Differentiating and Evaluating Common Good and Public Good: Making Implicit Assumptions Explicit in the Contexts of Consent and Duty to Participate

A. Bialobrzeski J. Ried P. Dabrock

Faculty of Philosophy and Department of Theology, Friedrich-Alexander University Erlangen-Nuremberg, Erlangen, Germany

Key Words

Biobank • Common good • Communitarianism • Consent • Public good • Public trust

Abstract

The notions ‘common good’ and ‘public good’ are mostly used as synonyms in bioethical discussion of biobanks, but have different origins. As a consequence, they should be applied differently. In this article, the respective characteristics are worked out and then subsequently examined which consent models emerge from them. Distinguishing normative and descriptive traits of both concepts, it turns out that one concept is unjustly used, and that the other one fits better to the context of a plural society. A reflected use of these differing concepts may help to choose an appropriate form of consent and allows public trust in biobank research to deepen.

Copyright © 2012 S. Karger AG, Basel

Introduction

The two concepts of common good and public good are regularly mentioned in ethical debates on biobanks in comments about the special public interest in that re-

search infrastructure and the expected results of biobank research [1, 2]. Despite the different fields of association they are traditionally linked to [3, 4], these two terms are usually not differentiated, but used more or less synonymously. However, this conflation means that the distinctive and normatively relevant differences between the two concepts are obscured, which affects the form and content of the ethical debate on biobanks, which in turn has a substantial impact, for example, on the consent model considered to be adequate and on the question of a duty to participate.

The most obvious differences between the concepts of common good and public good are linked to their domains of origin. The term ‘public goods’ is usually used in an economical context and marked by its nonrivalry and nonexcludability, that is, their use neither diminishes them, nor can other people be excluded from their usage, a classic example being clean air. But the term ‘common goods’, often used in noneconomical settings, refers to those goods that are identified as relevant for the community according to certain normative considerations and that then are defined as such in a political process of deliberation. A further question for separate consideration – and again in a political process of deliberation – is what is the distributing regime of those goods

KARGER

Fax +41 61 306 12 34
E-Mail karger@karger.ch
www.karger.com

© 2012 S. Karger AG, Basel
1662–4246/12/0155–0285\$38.00/0

Accessible online at:
www.karger.com/phg

Arndt Bialobrzeski
Friedrich-Alexander University Erlangen-Nuremberg
Faculty of Philosophy and Department of Theology
Kochstrasse 6, DE–91054 Erlangen (Germany)
Tel. +49 9131 852 6079, E-Mail arndt.bialobrzeski@theologie.uni-erlangen.de

defined as common that makes them actually generally accessible. In any case, the common goods cannot adopt the characteristics of nonrivalry and nonexclusiveness from the economic public goods without further examination. And, vice versa, public goods only rarely, or at least not primarily, function as deliberately worked-out identity markers of a community whose 'communio' can be deduced from such common goods, among other things.

The following deliberations aim at questioning the presently established synonymous use of the terms 'common good' and 'public good' in biobank discourse and critically examine the implied consequences of such a differentiation. Regarding a model sensitive to differentiations of both concepts, a heuristic that distinguishes between common good and public good shall be developed for describing and evaluating various normative frameworks of biobanking.

The Insufficient Reading of Biobanks as 'Public Goods'

Regularly using the terms 'common good' and 'public good' synonymously in biobank discourse can contribute to obscure normative issues in the context of the structure and usage of population biobanks – for example, the questions of consent models, participation, or compensatory mechanisms – or to put a certain complexion on them so that the public trust, which is necessary for the efficiency of the research instrument of the biobank, is fundamentally and lastingly affected. This section discusses in what respect a biobank can be understood as a common or public good, and which normative presuppositions and possible consequences can grow from this understanding in order to finally examine the extent to which differentiating common good from public good could lead to more clarity and transparency.

