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Genetics and Democracy – what's the issue?

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Abstract

Current developments in genetics and genomics entail a number of changes and challenges for society as new knowledge and technology become common in the clinical setting and in society at large. The relationship between genetics and ethics has been much discussed during the last decade, while the relationship between genetics and the political arena – with terms such as rights, distribution, expertise, participation and democracy – has been less considered. The purpose of this article is to demonstrate the connection between genetics and democracy. In order to do this, we delineate a notion of democracy that takes account on process as well as substance values. On the basis of this notion of democracy and on claims of democratisation in the Science and Technology literature, we argue for the importance of considering genetics issues in a democratic manner. Having established this connection between genetics and democracy, we discuss this relation in three different contexts where the relationship between genetics and democracy becomes truly salient: the role of expertise, science and public participation, and individual responsibility and distributive justice. As developments within genetics and genomics advance with great speed, the importance and use of genetic knowledge within society can be expected to grow. However, this expanding societal importance of genetics might ultimately involve, interact with or even confront important aspects within democratic rule and democratic decision-making. Moreover, we argue that the societal importance of genetic development makes it crucial to consider not only decision-making processes, but also the policy outcomes of these processes. This argument support our process and substance notion of democracy that public participation, as a process value, must be complemented with a focus on the effects of policy decisions on democratic values such as distributive justice.

Keywords: Genetics, Democracy, Expertise, Participation, Distributive Justice

Introduction

On-going debates regarding stem cells, gene patenting, gene modified crops, or private whole genome sequencing illustrate that genetics is a science at the cross roads of many societal interests. If we to these recent debates also add the historical aspects of genetics containing several ‘dark chapters’ it becomes even clearer that genetics harbours a great potential to influence and change not only medical therapeutic strategies or agriculture, but also our view of our selves and of the society as a whole. Expanding knowledge of human genetics might not only be seen in conjunction with an amplified ability to detect and map the blueprint for phenotypic variations at the level of the genotype and multiplying abilities to diagnose and treat various conditions on the basis of our genetic profile, but also with a possible novel reorganisation of the cultural, social, and political boundaries that divides the normal, abnormal and the pathological from each other. The case of dyslexia might function as an illustration. During the last 50 years the perception of dyslexia has been reorganized from a depiction of a ‘lazy person’ or ‘slow learner’, to dyslexia being an actual clinical diagnosis associated to several genetic susceptibility loci (OMIM). This change in how dyslexia is perceived might hold possibilities for medical treatment, but also for individual and collective demands upon the accessibility for various sorts of medical services. As the ability to read today is a prerequisite even for unskilled work, disabling conditions imply prospects for presymptomatic diagnostics at young age and, maybe in the future, medical interventions at an early stage in development. Moreover, with the uprising possibilities to perform whole genome sequencing in clinical settings combined with the actual epigenetic profile will give the possibilities to reveal the genetic background on any variation in the human constitution.

Increasing knowledge in human and medical genetics has resulted in the formation of new practices and new policies in the health care sector, such as risk profiling, surveillance programmes and presymptomatic genetic testing which have generated the ‘healthy patient’ as a novel form of patient hood. The consequence of the development sketched above leads to that the health care sector faces and adjusts to new demands from various stakeholders (patients, patient organisations, commercial interests and governments) in different ways. Potential problematic effects of augmenting genetic knowledge are also evident in certain segments of society. Concerns have been raised on the increasing use, or misuse, of genetic tests in the context of employment and health insurance, and on the widespread use of forensic DNA-based technology in measures against crime.

Developments in human genetics imply not only major changes for medical therapy and diagnosis, but also challenges for decision-makers to regulate the new technologies with respect for human integrity and democratic values. The purpose of this article is to demonstrate the connection between genetics and democratic values. We do that by arguing for a notion of democracy that consider not only decision-making procedures, but also the outcome of these procedures. In line with this position, we argue that citizen participation is a necessary but not a sufficient measure in order to make societal regulating of genetic technologies fully democratic. Our main contribution is that the notion of public participation in public decisions on medical applications of genetics must be complemented with a focus on the effects of these decisions on democratic values such as equality, autonomy, and justice.

We start this endeavour by first delineating a process and substance notion of democracy, and then demonstrate how this way to conceptualise democracy implies a strong connection between genetics and democratic values. In the following, we discuss genetic and democracy issues in relation to the role of expertise, science and public participation, and distributive justice. Here we refer to different aspects of genetic applications in order to demonstrate why both a process perspective and a substance perspective of democracy are necessary. In the conclusion we return to implications for society of the development of genetics and genetic technologies to inculcate the connection between genetics and democracy.

