

Northumbria Research Link

Citation: Wienroth, Matthias, Pearce, Caroline and McKeivitt, Christopher (2019) Research campaigns in the UK National Health Service: patient recruitment and questions of valuation. *Sociology of Health and Illness*, 41 (7). pp. 1444-1461. ISSN 0141-9889

Published by: Wiley-Blackwell

URL: <https://doi.org/10.1111/1467-9566.12957> <<https://doi.org/10.1111/1467-9566.12957>>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/43373/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)



**Northumbria
University**
NEWCASTLE



UniversityLibrary

Research campaigns in the UK National Health Service: patient recruitment and questions of valuation

Abstract: The National Institute for Health Research (NIHR) aims to improve national “health and wealth” by providing infrastructural support to enable clinical research in National Health Service (NHS) settings in England and Wales. Cognisant of the consequences of studies’ failure to achieve required numbers of participants, it also actively campaigns to promote patient awareness of research, and willingness to participate in trials. In this paper we analyse recent NIHR campaigns and policies designed to encourage patients to participate in clinical research to interrogate how they are implicated in the national bioeconomy. In doing so we expand the notion of ‘clinical labour’ to include the work of patient recruitment and highlight an emergent obligation on patients to contribute to research processes. Whereas once patient knowledge and experience may have been devalued, here we draw on the concept of ‘assetization’ (Birch 2017) to explore the emergent relationship between healthcare system and patient as research participant. We consider how patients’ contribution goes beyond the provision of standardised objects of valuation so that patients themselves may be perceived as assets to, not only recipients of, the national healthcare system. (184 words)

Keywords: Asset, bioeconomy, clinical labour, clinical research, ethics, patient recruitment, valuation

Acknowledgments & funding statement

The authors acknowledge the support of the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South London at King's College Hospital NHS Foundation Trust (NIHR CLAHRC-2013-10022) and the National Institute

In press: Sociology of Health & Illness (April 2019)

Authors: Matthias Wienroth, Caroline Pearce, Christopher McKevitt

for Health Research (NIHR) Biomedical Research Centre based at Guy's and St Thomas' NHS Foundation Trust and King's College London. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Introduction

In 2012, the United Kingdom's National Institute of Health Research (NIHR) conducted a 'mystery shopper' exercise at 82 hospital sites across England. Its aim was assessing the readiness of National Health Service (NHS) staff to provide patients with information about opportunities to participate in clinical research. The mystery shoppers concluded that little information was made available to patients (NIHR 2013). The UK press reported the results as evidence that citizens were denied the opportunity to take part in clinical research (Campbell 2013). Subsequently, NHS organisations were tasked to provide more information with an emphasis on encouraging patients to proactively ask about research and particular studies they might join.

This exercise was completed as part of ambitions to improve patient recruitment to clinical research. Established in 2006, the NIHR has a mandate to operate at the interface of healthcare delivery, research, industry, and wider publics, and to enable the inclusion of increasingly larger patient and public constituencies in clinical research¹. The NIHR provides a national infrastructure to support delivery and funding of, as well as training for, clinical research and research staff. It also contributes to partnerships such as the Biomedical Research Centres that bring together NHS organisations and universities, aimed at driving translational medicine.

Clinical research depends on the ability to recruit eligible subjects of sufficient numbers and within specific timescales to ensure studies are statistically powered to find meaningful results, yet there is considerable evidence that poor levels of recruitment to clinical research are widespread (Bower et al. 2014, Fletcher et al. 2012). Reported 'barriers' to participation include: organisational factors, lack of training, lack of eligible patients, lack of patient trust in clinical research, and expectation of harm (Ford et al. 2008, Treweek et al. 2010). Our

findings from two surveys (McKevitt et al. 2015, Wienroth et al. 2018) among clinical populations suggest that low awareness of what ‘research’ is and what research participation means are also important factors.

Obtaining sufficient numbers of patients for research and creating a robust evidence base is central to the objectives of the NIHR, and over the last decade a range of activities have been spearheaded by the NIHR to address poor recruitment levels. Activities have included nationwide campaigns that have sought to build public research awareness and understanding of the ‘idiom’ and methodology of clinical research; and the development of the Patient and Public Involvement (PPI) agenda, believed to help increase recruitment to studies by, for example, making research more acceptable to potential participants², with some emerging evidence to bear this out (Ennis and Wykes 2013).

Since publication of the UK Life Sciences Strategy (Department for Business, Innovation & Skills 2011, Bell 2017) the NHS has been positioned as an attractive site for commercial research, and policy has been directed at enabling the NHS to become an accessible research resource of biological samples, data, and potential research participants. In line with the aspirational research culture of the NHS, the NIHR funds ‘catapult’ agencies whose aim is to bring together research and business communities, adding business relevance and economic growth to clinical research rationales (Gardner and Webster 2017). Further, following the introduction of performance indicators, research recruitment rates have become a key performance measure of both individual NHS providers and the NIHR³, and since 2011, NHS providers are incentivised to meet recruitment targets and regularly submit performance data in order to receive NIHR funding (HM Treasury 2011). Recently, the UK health and social care regulator, the Care Quality Commission, announced plans, supported by the NIHR, to include evaluation of NHS trusts’ research activity as part of their routine inspections (Lintern

2019). Assessment of research activity will include questions concerning staff awareness of research and examine opportunities for patients to participate and be involved in clinical research.

Social science scholarship has analysed the calculations of value in trial participation (Cooper 2008, Patra and Sleeboom-Faulkner 2009), and the role of barriers and enablers here (Adams et al. 2015, Hallowell et al. 2010). Waldby and Cooper (2008) argue that patients become part of economies of value in biomedical data production through ‘clinical labour’ as a key element in the creation of values. Waldby and Cooper link clinical labour to the notion of commodification of biological materials such as tissue, genes, organic processes, and to the very bodily nature of work provided by trial participants via their *in vivo* biology. However, the concept of commodification – describing processes of transformation of bodily materials and work into standardised objects of value that can be traded easily – as it is used in these analyses, tends to presume an inherent ‘bioeconomical’ value of bodily materials and work.

Inspired by the critique of extant scholarship on bioeconomy and biovalue by Birch and Tyfield (2013) and Birch (2017), in this paper we engage with the economies of value in biomedical data production activities within the healthcare research sector by attending to patient and public recruitment. Specifically, through a critical analysis of NIHR recruitment campaigns, we explore valuation in the *assetization* (rather than commodification) of patients or publics in the production of clinical knowledge. The concept of assetization, developed in the context of the biotech industry, describes the transformation of something (in this case, patient and public knowledge and participation) into a revenue-generating and tradable resource. Applying this concept, we argue that the value of patients and publics is measured not (only) by bodily materials but generated by how they are governed and managed within the

organisational entity of the NIHR. As such we argue commodification cannot fully capture the process of trial recruitment and involvement in clinical research.

