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Diagonal Convergences: Genetic Testing, Governance, and Globalisation

Introduction:

The actual and sometimes quite unexpected uses to which individuals put new technologies can undermine social norms. Governments therefore often try to control access to new technologies. Beyond that, the notion of Converging Technologies (CT) stands for government programmes that not only monitor and regulate a new technology but plan and steer the convergence of emerging technologies and their future potential uses. In the early 2000s the U.S. and Europe set up government programmes to induce and configure the convergence of the nano-, bio-, information- and cognitive sciences (NIBC) into technologies that will alter humanity's ways of being. CT is a form of meta-level governance that aims to control not only individual technological developments but also the ways in which scientific and technical innovations might intersect and cause social and economic change. This paper treats CT as an especially ambitious and precarious instance of governance because it aims to predetermine future science, future technologies, their intersections and resulting societal changes. Drawing on examples of a convergence that is well underway, I aim to demonstrate some of the problems of such prospective policy-making and argue that it draws on an understanding of the power and means of national governments that is already technologically overcome. National or local CT policies represent what Foucault called governmentality, an overreliance on manageability, regarding the formation of new platforms for decision-making that is happening alongside and irrespective of such government programmes. This situation demands new ways of policy-making of certain social values are to be protected.

This chapter begins with two critical approaches toward policy-making and its philosophical validation. One is by Alfred Nordmann, who, after years of studying CT programmes, reflected on the role of academics in such science and technology governance. I refer especially to two of his criticisms in his article *Knots and Strands: An Argument for Productive Disillusionment* from 2007. The first concerns the coalition of academic research and policy-making, the second the universality of claims inherent in the resulting policies which themselves are markedly culturally distinct. Following on from this second point, I step back from the CT controversy and defer to a feminist philosopher, Susan Sherwin. In *No Longer Patient,* published in 1992, she proposes to overcome the divide between normative universalist claims and empirical cultural perspectivism through analysis of the power relations and participatory practices underlying the ethical judgments in policy-making. Reflecting on the epistemic status of EU or USA CT policies crucial for their assessment seems the idea of possible political governance under conditions where technological convergences with great perceived potential and uncertainty go global. In order to support this point with evidence, I then discuss two topical case studies dealing with attempts to control technology and its uses, both being about access to genetic tests; direct to consumer genetic tests sold online, and non-invasive prenatal genetic tests offered in the same way. Within a decade genetics has moved from being firmly in the hands of academic and state institutions. The convergence of information technologies and global marketing practices has taken it out of that controlled sphere. Converging Technology projects have partly reckoned with the change toward open access to genetic tests, but authorities have not found ways of restricting them and present only weak arguments why they ought to do so. The genetic case studies

illustrate four points: a) a systematic misrepresentations of consumers' knowledge and interests; b) a focus on the technologies instead of the cultural contexts of their application, which distorts the perception of ethical problems and prevents viable political responses to social concerns; c) the cultural specificity of ethical imperatives with which new technologies are examined; and d) that academics pursue an agenda of their own in their cooperations with regulators on genetic testing. The convergence of genetics, global information technologies and market infrastructures has created an environment in which genetic tests can no longer be controlled through the mediation of experts and prohibitions. Following Sherwin's suggestion about examining power relations, I consider the present debate about direct-to-consumer genetic tests to be about privileges of power and knowledge in the guise of stewardship and patronage over citizens' DNA-derived information. This has often been framed by experts as concern with quality management in genetic testing. Yet, the quality of the tests could and possibly should be safeguarded generally through international standards and certificates. Local quality control is impossible to implement in an open global market. In the case of non-invasive prenatal genetic tests for sex selection, the conflict between consumers interests and the long-term common good needs to be addressed at source, following the arguments pursued by Sherwin. Policy-making has to tackle the cultural values and practices that make it a rational choice for many to prefer a male infant to a girl child. That would not only prevent sex-selective use of genetics but address sex-discrimination in the relevant cultures on a much wider scale and enhance the welfare of the whole community, girls and women included.

Two Philosophical Approaches

Nordmann, who is one of the leading experts on the NIBC convergence in Europe and the U.S., has published both policy reports and academic critiques of the involvement of academics in the governance of science and technology. In *Knots and Strands: An argument for Productive Disillusionment* (2007), a paper that reflects his experience in government funded research projects for policies to manage convergence and its ecological, societal and ethical effects, he distinguishes two different approaches to CT. One justifies the direct steering of converging technologies with future national interests for economic prosperity. The other is explicitly motivated by ethical issues and aims to prevent societal risks of convergence beyond the risks that each science and technology alone is seen to carry. Nordmann aligns the first approach with the attitude taken in U.S. programmes on CT, where directing the convergence of Nano-, Bio-, Information- and Cognitive (NBIC) sciences and technologies is an important means to secure future economic revenue from technological advances. In contrast, in Europe:

"we find ourselves in a situation where various enabling technologies and many pressing societal issues (global warming, obesity, water and energy supply, etc.) challenge us to institute converging technologies as a means of gearing emerging capabilities towards common goals." (2007, 219)

The common goals are ethical and concern human welfare and social cohesion and inclusion.