Democracy

Democracy is a normative and highly contested concept, and every attempt to stipulate its meaning runs the risk of being questioned. On a sufficiently high level of abstraction, there is consensus on the purport of democracy as the *rule by the people* or, as in Lincoln's famous phrase, 'government *of*, *by*, and *for* the people' (Turner 2003: 7).[1] However, the question always remains of how this will be realised, as the emphasis of the three elements will vary, and the specific meanings of 'government' and 'the people' have to be established. There is also disagreement of the degree of public participation, of the role of experts, and of the scope of the political sphere, the latter being a fundamental question in the eternal debate about the boundary between the public and the private sphere (c.f. Young 2006; Hedlund 2012, in

[1] In line with Brettschneider, we contend that government 'of' the people refers to the authorisation of the people, that government 'by' the people refers to the people's status as rulers, and that government 'for' the people points at the content of decisions: "While government '*by*' the people is a claim about procedures, government '*for*' the people limits what counts as a democratic outcome" (Brettschneider 2006: 269).

press). While public matters are a common concern and within reach of democratic scrutiny and accountability, private matters are objects of individual self interest and the logic of the market, circumstances that appear in e.g. the business of direct-to-consumer genetic tests.

An understanding of democracy as the 'rule by the people' builds on the assumptions that all individuals have equal value and that people have the ability to rule themselves. In accordance to these assumptions, equality and autonomy are basic democratic values (Hyland 1995). Equality implies that every person has the same value and that the interest of all must be equally respected (Dahl 1989). Political equality is normally conceptualised as one person–one vote (Parker 2000). For this vote to be informed and express the meaning of careful consideration, people must have some amount of knowledge on society and be able to take in and value information. In other words, for the political equality to be effective, is must be founded on 'an informed understanding of public affairs' (Hyland 1995: 164) which presupposes some basic rights, such as free speech and free association. Such 'enlightened understanding' (Dahl 1998: 37) presupposes a reasonably equality with respect to resources. This does not mean absolute equality with respect to money or other substantial resources, but that every individual has to have such decent economic standard and level of education that s/he have time, energy and ability to engage in society (Post 2006: 32; Brighouse 1997: 157; Sen 1996: 399). Autonomy is the very presupposition for the idea of democracy, as democracy only can be warranted if one assumes that people in general are competent to rule over themselves. If we recognise every person as autonomous, we also recognise that every person has rights that make possible this autonomy and rights to the necessary resources to exercise these rights (Hyland 1995: 174). Equality, then, means that every person exercises as much autonomy as it is consistent with equal autonomy for others (Hyland 1995: 83; Held 2006: 264–265).

Democratic theory traditionally focuses on procedural values such as one person–one vote, and the decision-making procedures by which public policy is made. According to this view, a political decision is considered democratic has it been taken in accordance with due democratic procedures, e.g. majority vote, citizen inclusion, or deliberation, and the critical issue is to settle which procedure is most democratic. Consequently, procedural positions admit that the content of decisions taken could have effects that violate fundamental democratic values (Brettschneider 2006). In this article, we defend a position that goes beyond regarding democracy solely as a decision-making method – a process – and argue that it is necessary to take also the policy outcome – substance – into account (Brettschneider

2006). This does not mean that we deny the importance of democratic procedures. Evidently, we would not accept as democratic a situation in which the decision-making procedures do not meet democratic criteria of effective participation, voting equality at the decisive stage, enlightened understanding, control of the agenda, and inclusiveness (Dahl 1989), even if the outcomes of this procedure were in line with democratic values. This could be the case for a pure expert system or, worse, for a dictatorship, delivering decisions that people certainly like, but have no possibility to influence. What our position does mean, however, is that we do not regard a policy decision democratic *only* on merits of the rights procedures, but contend that also the effects of the decision on society must be considered. By this, we do not refer to the ideologically based worry of 'wrong' decisions by an 'ignorant' public, an issue that concerned debaters fearing a no vote in the Swiss referendum of gene manipulation of animals and plants in 1997 (c.f. Zinkernagel 1997). Our concern goes one step further and points at the need to regard democratic substance values, i.e. that outcomes of democratic procedures produce results that do not violate democratic values, which would be the case if the decisions were e.g. to prosecute certain ethnic groups, to abolish democracy or in other ways do not fulfil values of equality, autonomy and other fundamental democratic values (Rayner 2003: 169).