Instead we contend that patients have been reconfigured as ‘assets’ to the clinical research system as the delivery of healthcare has become linked to specific financial returns, and where patients are increasingly judged by their capacity to create value, or, in other words, *contribute* to the return of public money. The NHS continues to face economic uncertainty linked to, for example, increasing healthcare costs, decreasing political will to increase public spending on future-proofing the NHS⁴, and growing patient demand due to larger numbers of older patients with multiple chronic morbidities. However, research participation and involvement, is largely promoted through an appeal to the ‘mutual benefit’ (Will 2011) to patients and staff rather than the economic benefits to the nation. We analyse recent NIHR campaigns and policy aimed to improve clinical research recruitment. We do so in order to interrogate how the patient as potential research participant is represented in the NIHR imagination in an overall theoretical exploration of NIHR patient recruitment efforts as a locus for valuation processes. Our approach follows that of social science analysis of public health campaigns that seek to move beyond questions of efficacy to explore the ethical, political and moral dimensions of campaign discourse (Lupton 2015). We begin with an overview of research participation and involvement policies in the NHS, before presenting our analysis of NIHR campaigns.

Developing a research culture in the NHS

Since the late 1990s neoliberal values have entered healthcare policy, impacting on the UK healthcare system in various ways. One of these is the re-imagination of the patient as ‘service user,’ ‘customer’ or ‘client’ (Shippee et al. 2015, McLaughlin 2009), signalling a market-

oriented framing of healthcare provision and the role of the patient within it as an active consumer (Barnes and Shardlow 1997). The NIHR mystery shopper campaign reflects this changing role. Assuming that patients have a right to ask about taking part in trials is consistent with a wider revision of the notion of the NHS patient from being a passive recipient of healthcare to operating as an active and responsible contributor in sustaining personal health: care must be patient-focused (Department of Health 2010), and patients are helped to share decision-making⁵; to self-manage (Barlow et al. 2002) and to make healthy lifestyle choices (Department of Health 2015).

This changing relationship has been co-produced with policy to transform the NHS from a healthcare provider into a health research and care system (Department of Health 2006, 2012) resulting in increasing volumes of clinical research undertaken at NHS facilities and the need for higher numbers of available patients for clinical research (Treweek et al. 2010). The NIHR has proposed that health organisations develop a ‘research culture’, focused on delivering innovation in research and care provision, and encouraging patients to proactively seek involvement in clinical research (NIHR 2015a, Malby and Hamer 2016). The rationale for both is reflected in merging the ambitions of epidemiology with those of ‘precision’ and ‘personalised medicine,’ aiming to improve public health by increasing the efficacy of treatment, and stratifying groups of patients according to their health risks (prevention) and responses to treatment (individualised care). These ambitions gave rise to programmes such as the Health Technology Assessment (Faulkner 1997) and require considerable data on, for example, reliable strata for illness. Patient involvement in clinical research draws on and feeds back into the language and objectives of healthcare delivery paradigms ‘evidence-based medicine’ (Sackett et al. 1996) and ‘patient-centred medicine’ (Laine and Davidoff 1996),

positing the patient as both the basis for and beneficiary of clinical research and individualised evidence (Greenhalgh et al. 2014, Lambert 2006).

The shift to promoting research participation in some respects builds on the work of activists who demanded recognition for certain health conditions and wider inclusion in biomedical research (Epstein 1995, Klawiter 2008, Rabearisoa et al. 2014). The emphasis on the rights of stigmatised groups and the incorporation of ‘lay expertise’ or ‘lay knowledge’ (Entwistle et al. 1998) promoted a new model for the production of medical knowledge, reframing disease as a public matter of concern, where clinical research provides an interface for citizens to impact the direction and evaluation of medical research (Prainsack 2014).

While the policy of inclusion sought to rectify health disparities, tensions often exist between the democratic rationale for public participation and technocratic interests (Martin 2008, Davis and Abraham 2011). A blurring of research and care is evident for example in the 100,000 Genomes Project, delivered by Genomics England, where research participants may also receive a diagnosis and treatment through participation. As detailed by Timmons and Vezyridis (2017) this project and others such as the creation of NHS-led biobanks mark a departure from previous conventional ways in which participants are recruited to biomedical research, involving a considerable re-imagining of the relationship between the NHS and its citizens. The rationales and values of patient and public participation and recruitment in biomedical research are thus multiple, leading us to examine how patients are constructed as participants in the ‘experimental laboratory’ of the NHS (Faulkner 1997) by highlighting the strategies of the NIHR to appeal to patients and publics to regard research and their relationship with the NHS in a new way.

Methods

The dataset for this analysis is constituted of NIHR patient recruitment campaigns (online sources and brochures), institutional strategy and accounting reports, and a wider online search of NIHR websites and public documents that address aspects of patient participation and involvement in clinical research. Research was conducted from February to May 2017, with sources generated between 2012 and 2017, starting with the mystery shopper exercise. We pursued a problem-focused, thematic analysis of these sources (Braun and Clarke 2006, Vaismoradi et al. 2013). These texts were selected for analysis as they discursively construct a role for patients and publics in relation to clinical research. Following the method of document analysis (Atkinson 1990, Smith 2001) we acknowledge these documents are used, consumed and shared in different ways across different social contexts, and their significance is produced in how they are received and acted upon. The analysis included noting the form or genre of the texts, the implied audience for the different materials, and how the ideas are presented. We explored how the structure of the documents and online materials allow for different claims to be made and may seek to persuade by drawing on strategies such as linguistic devices, making reference to other authorities such as scientific data, or using personal narrative.

Campaigning to recruit patients and publics

The global issue of insufficient patient recruitment and retention in clinical research has led to different responses, including the outsourcing of clinical trials to low and middle income countries (Cooper 2008, Cooper and Waldbly 2014). In the UK, strategies to overcome this issue have focussed on targeted patient engagement, especially the annual International Clinical Trials Days. As part of these celebrations, the NIHR had, since 2013, organised a week-long campaign called 'OK to Ask' which positioned patient participation in clinical trials as a

right, framing participation, specifically the ability to ask about clinical research and potential participation, as empowerment.

