement'? How far may these overtures and relationships act as a foundation for a rapprochement between science (or scientific research) and a lay public, and what purpose would this serve?

### **4.2.2. Engagement in practice**

We suggest that the potential of clinical research as an engagement site lies in the combination of material engagement and the conscious commitment by participants to making a contribution to a specific project. There are also constraints and limitations as we discuss below.

It is characteristic of the clinical research encounter that the interaction is mainly about the here and now –the experience and outcome of being part of research in a particular context rather than engagement with broader issues. The primary goal of the participants, as of the researchers, is to complete successfully a particular clinical study: public engagement or dialogue is a spin-off, not a driver. Participants are in a 'work experience' situation where their contribution matters and where they are necessarily exposed to 'science-in-the-making' and are taking part in real-life, real-time research with its full share of failures, glitches and uncertainty of outcome. Participants engaging in this way showed readiness to recognise the opportunity and privilege of temporary admittance to the research world (Parsons, 1969). In addition, implicitly or explicitly, they strive for a more equal partnership. In engaging with the research topic and process, the researchers and the technology, they were observed drawing on their own resources (their own experience and interests) to configure themselves to be part of the enterprise, each in their own way (Morris and Balmer, 2006; Morris et al, 2009).

This has similarities to what Michael (2009) refers to as 'doing being a member of the public'. People taking part in research are also 'making themselves up' (Hacking, 2004) by taking on, and socialising, a new or unusual experience. They are taking up roles and identities to manage their social encounters (Goffman, 1971). Adding opportunities for them to contribute to shaping the research (and the policy questions it raises) gives scope for making oneself up as a citizen or user or taking some early steps in that direction. Hacking refers to this as the 'bottom-up' process that combines with the 'top-down' institutional and governmental structures that constrain and enable the making up of each individual. So, in this respect, participants are not simply the altruistic, 'gift-giving' collaborators identified by Parsons and Mead (Mead, 1969), but may be performing a number of identities simultaneously. While we do not regard this broader social dimension as a condition for the existence of 'engagement' with science, such a development would fit well with the movement among some patient leaders and activists to perform a more strategic role in research and health care matters (Morris, Balmer, and Hebden, 2011).

#### **4.2.3. Constraints and opportunities**

Clinical research sites of course have limitations with regard to serving any wider purposes. Neither 'clinical studies' nor 'research participants' are a homogenous group. Flexibility to amend or make space in a study protocol for participant input and reflections varies with types of study, participant and sponsor. Studies range from academic exploratory to multi-site clinical trials. Participants comprise patients and healthy volunteers looking for very different rewards. Whether

a trial is sponsored commercially or by the public-sector is also relevant, since commercial organisations are not constrained in the same way as public-funded bodies to demonstrate compliance with national policies for public engagement with research. There are, however, examples demonstrating at least the possibility of flexibility in designing multi-site, international clinical trials to incorporate participant views –though not with public engagement in mind (Donovan et al., 2002; Nyanzi-Wakholi et al., 2009).

Impediments may sometimes be turned into opportunities. As we have already noted, participants may choose to engage with research and researchers as quasi-collaborators for their own purposes. In doing so, they may run ahead of the researchers, who appear to be more inhibited about entering collaborative territory. Our interviews with researchers suggest that for them ‘collaboration’ implies a more equal relationship than the traditional medical-ethical framing of the research subject would readily allow, and so carry the risk of putting them in dereliction of their professional responsibility to protect vulnerable subjects. This permits (though does not guarantee) a situation in practice where any engagement agenda within clinical experiments can be largely at the discretion of the participants. If the effort of building an interactive, social, working relationship is undertaken largely by the participants, the degree and style of engagement may be likewise at their discretion. On arrival at the experimental site, it is up to the participant whether to adopt the role of passive subject, quasi-patient or active (‘engaged’) participant, or shift between such roles (Morris and Balmer, 2006). Thus, though the overall design and conduct of the experiment may be entirely researcher-controlled, within this envelope development of the engagement agenda might yet be participant-led.