"This comparison of U.S. and European definitions of 'converging technologies' leaves us in a paradoxical situation. On the one hand, it speaks very clearly to different cultural perspectives and thus to a kind of parochialism on both sides. On the other hand, neither perspective views itself as parochial but claims universality." (ibid., 220)

The passages above summarize critically the political attitudes and perspectives in the programmes on NIBC to which Nordmann has directly contributed. He authored the European Commission Research Report *Converging Technologies – Shaping the Future of European Societies* (Nordmann, 2004), which sets out the challenges arising from the transformative potential of Converging Technology (CT). This report begins with defining four problems of the NIBC convergence arising from the tension between potential economic and social benefits and "threats to culture and tradition, to human integrity and autonomy, perhaps to political and economic stability" (ibid., ii). The transformative potential of CT is described not in the language of profits but, rather, of an ethics of the human species. His four characteristics are: (a) Embeddedness: the ubiquity of artificial environments that may transform human self-understanding; (b) Unlimited reach: the potential that everything can be transformed into computable information and that everything molecular can be controlled. An attitude of technological quick-fix may come to reign supreme; (c) Engineering the mind and the body: this entails the proposal that CT policies must have a humanitarian bias; (d) Specificity: the conflict between the potential of personalized medicines and case-specific technology solutions, which may lead to social problems (Nordmann 2004, page 3). These characteristics mirror the risk aspects that were ascribed to genetics since the 1970s, strongly emphasizing concerns about injustice and the instrumentalization of human life. The European approach to CT stresses the need for ethical governance. The U.S. mode pronounces economic advance as justification for policy-making. Nordmann refers to Sheila Jasanoff's distinction between hubris and humility in her paper on cultures of modernity in the U.S and Europe. She identifies "hubris in attempts to politically manage potential resistance (Jasanoff, 2002). The opposing attitude of humility looks to ethics … in order to buy time for reflection and to mobilize the cultural resources that will allow for local adaptations of technological agendas and avoidance of uniform global diffusion" (Nordmann, 2007: 221). I would prefer to leave it an open question as to whether this U.S.-Europe difference is a general characteristic, or simply occasional PERHAPS "CONTINGENT" IS BETTER THAN "OCCASIONAL"? and possibly in part rhetorical and due to cultural codes of legitimacy for political governance. These value-laden characterizations cannot be readily applied to the policies concerning genetic testing. Humility as ethical attitude implies deference to established orders and values, and the case studies below show that with regard to direct-to-consumer genetic testing such ethical aspects are important motivators in current U.S. science and technology policy.

Following his involvement in the European NIBCT research programme, Nordmann reflects on the contribution of academics to policy-making. Through dedicated research funding, growing impact agendas and genuine overlap of interests, philosophers and social scientists are drawn into technology assessment and science governance. Academic experts are often called upon when government bodies, and research or ethics institutions consider policies on new sciences and technologies. In the publication of their research findings, and more directly in reports to policy committees bioethicists, social scientists and philosophers participate in the ideological and conceptual framings of the issues and thus share responsibility for the policies that emerge. Nordmann describes the entanglement of academics in framing the issues as a "deadly embrace" into normative political agendas, an issue of being drawn into set definitions of ethical problems which can undermine academic rigour and independence frequently discussed in bioethics in recent years (Eckenwiler and Cohn, 2009). He suggests that academics engage in the "disentangling" of normative,

sociological and ontological concepts as an analytic method to keep a self-critical distance from the conceptual and normative alliances formed in the policy development process (Nordmann, 2007: 226-227). Yet he remains vague about how to do this in practice. The gist is a stepwise self-reflexive disentanglement of the concepts tied together in the technology assessment discourses and their normative agenda-setting. The tension between culturally specific normativities in the European style CT programme and its inherent claim to universality when setting out ideas of human nature also troubles him. He does, however, not suggest an approach with which STS and bioethics might address this problem.

The tension between universalist claims and socio-cultural parochialism is highly relevant for the credibility and potential success of nationally- or geo-politically-focussed CT programmes. Feminist philosophers examining medical and bio-technologies in particular have analysed the problem of universalism, pluralism and cultural diversity in the context of ethical issues that are gender-specific. One such author among others is Susan Sherwin. In *No Longer Patient* (Sherwin, 1992), she discusses the conflict between the universalism inherent in moral claims and the fact of culturally diverse perceptions of what is right and wrong. She proposes to look not at the values and norms that are contested, but rather at the procedures and power structures in force in how policies are made and decisions taken. Discussing abortion and female genital mutilation, Sherwin defends a feminist moral relativism that examines the participation procedures that carry an established moral system. The power- and interpersonal relations of those engaged and subjected to normative expectations provide the clues about its fairness, "it is necessary to consider how the system evolved, whose interests are served by it, and, most importantly, whose interests are sacrificed to it" (Sherwin, 1992: 71). She stresses the need for both tolerance and the contextualisation of norms and practices on the one hand, and on the other hand, a strong and powerful critique of oppression, wherever it occurs, without false respect for cultural or national boundaries characterize her practical ethics (ibid., 73).