Figure 1 'OK to Ask' logo

In 2017 the campaign was rebranded 'I Am Research'. Whereas 'OK to Ask' promoted the right of patients to seek information, 'I Am Research' directly addresses patients as research participants, implying research values are an inherent part of being a patient⁶. The NIHR posits the campaign as a source of information for those as yet unaware of, or under-informed about health and social care research. Provided information focuses on the benefits of participation, vignettes of past and existing trials, and what to expect when joining a trial. The NIHR's contribution to the 2017 International Clinical Trials Day included those already engaged in clinical research, asking them to provide experiential data by presenting personal and personable stories about research involvement, and proposing reasons for getting involved with clinical research (Denegri 2017).

Figure 2 'Part of the landing page of 'I Am Research'

Central messages of the 'I Am Research' campaign also emphasise the moral benefits that can be accrued through participating by stating how research involvement supports the NHS in developing and delivering better healthcare, and ultimately in saving lives. The campaign encourages people to "be part of the solution" in achieving the NIHR's ambition to, as Chief Medical Officer Dame Sally Davies describes, "create an integrated health research system in

the NHS that improves both the health and wealth of the nation through research” (NIHR 2015b, 1).

The 2017 campaign day saw clinical sites across England provide information stalls and banners, however the campaign features significant online content on websites, social media sites Twitter and Facebook, podcasts, and blogs. This focus on social media and online content runs in parallel to NIHR efforts to enhance its digital communication with potential research participants, as evidenced by the ‘Let’s Get Digital’ competition, running between April and June 2017. The competition called for those currently involved with NIHR research, be they investigators, trainees, research staff, patients or members of the public, to submit entries to the categories: ‘video’, ‘photography’, ‘infographics’, ‘website’, or ‘online community’. The NIHR asked for outputs to promote research and show why research is important:

We are looking for entries that help to capture why NIHR research is important and exciting. We love research and we want your submissions to help us spread the word about how vital it is to the development of new and better treatments in the NHS⁷.

This call to ‘evangelize’ the benefits of research encourages people to show “what NIHR research looks like in real life” and to “explain what it is like to be involved in NIHR research,” evidences attempts to demystify the experience of being a research participant.

Figure 3 'Part of the landing page of 'I Am Research' with author annotations

One of the sources for further information identified by the ‘OK to Ask’ and ‘I Am Research’ campaigns is the UK Clinical Trials Gateway website⁸. Under the tag line ‘Better health starts with you,’ the website offers information on ongoing local and regional trials according to UK nation, and in 15 different areas of clinical research. Framing its offer in terms of providing

“informed choice” and instilling “confidence” in potential trial participants, as well as a source of potential participants to researchers, the website combines information on what may be expected of participants in trials with listing open trials that are seeking to recruit patients. The website acknowledges that “individual trial records contain complex scientific and medical terms and are hard to understand” and suggests that interested patients approach their physician or the trial co-ordinator for accessible information. The Gateway website details different rationales for taking part in research⁹. These refer to benefits to the general population, such as improving knowledge and preventing illness, and to the individual, such as learning more about an illness, accessing new treatments or taking an active role in care. These rationales are underlined by a statement that research can “only take place if people are willing to get involved”, emphasising the fruition of these outcomes is possible only by the ‘willingness’ of individual volunteers.

From participation to involvement

Recruiting patients into research participation is the focus of these campaigns and the Trials Gateway. However, a further type of enrolment effort, running under the tag line of “Health research has two sides and one of them is you,” aims to discursively broaden the possibilities of involvement in clinical research¹⁰. ‘Two Sides of Health Research,’ launched in February 2017, sought to offer patients, policy makers, healthcare professionals and other publics a way of getting involved in research processes that included participating in studies, but also: suggesting a research question, influencing decision-making, or joining a study team. At the same time, the tag line and online material suggests that everyone either is in some way already, or can easily become, part of clinical research.

Figure 4 'Two Sides of Health Research' poster

The combined efforts of 'I Am Research' and 'Let's Get Digital' place emphasis on conveying the 'lived experience' of clinical research to publics who may become involved in such activities. This production of a relatable human face to clinical research constitutes, on one hand, a strategy to lower the threshold or barriers to recruitment, including mistrust, expectations of harm, and lack of knowledge about clinical research, which might prevent patients from participating in research. On the other hand, 'Two Sides of Health Research' offers an additional pathway to clinical research, expanding the focus from simply participating in studies – as being subject to testing – towards *involvement* in the setting of research agendas and the governance of clinical research. Developed as part of the 'Breaking Boundaries' strategic review of public involvement in clinical research, the report 'Going the Extra Mile' (NIHR 2015a) marked a shift from imagining the patient as having the right to learn about and participate in research to a more deontological perception of patients' role in healthcare research. The report's chair and NIHR's National Director for Patients and the Public, Simon Denegri, states:

Within the NIHR, such is the extent to which the public have become involved that research is increasingly becoming a joint venture between patients and the public, researchers, clinicians and health professionals. If we are to meet the health and social challenges of the future then these partners must be empowered, encouraged and supported to work even closer together. (NIHR 2015a: 8)

This 'joint venture' is premised on the expectation that volunteer patient participation is more effective compared to research organisation-driven efforts of recruitment, especially when research participation is construed as of 'mutual benefit' (Will 2011). INVOLVE, a "national

advisory group,” aims to “support active public involvement in NHS, public health and social care research”¹¹. The agency’s website provides an online resource for public involvement in clinical research to researchers, patients, and others, offering rationales and aims of public involvement¹². The articulated goal of INVOLVE is to develop research that matters to both patients and clinicians and to inform researchers about PPI and why they need to integrate it into their work ¹³. The associated website ‘People in Research’ ¹⁴ is an NIHR-based information site that invites users to look for opportunities to get involved, or to register and add projects. Involvement, rather than trial participation, is conceived as wide-ranging with categories in the website search engine including: “identifying and prioritising,” “designing and managing,” “implementing,” and “reviewing” research, all of which patients and publics are encouraged to get involved with. The entire palette of facilitating public involvement in research by INVOLVE presents the idea of PPI as a beneficial, easy-to-integrate concept.

The NIHR’s multi-pronged campaigning efforts described in this section seek to overcome the perceived limitations of patient and public recruitment for clinical research and encourage patient-initiated participation. The NIHR describes its efforts in reaching patients as participation, engagement, and involvement, where the former is about being recruited into research, the second about information dissemination, and the latter describes an active contribution to setting research priorities and designing research (NIHR 2015a: 6). Participation and involvement are assertions about the role of patients in the national healthcare system, and both approaches attribute value to routinely recruiting patients, and to reducing barriers for recruitment. The main consequence of this development in NIHR strategy is the blurring of the boundary between becoming involved and being recruited into research.

