

The Biobank as an Ethical Subject

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Published online: 13 August 2011
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Abstract This paper argues that a certain way of thinking about the function of the biobank—about what it does and is constructed *for* as a social institution aimed at ‘some good’—can and should play a substantial role in an effective biobanking ethic. It first exemplifies an ‘institution shaped gap’ in the current field of biobanking ethics. Next the biobank is conceptualized as a social institution that is apt for a certain kind of purposive functional definition such that we know it by what it does and what it is designed to do. This purpose is then characterized further as essentially incorporating the human goods the institution is designed to serve, such that it plays a useful and indispensable role in how it should operate, i.e. in the ethics and governance of biobanking. Finally the ethical scope and limitations of such a theory is clarified by a discussion of some theoretical objections and suggested practical examples of its application.

Keywords Biobanks · Biobanking · Function · Ethics · Institutions

Introduction

[a]ll associations come into being for the sake of some good—for all men do all their acts with a view to achieving something which, in their view, a good. It is clear therefore that all associations aim at some good (Aristotle, *Politics* [1], 1252a1–a7).

It might seem odd to begin a paper on the ethics of biobanking with a quotation from a classical Athenian treatise on how best to run a political community. However, there is an insight in these opening lines from the *Politics* which I hope

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will illuminate the view I will outline and defend, namely that a certain way of thinking about the function of the biobank—about what it does and is constructed *for* as a social institution aimed at ‘some good’—can and should play a substantial role in an effective biobanking ethic. I start by exemplifying the ‘institution shaped gap’ in biobanking ethics with a brief look at the shape of its current debates. I then characterize the biobank as a social institution that is apt for a certain kind of purposive functional definition, such that we know it by what it does and what it is designed to do. I argue that this purpose, when understood as incorporating the human goods it is designed to serve, can play a useful and indispensable role in how it should operate, i.e. in the ethics and governance of biobanking. Finally I help set the ethical scope and limitations of such a theory by anticipating and responding to a couple of objections, and applying it to some concrete examples of biobanking problems.

Subjects of Biobanking Ethics and the Institution Shaped Gap

As a relatively new research practice biobanking, and in particular the development of large scale population biobanks, has thrown up a number of fresh challenges and debates in the field of bioethics. (See [17]; this issue) These problems have been increasingly well documented [2] and it is not my intention to rehearse them in any great detail here. However, a brief and non-exhaustive survey of how they have been dealt with will illuminate the gap which I hope to show can be filled by a certain conception of the biobank itself as an ethical subject.

It would not be an overstatement to say that the scope of an adequate biobanking ethic is, potentially, as broad as the scope of ethics and politics *per se*. This is because at stake as subjects in the key ethical questions of biobanking are the primary subjects of ethics and politics, namely the individual and society.¹ For example, one debate firmly in its focus concerns the rights and interests of the individual person, in particular participants’ rights and interests in relation to for example privacy, autonomy, dignity, and confidentiality. But ethical concerns of biobanking also extend to socio-political interests, goods and benefits—such as public health, the well-being of future generations and even, most generally, scientific knowledge and progress. A good example of this breadth is found in the debate over what sort of consent (if any) it would be appropriate for biobank participants to give, and why. (See Holm, this issue) In clinical research and in the patient/medic relationship, maintaining and protecting participants’ or patients’ autonomy has been viewed largely as a matter of insisting on the ‘informed consent’ of a subject or patient. But as they are human genetic databases, biobanks operate on the very premise that an individual’s genetic data contains information about connected individuals. These may be consanguineous relations or cohorts associated

¹ The opening sentence of this paragraph may strike the reader as either a startling or a mundane one, depending on for example whether they think that there can be autonomous sub-disciplines of applied ethics or, by contrast, that ethical inquiry into any topic necessarily involves something of a similarly wide scope. I remain neutral on this issue, and concentrate on the claim that the debates within this scope could be more fruitful with the inclusion of a previously neglected subject, namely the biobanking institution understood in a certain way which I go on to outline.