In conclusion, for the fundamental democratic values equality and autonomy to be fulfilled, citizens must have some basic rights such as free speech and free association, but also reasonable access to resources, like basic material welfare and education. Our position is that for a decision to be truly democratic, these values and rights must be met both in the decision-making processes (procedures) and in the outcome of these processes (substance).

Genetics and Democracy

A core assumption in this article is that genetics and the effects of the expanding knowledge in this field cannot be discussed without taking democratic considerations into account. Experts in the field must of course do the technical and medical assessments, but decisions on the application of technologies related to existential questions such as the ontological status of embryos, or the risk of stigmatisation of individuals with hereditary disorders must be carried out in ways allowing for transparency and citizen control. Science and Technology Studies (STS) literature on this theme energetically promotes direct citizen participation to democratise technically complex and expert permeated fields (c.f. Wynne 1996, 2006;

Jasanoff 1990, 1997). Genetics definitely qualify as a complex knowledge field in need of much expertise, but it is not only the profound dependence of different kinds of experts (molecular geneticists, population geneticists, clinical geneticists, statisticians etc.) who need to be 'democratised' that connects genetics to democracy. Genetics is closely connected to democracy also on its own merits as an ethically sensitive field. Embryonic stem cell research, pre-implantation genetic screening, and germ line therapy constitute just a few examples of applications that imply ethically delicate matters, which also invoke existential questions of the life worth of embryos or the right of man to intervene in nature and 'play god' (c.f. Evans 2002).

Genetics brings to the fore the balancing of interests between on the one hand the possibilities to cure and alleviate, and on the other hand the use of potential human life. Moreover, genetics arouse questions on the outlook on mankind and how we regard research and progress. Should everything be done that is possible to do? Could genetics develop into 'genetic engineering' contributing to the illusion that differences between people could be explained solely by their hereditary disposition (Lemke 2004: 550)? Is there a risk of instrumentalisation of human life? The prospect of 'changing' or 'repairing' genes to prevent symptoms of a genetic disorder, or parents having children with the risk of being affected by chronic genetic diseases are also questions about normality and how we regard abnormality. How does the sorting out of what is deemed undesirable affect our view on disabled and sick people?

In addition to being expert permeated, ethically sensitive and existentially contested, gene technology applications have impact on society in ways that might violate central democratic values of equality and autonomy (c.f. Buchanan *et al.* 2000: 308–309). A look back to the near history of eugenics illustrates this point. Beginning in the inter war period, compulsory sterilisation on genetic indication was applied in Germany, the United States, Sweden and several other Western countries. In the US, decisions on individual cases were often decentralised to the medicine practitioner (Wellerstein 2011) and in practice inaccessible to democratic control. In Sweden, an almost completely unanimous Parliament agreed to compulsory sterilisations by the Sterilisation Act of 1934. Under this law, which was made even sharper in 1941, 63 000 individuals (corresponding to 0.8 % of the population) were sterilised until its abolishment in 1975 (Broberg & Tydén 1996; Weindling 1999). The decision to promote by law compulsory sterilisation of individuals considered not to fit into society was made by the Swedish Parliament, the foremost representative body of the people,

presumably according to due democratic processes. Still, it is beyond doubt that the outcome of this decision violated equality and autonomy of those individuals who were sterilised *against their own will*, many times even without being informed of the meaning of the operation in beforehand. In a democratic setting where not only the decision-making process, but also the consequences of decisions are taken into account, decisions like them in the Swedish Parliament would hardly pass the democratic test. Our purpose is not to interpret the present in terms of past events, but rather to point out how seemingly democratic decisions, despite a proper procedural decision-making process, could generate undemocratic effects. Evidently, these are all extreme examples, but the principal issue is the same even in less controversial questions: when evaluating public policy from a democratic perspective, we cannot only pay attention to decision-making procedures, but must regard the consequences of policy decisions in society.[2]

To summarise, the main reason to juxtapose genetics and democracy is that applications of genetic knowledge bring to the fore problems that are urgent to pay attention to from a democratic perspective. Below, we will highlight three areas of particular interest for the problem area of genetics and democracy: the role of expertise, science and public participation, and individual responsibility and distributive justice.