The language of ‘partnership’ increasingly used in advocacy for UK health research and care suggests that patients and others can have an active and co-responsible role in and for clinical research efforts. While NIHR’s ongoing clinical research recruitment strategy has expanded to address not only patients but also other stakeholders in healthcare – as demonstrated by the ‘Two Sides of Health Research’ campaign and PPI efforts more widely – the focus tends to remain on patients, specifically on how patients are integral to improving healthcare through research. In this context, recruitment is framed as pro-active, or ‘patient-initiated.’

Assetization as valuation practice

In Waldby and Cooper’s (2008) understanding of ‘clinical labour’ patients become part of economies of value in clinical trials where biological materials such as tissue, genes, organic processes, and the very bodily nature of work provided by trial participants in their *in vivo* biology undergo commodification. As pointed out by Birch (2017) the concept of commodification presumes an inherent ‘bioeconomical’ value of bodily materials. Commodification tends to overlook both the diversity of ‘clinical labour’ (take alone the different ways of being engaged in clinical research) and the on-going nature of work delivered by patients and publics in clinical research, which requires continuous encouragement and support from research commissioners and staff in order to recruit and retain eligible participants. The concept of commodification cannot fully explain the processes of recruitment (and retention) for trial participation and other types of *involvement* in clinical research.

Birch and Tyfield argue that the biological nature of the body itself – in this case of the potential research participant – does not constitute value per se (2012: 313). Birch develops these ideas for the bioeconomy: “value is, rather, constituted by specific forms of knowledge

and practice that are necessary to make, govern, and manage valuation judgements” (2017: 479). He challenges the idea that the concept of commodity helps understand the role of value comprehensively and suggests that value judgements are made as part of the prediction of future revenue from *assets*. The value of assets, which are a form of property, is constituted without necessarily a change in the nature or composition of the asset by the owner itself; assets are supposed to continuously generate value without being used up. Drawing on Muniesa et al.’s work (2007: 4) who argue that value in the economy is primarily *performed* through different market devices which function by “rendering things more ‘economic’ or, more precisely, at enacting particular versions of what it is to be ‘economic’”, we understand these devices as constitutive of processes of *valuation* which bring together worth and value, or social and cultural values with economic ones (Stark 2009, Morrison 2018).

Valuation practices are key in assetization. We are interested in exploring two types of practice as the basis for understanding patient recruitment as assetization: ethical and practical valuations. We do so to propose a way of conceptualising the NIHR’s approach to patient and public recruitment, and to further develop the concept of valuation by showing that such processes contribute to the legitimacy of publicly funded clinical research and reflect the desire to increase public-private collaboration to generate ‘health and wealth’. In this context, we suggest understanding recent NIHR’s recruitment campaigns as processes of assetization: they posit potential recruits as the source and site for a breadth of clinical research that is not exhausted in trial participation but may enable further research recruitment through the types of activities represented by PPI. The NIHR itself claims that involvement of the public in developing and governing research contributes to the effectiveness and efficiency of both research and the patient recruitment process into clinical research itself (2015: 8). These framings, forming part of the NIHR imaginary of patients and

publics in research, do not necessarily reflect public understanding of research participation and involvement, as findings from surveys of patients about clinical research have shown (Adam et al. 2015, McKevitt et al. 2015, Wienroth et al. 2018).

The framings do, however, suggest an underlying logic of practical – policy, economic, technical/operational, and scientific – valuations of patients as assets in clinical research. Our analysis focuses on the recruitment strategies of the NIHR rather than patient encounters with research campaigns. We acknowledge that the messages of the campaigns may be negotiated by patients and publics in complex or unintended ways (Thompson and Kumar 2011). Thus, while we are unable to analyse how campaigns are received by intended audiences, our contribution is an examination of the construction of patients, participants or volunteers in research. In this approach, we suggest extending the concept of clinical labour to include the work expected of patients when engaging, participating in, or getting involved with clinical research. This is linked to the ability to engage with research in the first place, and to adhere to requirements placed upon patients and other publics by the clinical research system. Such labour of knowledge production and exchange has been understudied but holds a key role in the creation of value in clinical research. The NIHR provides the bulk of information about clinical research on their various websites, requiring patients to engage in knowledge labour that presumes online literacy, and ability to follow and read links. Some of these information sources also expect the reader, at least to a degree, to be able to access scientific language, such as on the UK Clinical Trials Gateway website. Online and scientific literacy as well as the will and capacity to search for information are elements of ‘immaterial’ labour (cf. Birch, 2012) that patients need to engage in during the recruitment process.

Ethical valuation

The NIHR conveys notions of patient right and duty to be engaged in and with clinical research in their public-facing activities and strategy. Valuation practices around rights to research participation have linked access to clinical trials to the recognition of certain health conditions as relevant and legitimate areas of research, and access to knowledge about clinical research as empowerment of patients who are active rather than passive. NIHR campaigns seek to motivate people to participate by equating research participation as being 'part of the solution' in improving the 'health and wealth' of the nation, and through providing relatable faces to encourage audiences to identify themselves as not only a patient but a potential research participant. Informing patients about the need for further research to ensure public and personal health while positing them as consumers of nationally provided healthcare services imagines a shared responsibility in ensuring effective and efficient healthcare delivery. It suggests that patients have an obligation to participate in research, as well as a right to know about clinical research. The change in terms from 'OK to Ask' to 'I Am Research,' in combination with the imaginary of the patient in the 2015 report 'Going the Extra Mile,' emphasises this shift in the NIHR's engagement strategy, illustrating the aspect of moral obligation on both patients and publics as well as health care and research professionals to engage in clinical research together.

Indeed, as a result of the programme of PPI, patient involvement has become an increasingly standard requirement for clinical and academic researchers (Evans 2014). At the same time, there is limited evidence demonstrating that PPI has changed clinical research practices (Boaz et al. 2016, Rise et al. 2013). The diverse and extensive efforts of the NIHR, especially the ongoing drive to build an evidence base as well as a practice framework, suggest that there is still work to be done to meaningfully develop PPI initiatives in practice (cf. Brett et al. 2014, Mockford et al. 2012). What this suggests is that involving patients in clinical research

processes and governance can be performative – it performs responsible and patient-responsive research, rather than rendering clinical research as such (Komporezos-Athanasidou et al. 2016). This is not to overlook the ways in which patients can and do contribute to the direction of health research in the UK, as described earlier, but to suggest that PPI operates as a device that generates legitimacy for wide recruitment into clinical research. This becomes particularly apparent in the way that these communications assume patients and publics share the understanding of and rationales for clinical research that the NIHR cultivates. A contradiction emerges in this gap between patients' lack of understanding of what clinical research entails, and the NIHR campaigns that position patients and publics as embodying research values.

