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Genomics at scale: participation to build the bioeconomy

Genomic research, with the aim of developing personalised cancer therapies, is not just being pursued through trials or smaller-scale studies in cancer clinics and laboratories. It is increasingly taking place on larger, national and industrial scales too, as data is gathered *en masse* from patients and publics (Hilgartner 2017). In this chapter we investigate one such flagship national genomic sequencing programme to explore how genomic data, alongside other health and social data, is being gathered via mainstream healthcare services and shared with companies so that its value can be rendered into new molecular profiling technologies and targeted drugs. Focusing on Genomics England's 100,000 Genomes Project, we trace the ways in which data-rich healthcare futures are being crafted via cancer patients' and professionals' engagements with whole genome sequencing (WGS), exploring how participants' everyday experiences sit within a wider nexus of complex relationships and rearrangements of the NHS. Throughout we trace the kinds of futures articulated and mobilised by 'the genomics vanguard' (Hilgartner 2017: 27) of politicians and policymakers, together with the experiences of practitioners and patients, contrasting bigger promissory futures with the range of contingent, sometimes doubtful, at other times quietly hopeful futures crafted by patients and practitioners involved in making this initiative happen on the ground.

We could tell the story of the development of these initiatives through familiar framings of innovation, focusing on the rapidly advancing capacity and reduced costs of DNA sequencing and information technology as the main driver of progress. But to do so would be to miss some of the crucial political, economic and organisational changes in how data, institutions and value are being

reconfigured to enable and extend these initiatives, changes which official discourses of success tend not to register. As Hilgartner has argued, to understand how technoscience such as genomic sequencing is a vehicle for the transformation of mainstream healthcare, we need to engage with the political and economic processes at stake, or in Hilgartner's words, 'how institutions, discourses, identities, constitutions, and imaginaries shape modes of decision making and guide public reason' (2017: 6). This includes tracing the production and effects of promissory and official discourses that underpin these developments: the futures envisaged for patients, services and the nation, the measures and processes underpinning governance and successful implementation, and the personal stories and affective repertoires of practitioners, advocates and participants. Considering what kinds of value are created for whom through these processes, and the work this involves for particular actors, is also key to our analysis, including with respect to how it is revealed or obscured in practice, replicating or subverting the roles ascribed to key actors through official discourses.

We interviewed a range of practitioners involved with the project at one institution which was part of a regional consortium – four of the project leads, the three nurses involved, and clinicians and scientists involved in implementation (including nurse consultants, histopathologists, pathologists, geneticists, oncologists, clinical scientists and biomedical scientists). We also observed 16 consenting clinic sessions (sometimes with two or three patient appointments) and interviewed 17 patients and three family members about their experiences of taking part in the project after these consent meetings. Interviews and observations were carried out between 2016 and 2018. We spoke to patients affected by breast, colorectal, gynaecological, brain and blood cancers. Participants ranged in age from the forties to the eighties. Some of these patients were in the early stages of breast cancer, prior to treatment, others were in remission following surgery for colorectal cancer, and some had more advanced or recurrent breast, brain or gynaecological cancers or were on long-term maintenance treatments for blood cancer.

In the next section, we trace how the promise of national genomic data and its analysis are articulated and realised as a form of economic growth and marketising public services, focusing on the 'knowledge-control regimes' (Hilgartner 2017: 13) of bioethics and

the 'participatory turn', arguing that both are crucial to the realisation of biovalue from these large-scale programmes. This includes two important 'governing frames' (Hilgartner 2017: 13) which elaborate previous forms of participation – extending informed consent and public engagement/participation, including via evolving ideas and practices of 'genomic literacy'.

Genomics and the health of the nation

As Fortun wrote in his ethnography of the Icelandic genomics company deCODE's sequencing of the genomic assets of the Icelandic nation:

> Genomics is building new zones of intensities, places in and between the lab, the corporation, the experimental assemblage … the successful scientists and corporations will be those who can continually rearrange software, hardware, netware into hybrid combinations that create new intensities … Completion isn't promised by genomics, future becomings are. (Fortun 2008: 47)

A decade after these insights, we see the further intensification of value in a complex global network of market-data assemblages offering the promise of further growth in the bioeconomy. Companies set up by nation-states, such as Genomics England, commercial actors and state-based assets such as the NHS all operate in these zones. A great deal of attention is focused on commercial direct-to-consumer genomic tests. But the marketisation of genomic data is taking place through the auspices of public health providers such as the NHS as well. This involves key partnerships with commercial organisations involved in sequencing and analysing genomic and other NHS data in order to build capacity in the UK bioeconomy.

Since its establishment, Genomics England has developed complex governance arrangements to ensure that companies working with patients' genomic data are appropriately vetted, and that the data remains secure. Companies involved in this work become service providers, which might involve providing data and/or the interpretation of data or other technical services. These companies range in size and scale, but their international links to other national sequencing endeavours are clear. For example, Congenita, a spin-out company

from the UK's Sanger Institute, funded by the Wellcome Trust, developed its clinical decision support software called Sapientia through involvement in Genomic England's 100,000 Genomes Project. In 2018 Congenita signed Memorandums of Understanding with Chinese companies and health providers at a trade event in China, which took place alongside a state visit by the then prime minister, Theresa May. These meetings received considerable press coverage in the run-up to Brexit as they became, for some, emblematic of the UK's capacity to develop global markets beyond the EU. The company's press release noted:

> Underlining Congenica's expansion and potential in China, it was one of only 5 UK companies to attend the signing event held in Beijing. Hosted by UK Secretary of State for International Trade, Dr Liam Fox, and China's ex-Vice Minister for NHFPC, Jin Xiaotao, each Government set out their vision for the future of digital health and confirmed the opportunities for international collaboration and trade.

The press release went on to give details of how the company had previously entered into an agreement to provide services for the Chinese '100K Wellness Pioneer Project', hosted by the Beijing 4P Health Research Institute. Congenita also has a contract with BGI Genomics in China and Series B fundraising to build its business, including investment from BGI.

The 100,000 Genomes Project emerges as more than just a project to provide UK patients with genomic information and the possibility of targeted drugs sometime in the future. It is also more than a matter of delivering sequencing and laboratory services differently in English hospitals: it is part of the development of the UK's commercial capacity, spun out by scientists who established their research with support from philanthropic and public funders committed to open genomic data, as UK businesses become embedded in a major new venture to transform the healthcare system through genomics.

The development of national genomic sequencing initiatives is not just driven by technological breakthroughs and reducing sequencing costs, as popular histories of genomics would have it. Instead this process was fundamentally enabled by a key set of political and institutional changes, led by state-actors and agencies and aimed at opening up population data and markets simultaneously. This is not so much a story of the 'invisible hand of the market' in Adam

Smith's famous formulation, as it is a story of the 'invisible hand of the state' (Goven and Pavone 2015). Monetising the nation's genomic assets is part of the marketisation of publicly funded health systems such as the NHS in post-austerity Britain (Hockings 2014).