## 5. Conclusions

Our opening questions were about what potential there might be for clinical research (research involving humans) to add to the public engagement repertoire, making use of the clinical research encounter where researchers and lay participants are necessarily brought into close proximity to work together on a common task. We have argued –both theoretically and empirically- for recognising this potential. Of course, the extent of influence and effects of such public engagement remain a matter for further empirical enquiry.

## 5.1. GOVERNANCE, HISTORY AND ACTIVE PARTICIPATION

We noted that the current institutions fostering public engagement in clinical research draw public and patients into strategic and managerial activities, and are necessarily dialogue-based. An apparent lack of interest in considering research participants as a public may follow from the way the governance of clinical research has been shaped by traditional bioethical assumptions and historical legacy. That is to say, by the model of the passive, vulnerable subject, and by fears of abuse. A further reason may be the practical circumstances pertaining in much of clinical research (as alluded to in the latter paragraphs of the Methods section in 3.1.). Our empirical studies of research participants however suggest that at least some are ready to take on a more active role than traditionally assumed. Their narratives and asides demonstrate how active participation can be important to them as a means of managing the social stresses of the research encounter by establishing themselves as partners or quasi-collaborators in the research. Interviews with researchers likewise showed they found benefit for themselves in dealing with the tensions of their role and benefits for their research in achieving a mutually supportive working relationship.

## 5.2. POTENTIAL FORMS OF ENGAGEMENT

Along with other sites for engagement, the clinical research encounter offers the opportunity to influence local decision-making, with possibilities for tangible results. Research protocols may be tweaked or revised to take account of participant feedback; researchers may become more conscious of the emotional needs of volunteers. Such local paybacks need not to be dismissed as trivial, and may have ramifications beyond the immediate research project. At the same time they offer opportunities for participants and researchers to work in partnership, addressing both user and research issues relevant to the project or beyond, including such generic issues as user and researcher anxiety, ethics, participant retention, and data quality. This implies a re-examination and possible renegotiation of taken-for-granted boundaries between 'research participant' (lay public) and 'expert researcher' roles in the experiment. Such a democratisation of researcher-participant relations is an aim shared with PPI and similar schemes, and is likely to be welcomed by research participants and patient advocacy groups alike. Like the two-way educational activities discussed in the public engagement literature, it can at best be a creative experience from which something new emerges for all taking part.



Most significantly, as we have argued, the special potential of clinical research as an engagement site lies in the combination of material engagement and the conscious commitment by participants to contributing to a specific project. Clinical research encounters are a site of knowledge production and offer participants the special facility of 'learning by doing'. The participants' material (bodily) involvement in performing research may not count at first sight as engagement in its own right, but the performance element generates a need to perform creditably and to forge comfortable working relationships with researchers. The combination of social and material engagement creates a potential platform for engaging the mind –and a resource for 'making themselves up' as thinking participants and as citizens or users through a bottom-up process.

We opened our paper by situating it in the context of the framework of the typology of public engagement mechanisms established by Rowe and Frewer (2009). While our first reaction was to think it would fit as an addition to the 'Participation' category, on further consideration we revised this view. The kind of engagement we have described is mediated by the lived experience of performing in a scientific experiment, whereas the other kinds of engagement in the Rowe and Frewer typology rely predominantly on language and exchange (or one-way communication) of ideas in boardroom, committee, or special engagement event. In the light of this difference, we suggest it might more appropriately constitute a fourth category. If developed, this form of material and performative engagement might take a place as an alternative or complement to the engagement-as-language paradigm and lead to a revision of what is frequently meant by public engagement.

We acknowledge that situations exist where social and structural conditions under which participants are recruited make any consideration of engagement (as we understand it) unlikely. Such situations would include the social and economic structures described by Fisher in the United States (Fisher, 2008), or Sunder Rajan in India (Rajan, 2005; 2006). Overall, however we have suggested that there is a public-in-waiting for a special modality of public engagement via the clinical encounter, performing a niche function in a distinctive style, and contributing to the ongoing clinical project as well as broader civic purposes.

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