

OPINION

Power to the people: a wiki-governance model for biobanks

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Abstract

Biobanks are adopting various modes of public engagement to close the agency gap between participants and biobank builders. We propose a wiki-governance model for biobanks that harnesses Web 2.0, and which gives citizens the ability to collaborate in biobank governance and policymaking.

Keywords Biobank, collaboration, genomics, governance, networks, public participation, social media, Web 2.0.

Participatory democracy, deliberative democracy and related models of inclusive, public engagement have recently gained a formidable foothold in biobank, genomics and science-and-society literature [1-9]. Despite its relative nascency, public engagement is already eradicating once-enshrined technocrat beliefs of expert-driven, top-down governance [10]. Indeed, public engagement is increasingly being implemented by biobanks around the world to close a perceived agency gap; witness the (Canadian) BC Generations Project's adaptive governance structure that includes the structural incorporation of participant interests into governance via participant bodies [8] and the UK Biobank's reflexive governance model that pushes for wide-ranging and ongoing commitment to stakeholder engagement [11]. Although there are many types of biobanks (Table 1), one may arguably postulate that a consensus is emerging in large-scale, public, population-based biobank governance: the collective, public nature of a biobank's constitution and stored material in the form of data and samples militates strongly in favor of the active involvement of contributors in decisions regarding the allocation and stewardship of biobank resources.

Given that many large-scale, population-based biobank projects are funded, regulated and sometimes managed by the state, meaningful engagement with tax-paying citizens is critical to build and sustain public trust and involvement. Public engagement in biobanks is manifold, ranging from information dissemination on biobank websites and town-hall-style panels and workshops, to community representatives serving on biobank boards and, in some cases, full power sharing. While these engagement modalities are an improvement from the relic models of top-down, expert-driven discretionary governance [12] that led to democratic deficits, sustained public criticism (for example, the Human Genome Diversity Project [13], UmanGenomics in Sweden [14], and the proposed biobank project in the Kingdom of Tonga [15]), or legislative failures (for example, the Health Sector Database Act in Iceland [16]), they too suffer several shortcomings.

These models may not: sufficiently reflect the values and interests of all stakeholders; be solution-driven; be fully transparent, accountable or non-arbitrary; or be fully independent from biobank management. Mere publication of policies for passive consumption is unidirectional transparency that forecloses any ability to engender openness and participation. Ethics and governance committees, even if composed of contributors or other stakeholder representatives to police decision-making, might be regarded as merely legitimating the decision-making and actions by the biobank itself and might not have real independence and access to effective enforceability mechanisms (for example, binding power to levy a fine or withdraw access privileges upon a material violation of a data or sample usage agreement) to act as a watchdog with teeth [17]. Some commentators have proposed innovative ideas. David Winickoff, for example, has proposed a shareholder model [18,19] that adopts a cooperative, charitable trust and corporate law outlook that allows participants to exert a share of control in distributive decision-making via representation by an elected donor association. Potentially beneficial for disease-based biobanks, it would be likely to encounter logistical and policy-oriented problems in large-scale, population-based projects, and engage only biobank

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Table 1. General typology of biobanks

Classification	Characteristics (non-exhaustive)
Nature	<i>De novo</i> (prospective) Retrospective collection of biological samples and associated data
Type	Population-based Disease-based
Age cohort	Adult Pediatric
Purpose of collection	Clinical trial Pathological archive Basic research Translational study Public health Forensic
Size and scope	Specific community/communities Regional National International
Nature of biological samples	DNA/RNA Blood Serum Tissues Urine Saliva
Type of data	Genetic Phenotypic Health related Genealogical Lifestyle
Period of storage	Fixed Indefinite
Level of security	Coded Anonymized Anonymous
Funding	Public Private Public-private
Venue	Hospital Academic or research institution Governmental institution Industry Foundation or disease-advocacy organization

Biobanks may be generally defined as an organized collection of human biological material and associated information stored for one or more research purposes. As this table illustrates, there is an open-ended and potentially non-exclusive typology in the rich tapestry of biobanks [25,68], but many stand at the intersection of multiple issues such as medicine, science, markets and public health [56]. This article focuses on large-scale, longitudinal, publicly funded, population-based biobanks. A population-based biobank has the following characteristics, based on the Council of Europe criteria [69]: (i) the collection has a population basis; (ii) it is established, or has been converted, to supply biological materials or data derived therefrom for multiple future research projects; (iii) it contains biological materials and associated personal data, which may include or be linked to genealogical, medical and lifestyle data, and which may be regularly updated; and (iv) it receives and supplies materials in an organized manner. Table adapted from [70].

participants - not all stakeholders in the biobank ecosystem [1,11].