This vision for genomic sequencing at scale, embedded across the health service, was largely 'top down' – what Hilgartner (2017: 27) calls a 'vanguard vision'. It was not broadly conceived within the scientific or medical community or the wider nation, but generated within elite scientific and government establishments. As Samuel and Farsides (2017) have written, the roots of what would become Genomics England can be traced to a House of Lords Science and Technology Committee report from 2009 (whose special advisor was Professor Tim Aitman, who would later become one of the leaders of the Scottish Genome Partnership), where the committee argued for 'a strategic vision for genomics in the UK'. The government set up the Human Genomics Strategy Group in response, chaired by Professor Sir John Bell, who would go on to sit as a non-executive director on the board of Genomics England. Bell also holds this position on the board of Roche (a prominent pharmaceutical and genomics sequencing company) as well as a host of other public and corporate appointments, including a period as president of the Academy of Medical Sciences (2006–11). The group's 2012 report, *Building on our inheritance: Genomic technology in healthcare*,[1] articulated the vision on which Genomics England would be based. Bell wrote in the Foreword:

> At present, we are in a position of strength. As the recent life sciences strategy highlighted, the UK is a recognised world leader in biomedical sciences and is home to many of the leading academic and commercial research centres spearheading the global development of genomic medicine and furthering the use of Clinical Genetics. This gives the UK an outstanding opportunity to exploit its scientific lead, via the NHS – a unique service delivery environment in which clinically validated genomic medicine will be able to thrive. The challenge is to make our vision a reality for the benefit of the NHS, for the benefit of the UK biomedical industry and, above all, for the benefit of patients and their families.
>
> It is also to move sufficiently rapidly that our leadership position is not undermined by other countries who have also recognised this opportunity and are now pursuing it. (Human Genomics Strategy Group 2012: 3–4)

The emphasis on leadership, nationhood, economic growth and the NHS as a valued public asset to be put to work to preserve its benefits for patients now and in the future has come to dominate the promissory discourses of this emergent field (Tarkkala et al. 2019). This gives a particularly British twist to the emphasis on genomics as a platform for global transformation, captured in a McKinsey Global Institute report of 2013 which called it one of 12 disruptive technologies that will 'transform life, business, and the global economy'.[2]

In the midst of a prolonged period of austerity in the UK, genomic research became a vehicle through which the British state, together with scientific and medical funding bodies and institutions, could transform the NHS to advance economic growth and social benefits in partnership with the private sector. Genomics England was set up as a state-owned company to coordinate and deliver these benefits, working in partnership with charitable funders and the private sector to sequence 100,000 genomes of cancer and rare disease patients by 2017. At a time when state funding to healthcare services was being reduced,[3] an initial £100 million of government funds was directed towards this flagship project aimed at transforming the NHS. This was part of a package of deals estimated to be worth £300 million, including a contract with the sequencing company Illumina (Sample 2014). The launch of the 100,000 Genomes Project was timed to coincide with the 65th anniversary of the NHS, and was given the personal backing of the then prime minister, David Cameron. Cameron focused on the transformation of the diagnosis and treatment of 'devastating diseases' in the NHS and beyond. Genomics England's press release at the time described the project as 'world leading research organisations join[ing] forces'.[4] The deal with Illumina was reported as being worth around £78 million for the company to deliver WGS, but it was also noted that Illumina would invest more than double this amount in this work in England, 'creating new knowledge and jobs in the field of genomic sequencing'. Alongside Illumina, the Wellcome Trust also invested a further £27 million in its Genome Campus in Cambridge where Genomics England's operations would be based, together with the Sanger Institute, one of the leading institutions involved in the Human Genome Project. This clustering of investments and location was further enhanced by Medical Research Council funding of £24 million to develop computing capacity and an NHS contribution of £20 million.

As well as building infrastructure, transforming healthcare and economic growth to position the UK at the forefront of the 'global race to implement genomic technology', it was noted that the expectation was that 'around 40,000 NHS patients could benefit directly from the research'. A transformed NHS was positioned as leading the way in contemporary healthcare through this initiative. The press release on the launch of Genomics England quotes Simon Stevens, NHS England's chief executive at the time:

> The NHS is now set to become one of the world's 'go-to' health services for the development of innovative genomic tests and patient treatments, building on our long track record as the nation that brought humanity antibiotics, vaccines, modern nursing, hip replacements, IVF, CT scanners and breakthrough discoveries from the circulation of blood to the existence of DNA.
>
> The NHS' comparative advantage in unlocking patient benefits from the new genomic revolution stems from our unique combination of a large and diverse population, with universal access to care, multi-year data that spans care settings, world-class medicine and science and an NHS funding system that enables upstream investment in prevention and new ways of working as demonstrated by this ground-breaking 100,000 Genomes Project.

In a session at the 2017 Bio International Convention, David Cameron, a prominent backer of the project, described his role in setting up the 100,000 Genomes Project as having been shaped by his experience of being a father to Ivan, his disabled son, who had a rare disease (and died at the age of 6 in 2009). He said that this had had a big influence on his thinking about science, discovery and life sciences, and was one of the reasons he commissioned the 100,000 Genomes Project and had the first sequenced genome delivered to his desk. Cameron said that he wanted to develop the life sciences and the wider economy through this project, reflecting that the NHS has the advantage of enormous amounts of usable data on which the project would draw.[5] He also referred to another feature of the discussions and politics around the NHS during his government, which focused on failings and reforms. Cameron had written about this in the tabloid newspaper *The Sun* one year before the official launch of the 100,000 Genomes Project. Additionally, in a report in *The Telegraph* his criticism was set out in emotive language of 'love' for the 'national treasure' that is

the NHS, shaped by his experience of being a father to Ivan, yet contrasted with the need to deal with the problems of 'cover ups' and elderly care, and the need for medical advances in the NHS: 'We don't demonstrate that love by covering up things that go wrong. Or by pretending the NHS can just ignore the big challenges it faces.'

As a King's Fund report reviewing the NHS under the then coalition government (Ham et al. 2015) noted, Cameron and his government had a troubled relationship with this iconic British institution, spending much of their term of office developing, implementing and trying to repair the problems arising from the fraught Health and Social Care Act (2012) in the face of trenchant criticism from medical and patient communities. Cameron had to temper his focus on privatisation, service improvements and marketisation through this period, turning to focus on patient needs, for example through a commitment to keeping waiting times down.

