

CONVENE, REPRESENT, DELIBERATE? REASONING THE DEMOCRATIC IN EMBRYONIC STEM CELL RESEARCH OVERSIGHT COMMITTEES

Rachel Douglas-Jones

In addition to experts in biology and stem cell research, ESCRO committees should include legal and ethical experts as well as representatives of the public (National Academies of Science, 26 April 2005).

STS research has been more effective in showing how people build scientific instruments, medical standards or large technological systems than legal rules, ethical principles or regimes of administrative rationality (Jasanoff 2012: 7).

THIS CHAPTER IS CONCERNED WITH HOW COMMITTEE MEMBERS, CHARGED with the oversight of a contentious domain of scientific research, reason with ideals of democracy in describing their work. The committee work I analyse is conducted by embryonic stem cell research ethics committees, or ESCROs¹ in the United States of America. I suggest that what makes ESCROs of particular interest within a discussion of STS and democracy is the largely tacit role that democratic ideals have within such spaces of research governance, and the

contrasting conceptualisations of the ‘appropriateness’ of an ESCRO-type committee in stabilising and settling anxieties about controversial research.

STS scholars have long advocated for, and participated in, the participatory turns in the democratic governance of science. As recent critics have pointed out, though, by promoting participation STS scholars have imported democratic ideals into the science-society relationship, putting some of today’s scholars, as Chilvers phrases it, in the ‘tricky position’ of shifting from a role *promoting* the ‘democratisation of science’ to ‘critically and reflexively analys[ing] these very same practices’ (Chilvers 2017: 117; see also Pallett and Chilvers, this volume). The move away from implicit theories of democracy towards an approach that considers the democratic as an emergent set of logics and practices refuses preconceived understandings of the democratic and instead examines it through its varied instantiations in bureaucracy, elections and discourse (Paley 2008). Today, researchers can map entire fields of contrasting consultative, participatory and inclusive models (Laurent 2017; Pallett et al. 2019). How decisions are made and authority is deployed across institutions has become a matter of empirical examination. Along the way, critical analyses of participation as performance also bring the recognition that models for participation are freighted with norms about what democracy is, and what it should look like. In the wake of often STS-led ‘democratisations’ of scientific engagement, scholars have found themselves taking the commercialisation of deliberation as an object of study and analysing consultants of the participation industry (Hendriks and Carson 2008; Bherer and Lee 2019). This reflexive turn has expanded the sites where STS scholars see questions of democracy to be at stake, and encouraged them to ask, for example, whether in particular cases democratic engagement is being done democratically. When scholars suggest ‘deliberately cultivating multiple alternative atmospheres of democracy within participatory processes to open up normativities of democracy and make them a focus of experimental comparison’ (Chilvers and Kearnes 2019: 12), the assumption remains that this ‘cultivation’ is *desired* by those responsible for the process. Once participation is viewed as constructed rather than as a normative good in its own right, how it is organised, argued for, and justified become empirical questions.

The work that happens in the settings of this chapter, ESCRO committee meetings, is not democratic in any straightforward sense: it is not cross-societal, it is not especially participatory, nor in pursuit of broad-based consensus. Meetings happen out of sight, and largely without public scrutiny. As the chapter proceeds, I make the case that a series of justificatory ideals about democracy are used – primarily by committee members – within the work of these unusual committees. What *do* institutions ‘do in practice when they claim to be reasoning in the public interest’ (Jasanoff 2012: 5)? Where does this reasoning take place, and through what measures? Committees have long interested me for their decision-making practices, their evaluative cultures and their negotiations over what will count as valid or authoritative knowledge (Douglas-Jones 2015; Jasanoff 2005: 250; see also Camic et al. 2011). As time-bound, topic-focused entities, they may be closed or open, present themselves as routine or extraordinary and constitute samples of various publics. More often than not, committees are brought into existence to mediate questions of concern, whether new scientific objects or technological devices. Committees exist within regimes of representation: members are often tasked with ‘speaking for’ others not on the committee or in the room. As such, my curiosity about their work belongs to the turn in STS towards making ‘participation and democratic practice [objects] of study and intervention in their own right’ (Chilvers and Kearnes 2019: 8).