Here, the limited power of the device of patient and public involvement becomes apparent for the rationale of patient-initiated recruitment. However, PPI retains its currency for generating legitimacy, despite – or perhaps because of – the difficulty of evidencing 'tangible' benefits for patient recruitment. PPI can be viewed as less about the creation of tangible value than it is about including in the valuation diverse aspects of worth such as goodwill, loyalty to the NHS, and patient labour that can lead to future value in the form of participation in clinical research. If patients involved in research are 'assets' rather than commodities their value is generated in the 'ownership' of their willingness, knowledge, time and commitment. Patient engagement to increase recruitment into research, as well as involvement, can also be viewed as elements of a wider effort by the NIHR (and the NHS) to account for its publicly funded role in UK society. The campaigning activities of the NIHR seek to present a national health service that both delivers healthcare and works in partnership with its 'constituents' to deliver 'health and wealth' for the nation.

Practical valuation

This anticipated impact of NIHR-supported research on UK society underlies in part the practical valuation of patients as assets. Such valuations require the NHS to be seen to respond to policy demands such as understanding the NHS as a motor for innovation (Bell 2017); to engage with metrics of economic value; and to satisfy operational research needs such as ensuring statistical power for meaningful results (more research participants means potentially more data). What is often foregrounded is the understanding of perceived value from clinical research in terms of ‘wealth’ through ‘growth,’ and patient recruitment into research is portrayed as vital in the delivery of such public goods – in as much as participation in research can contribute to fulfilling policy demands as well as generate economic value to the NHS Trusts that are paid for each participant in clinical research.

Described as an ‘engine for growth’, the NIHR seeks to develop health research through industry collaboration, international competitiveness, and a skilled research workforce; but also through efficiency savings in health care delivery and enabling patients’ self-assessment capacities (NIHR 2015b). For the NIHR, growth is measured by its investment volume, the number of commercial contract studies, patents, publications, and trainees as well as the number of patients recruited into research. NIHR-funded bodies such as Biomedical Research Centres measure growth across a variety of indicators including the number of studies, sources and total of external funding and revenue generated from intellectual property (Anandagoda and Lord 2016). These measures, attributing economic value to patient numbers in clinical research, are a means to account for public investment into clinical research and are indicative of how the patient is intricately interwoven into the fabric of the NIHR framing of economic growth, a practical valuation process.

Two aspects of assetization emerge as key in the practical valuation process; patients are imagined as becoming actively involved in the market of health research, delivering value by not only using services but also by participating in research, thus contributing to the delivery of public goods such as ‘growth through health research.’ Within this framework, patients offer immaterial labour in the form of *knowledge* to learn about and participate in clinical research activities, and material labour in the form of *adherence* to research protocols to be/remain eligible and to avoid invalidating results. Such *knowledge labour* is developed as a key asset in NIHR campaigns and strategies. Research participation is based on eligibility, where the patient is a provider of research materials such as a specific health or disease status, a facilitator for access to biomaterials and/or the *in vivo* locus for research, and a representative of certain demographics for which inferences are made in specific clinical research project. Valuation here is based not only on eligibility but is also reliant upon the competence and motivation to carry out the relevant cognitive work to understand and adhere to research instructions (Milne 2018).

Rentiership

In the work of Birch and others, the notion of rentiership – of making profit from something that is not newly made but that has been given to the owner – has an important role in understanding valuation practices. Although as yet the economic impact of patient participation and involvement in research is unclear, there is certainly an accumulation of worth in terms of accountability and utility, that is, social capital. Ethical valuation lies in creating *legitimacy*, as a kind of social glue, between patient and clinical health research system. Practical valuation focuses on the *availability* of patients for current and future research work. However, the engagement with publics through campaigns constitutes an

attempt at *enrolment* at two levels: of patients as recipients of moral benefits due to supporting clinical research, and as a form of investor relations with governing bodies and funders of clinical research and healthcare provision. The NIHR performs its commitment to research not only by funding research projects but also through public communications about research and can thus utilise public recruitment campaigns as a means of accounting for spending public funds on recruitment and research.

For the research process, patients become assets once they register to become research recruits or take on an active role in research processes. The shift from right to duty for research engagement suggests that assetization in the recruitment process is characterised by efforts leading to transformation as well as transposition: transformation of the traditional understanding of the patient as a recipient of health care goods into a market-active, desirable and productive patient; and transposition of responsibility for ensuring that patients are an integral part of the healthcare system as advocated, for example in the NHS constitution for England, from the health system to the individual. We propose that patient recruitment campaigns may be understood as institutional asset-making and asset management at the organizational level arising from the nature of the patient as both a social and a biological entity. This analysis delivers a conceptually revised example – in the context of assetization rather than commodification – for understanding valuation in clinical research recruitment as relational social practices, negotiated in the relationship the NIHR imagines and attempts to produce between clinical research and patients.

Conclusion

It may seem dismissive to link patients to the notion of asset, and yet in terms of the political economy of the NIHR the concept of asset makes clearer the relationship between the patient

and policy and research bodies in the UK's NHS. Assetization helps frame valuation processes in this domain and provides a means of engaging with the vision for the national health system in the UK, which faces the increasing pervasion of marketization (Pollock 2004). The analysis in this paper provides some of the tools that assist us in asking questions about the emerging impact of this shift on the patient role in clinical research and about 'returns' and 'equity' of patient contributions.

The NIHR campaigns show valuation processes around the assetization of the potential clinical research participant. Future research participation and/or involvement is made a property of, or inherent to, the UK's healthcare provision system via the NHS and NIHR's discursive linking of research and healthcare. The relationship and roles of patients/publics and the NHS are renegotiated in the campaigns via ethical and practical valuation processes. As we have shown, publics and patients are framed – both in the NIHR recruitment drives and the contextual public health policy discourse – as part of the clinical research system. Both campaigns and policy discourse imply that by virtue of being an NHS patient, of being able to use NHS services, patients and publics also become part of the research system.

The NIHR campaigns offer the possibility of learning more about research before becoming involved in it, consistent with an understanding that patients and publics become valuable when positioned in a system that requires and receives reward from research participation. Equally, the NHS as owner of research-generated biomaterials and data will generate worth—both ethical and practical including economic – from clinical research participation. In research discourse and practice, patient and public contributions to research become property of the national health system.

Patient knowledge and experience has historically been devalued in clinical research (Popay and Williams 1996), but now patient knowledge, participation and involvement have been

imbued with value by the NIHR to advance the self-enrolment and claiming of publics/patients as assets to the NHS. In this paper we have sought to track the development of a new form of relationship wherein patients have become assets to, not only recipients of, the UK national healthcare system, encouraged to do so by being 'active', 'involved' and participatory in clinical research. Research participation and involvement are framed as opportunities for patients to gain certain moral benefits, and, as is clear from NIHR policy, high recruitment rates and active research involvement have the potential to produce significant financial gains for the healthcare system. Applying the concept of assetization, patient value is calculated not as an inherent value but dependent upon a belief in the return of future revenue. The valuation processes through which patients become assets relies on patients carrying out what we have described in this paper as forms of clinical labour that are often invisible in previous applications of this concept, such as responding to and engaging with recruitment campaigns and materials.

