

# Participation in the BioResource

## Biobanking and Value in the Changing NHS

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**Abstract:** The National Institute for Health Research BioResource is not a typical biobank. It banks biological samples and other data, but also volunteer commitment to potential future research participation. Researchers can then, using the BioResource as an intermediary, invite volunteers who meet specific genotypic or phenotypic criteria to participate in studies. Using participant observation and semi-structured interviews with those involved in recruiting new and engaging existing volunteers, this paper explores how participation is understood and cultivated, and how (bio)value is produced in routine BioResource work. We contribute insights into a different configuration of biosocial participation where the engaged individual, as opposed to biological sample, is the site of value. Foregrounding the often ignored work of biobank staff, we demonstrate the iterative and reflexive way value is created and maintained through staff activity, and the different way actors make sense of the site and stability of this value.

**Keywords:** participation; biobank; biovalue; NHS; labour; health research infrastructure.

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## I. Introduction

Rushing down a long, sanitised, hospital corridor on my way to a meeting, I hear my shoes clatter on the hard, vinyl floor. Clinical staff in their colourful uniforms and rubber shoes glide with purpose towards me while other bodies look lost, eyes searching the corridor for signs to direct them. As I move further down the chair lined passage, I encounter three members of hospital staff at a table, trying to make eye contact with those who

pass by. Their table is laden with leaflets, clipboards, mugs, pens and, most distinctly, a large model of a double helix. A banner tells me that “Research Needs You.” At first glance, it appears to be a fundraising exercise, typical of the English hospital. However, this is something different. As I quickly pass by the stall, an individual is sat completing a form while another approaches the table, asks about the double helix model and, for the few seconds, I hear snippets of information about genetics and health research. This was my first encounter with the BioResource.

(David Wyatt)

The BioResource, discussed in this paper, is part of wider transformations in the National Health Service of England (NHS). Since the publication of *Best research for best health: A new national health strategy* (Department of Health 2006), the NHS has embarked on a process where its focus is not only on the provision of universal health care to the population but also on positioning itself at the forefront of medical research. One of the ways the Department of Health pursued this vision was by establishing the National Institute for Health Research (NIHR) (Department of Health 2006). The NIHR presents itself as “the most integrated clinical research system in the world” and claims to “drive research from bench to bedside for the benefit of patients and the economy” (<https://www.nihr.ac.uk/about-us/our-purpose/>). It aims to do this by funding research projects, supporting the training and development of researchers, working with industry, and providing research facilities and infrastructures. The BioResource discussed in this paper is one of these research infrastructures.

In 2005, through a collaboration between the University of Cambridge and the Medical Research Council Epidemiology Unit, a BioResource was established in Cambridge. Building on this BioResource’s perceived success, the NIHR funded its expansion. NIHR BioResource is now constituted by a federation of thirteen independent BioResources across England. These BioResources work independently and together to streamline and support the recruitment of research participants for specific studies. BioResource staff recruit volunteers, with or without existing health conditions, who are willing to take part in future research studies. To join the BioResource volunteers provide biological samples containing genetic information, lifestyle and health information and, for those with existing health conditions, access to their clinical records. Healthcare professionals, academics and members of the commercial pharmaceutical industry can then apply to the BioResource to identify volunteers that meet specific genotypic and/or phenotypic criteria and invite them to take part in new studies. The details of those willing to participate in the specific study are then passed to the researcher to contact directly.

David’s initial exposure to the BioResource, recounted above, affords an insight into some of the routine practices of BioResource recruitment. Drawing on findings from ethnographic observation of the day-to-day work of a BioResource and semi-structured interviews with its staff, we

explore how BioResource participation is performed, understood and configured. We examine the labour of running this biobank and focus on the mundane and often invisible work involved in facilitating participation in the BioResource and the production of value. Existing accounts of (bio)value in biobanking situate value in biological fragments (for example, blood or tissue samples), and the potential these fragments offer for medical innovation and research. We contend that the BioResource represents a distinct form of biosocial participation where its value is the engaged volunteer (as opposed to their partible samples and associated data) and this value is the product of the labour of both volunteers and BioResource staff. Value in this context is not fixed, inevitable or linked to the market but produced and maintained through the structured activities of the BioResource and ongoing engagement of volunteers. Our account suggests existing concepts of clinical labour and biovalue are insufficient in conceptualising and encapsulating all the work involved in producing value.

## 2. Biobank Participation, Biobank Labour and Biovalue

In his influential study of blood donation, Titmuss (1970) examines two different ways of developing a supply of blood for transfusions post World War II. While the United States offered payment for blood, Titmuss found that in the UK a better quality and quantity of blood was achieved through a system of donating for no financial reward. Titmuss claims this is a gift relationship and the act of giving blood contributes to the social good and creates ties between individuals, establishing communities. Titmuss' account infers a hierarchy of participation, with gift donation held firmly aloft of commodity purchase. Others have highlighted that the divide between gift and commodity is neither static nor mutually exclusive (Frow 1997; Harris et al. 2013; Lipworth et al. 2011; Waldby and Mitchell 2006) and have questioned the compatibility between Titmuss' 'gift' and Mauss' account of gift exchange (Tutton 2002). Yet, Titmuss' work remains important today, providing a compelling argument in support of the welfare state (Frow 1997) and embedded in public guidelines, such as the UK Medical Research Council's 2001 *Human Tissue and Biological Samples for Use in Research* (Tutton 2002).