by genetics, heredity, age, lifestyle, gender and so on, or whole populations. Thus genetic information given by donors is typically about a number of persons and the uses to which it may be put are not specifiable in a way that preserves individual ‘autonomy’ as informed consent is supposed to do. Moreover, the data and research it holds and may develop render it a ‘research library’ for long term projects it might support in the future, such that potentially affected parties include those affected by such research. The broad ethical scope exemplified by the difficulties with informed consent in biobank research, then, is that the ‘[r]isks and benefits of biobank research ‘go beyond the individual human subjects to population groups with which the subject is associated as well as the general public’ ([11] p. 90). Whilst this broad ethical and socio-political scope of biobanking ethics includes currently living individuals who may benefit or be harmed by biobank research, it could also include individuals who don’t yet exist and, in addition, present and future public goods such as health or knowledge—where such benefits and effects may, arguably, not even be wholly accountable in terms of any particular individuals [18].

Accordingly then, in addition to the individual participant, the ‘public’, communities, society and populations, as well as for example goods such as ‘public health’ have rightly been recognized as vital subjects in discussions of biobanking ethics and within the policies and ethical guidelines of biobanks. Winickoff ([16], p. 451) advocates a ‘shareholder’ model of ‘developing representational forms for the donor collective in biobanking’. Building on what they see as its shortcomings, Kathryn Hunter and Graeme Laurie propose a wider ‘stakeholder’ model which ‘would include (among others) participants such as the board of directors, ethics committees; funders and members of the company; researchers; communities; the wider public or society’ as well as ‘future generations whose health the resource is intended to improve’ ([7], p. 170; [18]). In terms of policy for example, UK Biobank’s Ethical Governance Framework recognizes UKB as ‘a major resource that can support a diverse range of research intended to improve the prevention, diagnosis, and treatment of illness and the promotion of health throughout society’. Hence the scope of that framework includes ‘the interests of participants and the general public in relation to UK Biobank’ ([19], p. 15).

This sketch indicates the size of biobanking ethics’ potential territory. More importantly it gives an idea of the wide ethical and political terms in which the discussion has tended to develop: balancing the rights of individual participants with the ‘greater good’; or the privacy and autonomy of participants with the ‘long term health’ of a society or the general public and the ‘public interest’ pursued by biobank research.²

Now, this kind of discussion is undoubtedly the right one to be having regarding what biobanks should and should not be doing. However, what has largely been overlooked in that discussion is a third and potentially useful, perhaps indispensable, subject of the biobank which, as a particular kind of institution, defines certain operative standards. As a subject of that discussion it should stand alongside individuals and communities of individuals (genetic cohorts, societies, populations)

² See also for example Mairi Levitt’s discussion, in this issue, of the appeal to national pride or solidarity in recruiting individuals in the case of Generation Scotland.

as well as concepts of public health or the future societal benefits of research. Why and how might it play this role? In attempting to answer that question I will claim that the biobanking institution can be conceived as an entity with certain standards of conduct derived from ‘what it is there for’, from its being ‘fit for purpose’, and that this can usefully figure in certain ethical debates about what a biobank should and should not do. As such *it* is ethically considerable.

From Biobank Functions to Biobanking Ethics

Biobanks, like other social institutions, are what they do. Notice firstly that the initial task of defining the concept ‘biobank’ invites questions about what it should and should not be *doing* if it is to be understood as such. A biobank can, for example, be described as it has been by the House of Lords Science and Technology Committee as “collections of genetic sequence information or of human tissue from which such information might be derived that are or could be linked to named individuals” (in [5]). Yet, taking it literally in order to illustrate a point, that description could also describe a graveyard or a hairdressing salon, the point being that implicit in the definition is, of course, the suggestion that deriving or linking such information is not merely a possibility (a ‘might’ or a ‘could’) but something the biobank *does*. It is not merely any old ‘collection’ of genetic material but is in the business of *collecting* that material in order to glean information from it. The ‘doing’ aspect is for example made more explicit in a different definition given by a Hungarian report on the legal regulation of biobanks as ‘a collection of samples containing genetic samples and related genetic and personal identification data for the purposes of a human genetic study or human genetic research’ (Sándor and Bárd [12], p. 3). Whether explicated as such or whether implicitly understood in the concept of biobanking as a practice, what matters is that we cannot grasp the concept ‘biobank’ without understanding the way in which the biobank operates, i.e. *does* certain things. The ‘biobank’ is a particular kind of research institution one which stores genetic material so as to employ that material for biomedical research purposes.