Sherwin argues that analysis of power relations and participatory practices opens up a space for critique beyond the verdict of Western moral imperialism. I will refer to this method when discussing the credibility and efficacy of current policies to control access to genetic testing. The social conditions following this convergence allow global citizens forms of self-determination that they seem to appreciate and which defy previous modes of regulatory prohibition and elitist restrictions of access to technology. The two case studies, direct-to-consumer genetic testing and its application in non-invasive prenatal testing for sex selection, are not commonly discussed under the label of convergence. Yet both are products of the recent manifest convergence of genetics with information technologies and globalisation. Fast and cheap genetic testing methods, global knowledge exchange and world-wide operating markets for goods and services create open access markets. Disputes about these new developments characterize the regulatory agenda for life sciences under labels such as do-it-yourself biology and open markets for drugs and tests. Government agencies, and the medical professions especially, aim to reign in the public use of genetics. Nordmann's distinction between nationalist economic and generalist humanitarian missions of CT programmes, and Sherwin's method of judging ethical regimes in terms of their participatory or oppressive qualities help me to evaluate the debates about open access and direct-to-consumer genetic testing.

The presentation of the case studies highlights two important aspects regarding the governability of convergence: the presupposed relationship between governments and their experts toward the public, and the empowerment for individual citizens that poses new opportunities and new challenges for the social impact of genetics.

'Genetic Exceptionalism' or the Private Management of Personal Data

Genetics has been the most extensively covered topic in bioethics because it was perceived as dangerous in many ethical and political dimensions, concerning human nature and human rights, concerns which reappear in the CT Report referenced above. Studies in and on genetics have been very well funded and consequently bioethics grew into an expert discipline that would inform policies and public attitudes. The multi-disciplinary bioethics field that studies the ethical, social and legal aspects of genetics evolved into a major expert sub-discipline alongside the sciences that make sense of DNA and what genetic tests may indicate about a persons biological make-up. *Genethics* (Suzuki and Knudtson, 1989), as this field became called, investigates the the regulations for genetics needed to protect individual rights and the social fabric at large. Important for my argument is that among scientists, regulators and the bioethics disciplines, genetics was perceived as so powerful that the control of its societal effects became a major political and societal issue. National and transnational legislations and moratoria are in place to restrict the use of genetic data[1], and informed consent to testing was made a necessary prerequisite for many tests. Genes were seen as providing conclusive and unchanging information about a person's phenotype, heath and future health, personality traits, race and ancestry, biological relatedness, and more.

Around the year 2000 this simplistic image of genetics, and with it the exceptional status of DNA test findings, began to disintegrate. The Human Genome Project found that humans have far less 'genes' than their complex biology seemed to require. It had to be concluded that many biological properties are not simply written in the genes and that DNA tests do not tell us everything about biological traits. Consequently, genetics has matured from a position of imagined omnipotence to an increasingly refined set of specific applications. Most tests available today only provide approximate information about health risks or other traits. The STS and bioethics literature has changed along with genetics and adopts a more observant attitude to new knowledge and testing practices and how they influence specific social configurations of identity and self (Petersen, 2006).

However, that people might use genetics in the same way as other tests and on their own account was not much considered. The genetics-information technology-globalisation (GIG) convergence that occurred was not well anticipated. The literature discusses the loss of the exceptionalist status of genetics and whether previously established prohibitions ought to be upheld. An example is price-setting in health insurance. Moratoria that prohibit the use of genetics for health insurance risk calculation are in force in Europe, the U.S., and other locations. However, if genetic information is only somewhat indicative of a person's health, these moratoria may be superfluous. Richard Ashcroft and Soren Holm exchanged arguments on this question in the British Medical Journal (Ashcroft, 2007; Holm, 2007). Holm argues that if genetic tests are of a predictive quality similar to that of family history of disease, which insurers can use, why should they then not use genetic information? The moratorium is in place in Europe until 2017. The convergence that changes access

and management of DNA tests may bypass the efficacy of such control strategies by then.