As the editors of this collection suggest, STS is particularly well equipped to unpack democratic politics in its various guises, both through its close attention to practices and through conceptual developments that identify and specify not only the character of claims to knowledge but also the processes by which decisions are made. This chapter contributes an analysis of a ‘mundane’ committee, a social technology that I suggest produces knowledge not *on* but *in the name of* democratic participation in science. Just as it is important that STS should explore the democratic through its everyday instantiations and practices, I suggest that we must also become attentive to where ideas of democracy are made to do justificatory work for institutional or bureaucratic processes. To act in the name of someone or something does not always require – or result in – their involvement. In the case of ESCRO committees, operating within a US tradition of public bioethics, most interesting, perhaps, are the ambiguity

of practices around democratic ideals as they have become contained within a model of scientific self-governance. What can analyses of invocations of the democratic show us? Let us first consider the cells that they seek to oversee, as I show why the question of democratic involvement in the governance of stem cells requires a history of their introduction into a fraught political environment.

MEETING CELLS, MEETING COMMITTEES

In 1998, researcher James Thomson at the University of Wisconsin in the United States found a way to isolate stem cells in human embryos and grow these cells in the laboratory. Stem cells were first derived from mouse embryos in the early 1980s, and their potential for medical research continues to excite scientists around the world (Taussig et al. 2013). As cells from which other more specialised cells can be derived, they can be used to model potential responses to drugs, or to explore the development of disease. ‘Lines’ of embryonic stem cells can be cultivated indefinitely, meaning that they are propagated in labs, but US governments through the years have differed as to whether public funds can be used to research these cells, based on moral concern for their origins in embryos (Wertz 2002, Salter and Salter 2007, Interlandi 2010, Robertson 2010). In 2001, the then US President George W. Bush instituted a moratorium on the provision of national funding for stem cell research. Calling research involving stem cells a serious matter of ‘dinner table discussions’ across the United States, he invoked the image of cells in laboratories, frozen, destroyed or donated. During the moratorium, reversed in 2009 by President Barack Obama, no new ‘lines’ of cells could be created.

During that decade, the US National Academy of Sciences took on the task of producing guidelines on stem cell research. On 26 April 2005, the National Academies of Sciences, Engineering and Medicine released the outcome of their discussions. In the press release, the co-chair of the committee producing the guidelines, Jonathan D. Moreno, argued that ‘[h]eighted oversight is essential to assure the public that stem cell research is being carried out in an ethical manner [...] set[ting] a higher standard than required by existing laws or regulations’ (Kearney and Petty 2005: np). While he admitted to hesitation

over ‘another bureaucratic oversight entity’, Moreno stated that the burden was ‘justified, given the novel and controversial nature of embryonic stem cell research’ (Kearney and Petty 2005: np). In their recommendations, the specific form of ‘heightened oversight’ recommended by the US National Academy of Sciences borrowed from the by-then well settled model of the Institutional Review Board (Friesen et al. 2018). ESCROs, described in some detail in the NAS document, were given procedural tasks such as monitoring the procurement of and provenance of stem cell lines, and reviewing the derivation and banking of hESC lines (with the ‘h’ standing for Human; see also Hinterberger 2018). They were also given responsibility for ‘local initiatives’ (Chapman 2015), such as educating stem cell researchers to understand ethical issues and meeting regularly to evaluate research proposals for their scientific and ethical dimensions. In short, ESCROs can be seen as a device which drew on certain familiarities of committee work to settle and stabilise compromise around the turbulent political scene in US American research politics (Robertson 2010, Johnston 2005, Streiffer 2005), where the impacts of scientific mistrust are now widely seen (Dillon et al. 2017). While the politically charged context for their introduction cannot be overlooked, the scope of their remit shifted over time due to changing mechanisms² of ‘deriving’ cells useful to research (see Douglas-Jones 2022).