How might we start to connect this functional understanding to a biobanking ethic or, prior to that, even to any kind of claim about what a biobank *ought* to be doing? To answer this question we should first consider a general account of standards in relation to functions, and then show that social institutions, similarly generally speaking, fit such an analysis.

The question of how certain standards of goodness or excellence are in this way attached to things has been discussed by, among others, Phillipa Foot. ‘One would not know the meaning of the word “pen” if one did not know that a *good pen* has to write well, or the meaning of “writing” without understanding that good writing had to be writing which it was possible to read’ ([3], p. 135; [4]) What Foot calls ‘strong functional words’ (and, we can assume, strings of words as terms) have a strict relation to normative claims about things they describe. We can begin to strengthen further the link between what a biobank is (i.e. in terms of what it does) and how it should be operating if we consider the specific *kind* of functional understanding it suits, namely one related to purposive design [15]. That is to say that a biobank, like

any other social institution, is made *for* a purpose. Other objects such as natural organisms or their parts may have characteristic functions, by which we can identify them without their necessarily having been *designed for* that purpose, as with for example the claim that ‘a good heart pumps blood well’. But by contrast, in general social institutions are very much like tools insofar as we can best assess whether they are ‘fit for that purpose’ by seeing that they are *constructed for* some purpose, such that this purpose must figure in any explanation of how and whether it is functioning well—doing what it *should*.

To grant these points about social institutions in general is of course not yet to say anything about the *ethical* standards applicable to any social institution. Functional and constructive criteria are not alone co-extensive with, nor do they necessarily even overlap with, ethical standards. For example it might be reasonably objected that a very important task of *bioethics*, as is the case of business ethics or just war theory, is precisely to constrain and *delimit* the ‘well-functioning’ of biotechnological, profit-making or war-waging institutions and practices when they aim with all too much precision and vigour at fulfilling their purposes. I return to this objection later, but it is at this point that Aristotle’s insight can, in my view, ground an ethically informative conception of its function, one such institution being the biobank.

In augmenting this notion of purposive design towards seeing institutions as ethical subjects, we can first add the thought that social institutions are made for reasons. What this means is that a normative notion of what some social institution *characteristically does* and should be doing must relate to the justifying reasons and purposes that people have for forming, participating in and sustaining that institution. The ‘life’ of a social institution is always *constituted* by persons’ actions, where to look closely at its activity will be at some point to come across the reasons for these persons acting this way. In essence, to ask ‘what should this particular institution be doing *qua* this kind of institution’ will be at some point to ask not only about what it happens to be doing at any given time, but about the reasons that people have for creating and sustaining that institution. This is because the activities of any social institution are born and sustained by persons who could have failed to bring about and sustain them in the particular ways they have. Thus to examine the properties of, say, an association or club in order to infer from these what it should be doing *qua* that association or club, cannot be to look only at for example its structural features—such as its rules, constitution and procedures without looking also at why *these* rules, constitution and procedures, and not others, were established and are in place. Considering these reasons shows the sense in which looking merely at the contingent facts what a social institution is actually doing, or has done, cannot itself yield a normative account of what it—as a good instance of its kind—should be doing.

Consider, for example, how we would properly identify a school as one that is ‘failing’. We would do so not only by looking at it along with lots of other schools—they could also possibly be failing—but also by considering what the school is designed to do, where an adequate explanation rests on *why* it was designed as such. Evaluating different kinds of institutions in this way will appeal to the appropriate reasons in each case. A fire service functions well to the extent that

it extinguishes fires and rescues people, because that is the purpose for which it is designed. But understanding this purposive design requires us to see that it is designed this way *because* we don't want uncontrolled fires and we want where possible to prevent casualties, and so these reasons are salient in an evaluating what that purpose *is*. Similarly, a biobank stores human genetic material and advances medical research, a purpose which we have reason to pursue insofar as we value better health, improved diagnoses prevention of diseases, and identification of genetic trends which might enable such things, and so on.