The 100,000 Genomes Project was the ideal vehicle for transformation in this fraught context; a way of generating value by capitalising on the assets of the NHS, transforming the bioeconomy and healthcare for the twenty-first century. Its success hinged, above all, upon patients and their families participating in the venture, which, in turn, relied upon the trust and confidence of patients and the wider public. This would build on other large-scale projects, such as UK Biobank, and draw on the UK's global reputation for robust oversight via bodies such as the Human Genetics Commission. The Commission had, in fact, been disbanded in 2012 as part of a process of removing Whitehall 'quangos', so a new committee and oversight process had to be established as part of Genomic England's work. The close alignment of the project with NHS data and resources increased the perceived need for comprehensive and robust ethics, not least because of public controversy around the opt-out policies of the failed Care.Data initiative and deCODE Genomics Ltd. A series of public and professional consultation exercises underlined the importance of getting these processes right, given ongoing public concerns about insurance companies accessing data, the moratorium on this practice notwithstanding.

It was within this context that the then Chief Medical Officer (CMO) for England set up a group to provide advice on the ethical issues involved with the 100,000 Genomes Project, led by Professor

Mike Parker from Oxford University.[6] Informed consent was especially salient here, given the difficulties with past national projects such as that of Iceland, and the technical and organisational arrangements around this formed an important part of the group's work. The advisory group outlined what they called an 'appropriate and rational' approach to the ethical issues in a letter to the CMO in 2013. Stressing the guiding principles of decision making and commitments to the public interest, patients and the NHS, they placed considerable emphasis on the processes of informed consent and patient and public involvement and engagement. The group noted that data could not be irreversibly de-identified, so there was a need for data-access agreements and accountable governance processes that would 'provide participants, and the public, with the assurances they require and promote acceptability and involvement', especially since private companies would be involved in testing and possibly also other services. Again, the group stressed the importance of policies and procedures to ensure that commercialisation was in the public interest and of benefit to the NHS to ensure public confidence and participation.

These considerations formed the basis of the group's recommendations about informed consent processes, in which the importance of 'broad consent' that did not present too much of a burden to staff and patients was stressed. This involved considerable refinement and specification of what 'informed' should mean in this context. Although no doubt familiar with the extensive ethical and social scientific literature on how consent in many medical settings is not based on participants making dispassionate choices, but on a mixture of reasoning which depended on the context, including a sense of commitment to the health service and to the professionals involved in their direct care (Corrigan 2003; Dixon-Woods and Tarrant 2009), the committee had to use standard and established governance mechanisms to establish the credibility of the programme. This presented a number of challenges. A key issue was the difficulty of combining consent for data to be analysed as part of care and as part of research, both known and unknown. This blurred the line between care and research in a way that ethicists are often concerned to avoid because of the problem of 'therapeutic misconception', wherein patients consent because they are motivated by an expectation of improved care. This may leave them vulnerable to being misled

or disappointed, rather than enabling a form of 'altruism' which ideally should determine their involvement in the logic of contemporary research ethics (Dheensa et al. 2018).

The importance of securing consent to future use of the data, which would drive the service transformation and economic benefits sought from the programme, was such that patients' opportunities to receive results became conditional on their consent for their data to be used in research. To avoid the need to go back to patients in the future about what precisely this research would involve, given that future uses cannot be known in advance, the group reasoned that a clear governance process for deciding on appropriate use and access would need to be put in place on participants' behalf, and recommended that this should be discussed in the consent process to give participants confidence to proceed. Moreover, they noted, 'participants will also need to understand that consenting to research involves a waiver of any personal rights to benefit from commercial exploitation. Mechanisms will need to be introduced to ensure that the NHS benefits where data from this programme are put to commercial use.' These recommendations narrowed the burden but also the boundaries of choice considerably – participants were given choices about what kinds of additional information they might want to receive, but were not invited to decide what kinds of research their samples or data could be used for. Here the possibilities for future research using the data accrued were deemed more valuable than the opportunities for individual crafting of involvement, the latter of which was seen as more of a potential burden than an opportunity.

Processes for developing and enacting these complex arrangements for informed consent constitute important governing frames in projects of this scale and complexity – they are as key to their realisation as sequencing technologies and laboratory standards. Yet informed consent processes are known to be problematic in practice, given to ritualised and superficial performances, what Corrigan (2003) aptly called 'empty ethics'. The committee therefore tried to make informed consent more meaningful by offering clarity and managing expectations. The group were particularly concerned with the question of how to report back information to patients in this emergent area of medical science, including how clinicians would be supported to make judgements and how families would be supported to manage

the implications of results. The need for participants to make choices about data relevant to other family members had to be managed, as was the need for ongoing professional development and resources for re-contacting patients over time. These considerations point to one of the key challenges in this area: how to make results meaningful in the absence of clear and established protocols for interpretation, given the experimental nature of the science and the complexity of the data involved.

This is part of a new style of scientific governance that Braun et al. (2010) call 'reflexive governance', encompassing participation and engagement with a range of experts, including critical social scientists. Another important aspect of these forms of governance is participation by patients and publics, with a great deal of emphasis placed on inclusion and engagement. Education, support and training for staff and patients was particularly important. This extended engagement and cultivation of ethical participation (Braun et al. 2010) was seen as pivotal to the successful implementation of this part of the programme. A range of responsibilities for practitioners and patients to participate, learn and engage with new choices and forms of interpretation were therefore anticipated, in contrast to the circumscribed rights to choose how one's data might be capitalised, as discussed above. This framed additional responsibilities for a wider pool of potential participants from the public more generally, anticipating an expansion of participation in genomic research in the future. At the same time, the committee also prescribed a range of responsibilities for project leads and other practitioners involved in its delivery to take a role in education and public communication about the project, including about the relationship between the state and the market that is at its heart.

Genomics England took up these recommendations as part of its efforts to 'build a social contract' for the initiative,[7] and went on to establish a detailed informed consent and data governance process as well as a wide-ranging series of events, publications and a website with extensive resources for participants and links to training initiatives for staff. An ethics advisory group also became an established and important aspect of these governance arrangements. The consent form, initially lengthy and complex, went through a number of revisions and iterations as the project proceeded, partly in an effort to clarify and shorten sections to enable the process to be completed in less time. Genomics England has also sought to develop resources

aimed at educating publics, professionals and participants about genomics, after identifying a lack of awareness about this area of science as part of a programme of improving 'genomic literacy'.[8] Here practitioners and publics acquire responsibilities for becoming more educated and educating others about genomics and its implications for health, in order that genomic medicine can be developed successfully. Notable among these initiatives is the 'Socialising the Genome' project, which includes a number of short YouTube videos utilising animation. One of these videos involves a play on the confusion between genomes and gnomes and features a cartoon gnome 'fishing' for pieces of DNA. This is prominently displayed on the Genomics England website and has been taken up in consent processes too.