Referring to Kaul et al. [5], Knoppers and Fecteau [6] define biobanks as a global public good. On one hand, the goods would show a high degree of publicness since their usage does not imply consumption and, in general, no one can be excluded from using them. Hence Knoppers and Fecteau apply a definition of 'public good' that is common in economics [7]. On the other hand, the characteristic of the *global* public good would be based on the fact that a global public would benefit from it transboundarily, that is, its benefit could develop universally. One cannot deny that biobanks – and indeed the whole network of biobanks – have an enormous poten-

tial for medical research in the broadest sense and, consequently, for clinical applications to be developed, for example in the area of so-called individualized medicine or pharmacogenomics. It remains to be seen whether or to what extent the ascribed or hoped-for potential will actually be realized. In any case, it is neither mandatory nor possible without further consideration to conclude from this potential that biobanks can be defined as global public goods, especially not, if that implies deducing far-reaching consequences, for example, regarding funding and using biobanks in an international framework [6].

However, certain aspects make it implausible for us to understand biobanks as global public goods, which are defined by nonrivalry and nonexclusiveness. First, biobanks may be bound by legal restrictions on the transboundary transfer of body samples and data that must be ethically justified and possibly can hinder global access. Second, there is occasionally a lack of cooperation between publicly funded and commercial biobanks because of their differing approval of economic goals so that the access also can be restricted. Also contrary to the nonexclusive aspect is the tension between the partly unresolved property rights of samples and the legitimate but nonetheless problematic resistance of researchers to share samples or results with other researchers. Considering these factors, it is not implausible to assume that speaking of biobanks as global public goods is normatively wrong because real conditions and actual rules on how to position biobanks in society are deduced from the idea of putting the public interest in biobanks into a concept based on economics. This includes in particular the notion that qualifying something as a public good always presupposes the active good will of the whole society, which consequently requires the exclusive or at least primary provision of such a good, granting general access and respective appreciation at least by the vast majority of the population. Ensuring even 1 of these 3 points is at present hardly certain regarding biobanks, especially when we consider networks that operate internationally. Thus, it becomes clear that the concept of biobanks as global public goods cannot be made sufficiently plausible; yet, at the same time, in biobank discourse certain normative presuppositions are framed as nonjudgmental descriptions. That circumstance can be observed in another respect, too.

Knoppers' [1] statements on public health measures in general and on genomics, in particular, show even more clearly how the boundaries between the normative and the descriptive level can be blurred in bioethical discourse. First, she assumes that global public goods prefer

mechanisms of public information resources and their free and open communication; thus, genomic data banks, which she counts among such goods, should be used to be beneficial to present and future generations. If this connection is established, what follows is the demand for increasing public health measures for the health promotion of all, which can only work effectively by asserting pressure or even by forcing everyone to participate [1]:

Norms for the emergence of a new paradigm for public health interventions must be informed by issues beyond the legal and ethical parameters of autonomy and privacy. Indeed, the fundamental reason why contemporary medical ethics has so little to say about public health is that its focus on individual autonomy suggests that all compulsion for the sake of health is wrong. Yet 'many public health measures must be compulsory if they are to be effective.' Thinking at the level of populations or groups requires a vetting of current ethical and legal principles and the development of a concept of the public good or of 'common' goods.

According to this opinion, it would be advisable to substitute liberal, individually focused ethical principles by more collectively shaped concepts of a public or common good – here again used synonymously. Hence, the seemingly impartial description of a public or common good is related to the demand for a new normative framework. This requires revising some of the central aspects of the previously established standards while being able to legitimize the individually focused ethical principles' option to resist, especially the respect for autonomy, by referring to public or common goods. Here, Knoppers [1] does not differentiate between an economic and a normative concept, which would make it possible to distinguish between public good and common good.

Differentiating Public Good from Common Good

In comparison to Knoppers [1], Chadwick and Wilson [8] do take note of the widely used economic definition of public good in the sense of nonrivalry and nonexclusiveness, but distinguish a normative concept of a public good and develop a primarily ethical definition supported by a communitarian argument. This model includes a teleological orientation that aims directly at achieving collective interests and that leads to enforcing the idea of a good life in society, where collective values such as equality and solidarity have clear priority over individual interests. Guiding principles here are that each individual always is also a social being, and that some conditions for a successful life can only be fulfilled in community with other people [9].