For Titmuss, altruism was a central feature of the rationale to give blood. While altruism dominates clinical researchers' understandings of participation (Adams and McKevitt 2015), in research and biobank participation there is an acknowledgement of a more complex set of rationales (Adams and McKevitt 2015; Tutton 2007). For example, in the Swedish context, Hoeyer (2006) foregrounds the issues of trust in the organisation and notions of fairness, (see also Cool (2016) and, in the Norwegian context, Steinsbekk et al. (2013)). Hoeyer (2006, 791) reports that some experienced participation as "taking part in a shared welfare state

project.” In the NHS, participation in research has been framed in a similar way: healthcare is provided, and in return, citizens have a responsibility (or at least are expected) to “give back” by participating in research as a moral duty, civic virtue, matter of citizenship (Chadwick and Berg 2001; Mitchell 2012; Woolley et al. 2016) or even as an entitlement – patients have a right to be aware of opportunities to participate in research (Adams and McKevitt 2015; Wienroth et al. 2018).

Tutton’s (2007) focus group study on biobank participation adds texture to our understanding of what counts as participation and how this term can be operationalised instrumentally by institutions. “Participation” is often used to infer a democratic process linked to notions of public involvement or ‘active citizenship’, said to “emphasise people’s rights (and duties) to participate in decision-making processes” (Tutton 2007, 174). Such accounts present citizens as informed, engaged and knowledgeable. In practice, however, participation rarely provides space for citizens to enact these qualities (Tutton 2007). Instead, it often entails the provision of samples, the completion of forms and the ad hoc receipt of news from the biobank about recent research. Viewing citizens as informed, astute, and able to make free, rational choices is the cornerstone of contemporary informed consent (Corrigan 2004). Yet even this is complicated further by biobank participation, as being able to define how data will be used in advance is not always possible (Shickle 2006; Tutton and Prainsack 2011) and the right to withdraw is difficult to facilitate (Melham et al. 2014).

In the UK the most prominent biobank is the non-profit, publicly funded charitable company, *UK Biobank*. Having collected samples, lifestyle information and established links to the “cradle-to-grave” NHS health records of 500,000 volunteers, it is lauded as “a major national and international health resource” and claims that, “over many years [...] will build into a powerful resource to help scientists discover why some people develop particular diseases and others do not” (UK Biobank n.d). Tutton and Prainsack (2011) suggest that *UK Biobank* utilises a notion of “public good” and report that it promotes a particular kind of subjectivity in its participants, that of the “altruistic self.” The altruistic self “is addressed through a discourse of communitarianism, and [...] enrolls in the biobank, freely giving of themselves with no expectation of anything in return” (Tutton and Prainsack 2011, 1090). Busby and Martin (2006) frame participation in *UK Biobank* slightly differently. Rather than altruism specifically, public good is operationalised in terms of British identity, community, the benefits for the country now and for future generations. Across both accounts, participation in research with the potential to benefit the wider community is, at least in part, expected.

The NIHR BioResource has many similarities with *UK Biobank* but differs in some noteworthy respects. Whereas *UK Biobank* is supported by but situated outside of the NHS and NIHR, the BioResource is funded through the NIHR and thus the NHS. While both occupy a landscape

where in the last twenty years the UK government has set ambitions on utilising the life sciences industry to invigorate the economy and develop its competitiveness on the international markets, the NHS context of the BioResource is significant for how we understand participation. With the publication of *Best research for best health: A new national health strategy* (Department of Health 2006) and numerous initiatives (including establishing the NIHR), the NHS situates research and support for research not as peripheral to its jurisdiction but embedded at the heart of its work. Though for some time there has been an expectation that patients are willing to participate both in defining research priorities and in health research, it was only in the NIHR (2015) publication, *Going the extra mile*, that participation in health research was framed not as an altruistic act but as a patient duty. This shift to develop a “research culture” in the routine functions of care provision (Malby and Hamer 2016) and transform the NHS into a research leader, reframes the relationship between citizen and state: universal healthcare is provided as a right (and from taxpayers’ money), but citizens also have a duty to participate in research and, by extension, contribute to the health of the wider population and the wealth of the nation through the bioeconomy.

The biobanks also differ in how they can be used for research. *UK Biobank* records remain viable research data unless the individual withdraws consent. BioResource records can only be used by BioResource staff to identify and contact those who meet the specific genotypic and/or phenotypic criteria required for a research study. *UK Biobank* has the ability to re-contact participants too, but this is a secondary function. For the BioResource, this is its only function. It is dependent on volunteers enacting their supposed duty to participate in research when invited and researchers opting to utilise the BioResource in identifying eligible research participants.

The specific NHS/NIHR and English socio-historical contexts foreground a convergence of biotechnology and capital production in what was previously a site of solely healthcare provision. This “implosion of capitalism with ‘life itself’”, referred to by Sunder Rajan (2006, 171) as biocapital, brings into focus questions about how value is created, how it circulates and to whose benefit. We focus on the first of these points in our analysis, exploring how BioResource value is constructed, understood and reinforced in the practices of BioResource staff.

To understand value, we first draw on Waldby’s concept of biovalue to emphasise the potential offered by the collection and use of biological fragments in the bioeconomy. Defined as “the yield of vitality produced by the biotechnological reformulation of living processes” (Waldby 2002, 310), biovalue is not rooted in an inherent property of biological material. Instead, it is realised in market exchange or in its potential to improve the health of the population. While in this initial conception, the fragment is divorced from the individual who donated it, in the context of biobanks, this continued link between individual and biological sample can be an

important part of biobank biovalue (Mitchell and Waldby 2010). For example, access to an individual's ongoing medical records provides more data and context to any biological samples held and may offer a greater potential for biomedical research.