The Genomics England website as a whole has more resources, case studies and patient testimonies concerning rare disease, as part of its efforts at engagement and education, reflecting the relative success of this part of the programme in terms of recruitment and delivery of results compared with those regarding cancer. For cancer patients there is, instead, a series of hedged statements about the ambition to deliver results in the future, and a lack of specificity about how and when this will happen, which contrasts with some of the earlier stated ambitions for the project. There is also a focus on explaining how the project has evolved and the technical difficulties that have been overcome in the process, for example the move from using formalin-fixed samples to fresh, frozen samples which are easier to analyse.

The website presents project news in relation to the numbers of genomes sequenced and features a counter to illustrate this. Numerical milestones are presented as important markers of success for the project. There is also considerable hype about the benefits of the programme, which sits at odds with the working groups' recommendations in this regard. For example, in a story about more than 70,000 sequences being completed on the 70th anniversary of the NHS, it was reported that Health Minister Lord O'Shaughnessy said:

> Genetic sequencing can revolutionise healthcare by offering truly personalised care to patients and their families. This project is a shining example of a partnership between the public sector, the life sciences industry and the research community – with NHS patients reaping the benefits. Genomic medicine is no longer a thing of the future, it's here now and helping to save lives.[9]

These kinds of promissory claims are more prominent than information about the involvement of commercial companies in the project, which is scattered across the site and difficult to connect together to form a picture of what kinds of roles these companies are taking, and the financial arrangements involved.

Together, these recommendations and practices constitute the 100,000 Genomes Project as a vehicle for the transformation of the national economy and health service, monetising the genomic data of the nation to change how medicine is delivered, and responsibilising practitioners, patients and publics to become genomically literate in order to deliver these benefits. To enable and enact this transformation, institutions, practitioners, publics and patients acquire new responsibilities for participation, engagement and deliberation, but these are carefully circumscribed within a web of governance and educational arrangements which limit participant choices and, for cancer patients in particular, have not delivered personalised information on the scale envisaged by some of the more optimistic accounts of politicians and leading civil servants. The importance of not burdening patients with too much information and too many choices as part of the consent process can be contrasted with the emphasis elsewhere on educating and informing patients about the programme and the science involved as part of 'socialising the genome'. Presented as short, fun encounters, these activities expose and seek to remedy the deficit in public understanding about genomics through a growing portfolio of educational tools and events, which produces an audience with responsibilities to engage in turn. At the same time, however, as we go on to consider later in this chapter, the details of the economic arrangements at the heart of the programme or the choices with regard to investment in personalised therapies versus other kinds of structural public health interventions targeting the causes of cancers are opaque and less easy to engage with and critique.

Transformations in cancer care: participation for practitioners

Transformative visions and the knowledge-control regimes that seek to implement them are, of course, key features of how genomics at scale took shape in the UK bioeconomy. But as Hilgartner (2017) amply demonstrates in the case of the Human Genome Project,

vanguard visions and governance frames are taken up but are also subject to resistance, struggles and challenges. Key actors can reconfigure processes, agendas and envisaged identities, reworking their responsibilities and asserting autonomy in the process.

Our first encounters with the 100,000 Genomes Project were at the early stages of our own project when we made contact with some of the project leaders in a nearby region. From the outset we were invited to be part of the development of a consortia bid for a regional genomics medicine centre (GMC), because the practitioners involved were keen to engage us in developing the participatory and evaluative agendas that they viewed as crucial to the success of their bid and the wider initiative. As part of this we attended a meeting with representatives from Genomics England and the NHS where the bid was assessed and discussed, alongside patient representatives, laboratory and service leads and senior managers from relevant hospitals. This encounter, and discussions prior to and following it, were marked by a sense of the need for the practitioners and managers involved to present a suitably ambitious, coherent and compelling case for support, even as they also expressed doubts and concerns in more private settings about the difficulties that this would involve, given other service and resource pressures. In so doing our gatekeepers simultaneously performed the hopeful promissory futures of genomic medicine and service transformation through recruiting practitioners and other allies to participate in the programme delivery, and a more muted set of concerns and ambivalence about the prospects of success for the science and the services involved. The project leaders adopted a kind of strategic uncertainty as part of their negotiation of the demands for practitioner participation, empathising with the doubts and concerns that were also being expressed by colleagues expected to deliver on the initiative.

Our efforts to be part of the project, to follow how it was developed and enacted locally and to share results were, however, constrained by its complex architecture, changing personnel and difficulties of implementation across different cancer clinics, clinical leads and institutions. Jurisdictional disputes around the ownership and purpose of the project were ongoing, as was ambivalence among key actors about their role and its value. We encountered numerous uncertainties about how the project would be delivered. Consent processes were difficult to observe because of ongoing issues with staff training,

patients not attending, and clinicians not advising staff about suitable patients. The project was being introduced to a service under strain, where efforts to meet waiting time targets and manage staff absence and well-being came into tension with its delivery. Practitioner participation was patchy, uneven and markedly ambivalent.

The project lead, who was tasked with advocacy for the project, nevertheless framed it as the beginning of a new kind of healthcare based on 'big data' and Artificial Intelligence:

> And the Genomics Project is part of the wider personalised medicine agenda of the NHS, which is a top level objective of the NHS. And very few people really quite get what that means. And in reality what it means is that – it's really a big data project, so it looks like a lab based project but it's actually – actually a project about the, the – about leverage of large datasets. And so the end point of the programme really is that genomics data, er, will be merged with all the other data that can be linked through someone's NHS number into a central data repository.
>
> And from that, tools will be developed that can then apply the, the power of that dataset to the care of individual patients. And that's what really personalised medicine – the personalised medicine agenda is about. And that is an enormous transformation in medical care, um, absolutely huge.

But this was not a view that was widely shared among practitioners concerned about the practicalities of implementation. As another clinician involved in leadership of the project commented:

> in order to know what's relevant to that particular patient at that particular point of time of course you've got to know what their cancer is doing at that particular point in time. So it takes us from a situation where you've … almost got to have a real time readout at any point in time to know what are the particular drivers of … this particular patient's cancer which brings us into personalised medicine … and as exciting as that is, the idea of personalised medicine, the practicalities of that are … really … challenging … financially, organisationally, um, um, diagnostically, therapeutically … in terms of comprehension and understanding (laughs), you know, of, of the clinicians and the population – all of those have … got challenges.