Chadwick and Wilson's [8] advocacy for communitarian reasoning evolves over the years: first, Chadwick promotes communitarian values only in order to introduce them; second, she identifies them as a new evolving trend in the bioethical debate; and third, she looks back at the past years of communitarian bioethical argument with similar conviction, but at the same time, she qualifies its powers of self-assertion.

At the beginning of her communitarian promotion in the biobank community, Chadwick and her coauthor Berg [10] state that the justification of informed consent as a means of building trust is under scrutiny and should be regarded in a similar way to securing autonomy and other interests that could be realized much better using another model. The allegedly no longer sustainable individual-oriented ethical approach of the informed consent could be replaced by the alternative of a society-oriented principle of solidarity that is expressed by research participation motivated by a sense of common good will.

In the second phase of Chadwick and Wilson's [8] process of deliberation, Chadwick promotes a better world, which is characteristic for teleological ethics, leading to the conclusion that an ethical turn has taken place toward communitarianism. Together with her coauthor Wilson, she takes up the bioethical discourse on global goods and examines it due to its sustainability. The authors distinguish between biobanks as a natural good and as a social good, leading to a differentiation between a more economical and more ethical perspective. From an economical point of view, biobanks would probably not be considered a public good because, though the use of the available data does not imply any form of consumption, this knowledge resource is not always accessible to anyone interested, which precludes it from being called a public good in the strictest sense. Not even the statement that 'the sequenced human genome is a global public good since anyone has a share in it and it is publicly accessible' is completely applicable because each genome has individual parts that are used only by the respective organism in a competitive way, and furthermore, access could be made exclusive very easily. According to Chadwick and Wilson [8], biobanks could be regarded as a social public good that the market provides in an insufficient way; however, this social public good should be actualized for everyone's benefit. Biobanks are not good per se but would contribute to the provision of public goods, and only on these grounds could they be understood as a public good. Specific social normative goals that would be achieved by running biobanks sustainably could therefore be generally increasing human health or improving

health care for everyone, for example. Considering the narrowing and economically implausible definition of biobanks as a global public good and taking a rather normative socio-philosophical view, Chadwick and Wilson [8] conclude that there are more reasons for rather than against understanding biobanks as a global public good; however, they argue that this would have to happen due to normative rather than economic deliberations.

Accompanying such rather normative approaches of biobanks as a common good is the statement made by Knoppers and Chadwick [11] that there is an ongoing trend within the international bioethical debate on biobanks that turns toward communitarian values, which in the case of biobanks consists of the ethical principles of reciprocity, mutuality, solidarity, common spirit, and universality. These contribute to the success of a happy life in their own way because, being ethical principles, they seem to be more viable regarding newer technological developments than are conventional values, such as '[a]utonomy, privacy, justice, quality and equity'.

The normative outline of this model becomes particularly obvious when analyzing the implicit relation of rights and duties. Knoppers and Chadwick [11] promote communitarian values that emphasize common interests and rights of all, but they also include the moral obligation to serve the next generations. In particular, this implies to diminish the right to privacy by decreasing the medical confidentiality obligation that limits the use of biobank data by researchers and commercial users [12]. Regarding several possible consent models, Chadwick and colleagues [13] thus clearly prefer the privacy-weakening open consent model.

However, the fact that Chadwick [14] emphasizes obligations and simultaneously relativizes rights does not reveal whether she only wants to oppose and counterbalance the abundance of individually oriented values with communitarian values or whether she indeed rates social obligations higher than the individual's rights per se. This question is answered years later in her third phase, when she looks back at the decade that has passed during which she promoted communitarian values. She reveals her aspiration for balancing individual and social interests due to a pragmatic impulse. At first, she distances herself from the idea that individual interests should be completely neglected to propel research and thereby the collective good. It is not her point in particular that possible progress in health could be much more important than individual inconveniences of research participants, which are apart from that allegedly sufficiently protected by governance structures. Instead, her point is that – in a

pragmatic way – technological progress consecutively involves a modified ethical view, and old principles of action that have become useless must be replaced by new ones. Her primary question seems to be what society plans to do with science. If science is to serve society, necessary conditions must be created. Due to her vision of a good life that entails the flourishing of the *whole* society, it becomes obvious that she offers a normative ethical framework that could be identified as being teleological. The consequences of such normativity for the consent practice are discussed in the next section.