We believe biovalue is useful in foregrounding the often explicit promise of biotechnology and the bioeconomy, but also in demonstrating the process of actively producing and nurturing value that we argue takes place through the work of BioResource staff. It is, however, limited through its conception of biovalue as a commodity rather than an asset. This point is stressed by Birch and Tyfield (2013) who suggest that viewing biovalue as a commodity forces us to see biovalue as situated in market exchange. In market logic, increased supply should decrease value. Viewing biovalue as an asset, Birch and Tyfield (2013) argue, allows for tangible and intangible artefacts to have some value independent of the market. It also allows for the accumulation of artefacts as a means of increasing value.

In our case study, this distinction is important, particularly when one sees the emphasis some actors placed on accumulating new volunteers as a means of increasing the size and, by extension, the perceived value of the BioResource. As such, we avoid using Waldby's term, biovalue, in the following sections, adopting 'value' instead. The value of the BioResource is, however, neither fixed nor consistently understood by different actors. We argue that it is through an attention to the labour of both volunteers and BioResource staff in rendering the BioResource of value to biomedical research that we see processes of creating and maintain value that are both iterative and ongoing. Clinical labour, introduced by Mitchell and Waldby (2010) and developed by Cooper and Waldby (2014), encapsulates the embodied actions completed by volunteers in participating in research. Ranging from allowing their blood to be drawn and used in research, through to surrogacy, clinical labour foregrounds the work involved in and expected of participants giving access to in vitro biology for research and, by extension, aids in the creation of value. It does not, however, allow us to consider all of the different forms of labour involved in value production.

In their examination of *23andMe*, Harris et al. (2013) separate the clinical labour of providing a saliva sample and completing initial paperwork involved in purchasing the direct to consumer genetic testing services, from the ongoing "free labour" (Terranova 2000) involved in participating in *23andMe's* research arm. The transfer of the genetic test data paid for by the consumer to the research arm of *23andMe* is presented as a gift, donated by the consumer for the purposes of research. The consumer is then inducted into a community of other donors and invited to complete further acts of free labour such as the completion of online health questionnaires, participating in online fora and taking part in research studies. Entry into this research community promotes sociality and is framed as altruism. Harris et al. (2013) argue that this distracts con-

sumers from the free nature of their labour in the process of generating economic value for *23andMe*.

*23andMe* differs from the BioResource in some respects, particularly as the *23andMe* research database has value independent of the additional free labour completed by the community of volunteers. Once donated, the data obtained through genetic tests can be mined, aggregated and used in research. Its value, although enhanced by additional information from the community of volunteers, is not predicated on this additional volunteer work. It does, nonetheless, help us see clinical labour as just one form of labour at play in the production and enhancement of value. Our study extends this point further to highlight the limits of associating clinical labour straightforwardly with (bio)value production, the already held samples and other data as consistently sites of value, and the isolated (or collective) participant as an unmediated asset. In fact, our analysis highlights how the routine work of BioResource staff in not only accumulating new volunteers but in maintaining an engaged cohort of willing, stratifiable volunteers for future research is iteratively and practically accomplished in the everyday work of the biobank and how this contributes to the BioResource's value. Such work includes the labour involved in the recruitment process, negotiating recruitment sites, the maintenance of the database and ongoing engagement work. We contend that by looking at the labour involved in the formation, recruitment, engagement and participation in the BioResource, we are able to see a particular form of biobank where value is not situated solely in samples or links to individuals, or in its potential for research or market exchange, but in ongoing, biosocial participation by the engaged volunteer. While biosocial participation here does not neatly reflect more established kinds of groupings presented by Novas (2006) in his work on patient groups, the BioResource does, nonetheless, present a case where new groupings of biologically knowable volunteers are being formed and used for knowledge production. The BioResource is predicated on individuals acknowledging the importance and potential of biology, in particular genetics, in health research and believing they have a role to play in this research. However, in the case of the BioResource, as framed above and below, there is also a duty to participate; the BioResource produces "experimental subjects" (Sunder Rajan 2008) from the citizenry at large. Our focus here however is on how participation in the BioResource, along with the mundane, everyday work of BioResource staff, facilitates value and extends our understanding of the labours involved in this production process.

### 3. Methods

The BioResource where this research took place is located in one of the NHS Trusts in London, England, where four of the thirteen infra-

structures are based. Data was collected over a ten-month period. Interested in the mundane work of BioResource biobanking, we spent one day a week observing the everyday activities of the BioResource, including recruitment and office work. We attended weekly team meetings, one national BioResource coordinators' meeting and monthly management meetings within the NHS Trust. We conducted semi-structured interviews with seven of the eleven individuals employed by the NHS to work for the BioResource during the research period. Three members of staff, including the previous BioResource Manager, and two research assistants, left before the interviews took place. Of these three, only the manager was replaced. The other individual, the research nurse, declined to participate in an interview, giving no reason, but agreed to be observed. Interviews lasted on average 43 minutes. Despite having different roles, for example, laboratory technician or BioResource manager, all staff were involved in active recruitment. Interviews focused on their everyday work activities including the recruitment process, interactions with current BioResource volunteers and other BioResources and the interviewee's understanding of the role and function of the BioResource. These were recorded and transcribed verbatim. All resulting data was open-coded and analysed thematically (Miles and Huberman 1994). Codes were discussed with and agreed by all authors. In the following sections, we explore the everyday realities of doing BioResource work. Unless otherwise stated, we use "BioResource" to refer to our specific BioResource research site and not the overarching federation of thirteen locations.