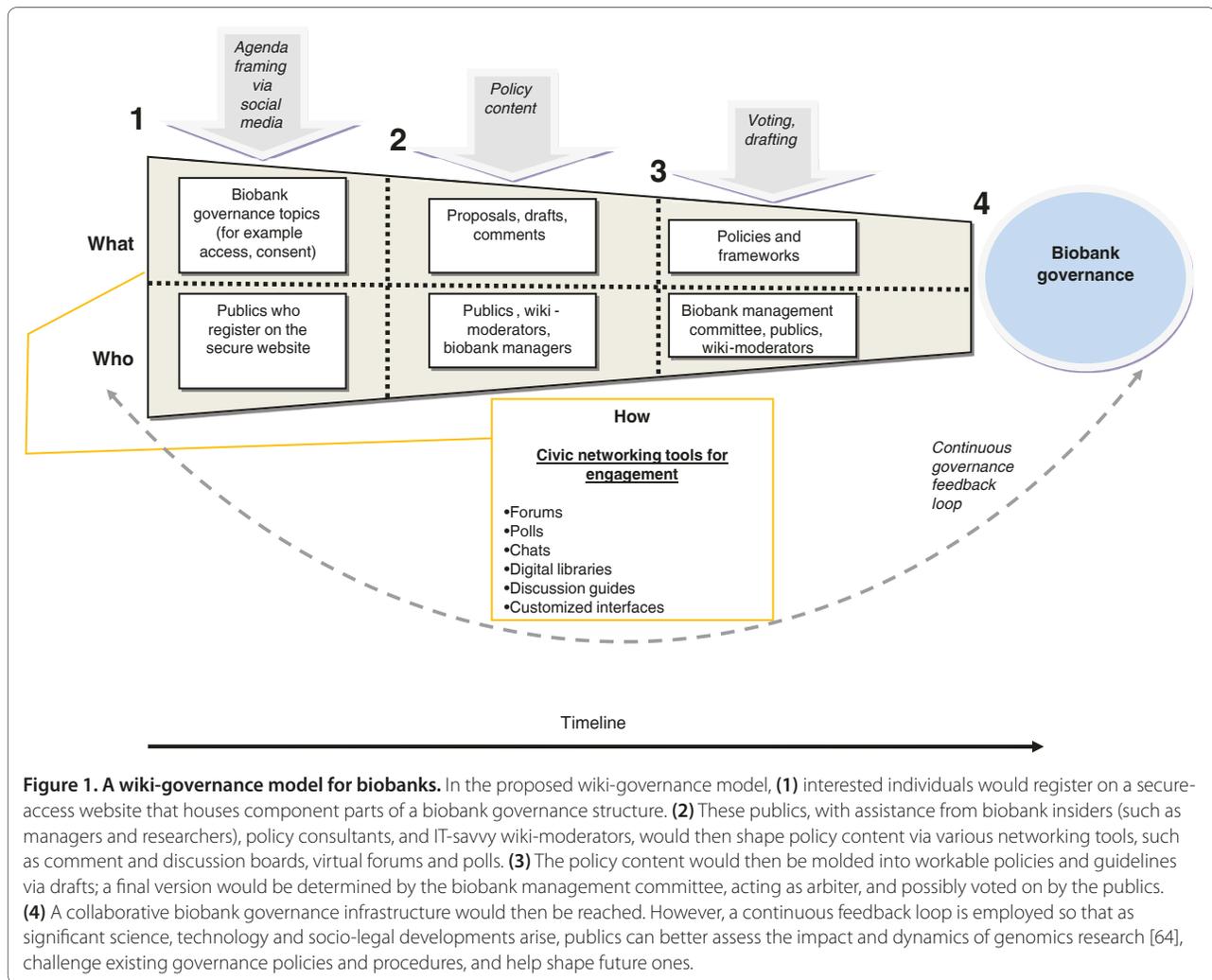
Thus, there is a real potential for citizens to be lulled into a false reassurance of sound, representative ethical

and governance approbation. This gives cause for concern and thought for better avenues of non-hierarchical engagement and oversight for large-scale, population-based biobanks. We therefore propose an alternative networked, reciprocity and mutuality-driven model [20,21] that engages all citizens actively [22] and that is not co-constructed or shaped top-down by state or other political authorities [23].