This meant that even as this grander vision of healthcare was being articulated at a range of meetings and events, it was hedged with caveats about the complexities of personalisation, not just in terms

of infrastructure, but in terms of the information it brought into clinical practice. As the project lead quoted above continued, the prospects of personalisation and precision were not necessarily straightforward, and could be difficult for practitioners and patients:

> I mean, it's easy if you've got a ninety-five per cent chance of being cured, but if you're saying to somebody, 'Actually, we know from all this data that this is just not going to work,' then that's … something that … people reject. Because if you open the box then you've got the information, if you don't do it in the first place you can just carry on regardless. So that's I think one of the big challenges of this, people see actually personalised medicine as something potentially very, very difficult.

The project leads also spoke of their sense that this project and personalised medicine more generally were 'battling against the biology', revealing much more uncertainty than the rhetoric of precision suggests and that patients might expect, and bringing challenges for practitioners in terms of implementation and interpretation (Metzler 2010).

Practitioners expected to implement the programme in their clinics by supporting patient recruitment also asserted their jurisdiction over healthcare, expressing wariness about top-down initiatives and in the words of one oncologist 'politicians' pet projects', referencing David Cameron's spearheading of the initiative. This oncologist commented: 'Happy to be proved wrong but … I am not a big fan of politicians interfering in healthcare … [with these kinds of initiatives] … we're struggling to pay for other things and I'm not sure it's good value for money.' Others expressed concern about the project being less about evidence-based science than service transformation designed to introduce the automation and centralisation of laboratory services or limit the role of clinicians in interpreting data. This evoked a counter-narrative about the need for clinically embedded analytics, as in the excerpt from an interview with a pathologist below:

> now we … feel strongly that that is in some situations dangerous because a lot of molecular testing is being undertaken by non-clinically … trained geneticists who don't necessarily understand some of the complexities of the material coming in … some centres don't even look at the material that goes through the sequencer so they will, will take sections of pathology material, put it through a box and come

> out with an answer and unless you really understand the details of what's gone in, you can't understand the details of what comes out. So we strongly feel that there needs to be a lot more clinical input … we do have that balance to a degree … working alongside the genetic clinical scientists to deliver the service so we can provide some clinical oversight … But other centres will offer blanket clinical interpretations which may not necessarily be appropriate and the problem is oncologists act on those clinical interpretations, not necessarily if they're, if they're up to speed and they're academic and … they've been to the big meetings recently and they're aware of the evidence and they understand how to interpret the result themselves, but if you're … a busy general oncologist working in a smaller hospital you're not necessarily up to speed with all the evidence for specific disease types then you make take at face value the clinical interpretations attached to these reports.

Here, concerns about service transformation were reframed not just as about being 'put out of a job', as one pathologist joked, but as a matter of ensuring that current patients benefited from participation. As another pathologist explained with respect to the need to collect fresh tissue for the 100,000 Genomes Project: 'I would put a wager that [fresh tissue] is not that critical for patients in the majority of cases.' Practitioners also expressed ambivalence about the cohort of patients being recruited, as illustrated in this quote from an interview with another pathologist:

> not necessarily the right cohort of patients are actually being recruited … for example, we have recruited a large number of … GI tumours, but none of those patients will require any sort of treatment and the data that is going to come out from tumour profiling is not going to change how they are managed currently. Now whether it will be managed – whether it will change in the future, we do not know. So … I've got to be careful about this, so whether it would have been appropriate to actually gather the evidence first and then spend the money building the infrastructure …

In this excerpt the interviewee intimates that efforts are being made to improve recruitment and meet targets but this is not necessarily involving patients who will directly benefit from the project, as suggested in its design and promotion.

Nurses and one clinical trials assistant (CTA) involved in obtaining participants' consent to the programme had less professional power

through which to resist or rework these new agendas. But they were also ambivalent about their role and the prospects of the project. Their ambivalence found particular expression in relation to their concerns about managing project information and encounters with patients, given the complexity of the project. These concerns often took the form of expressions of anxiety or jokes about our presence as observers in the consent meetings, where nurses sought to navigate their sense of being judged or evaluated against an established standard approach to consent where the virtues of the project were largely scripted in advance. Here the nurses framed our presence and that of the project around it as being a new 'script' to learn and implement, positioning themselves as in ongoing need of training and education around genomics to enable the programme to develop.

Nurses also expressed ambivalence about the project with respect to managing patients' expectations around delivery of results. There were significant delays in getting results to patients, and nurses had to field additional phone calls from patients about this, but they had little sense of connection to the 'background' of results being analysed and delivered. At the same time, however, nurses were clearly developing new kinds of expertise and skills in tailoring and navigating the consent process to accommodate patients' needs as part of their ethos of care. We can see some of this play out in an excerpt from an observation of and between consent meetings with patients where a specialist nurse and the GMC specialist nurse discussed their roles and how to support patients:

> The nurses chatted about this patient. The specialist nurse said 'she doesn't sound clued up' and it seemed like the patient was relying on her husband's support [they could hear her husband helping the patient in the background]. Both said it must be particularly difficult for brain cancer patients. They said 'the general gist is that getting sample, helping … and then a bit more of the nitty-gritty. And then ask if they understand.' The specialist nurse said 'you can pick that up'. The GMC specialist nurse said if you feel the patient doesn't comprehend and you are not confident, suggest not to take consent and suggest face-to-face meeting, although they may not be well enough to come in for an extra visit as they will have to drive, park, and wait etc. They added that electronic consent was discussed as a possibility but there was debate around it – not implemented in the end although not clear why. The specialist nurse chipped in by saying

> 'how do you know people understand?' [when the consent has been done electronically] and went on to suggest that there seem to be 'hiccups' in the project. The GMC specialist nurse said when the study was opened nothing was set up. The specialist nurse asked why? GMC specialist nurse: lots of high level activities went on to set up the Centre. Other Trusts used funding differently to engage nurses but for some there is no job security … Sounded like lots of people moved on to different work so constantly re-recruit the team and train. They ended up spending lots of her time in rare disease rather than cancer: resources could be better but exciting even though it wasn't up and running when she joined … The specialist nurse commented: it's like 'giving you a car but not the key, situation' … The GMC specialist nurse added that she doesn't have a job to go back to [after the end of the 100K project], she is 'not hopeful'.

A lot is going on in this excerpt: the nurses are engaged in training; they are trying to make a complex project work in the absence of guidance and resources, including lack of job security; and, at the same time tailor and make consent meaningful and participation valuable for patients without it becoming too burdensome. This results in a reframing of the project as problematic while maintaining and developing a professional commitment to try to make it work in the interests of patients.

Backstage, practitioners were cautious about the 100,000 Genomes Project, as well as being hopeful about its potential for patients. They wanted genomics to improve treatments for patients, but were sceptical of over-promising and concerned to maintain some of the boundaries between the state and the market that this project was designed to break down. Sometimes these concerns were shared with project leads and the visionary vanguard at events and other meetings. However, we observed that criticism was typically reworked by the project leads as a need for further training or buy-in from staff, or even as a form of professional inertia and protectionism. Difficulties with recruitment became institutional problems and the focus of the national initiative was on successes in terms of numbers of genomes sequenced as a key milestone of progress. In these ways, resistance was itself reworked to form part of the impetus for further transformation of services and institutions.