To maintain the anonymity of the research participants, pseudonyms have been used throughout.

#### **4. Forming the BioResource**

The BioResource was established in 2014 with the target to recruit 10,000 volunteers in a two-year period. To meet this ambitious goal, the BioResource initially employed six members of staff - a manager, a research nurse, a research assistant, an administrator, a database coordinator and a laboratory technician. All staff were trained in the recruitment process, but only the research assistants and research nurse were able to take blood samples from volunteers. When not contributing to recruitment work, the other staff supported the BioResource by processing samples, managing data, reporting to management and organising the everyday activities of the BioResource. During our fieldwork, staff numbers fluctuated due to staff attrition and the employment of additional research assistants.

Staff numbers and structures differed between the local BioResources. This was particularly evident when we attended a National BioResource meeting. Some had small teams but partnerships with other organisations. Others had large teams who not only recruit for the BioResource but oth-



er projects too. While the overall aim of recruiting volunteers to join the BioResource was consistent across different BioResources, recruitment strategies and practices were dictated by local NHS Trust managers, a point returned to in the next section.

Interested in the development of the BioResource at a local level, we pursued the process of setting up the BioResource with James, the database coordinator and the only member of staff who had worked at the BioResource from its inception. His initial task was to build from scratch the database that houses all volunteer information and draft the data procedures for staff. He was supported in this process through three monthly meetings with other data coordinators. However, there was no common database framework from which to start. The disconnect between national infrastructure and local practice from the very beginning, particularly the lack of a common database, was not lost on James, especially now that local BioResources are trying to integrate datasets, as he explained:

We've encountered some issues. I mean, the whole purpose of the BioResource in the first place was to have a national database. 100,000 people in the database [...]. The first years it was 10,000 patients [per local BioResource], then it was going to be merged into sort of a national database. The issues [we]'ve been hitting are merging each local BioResource's database into a national one. We haven't got there yet. We're still working on it but there's obviously lots of issues involved with data types and [getting] everybody working from the same page because there's not a centralised [system]. [...] It's not been organised from the top, it's been very federalised. Each BioResource is working to their own standards and things, so that's been an issue where when you want to actually merge it together.

(James, Database Coordinator)

This image of the National BioResource, developing from the bottom up in a “federalised” way with different local database systems, contrasts with more sophisticated biobanks like *UK Biobank* and *23andMe*. Mapping fields between databases, streamlining recording and coding practices are all necessary prerequisites for an integrated and efficient system. James' acknowledgement that the merge of records was not to take place until the “10,000 patients” target was met infers a priority for recruiting volunteers over other aspects of work. This is reflected in our experiences in the field and represents an important point of disjuncture in understandings of the site and stability of value. We explore these themes in the next two sections.

## 5. Recruiting BioResource Volunteers

The BioResource's initial recruitment strategy targeted outpatient clinic attendees. BioResource staff trained clinic staff (clinical nurses and phlebotomists) to recruit for the BioResource as part of the patient's visit

to the hospital. Fitting into wider imperatives to support and facilitate research within the NHS, as discussed earlier, the BioResource attempted to situate itself within such a narrative where recruitment activity is part of routine hospital work. With the paperwork completed and blood or saliva samples obtained by clinic staff, the BioResource team would then process this information. This approach to recruitment, however, proved difficult. An unpublished BioResource report on barriers to recruitment stated that clinical staff did “not recognise [BioResource recruitment] as part of their routine duties”, despite the national drive for research and this project taking place in a research-intensive hospital. This report also stressed that clinical staff see “no evidence of benefits for their careers” by contributing to BioResource recruitment work and that the “relevant managers/Principal Investigators do not ensure recruitment is happening.” Equally pressing were the “staffing issues and busy clinical workload” that prevent the undertaking of additional work. These barriers were reflected in informal conversations with the BioResource staff. Completing recruitment in this way not only relied on clinic attendees being receptive and willing to join the BioResource, but on clinical staff seeing research work as a crucial and routine part of their everyday work. This account speaks to a broader disconnect between the stretched healthcare workloads of hospital staff and the vision of a research-led NHS where research is embedded in everyday practice.

With a target of recruiting 10,000 volunteers, pressure to increase BioResource volunteer numbers was high. Local hospital management meetings often involved discussion of recruitment numbers and targets. Jennifer, the former BioResource Manager provided some context to this focus on numbers. She explained that participant recruitment is important in the research function of the hospital. Recruitment data is tracked and has implications for the NHS Trust and its future NIHR funding. As such, the accumulation of BioResource volunteers received significant attention. With the limited success of recruitment in outpatient clinics, senior NHS managers suggested a more direct method - weekly stalls in public spaces at the different hospital sites (Unpublished BioResource Recruitment Strategy 2015a). Approved by the hospital Trust, and enacted by Jennifer and her team, the adoption of this method not only asserted the importance of research to the hospital but presented communal hospital spaces as legitimate sites for research recruitment work. It transferred the responsibility and enactment of recruitment work from clinicians to BioResource staff and provided the BioResource with access to those visiting the hospital, not just those attending appointments. To support this greater focus on active recruitment work, two additional research assistants were employed. Figure 1 shows recruitment data for the BioResource. The adoption of stall-based recruitment occurred at Month 10, demonstrating the substantial increase in volunteer numbers this approach generated.