How wiki-governance would work: open but structured

In this wiki-governance model (Figure 1), taxpayer-funded, large-scale, population-based biobanks would harness Web 2.0 and the age of networks. Working in conjunction with funders and regulators, biobank builders would create and steward a social-media driven HTTP Secure online forum where publics (conceivably but not necessarily state citizens if the biobank is national, and global citizens if the biobank is international) would register (via username, password and email address) and collaborate in proposing, drafting and amending biobank digital governance structures, protocols, strategies and policies. Citizens would have the option of using either their username or their real name as a publicly visible author's name for content they submit. Unlike a crowdsourcing model that entails herds rushing to a problem, wiki-governance entails structured coordination of issue framing and role differentiation where individuals can choose the opportunities that best exploit their intelligence and represent their interests [24]. Forums, polls, digital libraries of past and comparative policies and documents, and chat interfaces would enable interested individuals to educate themselves about the biobank and the general scientific, ethical, legal and regulatory framework that girds it, such as laws concerning human material or data protection and regulatory bodies.

Though each biobank would contain individually tailored key policies, within the genus of population-based biobanks, there would be a structured set of minimum standards or permissible policies or practices, guided by legal and ethical doctrines [25] or generally accepted governance desiderata such as adaptability, coherence and internal consistency [11,26]. Individuals and interest groups would be empowered to winnow out, vote and comment on draft provisions or policies, such as a broad consent form, an access policy for samples and data, a return of results policy, or a model benefit-sharing agreement, as well as respond to comments posted by others. After engaging in such open and visual deliberation, the biobank's management (or similar) committee would then act as final arbiters in determining if and when a given policy should be adopted as final, and whether its contents are scientifically, ethically and legally valid (Box 1). This collaborative knowledge ecosystem



and subsidiarity structure is similar to how Wikipedia works successfully, where registered users may edit the contents of entries, which are then subject to peer approval and reviewed and validated by a group of core editors [27].

While wiki-governance may be viewed as a cousin of collectively engaged projects that allow scientists to annotate gene functions, protein structures and other information relevant to genome biology [28-33], as well as the growing citizen scientist movement [34-37], it is readily distinguishable from both. Wiki-governance is open to all citizens, not just traditional, expert-led communities of scientists; as a governance system, it avoids the potential pitfall of data inconsistency that could plague wiki biological databases [38]. Unlike projects that consist of individuals posting their DNA sequences in the public domain for various experiments (for example, Personal Genome Project, OpenSNP, Genomera), wiki-governance does not involve citizens collecting and analyzing raw data and directly engaging

in studies and trials (or proposing new ones), which carry unique scientific, legal and ethical issues.

Envisioned instead as a collaborative enterprise for governance (as opposed to research) purposes, wiki-governance would, in our view, greatly advance participation among biobank managers (and other insiders) and publics, be they contributors and their families or the greater citizenry. Rather than targeting a selected group of individuals as representatives of the public (as is often the current governance model), wiki-governance would, like current examples of citizen lawmaking (Box 2), attempt to reach across all segments of society for inclusive engagement and partnership [39] and allow citizens to work alone or in self-identified groups. It would pool diverse knowledge and skills [40] and make public engagement 'an integral part of the overall governance structure of the biobank' [41]. It would satisfy demands by the public for 'clear preferences for the design of biobanks' [42]. Most importantly, wiki-governance would produce a higher

Box 1. A hypothetical biobank wiki-governance scenario

The following is a very brief sketch of a hypothetical scenario for wiki-governance in a biobank. We wish to emphasize that each situation will call for creative and customized strategies, methodology, and tools that are carefully and transparently planned with multidisciplinary involvement.