Researchers across STS and the critical social sciences have taken considerable interest in the way stem cells become the site of intense negotiation across contrasting scientific, legal and social worlds (Bharadwaj 2018; Raval et al. 2008; Hogle 2010, 2018; Franklin 2018, Sleeboom-Faulkner et al. 2018; Sleeboom-Faulkner 2013; Landecker 2007; Svendsen 2011; Thompson 2013). This is not surprising – following the contortions of stem cell policies – ‘spectacle(s) ripe for anthropological analysis’ (Hogle 2005: 24–25) – scholars have gone as far as to call stem cells ‘theory machines’ (Bharadwaj 2012: 304; see also Jent 2018). Bioethicists have approached stem cells as a different kind of machine: one of professional advance. In his recent overview of the history of professionalising public bioethics in the United States, Ben Hurlburt explores various bioethics bodies struggling with the problem of how they could ‘represent’ or ‘stand in’ for a wider public (2017: 14), turning debates about stem cells into debates

over how scientific knowledge should figure in public bioethical deliberation and thus over the right relationship between science's epistemic authority and democracy's modes of collective moral sense-making' (2017: 8). By titling his book *Experiments in Democracy* and drawing our attention to how public reasoning might take place, Hurlburt argues that 'bioethical authorities drew upon the authority of science in constructing accounts of what forms of public reasoning were appropriate' (2017: 14) in their work of 'segregating reasonable disagreement – the lifeblood of democracy – from unacceptable ontological (and thus moral) confusion' (2017: 9). The question facing all involved, he suggests, was normative: how should a 'democratic polity reason together about morally and technically complex problems that touch upon the most fundamental dimensions of human life – through what institutional mechanisms, guided by what forms of authority, in what language, and subject to what political norms and limitations?' (Hurlbut 2017: 2).

How, indeed? Timothy Caulfield, a Canadian health law professor, describes stem cell research overall as a 'natural experiment that spans the globe' (Caulfield et al. 2009). Accordingly, its mode of governance is 'one of the great applied bioethics experiments of our time – the creation, through voluntary, nongovernmental action, of a special ethics review process for *one particular kind of research*' (Greely 2013:52, emphasis added). The committees at the centre of this chapter are 'experimental' because they are not a federally mandated form of review. Their introduction by the NAS meant that they were taken up as an 'entirely voluntary' form of oversight, written into requirements only in the states of California and Connecticut.³ This voluntary oversight continued quietly for eight years.

In 2013, eight years after National Academy of Science's 2005 guidelines were published, and three years after they were updated, the American Journal of Bioethics dedicated its 100th issue to the topic of stem cell governance. A collection of papers dedicated to ESCROs appeared, provoked by California-based bioethicist Hank Greely's proposal that it was time to 'begin moving toward a world without ESCROs, at least as we have known them' (2013: 52). Calling the work done by ESCROs a 'special ethics review process' Greely's proposal invited responses reflecting on what ESCROs had contributed, and

what it would mean to move toward the world Greely envisaged (Devereaux and Kalichman 2013).

I took the 2013 moment of potential dissolution of ESCRO committees as my starting point for the interviews that followed later that year. Using the proposal of an end to their work as a point of departure, I asked committee members what they thought about the work they did. We discussed the kinds of research they review and the processes involved, as well as broad questions (who is the committee for?) and more personal ones (what did they themselves do on the committee?). Some discussions covered the kind of work that committees do in ‘sorting new entities (and sometimes old ones) into ethically manageable categories’ (Jasanoff 2011: 77): in other words, ascertaining whether or not a researcher’s stem cell proposal details the kind of thing that warrants ethical concern. This sorting, which Jasanoff refers to as ‘ontological surgery’, is part of the boundary-drawing that states institutions and experts do around what will constitute life and non-life, human and nonhuman, person and property (Jasanoff 2012, Pottage and Mundy 2004). A full analysis of ontological surgery in practice would have required observation access to deliberations and minutes, which I did not gain. However, during the course of the three-month study on which the following analysis is based, the eighteen stem cell or ethics committee members⁴ across three committees in three different US states spoke with me at length about the purpose and role of the committees. The transcribed dialogues of 22 hours of conversation gave me an overview for coding themes. Institutions conducting stem cell research in the United States vary considerably, and state-specific rules apply. Site 1 is a private, research-intensive university on the east coast, Site 2 a large Midwestern university, and Site 3 a public university in the south-west. Each ‘choreographs’ its committee work differently, resulting in modes of reasoning that build local versions of systems to oversee research.