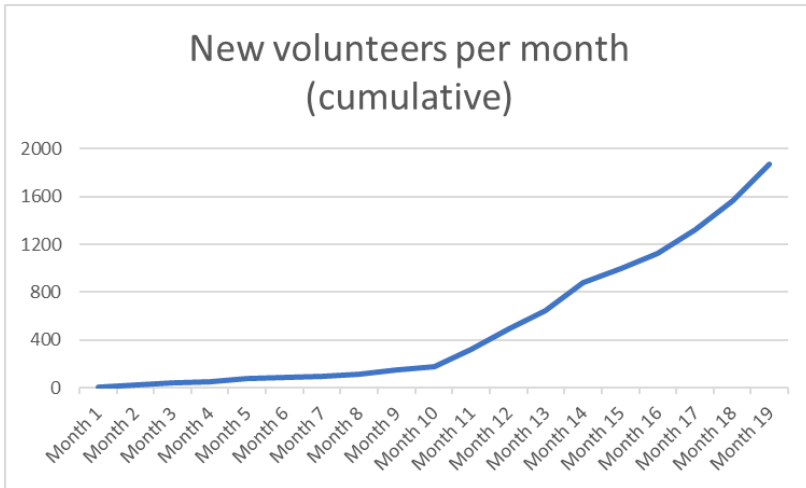


Fig. 1 – BioResource recruitment data  
(Unpublished BioResource Recruitment Strategy 2015b).

When our fieldwork commenced, these stalls were embedded in routine recruitment work, and staff had developed strategies to perform recruitment in this public setting. Sitting in a weekly BioResource staff meeting early in our research, we observed some of the mundane discussions and decisions that take place in facilitating this type of recruitment. They decided who would attend each of the hospital sites the following week and on which days, the recruitment targets by site and by day, and when couriers would be required to move blood samples to the laboratory site. News was shared about the previous week’s recruitment figures and a recent senior management meeting. At the end of this meeting, interested in how the stall recruitment process works in practice, we asked how they recruit in these public spaces. The BioResource staff’s responses reflect David’s experience, reported in the introduction. Stressing that they do not actively approach individuals, they explained that they use “the stand”, “banners”, “put catchy stuff on the table” and “offer mugs”, all to attract the attention of those on the corridor. In an interview with Matt, a Laboratory Technician we probed further:

Normally we would have something, I don’t know, fun maybe on our table. We might have a model of DNA or something and you would just make a remark about that maybe and try and engage them in a little bit of light conversation. Then introduce the thought of ‘do you want to actually partake in some medical research?’ I mean for people who actually go on the stall regularly I think it’s quite hard to be motivated and keep repeating the same [thing]. (Matt, Laboratory Technician)

These stalls were set up for five hour periods with up to three Bio-Resource staff members there at a time. Matt's account presents an ideal situation where the potential volunteer approaches the table and then he can start speaking to them and introduce the BioResource. However, the need for substantial motivation, repetition and the location in busy public spaces, imply the difficulty of this work. The generally polite hospital visitors were often either unwilling to participate or unwilling to commit to the twenty minutes necessary to complete the relevant forms and provide a blood sample. While this recruitment site was more fruitful than the clinic, a good day still only resulted in ten new volunteers against their 10,000 volunteer target.

These stands present a particular vision of participation and the Bio-Resource. With a model of the double helix representing "science" and a leaflet and banner both proclaiming "Research Needs You", reminiscent of the British 1914 wartime call to arms, "Your Country Needs You", participation in scientific advancement is presented as a collective, national duty. While this rhetoric is in line with *Going the extra mile*, mentioned above, it differs from the motives reported by staff through their interactions with volunteers. They reported volunteers emphasising "giving back" to the community or to the hospital for the care they received, having an illness themselves or having family or friends with an illness and wanting to help future research. While altruism is a convenient framework in which to understand volunteer action, as mentioned above, rationales for health research participation focusing on altruism alone oversimplify a complex array of motives. Nonetheless, these motives, however compelling, did not result in huge jumps towards the 10,000 volunteer target. Furthermore, the practice of using public spaces for this recruitment, such as hospital corridors raised some concerns for staff:

I don't particularly like the stall that much because for me, personally, if I were walking down a corridor, and it's a busy corridor, and somebody stopped me and I have to fill out information that might require disclosing my medical condition, I wouldn't feel comfortable doing it in an open space. (Claire, Research Assistant)

Despite airing this unease, practice did not change and corridor recruitment remained the main recruitment strategy. In authorising this work to take place in the corridor at an institutional level, the push to increase the number of volunteers trumps the ethical concern of privacy, raised by Claire. Our observations of everyday work and NHS management meetings reinforce this focus on increasing volunteer numbers. Numerous line graphs were projected on walls and distributed in handouts. Tables breaking down recruitment by hospital site and clinic were discussed and unpicked. Upward trends, such as that presented in Figure 1, were used as markers of success, milestones were celebrated

with cakes for the BioResource staff, from the first volunteer to the x thousandth. This association between the accumulation of volunteers and ideas of success was also present in numerous pieces of formal documentation (Recruitment Strategies and management reports), information presented at National BioResource meetings and in weekly team meetings, where recruitment statistics and targets formed a staple component. The focus on increasing numbers presents the value of the BioResource and its potential to contribute to the bioeconomy as situated firmly in the one-time clinical labour of volunteers joining the BioResource. This is an asset to be accumulated and is the central focus of the BioResource.