Nulleterre Biobank, a prospective, national, population-based biobank, wants to formulate a policy on consent, as well as a consent form, for participation in the biobank. Its management/scientific committee, in consultation with the advisory board, decides to use social media to encourage publics to visit and register on its secure website to partake in the task 'to develop a consent form and policy for Nullepart Biobank'. Part of the agenda framing exercise is to invite individuals to work on specific tasks or address targeted questions. The general issue is framed as: 'Nullepart Biobank wants to create a pool of openly available samples and data that realistically maintain and respect privacy. Our goal is to create a policy that allows people to donate their samples and data to our biobank and have them coded so that they can be securely delivered to all researchers around the world. The researchers must agree to strict conditions that prevent harm to the contributors and to share their research results freely. Contributors would have to go through a detailed informed consent process that includes online tutorials and information sessions and culminates in signing a comprehensive consent form'. Further background information is available on the website, as are clear instructions on the wiki-governance process.

Topics are parsed into component parts, including: general comments or voting on the proposal; responding to targeted questions; posting relevant background literature, laws or policies; drafting specific parts of the consent form; comments on and edits of particular consent form provisions already drafted; and producing the online tutorial. Individuals then self-select into groups and digitally and visually collaborate on responding to the specific parts depending on their interests, expertise and time availability. Wiki-moderators are available online to oversee the forum and help those who have technical questions, and policy consultants are available to address policy-oriented questions. The endeavor has an open period of 1 year, at which point the website is closed to further collaboration.

After the 1-year period expires, the scientific committee of Nulleterre Biobank, in consultation with the advisory board, reviews the various submissions and validates them. It decides to adopt the consent policy and accept most of the draft consent form. It rejects part of the drafted 'risks' section for ethical reasons, explaining them in detail, and states that it will need to add two short, currently absent sections on sources of funding and use after death (these in turn will be open for public comment and drafting for a further period of 1 month). The biobank also states that before implementing the policy and the consent form, it will vet them with its legal counsel, and that the policy and consent form will be continuously updated and revised through the wiki-governance system on an ongoing basis as new scientific, technical, ethical and legal issues arise.

quality biobank governance infrastructure for the following reasons.

First, biobanks would truly engage and appeal to their publics, welcoming contributions from all, yet without compelling any given individual or group to participate at a *de minimus* level. Each person would be entitled to contribute as much or as little perspective and skills as desired, and this could potentially deflect future criticisms of a biobank's operations [43]. At the same time, by engaging publics via virtual networks and a dynamic digital commons for outputs and action (that is, collaboratively evaluating and shaping information in order to create implementable solutions), wiki-governance would be likely to abate the pitfalls of consensus-driven, deliberative governance models involving both traditional, confined face-to-face and online encounters that fixate on inputs. Inputs focus on gathering diverse viewpoints and balanced representation for opinion formation and adherence to procedural rules for interaction that may produce endless talk and groupthink [44-46]. Second, the infrastructure would be the product of assorted, unbiased, non-insider opinions and skills untethered to the scientific imperative fuelling biobankers, researchers and the funding agencies. Third, wiki-governance would

facilitate a continuous feedback loop. As underlying science (for example, next-generation DNA sequencing) and technology (for example, cloud computing) advances and new ethical and legal issues arise (for example, return of research results and incidental findings), perpetual public dialogue would provide desired flexibility, adaptability and reflexivity, thereby consistently challenging existing governance policies and procedures and anticipating which challenges might arise [11,47].

Finally, though the governance structure may exhibit a form of non-legally binding self-regulation, its community-collaborative construction would be likely to impose a stronger level of control and influence on the behavior of the biobank: failure to uphold the policies formulated by citizens would be likely to cause a loss of public support and trust, and jeopardize the viability of both the biobank in question and future biobanks. Put another way, publicly crafted and citizen watch governance policies that are self-regarding can better convince outsiders that there are robust checks on insider conduct in place, as opposed to many hard law sanctions [27]. Moreover, as Graeme Laurie aptly remarks, 'the irony is that if recourse to law is needed even within traditional regulatory systems then the systems have already failed' [11].