Clinical research is conducted within the context of shifting global priorities, and under a different political and economic climate, the value of patients to clinical research recruitment may once again experience change. Particularly interesting will be the ongoing analysis of efforts to develop an integrated health care and research system in the context of already documented and analysed shifts of trial participation to low and middle-income countries (Petryna, 2009) that possess different ethical, legal, and regulatory frameworks. Lastly, questions of commercialisation, equity and integration of health care provision and research can prepare analysts to further explore the role of patients in a likely shift towards an increasing focus on intellectual property issues in clinical research undertaken by NHS.

References

- Adam, M., Caffrey, L. and McKevitt, C. (2015) Barriers and opportunities for enhancing patient recruitment and retention in clinical research: findings from an interview study in an NHS academic health centre, *Health Research Policy and Systems*, 13, 8.
- Anandagoda, N., and Lord, G.M. 2016. Boosting translational research in the U.K, *Science Translational Medicine* 8, 357, 357fs15-357fs15.
- Atkinson, P. (1990) *The ethnographic imagination*. London: Routledge.
- Barlow, J., Wright, C., Sheasby, J., Turner, A. and Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review, *Patient Education and Counseling* 48, 2, 177-187.
- Barnes, M., and P. Shardlow (1997) From passive recipient to active citizen: Participation in mental health user groups, *Journal of Mental Health*, 6, 3, 289-300.
- Bell, J. (2017) *Life Sciences Industrial Strategy—A report to the Government from the life sciences sector*. London: Office for Life Sciences.
- Birch, K. (2017) Rethinking Value in the Bio-economy: Finance, Assetization, and the Management of Value, *Science, Technology, & Human Values*, 42, 3, 460-490.
- Birch, K., and Tyfield, D. (2013) Theorizing the Bioeconomy, *Science, Technology, & Human Values*, 38, 3, 299-327.
- Boaz, A., Biri, D. and McKevitt, C. (2016) Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom?, *Health Expectations*, 19, 3, 592-601.

Bower, P., Brueton, V., Gamble, C., Treweek, S., Tudur Smith, C., Young, B. and Williamson,

P. (2014) Interventions to improve recruitment and retention in clinical trials: a survey and workshop to assess current practice and future priorities, *Trials*, 15, 399.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3, 2, 77-101.

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. and Suleman,

R. (2014) Mapping the impact of patient and public involvement on health and social care research: a systematic review, *Health Expectations*, 17, 5, 637-650.

Campbell, D. (2013) NHS patients thwarted in attempt to enter drug trials. Lifesaving therapies are being hindered by delays in matching tests to volunteers, research chief says, *The Observer*, 5 January. Available at:

<https://www.theguardian.com/society/2013/jan/05/patients-thwarted-nhs-drug-trials> (Accessed 16 October 2018)

Cooper, M. (2008) Experimental labour—Offshoring clinical trials to China, *East Asian Science, Technology and Society: An International Journal*, 2, 1, 73-92.

Cooper, M. and Waldby, C. (2014) *Clinical labor: Tissue donors and research subjects in the global bioeconomy*. Durham, NC: Duke University Press.

Davis, C., Abraham, J. (2011) Desperately seeking cancer drugs: explaining the emergence and outcomes of accelerated pharmaceutical regulation, *Sociology of Health & Illness*, 33, 731–747.

Denegri, S. (2017) Patients are part of the crew in health research, not passengers. Available at: <https://www.nihr.ac.uk/blogs/patients-are-part-of-the-crew-in-health-research-not-passengers/6242> (Accessed 17 October 2018)

Department for Business, Innovation & Skills (2011) *Strategy for UK Life Sciences*.

Department of Health (2006) *Best research for best health: a new national health research strategy*.

Department of Health (2010) *Equity and excellence: Liberating the NHS*.

Department of Health (2012) *Health and Social Care Act*.

Department of Health (2015) *The NHS Constitution for England*.

Ennis, L. and Wykes, T. (2013) Impact of patient involvement in mental health research: longitudinal study, *The British Journal of Psychiatry*, 203, 381-386.

Entwistle, V.A., Renfrew, M.J., Yearley, S., Forrester, J., Lamont, T. (1998) Lay perspectives: advantages for health research, *BMJ*, 316, 463–466.

Epstein, S. (1995) The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials, *Science, Technology & Human Values*, 20, 4, 408-437.

Evans, D. (2014) Patient and public involvement in research in the English NHS: a documentary analysis of the complex interplay of evidence and policy, *Evidence & Policy*, 10, 3, 361-377.

Faulkner A. (1997) 'Strange bedfellows' in the laboratory of the NHS? An analysis of the new science of health technology assessment in the United Kingdom. In: Elston M.A. (ed) *The sociology of medical science and technology, Sociology of Health & Illness Monograph No. 3*. Oxford: Blackwell, pp. 183-207.

Fletcher, B., Gheorghe, A., Moore, D., Wilson, S. and Damery, S. (2012) Improving the recruitment activity of clinicians in randomised controlled trials: a systematic review, *BMJ Open*, 2, 1, e000496.

Ford, J.G., Howerton, M.W., Lai, G.Y., Gary, T.L., Bolen, S., Gibbons, M.C., Tilburt, J., Baffi, C., Tanpitukpongse, T.P., Wilson, R.F., Powe, N.R. and Bass, E.B. (2008) Barriers to

recruiting underrepresented populations to cancer clinical trials: A systematic review, *Cancer*, 112, 2, 228-242.

Gardner, J., and Webster, A. (2017) Accelerating innovation in the creation of biovalue: the Cell and Gene Therapy Catapult, *Science, Technology & Human Values*, 42, 5, 925-946.

Greenhalgh, T., Howick, J., and Maskrey, N. (2014) Evidence based medicine: a movement in crisis?, *BMJ*, 348.

Hallowell, N., Cooke, S., Crawford, G., Lucassen, A., Parker, M. and Snowden, C. (2010) An investigation of patients' motivations for their participation in genetics-related research, *Journal of Medical Ethics*, 36, 1, 37-45.

HM Treasury (2011) *The plan for growth*.

Klawiter, M. (2008) *The biopolitics of breast cancer: changing cultures of disease and activism*. Minneapolis: University of Minnesota Press.