The second important (and very Aristotelian) point to raise here is that the reasons behind the purposive and functional explanations of institutions are intimately connected to some or other specific distinctive key *human good* or set of goods. ([10], p. 74) These are human goods the pursuit of which we have justifying reasons for making and sustaining an institution, and the particular human *goods* of education, or law or health, are linked to the purposive quality of educational, legal or healthcare institutions which they serve.³ Crucially, what this means is that understanding whether an institution 'fulfils its purpose well' cannot be understood as separated from those goods whose purpose it serves. Crucial to understanding whether a particular kind of institution is serving its human good or set of goods well is an understanding that these goods are served in quite specific ways.

To underline the importance of this specificity we can bring the discussion back to the example of biobanking, more particularly of the public/political aspect of debate in biobanking ethics outlined earlier. As these debates have recognized, Biobanks and their activities are indeed concerned with public health, but then so are the institutions and activities of clinical research institutions, hospitals, physiotherapists, overseas aid programmes, preventative health education initiatives, medical schools and arguably even gymnasiums and health spas. Similarly the activities of biobanking are in the 'public interest'—interests of present and future society—and are ethically considerable as such. But again, without a particular conception of how biobanking works towards these ideals, and of how it substantiates them in its specific practices, the notions of the public interest or of public health are just that, ideals. Most importantly these ideals are, if conceived so abstractly, up for grabs in terms of how we might actually serve them: they are somewhat practically indeterminate. As a general point regarding the determinacy of institutions, consider the relationship between abstract ideals such as 'health' or 'education' or 'justice' and the institutions that substantiate and serve those goods, such as hospitals, universities or law courts. Each institution serves (or should serve) some such relevant good(s) as part of its goal, but it is also the institution that more concretely specifies the goods of 'healthcare' or of 'higher education' or of a particular system of 'legal justice' via their policies, procedures, research and organizational structures.

To take an example of the indeterminacy problem, UK Biobank's chief executive in 2003 claimed that the organization had 'clearly defined the purpose of the biobank, which will be to undertake biomedical research in the public interest', and

³ This is not of course to deny that there are thoroughly *bad* institutions, such as criminal gangs or despotic regimes (see note 4 below).

cited its ethical framework as ‘a strict mechanism for making sure that all the uses we allow of the data comply with that purpose’ (in [2]). The problem highlighted here is not just that of quantifying the possible effects of such a large scale population biobank on the ‘public interest’, or that of deciding which matters ultimately serve or damage the public interest (though these might be considerable problems). Rather, the problem is that of a large and possibly infinite number of different practices and policies that could arguably serve, and be defended on the grounds that they would serve, the ‘public interest’ and indeed ‘public health’. More helpful in determining what this *kind* of large scale biobank should be doing in this respect would be a much more specific understanding of the particular and characteristic *way* in which it serves the good of public health, and the public interest, by collecting and storing genetic material for biomedical research. On this view, the human goods and benefits accruing from biobanking are integral to the concept of a biobank itself as a purposive, functional institution. Included *within* the ‘purposes’ and goals of biobanking, on this view, are those ideal human goods and the actual institutional practices and characteristic activities by which they are served in particular ways and not others. So even on a most basic understanding, what a biobank *does* is collect and store human genetic samples and associated data *so that* it is then used in biomedical and therapeutic research *in order to* serve the good of human health *by* developing diagnostic, preventative, remedial or palliative medical methods and treatment, for example. Note that this kind of analysis would be still finer grained according to more detailed specifications of a biobank’s purpose, such as when a particular biobank may be disease specific and concerned with cancer research, for example.

The conceptual story so far can be summarized as follows. In general, social institutions are purposive and made for reasons, such that a functional explanation of how an institution does better or worse *qua* an instance of its kind must include that purpose and those reasons. Those reasons always concern some human good or set of goods, and institutions themselves are crucial in determining the particular and substantive ways in which those goods are served. Accordingly the biobank serves the broadly defined human goods of present and future public health, but it does so in particular ways characteristic to the institution of the biobank, as distinct from the ways in which other kinds of institutions may also serve them. In the next two sections, I hope to clarify this idea and place the biobank itself, as an ethical subject, within the broad terrain of biobanking ethics. I do so by responding to some theoretical worries and then looking at examples of its potential application.