Box 2. Wiki-governance in action: citizen lawmaking

While of novel terrain in the field of genomics and biobank governance, wiki-governance examples are thriving in state and citizen-led efforts to increase public engagement in lawmaking [24]:

New York Law School's Democracy Design Workshop and Do Tank is a laboratory of governance innovation ideas [71].

Russia recently participated in WikiVote [72] by posting a draft bill on fishing in public waterways [73]. The draft bill went through two redrafts and received over 1,000 proposed modifications [73]. Russia has also since posted a draft education bill on WikiVote [74].

In July 2007, Estonia launched its Osalusveeb portal [75] (osale means participate in Estonian) whereby Estonians can initiate legislative proposals, submit petitions to the government, participate in public hearings and comment on draft legislation proposed by the government.

In 2007, citizens and non-citizens (for example, international constitutional commentators, policing experts and criminologists) alike helped revise the *Police Act 1958* in New Zealand via a wiki, which received more than 25,000 visits during the year [24,76]. While certain ideas, such as renaming the force 'The New Zealand Yum-Yum Teddy Bear Strike Force Z', were edited out, others were put into the new *Policing Act 2008*, including a suggestion to increase the minimum police recruitment age to 25, since research indicates that the human brain is not fully developed until then [76].

In June 2009, Brazil launched the e-Democracia Project [77]. It allows Brazilians to share information about a problem that a law may address, identify and discuss potential solutions to the problem, and draft a bill. Further, it transports citizen comments directly to the parliamentary agency that advises members of parliament.

Finally, a student-created citizen governance wiki called LexPop was recently created as the first legislative wiki platform in the USA (the website has since been put on hiatus until January 2013). Despite the uncharted territory, a Massachusetts state legislator agreed to propose a bill on net neutrality on LexPop for the site's users to draft [66].

Challenges and responses to the wiki-governance model

A biobank wiki-governance model is not flawless. The following points delineate what we believe are the main concerns that can be raised. (1) A closed system of experts (be they scientists, lawyers or ethicists) is better suited to craft complex governance policies; the madness of crowds is a genuine concern [48]. (2) Unless there is rational (for example, language compatibility, effective visualizations with specific, focused questions and topics), impartial (for example, agendas are framed in a non-loaded manner by those not seeking any one desired outcome) and appealing (for example, user friendly) design of a wiki-governance forum to present a generally understandable view of citizen collaboration, it is possible that confusion, narrow interest group commandeering or tune-out may ensue [49]. (3) Unlike Wikipedia and open source, wiki-governance involves collaborative efforts on both factual and normative issues. This is a new paradigm and there are as yet few examples of normatively driven policies truly crafted by publics. (4) Wiki-governance is difficult to scale and it is time and money sensitive. Capital investments must be made to properly run and maintain the IT logistics of the forums. (5) Policies must at some point be released; therefore, it falls upon someone to determine when the time is right to deem a policy final. (6) Though rapidly shrinking, the digital divide remains, so not all citizens, be they state or global, can have a legitimate voice in the collaborative decision and

policymaking process. (7) Small, pinpoint-focused contributions by citizens may lead to problems in seeing the big picture of a biobank policy. (8) Drafting policies requires a certain degree of technical skill (though this can be remedied with policy consultants, tutorials and a wiki-sandbox to practice, as well as FAQs). (9) An under-researched subject that is especially pertinent here is the paradox of public engagement and biobank governance in the 21st century: policy harmonization is increasingly seen as a necessity for translational research [50,51], yet greater public engagement could produce more policy variability based on local cultures, politics, values and histories.

These are neither insurmountable nor fatal hurdles. As a rejoinder to the 'madness of crowds' argument, we reject the 'public knowledge deficit' thesis; the putative ignorance of publics is not an obstacle (if it exists at all), but rather an opportunity to foster symmetry of knowledge and learning processes between purported experts and non-experts [52]. We also emphatically oppose institutional fetishism that places trust in only recognized experts for science and policy [53]. We believe that, (arguably) unlike in a wiki model for research, a wiki model for governance and policymaking necessitates real expertise, which for us is broadly defined to include all individuals with scientific knowledge and popular experience that can effectively supplement the knowledge of inside, traditional and credentialized governance experts [54]. The self-policing nature of a wiki, united with

diversification of decision-making processes into many constituent parts through various technologies, limits the risk of tyrannical factions and interest group commandeering. If a wiki-governance forum is designed (itself, in a collaborative and transparent manner) to facilitate teamwork and group projects rather than solo one-off contributions and is coupled with reputational metrics for participating citizens (that is, a rating system of the best contributors), potentials for tune-out, frivolous participation or collective distrust of working anonymously across distances could dissipate and at the same time augment participation rates.