Normative Implications of Different Consent Models

Having shown that (descriptive, but not value-free) economical and explicitly normative elements can be emphasized differently in the terms of common good and public good, it is reasonable to point out that such differing emphases can lead to consent models of different grades of autonomy and obligation. Therefore, it is worthwhile to examine whether the argument that biobanks are supposed to be regarded as a public good fundamentally entails a rather weak consent form like the broad or blanket consent. And whether it simultaneously requires a stronger duty to participate than could be the case if biobanks are understood as being a common good.

With few exceptions [15], a gold standard of medical research has long been to ask for consent for participating in a study, and this is codified as the 22nd article of the Helsinki Declaration of the World Medical Association [16]. Whereas informed consent is still routinely applied in clinical studies, some epidemiological biobanks now use other forms of consent in order to achieve a maximum utilization ratio [17]. An essential element of informed consent, which we do not pursue here, for example, is respecting the autonomy of the proband, or patient, so that he or she is never allowed to be put under a research risk without consent and never allowed to be exploited. The actual gradual arrangement usually varies depending on the context [18]. Here the focus distinctly lies on the principle of autonomy, which would be balanced if not outdone by the principle of solidarity in communitarian ethical frameworks, for example. To sum up: any consent model entails normative fundamental decisions on the priority of autonomy or solidarity. What is often neglected here is the relation between the respective consent forms and a possible moral or even legal duty to participate in biobank research. We turn to this aspect now.

Sass [19] advocates the so-called informed contract model, which is defined by distinguishing itself from informed consent, which he rejects as a form of 'traditional soft-paternalism'. The informed contract presents an annulable contract between donor, physician and researcher that informs each party involved about their rights and duties, and records them in written form. For example, it is stated that any knowledge that seems to be beneficial for the health of the individual or of relatives must be communicated to those parties. The possibility of withdrawing one's consent, including the destruction of all stored samples, is explicitly granted. Furthermore, the informed contract offers participants several notification options. They can decide whether they want to be told about predictive, preventive or therapeutic knowledge; whether they do not want to be informed about certain aspects or whether they do not want to be informed about anything at all; and whether they want to postpone those decisions to a later date. Illegal exploitation would lead to financial compensations, and commercial profits would have to be shared. Furthermore, the informed contract includes the usual information, such as general information on privacy, potential dangers for privacy and the donor's respective rights to knowledge and nonknowledge. According to Sass [19], all these elements show the informed contract to be more appropriate than informed consent, since the 2 parties have equal standing and are mutually dependent, and thus, probands and patients are in a stronger position than previously [19]:

Lay persons and health care professional [...] feel bound by an invisible contract of communication-in-trust and cooperation-in-trust, sharing responsibilities, rights, and obligations, also in the care of the less fortunate, the less healthy, and the less competent.

Analyzing the informed contract reveals that, though Sass [19] does not present an explicit model of a common or public good, he implicitly gives hints that can be assigned to the common good according to our definition. He foresees health literacy and health care playing a larger role in the 21st century, in which citizens not only benefit from a better health care, but also make their own contribution to it.

The situation arising from the informed contract is different from that with the so-called broad consent, which can be used relatively synonymously with the notions of general, generic or authorization consent. The concept of broad consent is used in discussions about biobanks being either a common good or a public good, but, almost exclusively in the context of the usage of the term

'public good,' it is argued for a duty to participate in biomedical research. That striking bias demands further examination.