The Role of Expertise

The relationship between democracy and expertise constitutes a classical problem field in political science as well as in other disciplines within the social and cultural sciences, and is of particular relevance for the expert permeated area of genetics, ultimately having an impact upon the whole of society. Policy-making on new genetic devices and methods making use of genetic information relies heavily on genetic scientists, clinical geneticists, bioethicists, and other experts in the field (Bonnicksen 2002). From a democratic perspective there is the danger of expert dominance at the expense of non-experts, which would violate democratic equality (Turner 2003). From a strict knowledge perspective, expert dominance might not necessarily constitute a problem. However, as the experts do not only have the advantage of superior knowledge in their specialist area, but also are accustomed to talk about their expert

[2] Compulsory sterilisation in the twentieth century is no doubt an extreme example of *biopower* or 'strategies for the governing of life' (Rabinow & Rose 2006). However, many would argue that contemporary genetic techniques and policies are nearly as extreme in terms of constituting life (c.f. Jasanoff 2011, 2006). Our purpose is not to interpret the present in terms of past events, but rather to point out how seemingly democratic decisions, despite a proper procedural decision-making process, could generate undemocratic effects.

field and to argue in favour of their views in this field in different contexts, they have a lead when it comes to agenda-setting and to defining the very issues to be object of decision-making (Rochefort & Cobb 1993). Experts could frame the debate both regarding what aspects of the issue being object of discussion and regarding the character of the discussion (e.g. consequences for society vs. narrow technical issues). Other participants might not only have to adapt to the language of the experts even to have a say in the subject matter, they are also more or less forced to accept the problem definition already made by the scientists (c.f. Hedlund 2011). So, both procedurally (as most self-evident participators) and substantially (with problem definition power) experts might violate democratic values.

However, as noted by Fischer (2009), it is increasingly recognised that 'as societies become more complex so does the importance of expert advice in matters related to governance' (Fischer 2009: 17). Power-holders turn to experts to inform their decisions in complicated matters, but also to obtain legitimacy deriving from the cognitive authority of the knowledge of scientific and professional experts (Boswell 2009; Turner 2003). However, there is a propensity by political decision-makers of asking for expert advice even when knowledge is uncertain, implying a risk of undermining public trust in political expert use (Weingart 1999; Jasanoff 1997). Together with an emphasis on citizen rights, this tendency has contributed to calls for 'democratisation of expertise' as a way of rebuilding trust between science and the public (Liberatore and Funtowicz 2003; Fischer 2009). Indeed, prominent and influential debates within the social and cultural sciences on the question of the role of expertise in complex societies have revolved around the tension between rationality and democratic values (Durant 2011; Jasanoff 2011, 2003; Wynne 2003; Collins & Evans 2002).

In the context of handling the different but mutually dependent logics of expert rationality and democratic values democratisation often is referred to as citizen participation. However, as many scholars have recognised, professional expertise required for political decision-making in complex issues can be barriers to proper and meaningful participation by citizens (Turner 2003; Wynne 1996; Jasanoff 1990). This circumstance is palpable in the issue area of genetics. Involvement in policy issues relating to advancements in genetics research and application such as genetic testing, forensic DNA profiling, or collection of biological entities to be stored in biobanks, are all ethically sensitive matters that beside technical expertise also require profound ethical reflection and consideration, which constitutes a particular difficulty in this regard. However, expertise in ethics, in policy-making processes normally provided by professional bioethicists, does not necessarily correspond to 'lay' ethical standpoints held by

ordinary citizens and other ethical non-experts (c.f. Delkeskamp-Hayes 2005; Tong 1991). Consequently, as governments are recognised by the public to deal poorly with political uncertainty, situations that contain risk, lack of hard evidence, and unexpected consequences, the issue of trust and rebuilding trust between science and the public have become an important aspect. One strategy to achieve deeper trust has been to promote an increased public participation (Fischer 2009: 8).

Science and Public Participation

For a long time, it was widely assumed that public reactions against new medical technologies were a result of ignorance and lack of knowledge, a situation that could be solved by more and better information to the public.[3] However, since the early 1990s, numerous studies have indicated that citizens indeed are able to assess the consequences of science and technology, and that the widespread public opposition (seen for example in relation to the bovine spongiform encephalopathy (BSE) scandal in the UK, the opposition against genetically modified food, and anxieties against developments within genetics) did not necessarily arise as a result of lack of information, but rather from distrust of the authorities which were set to direct the widespread societal application of science and technology (Nelis *et al.* 2007: 29; Wynne 2006; Cunningham-Burley 2006). As a consequence, the issue of rebuilding the trust through public participation has become an important aspect in various political initiatives, where such measures as consensus conferences, citizen juries, and public debates initiated by governments have been instruments in rebuilding the trust between science, authorities and the citizens (Rose 2007: 140; Nelis *et al.* 2007: 30).