Even when acknowledging the ongoing relationship with volunteers necessary for the BioResource to function as a broker of research participants, participation in later research is either assumed or ignored. Such an approach is consistent with the assumption that participation in research is a duty but is not reflected in the laborious process of recruiting small numbers across extended periods of time. BioResource staff, however, acknowledged more is necessary to transform this closed repository into a useful and valuable resource in the research process – as Claire notes, “...even though they've said yes, you can't really do anything with the sample unless you contact them a second time and they say it's OK.” As Claire recognises, recruiting a volunteer to the BioResource is just the first step in contributing to future research. Aware of the importance of volunteers remaining open to participating in future research through the BioResource, staff discussed the need to do something to develop and nurture a longer-term relationship with volunteers. Looking to the original BioResource in Cambridge as an example of success in this type of bio-banking, the BioResource staff noted how Cambridge incorporated engagement activity into their routine practices. With this precedent, and staff agreement, Jennifer decided they should also complete some engagement work with BioResource volunteers.

## **6. Engaging BioResource Volunteers**

Sat around a table scattered with pens, paper, plates of biscuits and mugs of steaming coffee, BioResource staff discussed what they could do to enhance and develop a relationship with BioResource volunteers. They had many ideas - from newsletters to performance art, social media platforms to public debates. While some ideas were already used by other BioResources, such as social media platforms, these were not viable options for the BioResource as they did not have the capacity to run social media accounts and maintain their recruitment activity without increasing staffing. This limited the type and extent of engagement activity the Bio-Resource could commit to. They focused on on-going engagement activities as opposed to a one-off effort. Equipped with a small budget from the BioResource's own funds, limited staff time and

guided by Cambridge who also use this method, they decided to produce a biannual newsletter for all volunteers.

The resulting newsletter, completed over an eight-month period, went through six substantive versions. BioResource staff sketched infographics; decided on exact content; drafted, redrafted and edited text; calculated postage costs; and arranged a platform to host and monitor the electronic version of the newsletter. The content provided updates on the BioResource, details of the recruitment figures and news on the BioResource team. The BioResource was situated in the context of the National BioResource and readers were told about the process of collecting and storing volunteer samples, data and the potential use of this data. The newsletter also provided accounts from volunteers, describing their experiences of joining the BioResource and the positive benefits of health research. BioResource staff had hoped to include examples of how the BioResource itself has contributed to medical research but as it was relatively recently established this was not possible.

The resulting newsletter did have an effect, as Helen the BioResource Manager highlights:

When we sent our recent newsletter out, people were keenly replying saying 'you haven't contacted me yet, do you want me?'. They're so keen to be involved, which is really good when you think about it because the first lot were emailed out and, you're a busy person too, not everybody looks at their emails religiously. It's good that people are responding positively and clicking through. (Helene, BioResource Manager)

Luke, the Database Administrator, expanded further on these interactions sparked by the newsletter:

We sent out some newsletters recently and we are getting responses back, so I had to reply to these people, lots of them. [...] Some wanted to join the BioResource as well, having heard about it from family. [...] We got some [responses] where people were very happy to receive the newsletters and to know that they are really contributing, assisting the BioResource. Some wanted to know if there are studies which they can participate in. They were really willing. (Luke, Database Administrator)

Luke and Helen's accounts present an encouraging response to the newsletter. The newsletter served to inform and generated interaction from some volunteers. It also resulted in the recruitment of new volunteers through introductions from the existing cohort. Luke's account reflects this positivity. Responses such as these led the BioResource to judge the newsletter a success. This success was particularly focused on its role in creating dialogue between the BioResource staff and volunteers. Staff saw it as a way of reminding volunteers of the BioResource and, by extension, the need to keep contact details up to date and maintain willingness to participate in research. The newsletter became part of an active process

of maintaining and nurturing the utility of the BioResource. These activities and the perceived need to sustain long-term engagement with volunteers present the BioResource as not constituted by the properties of the database entries and samples, but by individuals and their labour.

## 7. Discussion

We have explored how participation in the BioResource is understood by different actors and how this relates to understandings of the site and stability of its (bio)value. Drawing on ethnographic data we document some of the mundane aspects of BioResource work, from recruitment activity through to engagement, along with local and institutional drivers for how these activities are configured. Embedded in these drivers are different understandings of the value of the BioResource. At an institutional level, the BioResource is understood as something with a tangible, stable and material value; it is not contingent on further activity. Graphs plotting upward trends in recruitment numbers are viewed as symbols of success. In this conception, database entries are the asset viewed as of value to the bioeconomy. The institutional understanding conforms to an audit culture where success is measured within the NHS Trust and more broadly by the NIHR through simple metrics. The need to demonstrate consistently increasing volunteer numbers was instilled further by the suggestion, approval and adoption of recruitment in hospital corridors and the provision of dedicated staff for such work. These stalls also present a visible shift in the nature of the hospital, signalling that public spaces within this typical care site are now legitimate sites for recruitment and research work.