As with informed consent, broad consent obliges the biobank to thoroughly inform prospective participants, which includes pointing out that their participation is voluntary; broad consent, however, differs in the range of its application. There is no narrow confinement to a certain purpose concerning a single project, but it is explicitly possible to participate in a broad array, which is determined by the biobank and the participant together [20]. What distinguishes broad consent from blanket consent is that it is not giving *carte blanche* to the researcher to run any research project without restrictions [21, 22].

There are 4 main reasons that epidemiological research prefers broad consent over the informed consent commonly demanded by medical ethics. First, it is problematic to gain thoroughly informed consent, because the purpose for taking the biosample is often unknown at the time of collection, with the research purpose specified only many years later. Second, informed consent can be problematic if biosamples resulting from diagnostic processes (e.g. blood tests) or therapeutic procedures (e.g. surgeries) are simply leftovers, but then shall be used differently for research purposes, but no one secured an explicit informed consent for further research use when the samples were collected. The physician did not do it since he/she does not feel responsible as he/she is not the one doing the research, and the researcher cannot carry out the informed consent since he/she does not take the samples or does not even consider himself/herself responsible, as the leftover body samples would have been destroyed otherwise. The third reason is that, according to empirical studies, the majority of people only want to give their consent once and then be left alone; thus, recontacting them for additional consent should be avoided. The final reason that epidemiological researchers prefer broad consent is that the informed consent allows donors to withdraw their samples at any time from the biobank, which reduces the quality of the biobank as a scientific resource [23]. The authorization model of Caulfield et al. [24] and the broad consent model both point in the same direction, but the authorization model emphasizes the role of safeguards stronger. It is their goal to create an atmosphere of mutual trust, responsibility and accountability accompanied by the permanent institutional inclusion of oversight bodies.

In order for us to address the question of which hidden normative implications are entailed by broad consent, it

can be helpful to look at Gordijn and Pijnenburg's [25] assumption that there probably exists a connection between consent models weakening autonomy and communitarian ways of thinking:

An appeal to the common good often involves the claim that individual interests must be superseded by the common good.

This connection is documented several times, as is shown later; however, what is missing is an urgent call for a general duty to participate in studies, which gains force only in the discourse of the biobank as a public good. Thus, Knoppers et al. [26] state in the description of the Public Population Projects in Genomics (P3G) that this biobank network builds on values such as common good, responsibility, mutual respect, transparency, accountability, and proportionality, and the broad consent used here strives to address the lack of individual autonomy with strict data security and an elaborated governance structure:

Indeed, the fundamental reason why contemporary medical ethics has so little to say about public health is that its focus on individual autonomy suggests that all compulsion for the sake of health is wrong. Yet 'many public health measures must be compulsory if they are to be effective.' Thinking at the level of populations or groups requires a vetting of current ethical and legal principles and the development of a concept of the public good or of 'common' goods.

Although Knoppers et al. [26] and others who use the term 'public good' as an implicitly normative concept do not deduce an at least explicit duty to participate from the public and common relevance of the research tool 'biobanks' [27, 11], still others take up the model of the public good and advocate for such a duty to participate in connection with favoring broad consent. Hence, Chan and Harris [28] argue that there are many public goods – for example, school education – that are obligatory and that not only is it our duty to preserve essential social institutions, such as medical research, by participating, but we also have a duty to save future invalids, which would apply to everyone. Similarly, Forsberg et al. [29] argue that those who draw benefits from the health care system should not act as free-riders by benefitting from past study participants without giving anything in return themselves; rather, they should make their own personal contribution to future health care by participating in studies themselves. Negative individual consequences are not to be expected. Obviously, the authors are not bothered by the fact that other researchers hold a decidedly different position concerning this and warn about the considerable future risks of the broad consent [30].