Practitioner resistance and concerns were also reworked frontstage where patient encounters were concerned, where the focus switched

to careful handling of patients' expectations, balancing appeals to patients' altruism and faith in research with management of their hopes and expectations. Practitioners also had to navigate some of the more complex issues around access to data and commercialisation with care, given their qualms about the intricacies and politics of these arrangements. Transformation, however fraught, relied upon practitioners recruiting patients to the project and good care relied upon spending time to reassure and support patients in these and other clinical and research encounters. As we shall now go on to discuss, patients and accompanying relatives were also active participants in these processes, which involved their own resistance and reframing, particularly in relation to informed consent and genomic literacy.

Patient participation

Cancer patients were approached about their involvement in the 100,000 Genomes Project at various points, including before initial surgery or after they had been living with cancer for a number of years (e.g. haematological cancers). They typically received a letter or a phone call inviting them to make an appointment to come along to hear more about the project and to consider participation. These initial encounters with the nurses or CTAs who were trained or in training to conduct the consent appointment lasted up to one hour and covered a range of complex information and deliberation. Patients were often, though not always, accompanied by a family member to these meetings.

A major concern of the project architects was to ensure that patients did not experience participation in this research as too much of a burden and that they understood that receiving potential results of interest to their care, or that of their family members in the future, was contingent on sharing their data and waiving rights to personal financial benefit. This resulted in a detailed consent process which caused concern for practitioners who felt it could be too difficult for patients to manage given their health and other pressures.

In our observations and interviews we found that patients, alongside practitioners, worked to reduce or resist this burden. One way in which this was achieved was by deriving care from the

consent meeting. This involved reframing participation from a research experience which might provide better care in the future into an occasion for care in the present. This meant discussions in the meetings could be wide ranging, as patients articulated their experiences and concerns about their cancer, the care they had received, and the prospects of further diagnostic information. The appointments with the consenting nurse or CTA were also a space where patients and family members could discuss immediate, ongoing concerns and worries for the future and to ask questions about their care. None of this was necessarily related to the 100,000 Genomes Project. This included questions about treatment and surgery, as in the following example:

> [After agreeing to take part in the 100,000 Genomes Project] The patient then took out a couple of sheets of paper from her handbag and started to ask the research nurse a series of questions she had prepared. Her questions however were not relevant to the 100,000 Genomes Project but were mostly about her surgery. The research nurse reminded the patient that she can get in touch with a nurse specialist who will be able to answer her questions. … The husband who had been silent then asked a question for the first time, but it was again about the logistics of the patient's surgery: he wanted to know whether he needed to take time off from work. The patient jokingly said to her husband, '[the research nurse] is doing research, not work arrangement' and laughed.

At other times patients sought more practical support, as well as reassurance and advice from the NHS and nurses in particular, as the following example from our observations illustrates:

> The nurse went on to discuss data security and access and how there won't be any financial benefits for patients although it will benefit the NHS. This is normally the point where patients quietly nod or smile/joke … but the patient says, 'some financial help would have been nice; there's no help at all'. And he goes on to talk about how he cannot work but hasn't been offered additional help because his wife is working a few hours a week. The nurse signposted Macmillan nurses to discuss financial issues…
>
> … The nurse then explained the main findings and extra findings e.g. about high cholesterol. The patient says he doesn't worry really but his wife says 'I'm the worrier.' When the nurse explains the genetic carrier testing the patient's wife talked about their decision not to

> have children because they were 'too selfish' and wanted to keep enjoying motorbiking …
>
> … the patient asks if people ever come into this meeting but don't want to sign and the nurse says, 'people want to contribute'. His wife agreed about the importance of 'helping future generations', continuing 'breakthroughs happen in science all of the time'. The nurse responded, 'science relies on people like you.' The patient's wife goes on to explain her husband's history of blackouts and a pacemaker being fitted prior to his diagnosis with cancer and wonders if the blackouts were connected to his cancer. The nurse says she cannot answer that question. The patient's wife asks if the project might be able to find out more about this, but the nurse said she was not sure what kind of information was relevant to the project. She added that a copy of the form would be sent to their address and the patient said it will be 'helpful to research but also helpful for my brain' and the nurse added that the overall aim of the project is to 'transform the health service'.

Although these exchanges might be framed as tangential to the core purpose of consent meetings, departing from the framing of the consent protocols and forms, they were key aspects of the meetings which enabled nurses to reciprocate care for patients' involvement, and for patients and family members to generate tangible value from their involvement rather than the remote prospect of personalised results emerging in the future. Being able to articulate positivity and to express concerns, even though the nurses often responded by signposting other kinds of care, was also an opportunity for patients and relatives to perform good patienthood and care giving, bolstering their sense of self-worth in the process. Patients frequently sought the advice of the nurse, or used this unusually lengthy encounter with the nurse to explain their concerns or express gratitude for the care they had received from the NHS. Patients also frequently contextualised the possibility of receiving their results at some point in the future with accounts of their more immediate and pressing concerns about financial issues, pain management and disease progression, for example the question 'Will I be alive by Christmas?'

In so doing, practitioners, patients and family members reconstituted the 'consent to participate' process as a moment of reciprocal care rather than an exercise in deliberation and choice, already generating experiences of care from the encounter rather than awaiting results and future care. As with other encounters with genomic

medicine discussed throughout this book, patients situated the 100,000 Genomes Project as but one step on a lengthy and complicated personalised search for care, rather than as a matter of participating in a research project aimed at generating value from their data. This meant that each consent meeting was effectively tailored to different patient experiences, concerns and accounts, as the nurses sought to navigate the encounter as a way of delivering more personal kinds of care and consent. The consent process became an occasion of personalised medicine of a rather more immediate and mundane sort than the high-level, high-tech vision of the programme's leading proponents.

The burden of consent and the specialness of the 100,000 Genomes Project was also resisted by normalising participation as part of 'routine' involvement in other research studies or trials which were integral to being a cancer patient. As one breast cancer patient in the early stages of cancer commented, echoing comments from participants in SMP2 discussed in Chapter 4, 'Why wouldn't I participate? I have no good reason not to.' Another patient, Joe, a former engineer in his sixties who had had surgery and chemotherapy for bowel cancer, commented about donating tissue being an obvious and easy way to help:

> But like I said to (Research Nurse), as long as I don't have to have my leg cut off, or I'm not going to be in pain for weeks and weeks, or I'm not going to be locked up in prison … I [am not] bothered.
>
> **Okay.**
>
> How else are you going to learn [and] advance cancer research … I mean you can't go cutting people up who haven't had cancer just to check, obviously, but … it's the nearest thing you can do with … not live tissue, but with real tissue as opposed to doing it in the classroom.