If the overall argument of this collection is that democratic practice can, through the techniques of STS, be seen as a series of situated events, then my contribution is the thesis that studying ESCRO work closely allows us to see how ideas and ideals of *the democratic* are brought by committee members into their practice. Each of the following sections works through a different facet of the way committees imagine and enact their role within this non-mandatory

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oversight regime of stem cell work. I draw out their sense of the necessity or appropriateness of public participation in committee work. As we shall see, many committee members felt their work should be open – in multiple senses of the term – but this was not the practice they lived with.

OPENNESS

Inspired by the detailed observations of decision making emerging from STS collections (Camic et al. 2011), my initial research design rested on observational access to committee meetings. I wanted to see how committees sorted ethically challenging cells from familiar ones, and how different disciplines managed risk and uncertainty in new spheres of stem cell research. Seeking access, as is often the case, became a revelatory probe, allowing me to regard the attempt as part of my study (Stryker and González 2014). Whether a researcher could observe committee practices raised many questions for committees themselves and prompted discussion of a longstanding question around the degree to which their activities should be ‘open.’ Consequently, openness became my starting point for how the idea of the public figures in the way the committee thinks about itself.

My first meeting with the committee at Site 1 began with Maria, the full-time administrator employed by the ESCRO to process applications, make decisions about what issues demanded full board attention and convene meetings. Physical access to the administrative buildings was guarded by uniformed officers, who checked me against a clip board and tested my ID card at the gate. Satisfied with my pre-arranged appointment, they handed me a visitor tag, let me through the turnstile and allowed me to call a lift that would take me up ten floors. Beyond Maria’s name and job title, I knew little about what and who I would be encountering. My searches online had yielded remarkably little: no composition of the committee, no names of current or past members. Once settled in her office, I asked Maria if she could tell me why there had been so little available online to help me prepare. Had I missed something? Maria confirmed that they did not publish members’ names:

It was before my time, but I think there were concerns at the beginning about... well. There were death threats or something, so with the concern about protecting members, we decided not to publish their names online (BL 1.4).

Traces of prior controversy around stem cells – what they are and what should or should not be done with them – thus haunt bureaucratic practice. Maria's committee was not unique in its wariness. The committee at Site 2 similarly withheld the names of its members for a long time. While names are now published online, their administrator told me that worries remain. In my meeting with Site 2's committee administrator, she was at pains to show me how she makes public how many *kinds* of stem cell protocols Site 2 receives, and the 'lay descriptions' that are published of the research proposal. Taking our interview as an opportunity to reflect, one member of the committee at Site 2 explained his desire that information about the committee be published 'so people have a realistic sense of what's going on'. Yet this nonspecific 'people' was followed with an anxiety in the same breath: the publishing of even anonymised work might, he fretted, make it possible to figure out which lab or researcher was involved in research that had been through the committee. It felt right to this interviewee to make the protocols under review 'open' in some way, yet the conditions of openness left him uneasy. Moments such as this characterised the unsettled nature of openness across my interviews, with committees ultimately still uncertain of the scrutiny they remained under. When I asked whether there was any 'external' interest in the committee's meetings, a member of Site 2's committee was dismissive:

I don't know if they know that we exist. I mean, I think that the broader community doesn't realise, necessarily, that these different committees are separate. So, I don't know that they know a lot about us (BL 2.4).

The 'they' of this sentence, my interviewee clarified, is both the university's own research community and beyond it. The committee, despite now quietly publishing its membership and bothering to create non-specialist summaries,

does not know whether its work is known about by those external others. Site 3 does not have an ESCRO but uses a mix of Institutional Review Boards (IRBs), Institutional Animal Care and Use Committees (IACUC) and Biosafety committees. If stem cell research does happen, what might be considered worthy of review would fall to one of these three established oversight entities. James, a member of the IACUC during our interview, reflected more broadly on this issue of committee openness:

These committees [referring to IRBs, IACUCs, Biosafety] are set up in such a way that we *say* they're open to the public, we say they're accessible, but try finding it. Try finding minutes from meetings. It's not easy. And uh, I would prefer, all institutions to be more transparent in how they do their work but I also recognise there may be a security risk in doing that (BL: 3.2).