Viewing the value of the BioResource as material, the institutional understanding does little to acknowledge that volunteers have not agreed to participate in research studies by joining the biobank. Instead, it follows the logic pressed by the NIHR in *Going the extra mile* that research participation is a duty and, thus, participation can be assumed. In this configuration, it is not altruism (Titmuss 1970) or an imagined community alone (Busby and Martin 2006), but an obligation between citizen and state. While we did not include interviews with volunteers in our data collection, the practices of recruitment and the reported volunteer motives for participation suggest a more complex picture. The recruitment labour of the BioResource staff does not result in large, new volunteer numbers - on a good day, five hours spent on a recruitment stall results in just ten new volunteers and numerous rejections. Citizens do not appear to rush or feel compelled to participate, at a general level, to “give back”.

Whereas at an institutional level increasing volunteer numbers is the focus of the BioResource, its staff acknowledge the importance of also maintaining the existing cohort's willingness to participate and, in doing so, draw on a more granular understanding of the BioResource as a bro-

ker of research participants. Biosocial participation in this context is ongoing, long-term and not to be assumed. It is through our attention to the everyday practices, and the labour involved in BioResource participation, that this disconnect between institutional and local understandings of value and participation is brought into stark relief. In particular, our case study of staff demonstrates the importance of not only considering value, but the varying ways it is assumed, produced and maintained, by different actors. In the context of everyday practice, this occurs through the ongoing labour of BioResource staff and volunteers. The activity of recruiting new volunteers (often absent in other studies) and engagement work of BioResource staff help to target and sustain engagement. A volunteer's clinical labour in joining the BioResource and their free labour (albeit less sophisticated than that envisaged by Terranova (2000) or highlighted by Harris et al. (2013)) in keeping contact details up to date and remaining willing to participate in research are not taken for granted. They are nurtured through engagement activity and, we contend, all contribute to this BioResource's value as a broker of research participants, but also the value of each individual asset, a willing research volunteer. Unlike other conceptions of value in the bioeconomy, which focus on the potential of biological fragments and/or database entries, the BioResource staff's labour present BioResource value as best understood as situated in the ongoing biosocial participation of the willing research volunteer. This value is not fixed, but iteratively produced through the accumulation of more volunteers, and, significantly, through the nurturing of the existing cohort. The practices of the BioResource, through an attention to the everyday labour involved in running this biobank, present participation and value production as an ongoing practical accomplishment. In doing so, it further highlights the limits of using the concept of clinical labour alone to conceptualise biovalue production and the process of participants giving access to their *in vitro* biology. While this is an important aspect of BioResource participation, the ongoing labour of participants and BioResource staff in maintaining involvement are needed to produce value in an ongoing way. The BioResource complicates understandings of the site of (bio)value as the result of commodity exchange or the production of knowledge assets. In the case of the BioResource, value resides not only in the biological fragments and associated data held within the database, but most significantly in the maintained willingness of these genetically and phenotypically known individuals to engage in future research projects.

As one example of the developing research capacity of the NHS, our study of the BioResource and BioResource routine work highlights different ways in which emerging research infrastructures, their value as well as citizen participation can be envisaged and understood by actors. We provide insight into this process by focusing on labour and value production. We have not examined how the BioResource translates its value into varying forms of capital by fulfilling its purpose of brokering willing research



participants. A focus on the performance of this brokering role would help illuminate how value circulates and for whose benefit. Although important questions for further research, these points are beyond the scope of this paper. Our account does, however, foreground the importance of considering the routine labour involved in running a biobank and the role it can play in (bio)value production and expand our understanding of the potential sites and scope of (bio)value beyond fragments, to include long term biosocial participation of engaged volunteers.

## 8. Conclusions

In this paper we have highlighted how volunteer labour, staff labour and ongoing volunteer participation converge in the work of the BioResource and in value production. Value, in this context, is produced not in the laboratory or situated in the partible sample of the individual, but in the willingness of the BioResource volunteer to participate in future research. We demonstrate the different ways the value of the BioResource is understood from within the NHS, with management focused on the accumulation of biobank entries and BioResource staff working both to increase volunteer numbers and maintain the engagement of existing volunteers in this biobanking project. We contend that BioResource draws into relief the routine labours involved in the value production process. Clinical labour and free labour may present certain aspects of this activity, but they fall short of encapsulating the numerous decisions and negotiations that are involved in the everyday work of maintaining (the value of) volunteers. The BioResource presents an example of a biobank where value is not fixed or predictable, but iteratively constructed through the ongoing labour of volunteers and staff. In doing so, it questions the limits of existing conceptions of value as commodity or asset and of clinical labour as the (sole) means of value production.