Other patients, especially those who had recently had surgery or those who were about to have it, told us that getting rid of the tumour – 'why would I want it?' – by donating it to the project was an easy decision, perhaps as part of a wider effort to show their willingness to participate.

Reframing participation as obvious and routine, as opposed to special and burdensome, allowed patients and their relatives to

maintain self-worth in the face of cancer, asserting their agency and dignity as well as their care and concern for future patients. But in other respects we saw that participation was not routine – not only was the meeting quite time consuming, it also involved logistics such as transport and parking, enrolling relatives into the process. Patients and their relatives nevertheless made this workable by coordinating their involvement alongside other appointments at the hospital. This articulation work was key to the successful recruitment of patients to the project. For instance, one elderly patient, Brigit, who was frail and forgetful due to her recent major brain surgery, told us that if consenting to the 100,000 Genomes Project or speaking with us had required 'special trips' to the hospital, she would not have participated as she relied on her sons and a daughter-in-law to take turns to drive her to hospital. On the day of the consent meeting, her daughter-in-law accompanied Brigit, and when we interviewed her on a different day one of her sons had taken the day off to accompany her for a clinic appointment. In the interview they told us they were happy to help 'as long as things like this interview could fit in with when we're here'. Brigit also explained her desire to participate in the consent meeting to her son:

> And I just said, 'Well, I – as I told you, I was gonna do this,' and I just says to him, 'Don't forget … it's something that I want to do,' I said, 'But I'm not at a position where I can go like talking to anybody or go here or [there or] anything like that,' I says, 'But on paper I can do it.' So that's … was basically it, you know…

This reworking of participation as routine and unremarkable was also associated with ideas of their data already being available elsewhere and research of this sort as a social good which might also benefit the patient, and future patients, including family members.

Arranging an interview with one patient, Giles, was difficult because he was adapting to living with some complications after his surgery while undergoing a phased return to his work as a data scientist. However, Giles was particularly keen to participate, telling us he would have felt he was being 'hypocritical' if he refused. He told us that he already knew about the project and was confident it was beneficial:

> I'd heard, I'd heard of it on a … level when I worked for the [name of company where the patient works], but I didn't know any details

> of it. So I knew, I knew such a thing existed and they were gathering genetics on people with cancer for future study.
>
> **So when [you were] formally approached by health professionals, did you, did you find more about the 100,000 Genomes Project then?**
>
> They gave me … plenty of information but I didn't read a lot of it … I knew enough to know that it was a beneficial study based on genetics of cancer. And I didn't see any reason not to take part in such a thing and I didn't feel the need to learn more details about what I was helping with because I was happy to help.

He also saw data sharing as an unproblematic: 'I don't believe that storing data on people is going to cause me a disaster … I mean I didn't pay that much attention to the opt-out process because I wasn't particularly worried about it, or the data protection issues…' Giles went on to 'call out' people who worry about this because of the acceptance of surveillance in everyday life, and even its inevitability: 'The ones selling [data] to people are not the NHS – it's Facebook and Google … And if the government wants to spy on me they will regardless of whether or not I've signed a consent form!' Another older breast cancer patient, Ally, introduced in Chapter 2, explained that she had chosen to participate in the hope that genomic information that might help her extended family would be uncovered:

> it outweighs the thought of, oh somebody's got my details, for goodness sake, everybody has got people's details nowadays … your mobile phone, if you've got your location on that, big brother is watching you! … at the end of the day, if you've done nothing wrong, what is there to worry about?

Patients were much more concerned with the practicalities of participation such as whether it might involve more hospital visits, than about data security. Through these kinds of narratives participants were not necessarily expressing strong commitment to the project, including trust in its data security arrangements, but a sense that participation was not likely to be problematic, especially given that data is already being shared in ways we inevitably have little control over, by governments and corporations (Zuboff 2019). By actively not worrying about these kinds of things they once again asserted their self-worth as rational and sensible citizens willing to help others. The only exception to this concerned the possibility that insurance

companies might access data, which can be a source of concern for participants, as has been established through a range of survey and consultation exercises.[10] The nurses therefore sought to incorporate information about this – for example, the moratorium in place – in the consent procedures. We noticed that as similar questions were asked at each meeting they presented this information upfront even before the related questions were raised by participants.

We also found that where concerns did arise, these were often softened afterwards. For example, Lillian, introduced in Chapter 2, explained how she and her husband were initially wary of private, for-profit companies accessing her genomic data when this came up in the consent meeting:

> it was a bit of a knee jerk reaction … a lot of commercial organisations kind of jump on the bandwagon … to get your information … to prey on people … and once it's gone outside this kind of ethical boundary … But then of course, I know that most medical research is done by this kind of company, when I thought about it, I thought, well how stupid. Private companies, they're the ones that have got the finances … to put into medical research.

Here, being a good participant meant reflecting back on excess reactions and accepting the role of market forces and privatisation in genomic research.

Patients and relatives engaged with the information provided, including before and during the consent meeting, in a range of ways, sometimes asking a lot of questions or commenting on their own expertise in a related field to reinforce their understanding, and at other times disengaging or resisting a lot of information. For example: 'The patient says she does research in an allied health field so she understands ethics and consent. She added that personalised medicine has been practised in her field for a long time and for her "genomics" is too "medical" a term to describe this.' Here, the patient establishes that she has sufficient expertise to make informed decisions.

Resisting information was another strategy we observed, when participants might wave away the consent form or interrupt the nurse to say they were happy to sign without her going through her scripted explanation. Participants also sometimes commented about there being too much information – 'like an examination!' – but laughed this off or didn't read all the material because it would

'take all day', and went ahead and consented. When asked about the information previously provided, a colorectal patient in his late forties, Stevie, commented: 'I read it. Don't ask me about it 'cause I can't remember.' Nevertheless, Stevie expressed his excitement and interest in the 100,000 Genomes Project, telling us he was 'fascinated' and looking forward to seeing the results. This is also illustrated in the following extract from one of our observations of a consent meeting:

> The nurse asks how they were informed about the project and they say it was a letter through the post. The patient's wife then took the consent form out of the envelope. The patient says, 'I haven't read it', with a big smile, and the nurse answers, 'don't worry, we'll be talking it through'. The patient says he is not an expert and not a medic so 'do whatever you want to do'. He says he knows how to mend bikes but not mend brains. When the nurse asks if his tumour has been removed they both say 'biopsy' and the patient went on to say 'they wanted to drill but realised my brain wasn't that big' and we all laughed.