As a rejoinder to the paradox of policy harmonization, it may well be that different biobanks require different means of engaging in their social environment to include publics; the price of welcoming a diversity of different biobank constituencies is heterogeneous structures [23,55]. Harmonization of basic epidemiological and policy tools - distinct from harmonization of ethics [56] - is possible and in fact advisable, given increasingly collaborative transnational research and transfer of data and samples [57]. This is an ongoing aim of the Public Population Project in Genomics and Society (P³G) [58], an international consortium dedicated to the harmonization of policies and research tools for large biobank projects across the world.

Global approaches to some aspects of governance are currently being assessed. DataSHIELD [59] is a bioinformatics tool to provide access to research results via simultaneous parallelized analysis of the individual-level, harmonized data from each study, without breaching data protection or privacy laws and research governance requirements. The Ensuring Consent and Revocation (EnCoRe) project [60] empowers individuals to control their consent and shape what happens to the personal information they disclose to organizations. The Open Research and Contributor ID (ORCID) [61] initiative creates a central registry of unique identifiers for researchers and a linking mechanism between the registry and other current author identity schemes so as to facilitate scientific discovery and global research community collaboration. And the BioResource Impact Factor (BRIF) [62] project seeks to provide a global registry for databases and allow a unique identifier to cite and acknowledge the use of bioresources in publications, thereby measuring their impact. The project aims to assist groups in tracking submissions and data release and promote the international sharing of bioresources [63].

Harmonization is conceptually and operationally distinct from a one-size-fits-all regulatory approach. Broad-based, shared scientific, legal, and ethical norms can be a foundation upon which kaleidoscopic, but global and digitally linked governance architectures, can be built. This is the aim of the newly established, P³G-hosted

ELSI 2.0 Initiative, for instance, which mobilizes networked international collaboration in ethical, legal and social implications (ELSI) research by establishing a web-based research collaborative infrastructure for publics that will accelerate the translation of ELSI research findings into practice and policy [64].

We acknowledge, nonetheless, that these obstacles hinder a fully libertarian wiki. A workable wiki-governance model may therefore be a modular, collaborative one, where citizens participate in and vote on a given proposal, protocol, policy or more contentious aspect of the project, and submit it to the biobank management committee, who must, acting as a central arbiter, then post a response, explaining what action was taken and why. Each time components of a biobank's governance beckon revision (whether through voting on the wiki forum, imposed periodic review of a policy or management committee decision), the wiki-governance process outlined in Figure 1 would repeat itself and the biobank management committee would be called upon to act.

Concluding remarks

Even in the blazingly fast world of genomics and biomedical research, large-scale, population-based biobanks are still a rather new phenomenon. Much progress has been made in a short period of time to better respect and incorporate the views of those upon whom the success of a biobank stands: citizens. Now that much of the world is entering an era of perpetual online existence and social media technology where youth are particularly active participants, new tools can and should be utilized to gauge public sentiment, engage citizen collaboration, share work and embrace the wisdom of crowds [48]. If 'the relational, open and global nature of modern science is leading to more devolved regulatory approaches' [65], and if the success of a biobank depends on an effective 'strategy for patterning a network of interaction' [23], paladins of participatory democracy should view wiki-governance as a promising avenue. Indeed, we think it can spawn new biosocial group identities [66,67] and lead to the establishment of biobanks from the bottom up, by citizens rightfully envisioning themselves as co-creators of genomic science and policy. At a minimum, wiki-governance would be a welcome application of biobankers' fundamental socio-ethical aspirations of public understanding, engagement and motivation, trust, transparency and open dialogue, thus simultaneously promoting scientific aspirations of successful translational research. In the spirit of such engagement and open dialogue, we encourage the entire readership to submit their comments on our model.

Abbreviation

ELSI, ethical, legal and social implications.

Competing interests

The authors declare that they have no competing interests.

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