Komporozos-Athanasiou, A., Fudge, N., Adams, M. and McKevitt, C. (2016) Citizen participation as political ritual: towards a sociological theorizing of health citizenship, *Sociology*, 52, 4, 744-761.

Laine, C., and Davidoff, F. (1996) Patient-centered medicine: A professional evolution, *JAMA* 275, 2, 152-156.

Lambert, H. (2006) Accounting for EBM: notions of evidence in medicine, *Social Science & Medicine*, 62, 11, 2633-45.

Lintern, S. (2019) Trusts to be quizzed on levels of research. *Health Service Journal*. 20 March. Available at: <https://www.hsj.co.uk/policy-and-regulation/trusts-to-be-quizzed-on-levels-of-research/7024682.article> (accessed 11 April 2019)

- Lupton, D. (2015) The pedagogy of disgust: the ethical, moral and political implications of using disgust in public health campaigns, *Critical Public Health*, 25, 1, 4-14.
- Malby, R., and Hamer, S. (2016) *Creating an innovation and research culture in a complex system*. London: National Institute for Health Research.
- Martin, G.P., 2008. 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare, *Sociology of Health & Illness*, 30, 35–54.
- McKevitt, C., Fudge, N., Crichton, S., Bejot, Y., Daubail, B., Di Carlo, A., Fearon, P., Kolominsky-Rabas, P., Sheldenkar, A., Newbound, S., Wolfe, C.D.A. and the European Implementation Score Collaborative, G. (2015) Patient engagement with research: European population register study, *Health Expectations*, 18, 6, 3248-3261.
- McLaughlin, H. (2009) What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'—What's Next?, *The British Journal of Social Work*, 39, 6, 1101-1117.
- Milne, R. (2018) From People with Dementia to People with Data: Participation and Value in Alzheimer's Disease Research, *BioSocieties*, 13, 3, 623-639.
- Mockford, C., Staniszewska, S., Griffiths, F., and Herron-Marx, S. (2012) The impact of patient and public involvement on UK NHS health care: a systematic review, *International Journal for Quality in Health Care*, 24, 1, 28-38.
- Morrison, M. (2018) Making Cells Worthwhile: Calculations of Value in a European Consortium for Induced Pluripotent Stem Cell Banking, *Science as Culture*, DOI:10.1080/09505431.2018.1538331.
- Muniesa, F., Millo, Y. and Callon, M. (2007) An introduction to market devices, *The Sociological Review*, 55, 1-12.

National Institute for Health Research (2013) Mystery shopper campaign highlights NHS

shortcomings in promoting clinical research. Available at:

[http://www.mynewsdesk.com/uk/nihr/pressreleases/mystery-shopper-campaign-](http://www.mynewsdesk.com/uk/nihr/pressreleases/mystery-shopper-campaign-highlights-nhs-shortcomings-in-promoting-clinical-research-826993)

[highlights-nhs-shortcomings-in-promoting-clinical-research-826993](http://www.mynewsdesk.com/uk/nihr/pressreleases/mystery-shopper-campaign-highlights-nhs-shortcomings-in-promoting-clinical-research-826993) (Accessed 17

October 2018)

National Institute for Health Research (2015a) *Going the extra mile. Improving the nation's*

health and wellbeing through public involvement in research.

National Institute for Health Research (2015b) *Growth through health research. The NIHR as*

an engine for growth.

Nuffield Department of Primary Care Health Sciences (2015) It's 'OK to Ask' about clinical

research on International Clinical Trials Day. Available at:

[https://www.phc.ox.ac.uk/news/its-ok-to-ask-about-clinical-research-on-](https://www.phc.ox.ac.uk/news/its-ok-to-ask-about-clinical-research-on-international-clinical-trials-day)

[international-clinical-trials-day](https://www.phc.ox.ac.uk/news/its-ok-to-ask-about-clinical-research-on-international-clinical-trials-day) (Accessed 17 October 2018)

Patra, P.K. and Sleeboom-Faulkner, M. (2009) Bionetworking: experimental stem cell

therapy and patient recruitment in India, *Anthropology & Medicine*, 16, 2, 147-163.

Petryna, A. (2009) *When experiments travel: Clinical trials and the global search for human*

subjects. New Jersey: Princeton University Press.

Pollock, A.M. (2004) *NHS plc: The privatisation of our health care*. London: Verso Books.

Popay, J. and Williams, G. (1996) Public health research and lay knowledge, *Social Science &*

Medicine, 42, 5, 759-768.

Prainsack, B. (2014) The powers of participatory medicine, *PLoS Biology*, 12, e1001837.

Rabeharisoa, V., Moreira, T., Akrich, M. (2014) Evidence-based activism: Patients', users'

and activists' groups in knowledge society, *BioSocieties*, 9, 111-128.

Rise, M.B, Solbjør, M., Lara, M.C., Westerlund, H. Grimstad, H. and Steinsbekk, A. (2013)

Same description, different values. How service users and providers define patient and public involvement in health care, *Health Expectations*, 16, 3, 266-276.

Sackett, D.L., Rosenberg, W.M.C. Muir Gray, J.A., Haynes, R.B., and Richardson, W.S. (1996)

Evidence based medicine: what it is and what it isn't, *BMJ*, 312, 7023, 71-72.

Shippee, N.D., Garces, J., Lopez, G., Wang, Z., Elraiyah, T., Nabhan, M., Brito, J., Boehmer, K.,

Hasan, R., Firwana, B., Erwin, P., Montori, V. and Murad, M.H. (2015) Patient and service user engagement in research: a systematic review and synthesized framework, *Health Expectations*, 18, 5, 1151-1166.

Smith, D. E. (2001) Texts and the ontology of organisations and institutions, *Studies of*

Cultures, Organisations and Societies, 7, 159–198.

Stark, D. (2009) *The sense of dissonance: Accounts of worth in economic life*. Princeton:

Princeton University Press.

Thompson, L. and Kumar, A. (2011) Responses to health promotion campaigns: resistance,

denial and othering, *Critical Public Health*, 21, 1, 105-117.

Timmons, S., and Vezyridis, P. (2017) Market-driven production of biospecimens and the role of NHS hospital-led biobanks, *Sociology of Health & Illness*, 39, 1242–1257.

Treweek, S., Mitchell, E., Pitkethly, M., Cook, J., Kjeldstrøm, M., Johansen, M. Taskila, T.K.,

Sullivan, F., Wilson, S., Jackson, C., Jones, R., and Lockhart, P. (2010) Strategies to improve recruitment to randomised controlled Trials. *Cochrane Database of Systematic Reviews*, 20, 1.

Vaismoradi, M., Turunen, H. and Bondas, T. (2013) Content analysis and thematic analysis:

Implications for conducting a qualitative descriptive study, *Nursing & Health Sciences*, 15, 3, 398-405.