James is pointing to the collective entity of the university – ‘we say [the committees are] open to the public, we say they're accessible’, and expressing a personal preference for more transparency *in general*. However, he knows it would be very difficult for someone to gain that access. From his position on the Animal Care and Use Committee, he also acknowledges that ideas of ‘security’ play into how information is made available – or not. Initially concerned in our interview that I might be interviewing him on the basis of animal protection activism, the openness that James would imagine as desirable involves digital searchability, published minutes. Yet as each interviewee indicates a way they would like the committee to be, they admit (and point to) how this is not what is currently practised. From references to a controversial past to worries about ‘security’, the act of making public who is on a committee or providing access to minutes is not seen as possible.

Committee members carry these concerns about the openness of the committee into how open they feel they can be about their committee work. A legal member of the committee at Site 1, who classified herself as ‘non-scientific’ (but not ‘lay’, either, as she saw herself as bringing specific legal expertise to bear), was particularly displeased with internal committee-agreed restrictions on her ability to speak about what the committee talked about beyond the committee itself:

To me, we [committee members] have to be free to talk to students, write papers, talk to the press in extreme cases about the very.... these issues, isn't that why you put some of the non-scientists on this committee? To at least give the appearance that this is a regulatory body that's going to protect the public against scary things happening, and yet you're trying to tell us you want us to be bound by confidentiality so that if scary things *are* happening, we can't talk about it? (BL: 1.5)

This interviewee is pointing to a contradiction. Non-scientists are appointed to the committee to provide a non-scientific view. Yet by having strict limits placed on their capacity to act upon what they see on the committee they are granted access to a predominantly scientific world only to remain within it: they cannot speak outside its walls. James and Maria admitted that the committee was hard to locate physically and digitally, inaccessible in content and illegible in membership. Members revealed the continued enclosure of their debates against a backdrop where their work was deemed too dangerous to be done in public view. On whose behalf, then, are committees operating? While a valued relationship of openness had been built between the committee and the scientific community it served, the committee also constituted the enclosure of debates within a forum composed of people at least some of whom nevertheless carry openness as an ideal.

DOING REPRESENTATION

If it is difficult to access the membership and materials of ESCRO work, this is not to say that publics are not brought in. As Jasanoff notes in the context of committee work, representation is a legitimising function (2011: 74). So, who sits on ESCROs? Some background to the *recommended* composition is useful here. When the National Academy of Sciences drew up its first guidelines in 2005, the expert knowledge deemed relevant included that of developmental biologists and immunologists or reproductive biologists, alongside a layperson, and other 'non-scientific' members such as lawyers. Since ESCROs borrow from the model of the Institutional Review Board, they inherited the expert/

layperson dichotomy common to Euro-American framings of engagement. Participants not identified as a particular form of expert are described as ‘at least one member from the community’, shifting later in the 2007 clarifications to ‘independent representatives of the lay public’.

In this, the authors of the NAS guidelines borrow from a longer tradition of the ‘layperson’, who takes on the role of standing in for a national public. The layperson is a well-established figure in Euro-American discourses of public engagement with science, borrowing from particular forms of both institutional and scientific authority. Maranta et al. argue that this figure is ‘not a sociologically comprehensive representation of lay persons but rather an action in the knowledge production which ascribes epistemic and functional competences to lay persons’ (2003: 154). Recognisable renditions of laypersons are distinguished by their medical ignorance, and in standing in contrast to the medical members of the committee, they assist in creating the latter as experts (Strathern 2004; Michael 1996).

Since the formation of ESCROs is not mandatory, the guidelines merely advisory and the membership not routinely published, it is not easy to find out how committees are composed in practice. In 2007 the philosopher and chair of the University of Connecticut’s ESCRO, Anne Hiskes, and a PhD student in the Department of Sociology, Krysten Brown, conducted a national survey for the National Academy of Sciences Eastern Regional Meeting (Brown and Hiskes 2007). Their aim was to obtain a national snapshot of the state of stem cell research oversight, and they approached 118 different institutions across the United States. Amongst a range of questions, they asked about the membership of these committees.