In relation to the situation accounted for above, during the last 30 years, patient organisations have accumulated an increased role and power in relation to medical research, as well as in relation to the health care sector (c.f. Jasanoff 2006: 188–192). Among others, Novas (2006) points to the role played by patient organisations as a sort of socio-political activism which harbours new forms for a wider public participation in medical research whose engagement and participation include aspects such as fundraising, lobbyism, orientation and management of research, and evaluation of research, as well as founding and managing of biobanks (Silverman 2008; Rose 2007; Rabeharisoa and Callon 2004). Within the context of genetics, Huntington's disease (HD) was one of the first diseases in which this development became

[3] The so called 'knowledge deficit' model (see e.g. Brunk 2006).

visible, most notable through the work of the Hereditary Disease Foundation, founded by the American psychologist Milton Wexler. Wexler, whose wife were diagnosed with HD, took several initiatives to set up interdisciplinary scientific workshops as a strategy to promote new and innovative research on HD, and the foundation is today one of the major financial benefactors within research on HD (Wexler 1995). Another example can be seen within the US context of autism spectrum disorders, where parents of affected children were able to achieve considerable influence on biomedical research by attaining in-depth scientific knowledge on the genetic components of autism, but more so by taking charge and residing over vital research infrastructure. As a way to foster cooperation and sharing of results among researchers, involved parents used their status as a patient organization to found and run a genetic repository, which contained DNA-samples from families with autism spectrum disorders (Silverman 2008: 44). Other examples of this successful 'lay expertise'[4] can be found within the context of research on muscular dystrophy in France (Rabeharisoa and Callon 2006).

However, it remains to be seen whether the kind of active involvement in medical science depicted above actually enhances public participation and inclusion in science. As Nelis *et al.* (2007) point out in relation to the role attained by patient organisations in ethically controversial issues related to scientific and technological development (such as stem cells research), a number of important questions arise in relation to an increased role of patient organisations in medical research: To what extent can these organisations claim to legitimately represent affected individuals? If a patient organisation raises its voice in a controversial issue, what does it actually achieve? And, in which way does its contribution differ from other voices that are raised? Do the voices of these organisations provide anything to the spectrum of other opinions expressed through other channels (Nelis *et al.* 2007: 30)? Moreover, as pointed out by Davis and Abraham, patient organisations also collaborate with pharmaceutical industrial interests in order to promote research (2011). These are important questions that need to be investigated further as the role of patient organisations increase in medical research. However, the relationship between genetics and democracy are not only to be located within issues that concern the role of patient organisations and medical research, but also in relation to issues that ultimately concerns such aspects as individual responsibility and the notion of distributive justice. In the context of this article, this refers to individual and societal responsibility for obtaining social and economical assets. The notion of societal

[4] The concept of 'lay expertise' (see e.g. Fischer 2009) refers to the local and/or experience based expert knowledge possessed by people who are 'lay' in relation to the current expert area.

responsibility is here understood in terms of distributive justice, referring to the redistribution of resources in order to prevent major social and economic inequalities within society (c.f. Denier 2007).

Individual responsibility and distributive justice

A prominent issue for the connection between genetics and democracy concerns the relationship between genetics, individual responsibility and distributive justice, which can be illustrated by the hereditary dental disorders *amelogenies imperfect* and *dentinogenesis imperfecta*, the subject of interest for Aldred *et al.* (2003). Individuals suffering from these disorders have a defect in tooth mineralisation and poorly developed roots make their teeth prone to decay, causing a need for specialist dental reconstruction and care all through their lives. A crucial question is whether these disorders should be considered severe enough to justify various types of reproductive interventions. The cost for the dental interventions is high per individual and/or family (which may have several affected members). In countries with no state support, these hereditary dental disorders may therefore cause severe financial constrains on individuals and families. If there is no treatment, affected children develop grave dental problems and often suffer from nutritional deficiencies and considerable social stigma. In such situations a family may ask for prenatal diagnosis to avoid the plague of not having the financial strength to give the child an adequate treatment. On the other hand, in countries where the health care system covers costs for treatment this becomes almost a non-issue. This example of a hereditary disease with severe effects on the living conditions of affected individuals and their families clearly demonstrates the ideological question of the responsibility relation between individuals and society, and how this question also has implications beyond ideology.