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## References

- Adams, M. and McKeivitt, C. (2015) *Configuring the Patient as Clinical Research Subject in the UK National Health Service*, in “Anthropology & Medicine”, 22 (2), pp 138-148.
- Birch, K. and Tyfield, D. (2013) *Theorizing the Bioeconomy: Biovalue, Biocapital, Bioeconomics or... What?*, in “Science, Technology, & Human Values”, 38 (3), pp. 299-327.
- Busby, H. and Martin, P. (2006) *Biobanks, National Identity and Imagined Communities: The Case of UK Biobank*, in “Science as Culture”, 15 (3), pp. 237-251.
- Chadwick, R. and Berg, K. (2001) *Solidarity and Equity: New Ethical Frameworks for Genetic Databases*, in “Nature Reviews Genetics”, 2 (4), pp. 318-321.
- Cool, A. (2016) *Detaching Data from the State: Biobanking and Building Big Data in Sweden*, in “BioSocieties”, 11 (3), pp. 277-295.
- Cooper, M. and Waldby, C. (2014) *Clinical Labor: Tissue Donors and Research Subjects in The Global Bioeconomy*, Durham, Duke University Press.
- Corrigan, O. (2004) *The Contradictory Ethical Safeguards in Pharmacogenetics*, in R. Tutton and O. Corrigan (eds.), *Genetic Databases: Socio-Ethical Issues in the Collection and Use of DNA*, London, Routledge, pp. 78-96.
- Department of Health (2006) *Best Research for Best Health: A New National Health Strategy*, London, Department of Health.
- Frow, J. (1997) *Time and Commodity Culture: Essays in Cultural Theory and Postmodernity*, Oxford, Oxford University Press.
- Harris, A., Wyatt, S. and Kelly, S.E. (2013) *The Gift of Spit (and the obligation to return it)*, in “Information, Communication & Society”, 16 (2), pp. 236-257.
- Hoeyer, K. (2006) *The Power of Ethics: A Case Study from Sweden on the Social Life of Moral Concerns in Policy Processes*, in “Sociology of Health & Illness”, 28 (6), pp. 785-801.
- Lipworth, W., Forsyth, R. and Kerridge, I. (2011) *Tissue Donation to Biobanks: A Review of Sociological Studies*, in “Sociology of health & illness”, 33 (5), pp. 792-811.
- Malby, R. and Hamer, S. (2016) *Creating an Innovative and Research Culture in a Complex System*, London, National Institute for Health Research.
- Medical Research Council (MRC) (2001) *Human Tissue and Biological Samples for Use in Research*, London, MRC.
- Melham, K., Moraia, L.B., Mitchell, C., Morrison, M., Teare, H. and Kaye, J. (2014) *The Evolution of Withdrawal: Negotiating Research Relationships in Biobanking*, in “Life Sciences, Society and Policy”, 10 (1), 16.
- Miles, M. B. and Huberman, A. M. (1994) *Qualitative Data Analysis: An Expanded Sourcebook*, London, Sage.
- Mitchell, R. (2012) *US Biobanking Strategies and Biomedical Immaterial Labor*, in “BioSocieties”, 7 (3), pp. 224-244.
- Mitchell, R. and Waldby, C. (2010) *National Biobanks: Clinical Labor, Risk Pro-*

- duction, and the Creation of Biovalue, in "Science, Technology, & Human Values", 35 (3), pp. 330-55.
- National Institute for Health Research (2015) *Going the Extra Mile: Improving the Nation's Health and Wellbeing through Public Involvement in Research*, London, National Institute for Health Research.
- Novas, C. (2006) *The Political Economy of Hope: Patients' Organizations, Science and Biovalue*, in "BioSocieties", 1 (3), pp. 289-305.
- Shickle, D. (2006) *The Consent Problem within DNA Biobanks*, in "Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences", 37 (3), pp. 503-19.
- Steinsbekk, K.S., Ursin, L.Ø., Skolbekken, J.-A., Solberg, B. (2013) *We're not in It for the Money – Lay People's Moral Intuitions on Commercial Use of 'Their' Biobank*, in "Medicine, Health Care and Philosophy", 16 (2), pp. 151-162.
- Sunder Rajan, K. (2006) *Biocapital: The Constitution of Postgenomic Life*, Durham, Duke University Press.
- Sunder Rajan, K. (2008) *Biocapital as an Emergent Form of Life*, in S. Gibbon and C. Novas (eds.) *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*, London, Routledge, pp. 157-187.
- Terranova, T. (2000) *Free Labor: Producing Culture for the Digital Economy*, in "Social Text", 18 (2), pp. 33-58.
- Titmuss, R. (1970) *The Gift Relationship. From Human Blood to Social Policy*, Oxford, George Allen and Unwin.
- Tutton, R. (2002) *Gift Relationships in Genetics Research* in "Science as Culture", 11 (4), pp. 523-42.
- Tutton, R. (2007) *Constructing Participation in Genetic Databases: Citizenship, Governance, and Ambivalence*, in "Science, Technology, & Human Values", 32 (2), pp. 172-195.
- Tutton, R. and Prainsack, B. (2011) *Enterprising or Altruistic Selves? Making Up Research Subjects in Genetics Research*, in "Sociology of Health & Illness", 33 (7), pp. 1081-95.
- UK Biobank (n.d.) *About UK Biobank*, in <http://www.ukbiobank.ac.uk/about-biobank-uk/> (retrieved December 14, 2017).
- Waldby, C. (2002) *Stem Cells, Tissue Cultures and the Production of Biovalue*, in "Health", 6 (3), pp. 305-23.
- Waldby, C. and Mitchell, R. (2006) *Tissue Economies: Gifts, Commodities, and Biovalue in Late Capitalism*, Durham, Duke University Press.
- Wienroth, M., Caffrey, L., Wolfe, C. and McKeivitt, C. (2018) *Patient-initiated Recruitment for Clinical Research: Evaluation of an Outpatient Letter Research Statement*, in "Health Expectations", 21, pp. 494-500.
- Woolley, J.P., McGowan, M.L., Teare, H.J.A., Coathup, V., Fishman, J.R., Settersten, R.A., Sterckx, S., Kaye, J. and Juengst, E.T. (2016) *Citizen Science or Scientific Citizenship? Disentangling the Uses of Public Engagement Rhetoric in National Research Initiatives*, in "BMC Medical Ethics", 17 (1), pp. 1-17.