Problems and Clarifications

An initial and serious worry about linking function of a biobank to ethics is, simply, that there may be some quite unethical ways of fulfilling its function or reaching its goals. But the worry can be seen to be misplaced when the conception of purposive function is properly understood in two ways, both of which help explain the appropriate limits of such a theory. Firstly, it is vital to reiterate the link between purposive function as described here and the human goods of health with which the

institution is concerned and for which we have reasons to construct and maintain it. This is to recognize the biobank's purpose as inextricable from its human goods, in a way that at least constrains the biobank against violating or diminishing those goods in any of its activities.⁴ Now, this constraint alone cannot of course be anything like the whole of a biobanking ethic and that is the second thing that should be understood in response to the worry. To offer a plea of humility on behalf of the theory, it is not suggested that for example respect for certain individual rights is always covered by understanding a biobank's purposive function. Such a view will neither supersede nor encapsulate the ethical or socio-political concerns relating to individuals, societies and populations. On the contrary, as I hope will become clearer, such an understanding should stand alongside those concerns and can focus them in the right way given the biobanking context.

Another obvious and general concern with the conception of an institution's purposive function as normative guide to its conduct is its apparent rigidity. Why, it might be asked, should we think that what a biobank was or is *designed* for remain in some way its defining function, such that this tells us what it should be doing? The objection can be developed by thinking about other functional objects, in particular artefacts or tools, where over time their 'function' may have adapted or they may have adapted to incorporate other functions. The telephone, for example, was at one time essentially a device for people to speak vocally to each other at a distance, but now the concept can without confusion include an all singing all dancing hand-held centre of communication, information and entertainment.⁵ Similarly then, how can and why should we tie a once-and-for-all understanding of a biobank to a notion of what it *came* into existence to do? Why can't it its function—and its purpose—evolve in quite the same way?

Despite evolution and changes there might remain some enduring feature necessary for determining a functional object. Continuing with the telephone analogy, whilst today's mobile phones do indeed tend to come with an array of features and 'applications' that we might now take to be standard, there is nonetheless arguably at least one of those features which all telephones always had—the facility to speak to others at a distance—and the absence of which would render the 'new' thing something other than a telephone, however useful that may be at doing all the things it does. Hence, similarly, the possibility itself of future changes in and additions to the function(s) of a biobank need not mean that the purposes for which it is made should fail to determine what *it* should be doing.

Still, it may be asked, why should we take even *this* basic understanding of 'what it is made for' as determining anything about what it should be doing at any given

⁴ Of course not all social institutions are good ones. Cautiously however, I would suggest that even in cases of straightforwardly evil and socially destructive institutions, there is always some person or group of persons who get, or *think* they get, some *good for them* from the formation and sustenance of a social institution. Any credible explanation of why the institution of slavery endured as long as it did, for example, would seem at least to accommodate this explanation. Furthermore, the human goods conception of purposive function under discussion can be crucial to identifying who is getting which 'goods' from such evil in which ways. For the reasons the beneficiaries sustain the institution can be crucial also in establishing *that* such institutions are evil and the reasons they should be dismantled or modified.

⁵ My thanks to Søren Holm for this example.

time in its history, such as when it may end up doing something else altogether? One answer already touched on is that the biobank, as a social institution, is a ‘living’ thing. It is a human social entity, where an explanation of why ‘it is doing’ something must make reference to why people constitute it and are operating it in a certain way. So if a biobank were to evolve or expand its activities in some way, an explanation of this change would also have to include some account of the reasons people have or had for altering or expanding upon the putative ‘what it is made for’ model. Suppose for example that an Executive Committee of a biobank was considering endorsing a policy or practice that appears to diverge radically from its previous activities. Here we can see how an implicit notion of purposive function which is as yet not articulated, already does some intuitive normative work. For the fact that this proposal would need to be seriously discussed at all rightly presupposes that such divergence *is* a problem for the biobank. But it is not obvious that the source of the problem would necessarily be reducible to, for example, ethical or legal factors external to the biobank and its characteristic practices. That is, the justifying reasons for or against the proposal need not all be to do with, for example, infringing participants’ rights or operating within the law, although these might of course be relevant in a particular case. A great deal of the discussion could also, intelligibly, be internal: about whether or not effecting the proposal would necessitate the biobank doing ‘what it does’ As should be obvious by now, my view is that the ‘what it does’ point of reference or contrast is best thought of as connected to purposive function and human goods construed in the way I have outlined.