In these kinds of interactions humour was deployed as a mechanism through which participants could mediate their lack of knowledge and understanding while also building rapport with clinical professionals and bolstering their identity as a competent participant.

Participants also complied with, but subtly reworked, the educational aspect of the consent process by adopting the position of critical observer or media consumer when viewing the accompanying video used as part of the consent process, often nodding appreciatively or commenting on its quality, for example 'very well put together'. In another consultation, we observed the following:

> The 4-minute video clip played, and the couple watched it with concentration. Both smiled especially at the 'Giant Super Secure Database' section [explaining the security of the 100,000 Genomes database]. Once the clip ended both smiled and the patient's husband said 'Excellent! Sorry, that [video] answered my questions.'

Together these kinds of encounters and discourses reframed the consent process as an occasion for care and the performance of gratitude, competency and good patienthood.

Participation was also sometimes rationalised as a way of keeping practitioners on side to keep care foregrounded even when it was

lacking, something that takes more work than giving consent. For example, one breast cancer patient, Nicky, a healthcare practitioner and teacher who had lived with cancer for over a decade, told us how she was not concerned when her consent meeting was very short with little time for reflection or discussion (because the nurse was not experienced in the consent process for cancer patients):

> to me it was just signing the forms, honestly … it's funny, I think because I've had so many different experiences and positive and negative … you don't get angry any more about if – if you're not treated in the best way that you could do. You know, I used to get really angry at the start if I got bad care or someone wasn't treating me, you know, right and, you know, and … to be honest, I just let it go now because, you know, people have bad days. People struggle, you know. There's lots of stuff going off and really if I kicked up a fuss and got arsy, it makes … no joy for anybody, least of all me really … you've gotta work with these people and you might meet them again in the future, so that plays on your mind as well. Might it affect my future care, future, you know, how that person responds and is with me? Um, it shouldn't do that, but … you do think about that.

This extract shows that patients situated their consent to this project in relation to a much lengthier ongoing experience with cancer and care. For some, participation in this project faded into the background of ongoing efforts to stay well, but in this case, it could also be a form of investment in future care and good relations with care staff.

These ways of reducing the burden of consenting to participate and deriving care in the present or future complement the efforts of those involved in the governance of the project to simplify and shorten the consent process as a way of ensuring higher levels of participation in the project. But they also trouble the model of consent in the project governance, where emphasis is placed upon patients engaging with the project on its own terms and being fully cognisant of the waiver of their rights to financial benefits, and the limited opportunities for results which will direct their care. Instead they involve patients by strategically ignoring or discounting the ways in which data and profit flow in the project, and importantly and empathetically searching for care within this encounter.

Through these practices, patients subtly reworked the governing frames of the 100,000 Genomes Project by turning the consent

meeting into an occasion to display a good enough level of expertise about genomics and cancer. This was an exercise in preserving dignity and competency as a person, not just a cancer patient. We see this kind of work as part of patients constituting themselves as worthy-of-a-future, where care would continue to be offered and received on a reciprocal basis. Together these practices reclaimed dignity in a kind of ordinary personhood as distinct from a more educated patienthood which the 100,000 Genomes Project seeks to cultivate. At the same time, however, the overarching knowledge-control regime is enacted rather than undermined via these reworked forms of participation, as data is collected and participation is valued as a personal and social good.

Conclusion

The next stage in the mainstreaming of genomic medicine in the NHS, the development of the Genomics Medicine Service in England, aims to put the service in 'pole position' to make use of the technology, according to Dame Sue Hills, Chief Scientific Officer for England. Genomics once again became a key reference point in politicians' vision for the service in 2018, as in this quote from Matt Hancock, the newly appointed Health and Social Care Minister: 'The power of genomics plus AI to use the NHS's data to save lives is literally greater than anywhere else on the planet.' Initially, however, WGS will only be available for some rare diseases and 'hard to treat cancers', with an aspiration to sequence one million genomes by the NHS and UK Biobank within a year, and up to five million by the Genomics Medicine Service within five years. Illumina and other companies involved in organising and interpreting genomic data are key to turning what Hills described as the 'cottage industry' of genomic laboratories into 'factories [with] higher quality, faster throughput and turn-round, and cheaper prices', in her evidence to the House of Commons Science and Technology Committee inquiry into genomics in the NHS. But we remain unclear about how these 'factories' will deliver the benefits of expensive targeted therapies to a cash-strapped NHS once it has delivered its genomic data to the commercial market.

Genomic sequencing initiatives at a national scale are a major part of the bioeconomy and the personalisation of healthcare for common diseases such as cancer. For countries such as the UK, being a key part of these developments is crucial to economic growth and prosperity. To cultivate these values, a genomic vanguard has sought to leverage one of the UK's true great assets, the NHS, transforming the service to embed genomic data collection and analysis across its cancer clinics and beyond. Patient participation on a large scale is vital to success, but the burdens and benefits of participation must be carefully circumscribed as part of the new era of reflexive governance, as patients' data is being put to work in the national interest. Scientists, clinicians and social researchers are recruited into this task to develop appropriate methods of governance and understand how patients participate in order to improve levels of participation, including via enhanced levels of genomic literacy.

Patients and their families participate in these initiatives willingly, but the terms of their participation are reworked in the process as the value they realise consolidates around care in the moment and giving back to carers and future patients. Patients resist the burden of consent by asserting a good enough level of knowledge or normalising participation as a routine part of hospital visits and engagement with care givers. Their engagement with the economic value that their participation might generate is, however, curtailed, in a complex consent process which evokes trust in practitioners and providers to use their data for the common good. Facing a difficult diagnosis, or recovering from major surgery, patients are vulnerable, sometimes confused and emotional about their experiences and participation, and keen to make a good impression on the nurses who take them through the consent process. Staff also find ways of resisting and reworking the governing frames of the project, including consent and recruitment processes, prioritising care during consent meetings and querying efforts to improve recruitment and reorganise services backstage of clinical and policy encounters. Their resistance can, however, give further impetus to the genomic vanguard's efforts to intensify transformation, locating responsibility for change with institutions already experiencing a range of financial and service pressures.

Notes

1 https://assets.publishing.service.gov.UK/government/uploads/system/uploads/attachment_data/file/213705/dh_132382.pdf (accessed 20 June 2020).
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3 The Institute of Fiscal Studies reports that 'The period between 2009–10 and 2014–15 saw historically slow increases in UK public spending on health, averaging 1.1% per year. This was the lowest five-year growth rate since a consistent time series of health spending began in 1955–56. However, due to cuts in other services, health spending continued to increase as a share of public service spending.' www.ifs.org.UK/publications/8879 (accessed 20 June 2020).
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