In a reply to Aldred *et al.* (2003), Boddington and Clarke (2004) comment that this issue concerns the notion of distributive justice and a moral incentive for societal inclusion. Instead of changing the human body to fit society through various sorts of reproductive interventions (e.g. selection of healthy embryos for implantation), Boddington and Clarke claim that we, as a response towards the inequality and distress inflicted upon affected individuals and their families, should change society through societal measures such as publicly funded dental services and measures to counteract social stigmatisation. This discussion also illustrates effects of the social setting on the distinction between the normal and the abnormal – in some

societies the discussed dental defects appear as truly abnormal, while in other situations they appear as unfortunate and unwanted traits that may be remedied in a taken-for-granted interaction between the individual, the family, and society/the state. The case of these dental disorders also relate to the debate on chance or choice flaring in the wake of genetic research advancements (c.f. Buchanan *et al.* 2000). From our genetics and democracy perspective, this case serves as an illustration of the importance of including not only decision-making procedures to judge if a policy is democratic or not; the content of the policy and its effects on concerned individuals and society at large are crucial factors if we want to evaluate the justice of a decision.

The tension between individual justice and distributive justice is also present in the case of genetic testing (c.f. Howard & Borry 2012). Since the mid-1980s, developments in molecular biology have generated large numbers of genetic tests, providing the possibility to assess and to identify the molecular abnormalities underlining various conditions through molecular genetic methods (Burke 2003). However, there is a growing body of empirical evidence that developments and introductions of genetic tests alter the way in which particular diseases are classified (e.g. Hedgecoe 2008; Miller *et. al.* 2006). The increasing deployment of genetic tests in the clinical context might therefore produce an alteration in several systems of disease classification, bringing us not only 'thorny' ethical questions upon the boundaries between medical treatment and enhancement, but also considerable strain on health care systems as new categories of patients might evolve with demands upon care and treatment. Moreover, the current framework of genetic testing is now facing a potential major change as tests for a variety of traits are provided by private companies direct to the public though the Internet. As pointed out above, this development might not only undermine the influence of the medical community, but also public decision-making through democratic channels on the use of genetic testing and genetic screening within the society (Cornel *et al* 2012; van El *et al.* 2012). Another issue concerns the growing importance of biobanks, and different attempts to include the public in the governance of biobanks (Gottweis and Lauss 2012; Gottweis and Petersen 2008). On the other hand, we also witness examples of a democratic participatory movement, involving patients and patient organisations/networks, within biomedical research which spans everything from traditional lobbyism to the creation and control of biobanks by patient organisations/networks (Silverman 2008; Heath *et al.* 2004).

Conclusion

The potential changes arising in the wake of increased use of genetics within the health care sector, as well as within the society at large, demonstrate the complexity that society encounters when trying to evaluate ongoing applications of the development in genetics and genomics. Complexities arise where scientific research merges with commercial interests, democratic development, special interests, and a potential shift whereby decision-making on these matters might be transferred from the public to the private domain. For legislators, social welfare and health care systems this complexity entails major challenges when new knowledge is put into operation in day-to-day practice, underlining the importance of improving the possibilities for informed choice and personal responsibility in order to protect the individual from being harmed by the use of this new knowledge. As public understanding of genetics often is low in society (e.g. Lock 2008), and there is hype and hope around the possibilities of new technological advancements (Nordahl-Svendsen and Koch 2006; Brown 2005), it is a challenge for the genetic scholars to spread sound knowledge to the medical community, policy makers, other stake holders, and the public at large. In order to evaluate and address the changing framework in the practice of clinical genetics, a broad approach is needed that gathers participants from clinical genetics, other health care providers, as well as representatives from the social and cultural sciences.

In this article we have argued that genetic development must be discussed in democratic terms, both in terms of procedures such as increased citizen participation in political decision-making on genetic applications, and in terms of substance, namely the content of decisions and the effects of these decisions on society. To answer the question posed in the title of this article – 'Genetics and democracy – what's the issue?' – we conclude that genetics is connected to democracy by several factors. Genetics is an expert permeated problem area in need of democratisation on similar terms as other expert areas, but genetics also gives rise to intricate and ethically sensitive issues that deserves democratic attention in its own right and highlight the importance of paying attention not only to democratic processes, but also to democratic substance. This means that not only political decision-making procedures, but also the content of political decisions must be evaluated against democratic values such as equality, autonomy, and distributive justice.

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