A similarly normative outline is presented by the model of open consent that endeavors to take into account the interest of science and society and thus easily can ignore individual interests. This model, which became known because of the Personal Genome Projects, is equivalent to the form of consent that consciously omits a concrete purpose for the acquisition of data as a standard of privacy in order to gain maximum research freedom for large-scale biobanks. One of the main arguments for this model was that previous concepts of privacy had been undermined by newer technological developments and thus lost their adequacy. Hence, the goal was to adjust ethical principles according to the scientific progress while maintaining a certain moral basic orientation. Instead of privacy and confidentiality, more transparency and veracity were promised [13].

The so-called blanket consent works in a similar way; likewise, any kinds of restrictions for research and later talks with probands are avoided, but the aspect of extensive data sharing is not stressed in the same way. The WHO is one of several influential organizations that supports this model because it 'would allow use of a sample for genetic research in general, including future as yet unspecified projects, appears to be the most efficient and economical approach, avoiding costly re-contact before each new research project' [31]. What makes blanket consent special is its attractiveness for researchers, as it guarantees enormous freedom of research because of the lack of restrictions on the part of the participants, but, at the same time, it defies the privacy standard of the collected data's confinement to a certain purpose. If a biobank is supposed to raise the research potential of its biosamples and sensitive data specific to the individual in a rather optimal way, its methodical opportunities must remain preferably open in order to be able to apply future technologies and research methods that are as yet unknown. It can be regarded as problematic that the idea of informed consent is nullified by the fact that the future usage remains unclear because the probands cannot be informed in an effective way and thus cannot really attend to their interests, which therefore brings into question the legitimacy of a consent, as it presents a blanket approval of something that cannot be understood, about which one knows nothing and which divests itself from any means of control one could have over it [32]. Arnason [33] aptly expresses this oxymoron:

There is no such thing as 'general informed consent.' The more general the consent is, the less informed it becomes. It is misleading to use the notion of informed consent for participation in research that is unforeseen and has not been specified in a research protocol.

As Caulfield [34] states, it is not only the flawed information policy of consent and thus the undermining of a decades-old ethical framework that are at stake, but also the annihilation of all rights as far as the liquidation of universally accepted fundamental human rights; it becomes obvious that there is a need for a moral power of judgment to prevent the blanket consent model from being widely implemented or to add compensatory measures to ensure the protection of the study participants on other levels instead.

Biobanks as Common Good – Implications for Ethics and Governance

Differentiating between a public good and a common good, as suggested here, can contribute to the biobank discourse by pointing out public interest in biobank research by emphasizing the unexpressed, implicit conditions and by distinctly stressing the deduced, or at least deducible, normative consequences in order to evaluate how they measure up ethically. The economically oriented framework evoked by the notion of public good is not plausible as a category for interpretation for the public relevance of biobanks because the essential characteristics of nonrivalry and nonexclusiveness cannot be detected entirely in the present competitive and competing research scene. However, if biobanks are understood as promoting a common good, their structure, operation and output will be questioned regarding normative values that will be handled and examined in public processes of deliberation. Surprisingly, here the advantage is present in the constellation of the biobank as a common good instead of as a public good – and only as the result of public deliberation – which apparently overcomes the exclusiveness as a feature shaping the research scene, which has previously been expected of the definition of biobanks as a public good. That means that only the common good can fulfill what the public good promises: to create knowledge that is available and accessible again and again. At the same time, this means that only a public deliberation process successfully conducted can achieve this and *sine qua non* entails the question of chances and limits of the public organization.

When we use this differentiation to clarify biobank discourse, we explicitly show unconsciously normatively relevant presuppositions that certain concepts contain. Thus, the differentiating heuristics suggested here can simultaneously contribute to strengthening the trust in re-

search in and with biobanks by compelling the public debate to be conceptually clear and thus transparent and more objective. Those who claim that biobanks are public goods in order not only to demand public funding, but also to make them accessible for everyone and achieve as broad a research benefit for the population as possible – but then cannot keep their promises – will inevitably cause disappointments. Public disillusionment will certainly work against the goal of biobanks to create within the population an acceptance as high as possible in order to maximize the participation rate, and thus, in the long run, to improve the health care as profoundly as possible. At present, biobank research is still in the basic research phase, and first clinical uses are not yet around the corner. Considering these different temporal perspectives, again what is underlined here is the necessity of a deliberation that cannot be evaded by pointing at a goal only achievable in the long run. Hence, the necessary public contributions will only be made and carried out if they are supported precisely in a long-term perspective.