Secondly however, even if one does not accept that the notion is implicit or intuitive, the idea of purposive function itself is quite unashamedly normative in its construction. That is, conceptualizing the biobank in this particular way is designed in advance to capture the ‘what it does’ so as it can set boundaries on which activities it should and should not carry out. This way of understanding the purposes of a biobank is as it were ‘built’ to serve as a check on both the possible diminishing of a biobank and on its expansion which could, if unchecked, be potentially ethically problematic. As to placing a limit on the diminishing of a biobank, it may help to set substantial limits beyond which we have good reasons not to ‘shrink’ the biobank and its activities such that it would become something it was never intended to be. And as to limiting its expansion, there will likely be activities and policies that, if carried out, that would take the biobank too far away from this purposive function, so construed and so constructed.

At this point it is important to resubmit the plea for humility by recognizing that what is being advanced here is not a decisive solution to all arguments or even any particular argument in biobanking ethics. Rather, what is offered is merely something tangible to argue *about*: a way of thinking about the biobank such that it figures instructively in those debates along with the hitherto broadly conceived subjects of the rights and interests of the individual and wider socio-political factors. A certain biobanking activity or project might be seen to further the quite generally serviceable purpose of the ‘public interest or public health’ in *some* way, and it could do so without significantly infringing any individual rights or interests. But the question then for the biobank is: in which ways and why? In debating this

question in the context of a biobanking ethic, adequate consideration of whether to go ahead with such an activity or project should include consideration of the human goods of biobanking and the characteristic way the biobank serves them. In the next and final section I hope to show how this model could instructively play this role in a biobanking ethic via some examples familiar to biobanking ethics.

Applications: Examples

To flesh out how this conception might be employed to address such questions, take as a first example the issue of commercial involvement in biobanking research. Consider a biobank that is in the process of deciding whether it should allow a particular commercial venture to invest in or make use of its facilities. Existing laws, guidelines or codes of practice may not give a definitive answer. For commercial investment and partnership involvement is by no means in itself disallowed nor is it inimical to biobanking. It may be clearly not only financially necessary for the continuation of a biobank but also in keeping with its projects. Commercial investment may well be ‘good for biobanking’ in some way, but this does not of course mean that every instance of commercial investment will be ethically acceptable for a biobank. Thus it is when faced with this kind of question about what to do or not to do in a particular case, where an answer is not codified or is open to interpretation, that the biobank’s purposive function gives the discussion something to go at. One interested party in such a debate, for example, could argue that accepting *any* financial input would, ultimately, serve public health in the long term because it helps the biobank sustain itself, and conclude on that basis that accepting the transaction is both permissible and conducive with a biobank’s general aims. Another party, however, might counter this by questioning whether, in this case, accepting this particular commercial investment is conducive with the biobank’s *purpose* on the particular understanding I have outlined, which evokes the reasons we have for sustaining the biobanking institution and the human goods it serves in that capacity.

With the possibility of addressing such questions in mind, a useful and basic employment of this conception could be in the construction of ‘mission statements’. These statements could be explicit in detailing the particular and characteristic ways in which a biobank operates and how this distinguishes it from other research institutions, and be as clear as possible about the particular way these specific activities serve the good of medical research (or the more specific areas of that research, depending on the scope of that biobank’s purpose). This would be to close a gap between a non-normative description of the biobank’s activities on one hand, and additional statements that these activities will be subject to ethical regulation or, for example, be in keeping with the public interest on the other. Properly formulated, such purposive and human goods oriented statements would be declaring and explaining some ethical qualities and standards that are internal the biobanking institution, rather than just tacking on a pledge that it would operate according to ethical standards or less determinate and multiply realizable ideals of health and public interest.