In press: Sociology of Health & Illness (April 2019)

Authors: Matthias Wienroth, Caroline Pearce, Christopher McKevitt

Wienroth, M., Caffrey, L., Wolfe, C. and McKevitt, C. (2018) Patient-initiated recruitment for clinical research: Evaluation of an outpatient letter research statement, *Health Expectations*, 21, 2, 494-500.

Will, C.M. (2011) Mutual Benefit, Added Value?, *Journal of Cultural Economy*, 4, 1, 11-26.

Figure 1 'OK to Ask' logo

(source: Nuffield Department of Primary Care Health Sciences, 2015. "It's 'OK to Ask' about clinical research on International Clinical Trials Day." accessed 19 April 2018.

<https://www.phc.ox.ac.uk/news/its-ok-to-ask-about-clinical-research-on-international-clinical-trials-day>.)



Figure 2 'Part of the landing page of 'I Am Research'

(source: NIHR National Institute for Health Research. "I Am Research". Accessed 19 April 2018. <http://www.nihr.ac.uk/news-and-events/support-our-campaigns/i-am-research/>)

I Am Research

Home → News and events → Support our campaigns → I Am Research



"I Am Research" gives patients, the public and health and social care research professionals a chance to shout about how fantastic research is. We aim to raise awareness of the benefits of research and the positive impact it has on people's lives.

Every year, more than half a million people help the NHS improve healthcare and develop life-saving treatments by taking part in health research. This research drives new and better treatments and though there's not always a research study to suit everyone, there are other ways to be involved or stay in touch. This could be as a Patient Research Ambassador, advising researchers on improving patient experiences, looking at studies coming on to the UK Clinical Trials Gateway, signing up for mailings, or simply talking about research.

Get involved in "I Am Research" using the links below

You'll also find resources to improve your understanding of health and social care research:



Join the thunder!

By joining our Thunderclap, you agree to Tweet or post the same message, on Twitter or Facebook, on the same day and at the same time. You can do both if you want to! It's a great way to come together to promote the benefits of clinical research.

Visit our [Thunderclap campaign page](#) to join the "I Am Research" thunder!



"People are messy"

We are screening a film called 'People are Messy', at research awareness events across the country.

The film engages audiences in an informed debate around patient and public involvement in health research. [Find out how you can get involved...](#)



Events

There are "I Am Research" events taking place across England to promote the benefits of health and social care research on International Clinical Trials Day.

[Find out what is happening near you and how to organise your own event...](#)



Social media

- **Facebook** - tag us in your posts and join our Facebook Live event on 19 May
- **Twitter** - get involved by using [#iamresearch](#) and [apply a #IamResearch Twitter ribbon \(Twibbon\)](#) to your Twitter profile
- **Tweetchat** - join the 'Why research is important to patients' [#whywedoresearch](#) Tweetchat on 17 May at 8-9pm

In press: Sociology of Health & Illness (April 2019)

Authors: Matthias Wienroth, Caroline Pearce, Christopher McKeivitt

Figure 3 'Part of the landing page of 'I Am Research' with author annotations

The image shows a screenshot of the 'I Am Research' website landing page. The page has a blue header with the 'I AM RESEARCH' logo and the tagline 'Be part of the solution'. Below the header, there is a section titled 'Get involved in "I Am Research" using the links below' which lists various ways to get involved, including joining the Thunderclap, watching the film 'People are messy', attending events, and using social media. The page is annotated with four red handwritten notes and arrows:

- Enrolment of publics**: An arrow points from this note to the 'I AM RESEARCH' logo.
- Rationalising research involvement via simple messages**: An arrow points from this note to the text 'Get involved in "I Am Research" using the links below'.
- Producing a human face for clinical research**: An arrow points from this note to the 'Social media' section, which features a photo of a woman holding a sign that says 'I AM RESEARCH'.
- Social media & online focus**: An arrow points from this note to the 'Thunderclap' section, which encourages users to join the Thunderclap campaign.

Additional annotations include:

- Local opportunities to see the human face of clinical research**: A bracket connects this note to the 'People are messy' and 'Events' sections.

Figure 4 'Two Sides of Health Research' poster

(source: National Institute for Health Research. "Two Sides of Health Research". Accessed 19 April 2018. <https://www.nihr.ac.uk/news-and-events/support-our-campaigns/two-sides-health-research>)



1 Our purpose. Available at: <https://www.nihr.ac.uk/about-us/our-purpose/> (Accessed 18 October 2018)

2 Briefing note three: Why involve members of the public in research? <https://www.invo.org.uk/posttypesresource/why-should-members-of-the-public-be-involved-in-research/> (Accessed 8 March 2019)

3 Performance in initiating and delivering clinical research. Available at: <https://www.nihr.ac.uk/research-and-impact/nhs-research-performance/performance-in-initiating-and-delivering-research/> (Accessed 18 October 2018)

4 Though a recent poll by the King's Fund found that a majority (61%) of the UK public would support higher taxation to fund the NHS, <https://www.kingsfund.org.uk/publications/does-public-see-tax-rises-answer-nhs-funding-pressures#how-does-the-public-want-to-pay-for-the-nhs>

5 Shared decision making, NHS England. Available at: <https://www.england.nhs.uk/shared-decision-making/> (Accessed 17 October 2018)

6 I Am Research. Available at: <http://www.nihr.ac.uk/news-and-events/support-our-campaigns/i-am-research/> (Accessed 17 October 2018)

7 Let's get digital: About. Available from: <https://www.nihr.ac.uk/news-and-events/support-our-campaigns/about.htm> (Accessed 17 October 2018)

8 UK Clinical Trials Gateway home page. Available from: <https://www.ukctg.nihr.ac.uk/> (Accessed 17 October 2018)

9 Why take part in a clinical trial. Available at: <https://www.ukctg.nihr.ac.uk/clinical-trials/why-take-part-in-a-clinical-trial/> (Accessed 17 October 2018)

10 Two Sides of Health Research. Available at: <https://www.nihr.ac.uk/news-and-events/support-our-campaigns/two-sides-health-research/> (Accessed 17 October 2018)

11 Involve home page. Available at: <http://www.invo.org.uk/> (Accessed 17 October 2018)

12 Library of research projects. Available at: <http://www.invo.org.uk/resource-centre/libraries/library-of-research-projects/> (Accessed 17 October 2018)

13 Vision and Mission. Available at: <http://www.invo.org.uk/about-involve/vision-and-mission-2/> (Accessed 17 October 2018)

14 People in Research. Available at: <https://www.peopleinresearch.org/> (Accessed 17 October 2018)