Therefore, this article suggests (1) that ‘public good’ is defined as the economical understanding of goods that do not decrease by consumption (nonrivalry) and of whose use no one can be excluded (nonexclusiveness), and (2) that ‘common good’ is adopted as the notion that does not obscure normative implications and furthermore fits much better into a plural social system due to the implied necessity of deliberating. Consequently, it must be debated which goods are to be regarded as common goods in a society; public goods, on the other hand, can be taken for granted due to their characteristics and only require implementing respective rules and standards. Admittedly, the reference to the common good can be disadvantageous since its notion becomes less clear due to the deliberative contribution of all, but its content also becomes more open and less arbitrary, and thus, it fits much better into an open and democratic society than a static concept that pretends to be nonpartisan but that perhaps represents only partial interests.

Furthermore, it has been made clear that interpreting biobanks as public goods encourages the demand for a general duty to participate, which rejects individual needs on behalf of a common benefit that cannot be achieved immediately. However, if biobanks were defined as a common good, the form and the extent of a duty to participate would be themselves the subjects of deliberative processes. In that case, transparency and trust are necessary conditions that can be created only if existing reservations in society toward biosample donations, including the communication of sensitive data [35], are taken seri-

ously. As a trust-building measure, it would be reasonable to adopt a consent model that is more restrictive than the open consent, or instead, to implement stronger compensation mechanisms that would be able to guarantee individual benefit, however that may be defined.

Acknowledgements

The research for this article was conducted in the context of the project 'PRIVATE Gen' (Privacy Regimes Investigated: Variations, Adaptations and Transformations in an Era of (Post-)Genomics) which is supported by the German Federal Ministry of Education and Research (BMBF), DLR, Academy of Finland and FFG under grant number 01GP0905A. The authors would like to thank the funding agencies that made this research possible.