This kind of mission statement, and the idea it expresses, could also relate to the question of participant consent more directly than we might think. A much discussed way round the problem of informed consent has been the idea of general or ‘broad’ consent where the participant donor consents to the ‘multiple purposes of biomedical research and future consent to as yet unspecified biomedical research’ ([6], p. 266). Participants giving such ‘broad’ consent need to be well informed about what a biobank could reasonably be expected to do and not do with their samples. If broad consent is not to be ‘blind’ or ‘carte blanche’ consent to anything, then the specific nature of the activities one is consenting to must be understood by the consentor [9]. Perhaps participants can never be fully informed about all the uses to which a biobank will put their genetic material and data. They can, however, be better informed and reassured as to why they might be used some ways and not others. One aspect of such information could be clear communication of purposive function as something that sets certain limits on a biobank’s activities.

Related to the question of participant information is that of a more general perception of the biobank. A study of a Norwegian focus group of biobank participants discovered that ‘consenters base their participation on trust in the researchers and the regulation of research in Norwegian society, rather than on specific information on the research in question’ [13]. Thus if the Norwegian experience can be generalised to biobanking and publics, in the relation between biobanking institutions and public participants ‘*process* and trust *matter*’ [13]. In this respect it would be advantageous for the biobanking institution and the participating public to share an understanding of what the biobank is, i.e. what it does and does not *do*.

Similarly, a sharing of this understanding would go some way to providing a mutual reference point on which to compare and contrast interests that may not at first appear to be mutual. In the opening section of this article I mentioned briefly some conceptions of biobanks and participation that see the biobank as some kind of co-operative scheme, namely the shareholder and the stakeholder models. Winick-off ([16], p. 450) on the first view, identifies an ‘agency gap’ between donors and those who manage and biobanks, in that donor groups are under-represented. In response Hunter and Laurie, defending the second view, have seen difficulties in the shareholder model, not least ‘a danger that vocal minorities might come to dominate within the shareholder model, especially if connected to groups that are already well-organised, resourced and mobilised (e.g. patient or advocacy groups).’ (2009, pp. 158–159) One lesson to be drawn from this discussion is that the interests that a donor group *has* in being part of a biobank, the reasons the group has for being donors and getting involved, could be better articulated in the context of understanding what the purposive function of that institution is. By the same token, what may seem to be the conflicting or competing interests of the biobanking institution, and whether they do indeed conflict or compete, might be better communicated in light of it.

Such an understanding could in this way inform various organizations and individuals in deliberating about how to act and operate. When a Research Ethics Committee scrutinizes a biobank’s practices or establishes its criteria, for example, it should undoubtedly include consideration of individual participants’ rights as well

as communities, groups and future public benefits, such as were outlined in introduction. But if what I have suggested in this paper is at all plausible, it would do even better also to include the purposive functional biobank as a subject of that discussion. Turning to individual practitioners, researchers in biobanks will of course be subject to strict legal and ethical standards that apply to biomedical research practices in general. But as biobanking develops as a relatively new practice with new ethical challenges, so might the notion of a ‘good biobank researcher’ who, like those in other professional roles has certain specific responsibilities and for whom there are better or worse ways to interpret those responsibilities. And as with other professional roles to which ethics is ‘applied’, a substantive notion of what makes the ‘good teacher’, ‘good doctor’, or ‘good lawyer’ requires an understanding of the nature of the institution that is determining the demands of that role [14]. Again, this is not to suggest that, once we understand the purposive function of an institution, such as the biobank, we will thereby conclusively answer the question of how an individual is to act well in the role which the institution defines. It is, again, to state that we will have something indeterminate and useful to think and argue about in considering that question.

There is perhaps a more general point to be emphasised in an important final example. The internal purposive and functional standards which I have claimed can place ethical limits on biobanks could serve as criteria in drawing up more specific legal or advisory ethical guidelines. This would mean that as biobanks come to operate according to such rules and regulations of biobank research, the purposive functional understanding of the biobank presented here could play a part in determining, to some extent, which activities become standard in biobanking and which do not. To this extent the very notion of what ‘biobanking’ is and could become is, as it were, itself under construction. ([8], pp. 6–7) In my view this is all the more reason to get some grip on a conception of a biobank as a social institution which, building on Aristotle’s insight, is aimed at some good in a specific way.

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