Hiskes and Brown found that only four of the thirty participants answered the question about whether they had ‘a layperson’: half of those who answered said yes, and half said no (Brown and Hiskes 2007). So, two declared laypersons. Despite their scarcity in survey data, laypersons capture imaginations as a key site of ‘representation’ for publics. They circumvent the problem of making a committee itself ‘representative’, which is essentially the impossibility of creating a committee as a miniature of the entirety societal diversity. North American committees, with pragmatist considerations, sense limits to the number of

possible perspectives a committee can feasibly contain. Nonetheless, they tie representation deeply to the legitimacy of their declarations, and if the committee itself is not designed to be ‘representative’, then the weight of this can be carried by the layperson.

In this research I spoke to nearly every member about their role, and the role of others on the committee, but I spoke to only one self-described layperson. This was John, who had served on the committee at Site 1 for six years. John told me that he had initially wondered whether his having qualifications from the university where he was being invited to serve on the ESCRO might impede his membership:

On the one hand, I have 2 degrees from [Site 1 University], so I am not a ‘community resident sitting out in [named suburbs]’ that kind of thing, that was OK. It might have been different if I had had scientific credentials, which I don’t (BL: 1.1).

John differentiated himself as a specific *kind* of layperson: not a ‘community resident’ of the town’s suburb, but someone already familiar with the university, albeit not one in possession of *scientific* knowledge. As we spoke, he recalled how the invitation had come through a friend, and the introductory proposition put to him: ‘if you have reservations about stem cell research’, he was told, ‘the going-in proposition is, within bounds, it’s allowable. So, let’s talk about the bounds’. The ‘going-in proposition’ asked him to accept that stem cell research was happening and should happen as a starting point. John’s reservations were welcome *provided* they were channelled into a discussion about ‘the bounds’ in which research already going forward would take place. That is the conversation he has been a part of ever since.

This framing of the layperson’s role as facilitatory resonates with the concluding remarks in the 2005 NAS guidelines, where the authors state the starting ‘presumption that the work is important for human welfare, that it will be done, and that it should be conducted in a framework that addresses scientific, ethical, medical and social concerns’ (NAS 2005: 28). John was careful to emphasise the limits of his knowledge in addressing *scientific* concerns. Yet, in the spirit of

the guidelines, he emphasised that his perspective mattered for the validity of the committee. It mattered that he was there:

I've always understood the purpose of having those diverse perspectives as, I guess, in the end, bringing some balance. To judgements about the propriety of research (BL: 1.1).

John's concern with propriety is fascinating in this setting. The sense of suitability or appropriateness carried with the term invokes the social acceptability he is there to embody. While committee members generally agreed it was 'good' to have a committee member who was not involved in 'the science', nobody except the layperson himself actually challenged the adequacy of representation through having a single layperson on the committee. Initially siding with the benefits of pluralistic 'interdisciplinarity' and commending the thoughtfulness of his colleagues, John said

The things that aren't good, probably, if you were to think about really good oversight, there's little ... no opportunity for community input, even within the community, let alone ... we aren't doing sessions at churches and clubs to say, 'hey what do you guys think about this research'? Which I suppose in an ideal process would be a part of it (BL: 1.1).

This quote makes evident that there are ways of engaging publics that committee members are aware of but which are not pursued under the remit of ESCRO work. John knows who that 'public' is out there 'in churches and clubs'. As he summons the imagined public, he also summons a process through which ESCROs would be ideally engaged. As literature from STS demonstrates, traditions of participatory decision-making emphasise the kind of thing John is describing: roundtables, open fora and consensus events 'intended to involve the lay public in decisions' (Weingart 2008: 141; see also Maranta et al. 2003; Joss and Durant 1995; Flear 2009). This is also where John's imagination goes. Yet, this may not be where the committee wants John to take his role. Reflecting on her own involvement in the ESCRO committee at Berkley, STS scholar

and anthropologist Charis Thompson succinctly states that: ‘putting [NAS] regulations into action, then, is first and foremost about enabling research in an environment of ethical controversy, and not about ethical inquiry’ (2013: 64). Similarly, in her research into human-animal hybrids and the status of chimeric lifeforms, Amy Hinterberger, one of a few STS scholars to examine the mechanisms by which scientists engage with how their research is governed, has argued that ‘ESCRO committee deliberations are oriented toward providing a space for research to happen, not about questioning the basis of legal and ethical categories’ (Hinterberger 2016: 15). John’s imagined events in ‘churches and clubs’ would worry some committee members, who see their primary purpose as ensuring that the university avoids newspaper headlines. In the words of one committee member, ‘There is also a lot of emphasis on “it’s our job to protect the scientists and to keep things from going public”’. In what follows, I set the protective role the committee plays against an imagined public.