References

- Knoppers BM: Of genomics and public health: building public 'goods'? *CMAJ* 2005; 173:1185–1186.
- HUGO Ethics Committee: Statement on Human Genomic Databases 2002. http://www.hugo-international.org/img/genomic_2002.pdf (accessed December 29, 2011).
- Weale A: Public interest; in Craig E (ed): *Routledge Encyclopedia of Philosophy*. London, Routledge, 1998. <http://www.rep.routledge.com/article/S050SECT3Cf> (accessed December 29, 2011).
- Ritter J (ed): *Historisches Wörterbuch der Philosophie*, Art. 'Gemeinwohl'. Darmstadt, Wissenschaftliche Buchgesellschaft, 1974, vol 3, pp 248–258.
- Kaul I, Grunberg I, Stern MA (eds): *Global Public Goods – International Cooperation in the 21st Century*. Oxford, Oxford University Press, 1999.
- Knoppers BM, Fecteau C: Human genomic databases: a global public good? *Eur J Health Law* 2003;10:27–41.
- Cornes R, Sandler T: *The Theory of Externalities, Public Goods, and Club Goods*. Cambridge, Cambridge University Press, 1996.
- Chadwick R, Wilson S: Genomic databases as global public goods? *Res Publica* 2004;10: 123–134.
- Britannica Academic Edition: <http://www.britannica.com/EBchecked/topic/1366457/communitarianism> (accessed December 31, 2011).
- Chadwick R, Berg K: Solidarity and equity: new ethical frameworks for genetic databases. *Nat Rev Genet* 2001;2:318–321.
- Knoppers BM, Chadwick R: Human genetic research: emerging trends in ethics. *Nat Rev Genet* 2005;6:75–79.
- Lunshof JE, Chadwick R, Church GM: Hippocrates revisited? Old ideals and new realities. *Genomic Med* 2008;2:1–3.
- Lunshof JE, Chadwick R, Vorhaus DB, Church GM: From genetic privacy to open consent. *Nat Rev Genet* 2008;9:406–411.
- Chadwick R: The communitarian turn: myth or reality? *Camb Q Healthc Ethics* 2011;20:546–553.
- Hallmans G, Vaught JB: Best practices for establishing a biobank; in Dillner J (ed): *Methods in Biobanking*. New York, Humana Press, 2011, pp 241–260.
- WMA Declaration of Helsinki. <http://www.wma.net/en/30publications/10policies/b3/> (accessed December 31, 2011).
- Otlowski M: Developing an appropriate consent model for biobanks: in defence of 'broad' consent; in Kaye J (ed): *Principles and Practice in Biobank Governance*. Farnham, Ashgate, 2009, pp 79–92.
- Hansson MG: The need to downregulate: a minimal ethical framework for biobank research; in Dillner J (ed): *New York, Humana Press*, 2011, pp 39–59.
- Sass HM: A 'contract model' for genetic research and health care for individuals and families. *Eubios J Asian and Intern Bioethics* 2001;11:130–132.
- Hofmann B: Broadening consent and diluting ethics? *J Med Ethics* 2009;35:125–129.
- Chalmers D: Genetic research and biobanks; in Dillner J (ed): *Methods in Biobanking*. New York, Humana Press, 2011, pp 241–260.
- Nömper A: Open Consent – a new form of informed consent for population genetic databases; thesis Tartu, 2005. <http://dspace.utlib.ee/dspace/bitstream/handle/10062/818/nomper.pdf?sequence=5> (accessed December 29, 2011).
- Van der Graaf R, Van Delden JJM: Exploring an alternative to informed consent in biobank research; in Lenk C, Hoppe N, Beier K, Wiesemann C (eds): *Human Tissue Research. A European Perspective on the Ethical and Legal Challenges*. Oxford, Oxford University Press, 2011, pp 15–23.
- Caulfield T, Upshur RE, Daar A: DNA databanks and consent: a suggested policy option involving an authorization model. *BMC Med Ethics* 2003;4:E1.
- Gordijn B, Pijnenburg M: Does an appeal to the common good justify individual sacrifices for genomic research? *Theor Med Bioeth* 2006;27:415–431.
- Knoppers BM, Fortier I, Legault D, Burton P: The public population project in genomics (P3G): a proof of concept? *Eur J Hum Genet* 2008;16:664–665.
- Beyleveld D: Data protection and genetics: medical research and the public good. *King's Law J* 2007;18:275–289.
- Chan S, Harris J: Free riders and pious sons – why science research remains obligatory. *Bioethics* 2009;23:161–171.
- Forsberg JS, Hansson MG, Eriksson S: Changing perspectives in biobank research: from individual rights to concerns about public health regarding the return of results. *Eur J Hum Genet* 2009;17:1544–1549.
- Caulfield T, Kaye J: Broad consent in biobanking. Reflections on seemingly insurmountable dilemmas. *Med Law Inter* 2009; 10:85–100.
- World Health Organization Human Genetics Programme: Proposed international guidelines on ethical issues in medical genetics and genetic services. Report of a WHO meeting on ethical issues in medical genetics. 1998. <http://www.who.int/genomics/publications/en/ethicalguidelines1998.pdf> (accessed March 22, 2012).
- Deschênes C, Cardinal G, Knoppers BM, Glass K: Human genetic research, DNA banking and consent: a question of 'form'? *Clin Genet* 2001;59:221–239.
- Arnason V: Coding and consent: moral challenges of the database project in Iceland. *Bioethics* 2004;18:27–49.
- Caulfield T: Biobanks and blanket consent: the proper place of the public good and public perception rationales. *King's Law J* 2007; 18:209–226.
- European Commission (ed): *Europeans and biotechnology in 2010. Winds of change?* Eurobarometer 24537. Luxembourg, 2010. http://ec.europa.eu/public_opinion/archives/ebs/ebs_341_winds_en.pdf (accessed March 22, 2012).