IMAGINING OTHERS: ON SERIOUSNESS AND WATCHERS

Having looked at questions of representation through presence, let me now turn to the way publics are brought in through the imaginations of committee members. This requires moving from who is physically present in the room to who is brought into the room when committee members think of themselves as representing others ‘out there’. The first step in having discussions about ethical questions around stem cells on behalf of others is to consider what those non-specific others might perceive to be ethical issues. The second step is for the committee to evaluate whether those perceived issues warrant their attention. Throughout my interview notes, committee members imagine viewers into the room. I found these imagined concerns particularly interesting, given the lack of openness about discussion and decision. Viewers are external observers, watching the committee’s work. As such, committee members repeatedly returned to what – in the view of these external viewers – would constitute the committee’s ‘trustworthy behaviour’.

Susan, a committee member at Site 2 introduced me to the idea of ‘trustworthy behaviour’ during our interview on how to handle consent and re-consent

issues around donated embryos. Susan's committee was facing a series of questions about the question of what should happen to embryos donated for research. If, for whatever reason, these embryos were not going to be used, could they be destroyed without permission from the donors? If they were going to be used for something other than the originally described research, what was the responsibility of the researcher towards the donors? Susan said she had asked herself what would look like trustworthy behaviour from the point of view of the donors? Bringing this concern into the discussion, Susan said the committee asked itself:

Have we, or anybody else at the institution where they originally agreed to donate for research, have we made some kind of promise that would be violated if we did X or Y? (BL: 2.4)

In this framing, the trustworthiness of the committee is baked into checking what promises had been made – by them *or* by others at the institution. Some researchers would want to do right by 'their own sense of personal integrity', or their relationship to the donors, Susan said. But the sense of 'if this were to be seen by others' went beyond specific donors, being tied materially to donated embryos and their fates. A fellow committee member of Susan's at Site 2 brought up the way that this larger sense of imagined others was present to him in his role:

The question that sits in my mind, and literally the question has come up: if somebody was a voter in upstate [State] and they were *watching* this deliberation, would this look like a serious deliberation that is addressing the things that are of concern to them, that they would think we should address? (BL: 2.3, emphasis added)

Would this look like a serious deliberation? Does it address the things that are of concern to them? While John's proposal to take the question to the residents of his town was out of the question, committee members nonetheless spent time pondering how their processes would look from the outside. The phrasing shows the influence of both 'directions': the imagined, generic 'voter' coming

into the committee room, and the committee member projecting herself into that upstate voter's shoes to look back at the committee's discussion in order to evaluate its 'seriousness'. Generating seriousness is no minor matter, and its importance to committee members should not be underestimated, as this interviewee reflected:

I feel that there's a strong desire to have good oversight systems in place and to have a sense of accountability to the public, so the public knows that you have strong oversight systems in place, so that you could credibly say – this is a process that we went through, these are the things we took into consideration, so even if someone disagreed with you, they could at least feel that people were taking very seriously these concerns (BL: 1.2).

This worry, repeated across committees, about generating a *sense* that people were taking the concerns seriously, bears on Marres' argument that STS approaches allow us to see the 'mobilization of socio-ontological associations that mediate actors' involvement in the issues at stake' (2007: 776). In contrast to focusing solely on what is said in these interviews, we bear in mind how the committee, composed of people sitting in a room together, shapes what counts as an issue, and is itself a reflection of an established, 'appropriate' form of managing a controversial topic. By the time we arrive at this final quote, the particular views or perspectives of those *on whose behalf* the discussions were taking place have faded, and what virtue there is in the discussion, in the appearance of seriousness and trustworthiness, has become a *process*. Here, in one of the few interviews to speak directly about public accountability, the credibility of the committee's work rests on the committee itself becoming a machine of seriousness. Long into a discussion about the 2005 formation of committees, conducted with an interviewee who had been involved in the National Academies of Sciences consultation process, he reflected on why the committees had been introduced at all:

... what the ESCROs were trying to do, was to give the public some confidence that scientists are not off on their own doing all sorts of ethically challenging work, without some kind of oversight. So, the idea is to *comfort*

the public that there is some restraint and consideration of ethical issues (BL1.5, emphasis added).

CONCLUSION

Neither the institutions of scientific work nor democratic processes are stable over time. ESCROs were introduced during a turbulent moment in stem cell research, and these interviews with ESCRO members were undertaken in the shadow of their proposed dissolution. Committee members' reflections offer us insight into how voluntary mechanisms of oversight persist in the aftermath of political heat. Stem cell research itself continues, with new developments in the creation of synthetic embryos prompting reflections from ESCRO committees and ethicists alike (Trough and Lopez 2018; Aach et al. 2017). Neither the National Academies of Science nor the International Society for Stem Cell Research address synthetic embryos, and researchers are advised to ensure that their work is 'overseen and authorized by a special committee capable of evaluating the ethical and scientific justification of proposed research' until new guidelines are produced in 2021 (ISSCR 2020).

For a collection on STS and democracy, the committees' longevity demonstrates their quiet utility, revelatory of logics by which 'adequate governance' is constructed in the US context. Adequacy is participatory, yet in conditions of controversy, it is participation at a remove. A committee where no ideal of participation was invoked would not be adequate to the task, yet John's 'churches and clubs' would be insufficiently removed for the committees to 'work'. Interviewees reveal the negotiated detail of democratic themes in contentious, potential-filled research spaces. From the 'upstate voter' to the open list of names, democratic ideals of transparency and accountability fill my notes on the way that ESCRO committee members conceptualise their roles and responsibilities. The ideals largely remain ideals. Arguably, the existence of ESCROs, rather than their actions, provides a placeholder for broader, more difficult societal disagreements.

Turning the analytic eye of STS towards democracy as practice, enacted and constructed in specific moments and encounters, means meeting the gaze of researchers in other disciplines: empirical political scientists (Weeden 2010),

ethnographers of democracy (Paley 2002; Ellison 2018), bioethicists and historians, all of whom grapple with describing, analysing and perhaps re-prescribing how normative decisions are made. The contribution that STS scholars can make to these debates occurs not only through their ethnographic sensitivities to how artefacts, materials and technologies play a role in constructing the conditions of possibility for engagement and debate, but also through their critical engagement with the entanglement of expertise and authority within the knowledge traditions of science. STS orientations to democratic situations allow us to recognise that the *doing* of authoritative knowledge may entail the deployment or manipulation of tropes that have long since seeped into institutions and bureaucratic structures. For the members of ESCROs in this chapter, a lens attentive to the form of authoritative knowledge makes evident that despite explicit discussion of democratic ideals and principles of participation, committee practices remain at a remove from participatory engagement. If we are indeed to open up normativities of democracy (Bellamy, Lezaun and Palmer 2017) then we must also become attuned to the cultivation of ‘democratic atmospheres’ that remain atmospheric rather than substantive, where stories that include ‘representatives of the public’ result in public reasoning taking place behind closed doors (Jasanoff 2011: 84). Operating in a comparative mode, STS scholars can explore the social and material life of ideals such as ‘democracy’, to reveal the complex negotiations, compromises and contradictions that make up their institutional life.

ENDNOTES

1 As research using *embryonic* stem cells become one of several options for working with stem cells, some committees dropped the ‘E’ and became known as SCROs instead. For further discussion of this change, see Hinterberger (2018).

2 In 2006, four genes were introduced to adult stem cells, reprogramming them to work like embryonic stem cells (Takahashi and Yamanaka 2006). These became known as ‘induced pluripotent stem cells’ or iPSCs for short, and they are reported to vary in terms of what they can become. See Meskus 2018.

3 Yet as King and Perrin (2014:3) note ‘[m]any research institutions have created ESCROs or ‘SCROs’ to review hESC and iPSC research; others rely on their institutional review boards or their animal care and use committees or both.’

DEMOCRATIC SITUATIONS

4 As with many expert groups, committee members are very busy people, serving on the committee in addition to their existing academic work, teaching and service. Opportunities to speak about their committee work seemed few, and several welcomed the chance to reflect on what they do, and what the role of the committee is.

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