While not much may be written in the genes directly, global markets and global communication networks enable new ways of doing things with genetic tests that individual consumers are interested in, such as health status, bio-geographical origin, or race (Hauskeller et al., 2013). Members of the public buy genetic tests although regulators and experts recommend that genetics should be conducted with close supervision by scientific and medical authorities. There is a widening opposition between regulatory agencies and the private businesses and their customers' wish for self-management. The GIG-convergence troubles established knowledge and power relations in which layindividuals were fully dependent on experts and regulators.

Direct-to-Consumer Genetic Testing (DTCGT): A regulatory conundrum

The industry offering DTCGT sells intelligence about biological relations, race, bio-geographic origins, health risks and personality traits to private customers. Tests can be bought easily and at a low cost. In November 2013 a paternity test cost £130 in the British pharmacy chain Boots, and a health and ancestry test from 23andMe was £62. The transition of genetics from an expert-led to a lay-access technology has caused regulatory concern, not least because this shift undermines established safeguards against discriminatory uses.

Below I summarize briefly first the regulatory struggles to limit DTCGT and the related academic debates. I separate regulatory and academic discourses, although academics are involved in policy processes, in order to point out their alignment in content. The ethical and social science debates single out the same points that are raised in regulatory papers. This underlines Nordmann's notion of a non-obvious entanglement. In the direction of Sherwin's critique, this alignment signposts that expertise and power are closely entwined when the authority over new science and technology is at stake. Both DTCGT and prenatal sex-selection are instances of a growing tension, if not in fact directly opposing interests between expert and government bodies on one side and consumers on the other.

For over 30 years it was generally accepted that genetics needs to be regulated for the good of the public. For many, DTCGT only increases this need and creates new ethical problems (Wasson et al., 2005; Berg and Fryer-Edwards, 2008). Calls for regulation have been published by government bodies and ethics committees in Australia, the USA, European and Asian countries. The National Institute of Health (NIH) Task Force on Genetic Testing considered regulation as early as 1998[2] and published several recommendations in recent years. In 2009, the UK Human Genetics Commission (HGC) issued a 'Framework of Principles for direct-to-consumer Genetic Testing' ('Principles') which outlines criteria for acceptable practices with respect to informed consent, marketing, risk communication, availability of counselling, and data protection.[3] The Australian National Health and Medical Research Council's report for health professionals acknowledges problems with DTCGT, noting that marketing as such cannot be banned.[4] The shared assumption is that public users cannot make good sense of these tests and will burden health services with unnecessary expert visits. In the U.S. regulators have begun to proceed against testing companies. In March 2011, the advisory committee on molecular and clinical genetics of the US Food and Drug Administration (FDA) enforced NIH recommendations from 2000 concerning the adverting of DTCGT products as non-diagnostic.[5] This intervention followed the prohibition of some private genetic testing

companies operating in California in 2009 and the FDA's inquiry into US-based companies in summer 2010.

The academic debate emphasizes the lack of quality of the privately offered tests and consumers' ability to make sense of the findings. Also, wider use may adversely affect health services and wider society (Hall and Gartner, 2009). Other concerns include effects on the medical professions and their expertise requirements (Annes et al., 2010; Edelman, 2009), because of lack of professional training in genetics. Ethics committees and academics suggest new data protection and privacy laws (Javitt et al., 2004; Hogarth et al., 2008; Kaye, 2008) as well as comprehensive informed consent regulations (Bunnik et al., 2012). Genetics has put notions of informed consent under strain in several ways, not least because genes are shared among relatives (Corrigan, 2003; Hauskeller, 2004; Lunshof et al., 2008; Mascalzoni et al., 2008). Genetic and biobank research projects, such as the UK Biobank or the Iceland National Human Genome Project, operate with open unspecific consent to data use (Palsson and Rabinow, 1999) in order to reduce cost and widen the usability of collected information and body materials. However, open consent to public or private biobank enterprises implies that the participating public understands what goes on and must trust these institutions with their personal data. I consider it self-contradictory to invite the public to donate to biobanks with open consent, yet not trust its members to be able to comprehend the vagueness of DTCGT tests and use them sensibly. The academic critique of DTCGT concentrates on common complex disease and ancestry testing, and how difficult it is to understand and contextualize the information. Regulation is needed to prevent social harm (Kolor et al., 2009; Messner, 2011).[6]

The academic and regulatory literature on DTCGT portrays the consumer as emotion-ridden and without sufficient scientific understanding. This person is a potential threat to society because she will respond unreasonably and cause increases in the cost of health care and social services. Following previous requests for stricter DTCGT marketing strategies, the FDA issued an enforcement action against 23andMe in November 2013, stating that the "FDA is concerned about the public health consequences of inaccurate results from the PGS device; the main purpose of compliance with FDA's regulatory requirements is to ensure that the tests work." and "23andMe must immediately discontinue marketing the PGS until such time as it receives FDA marketing authorization for the device." Among its motives to act, the FDA states that "[t]he risk of serious injury or death is known to be high when patients are either non-compliant or not properly dosed; combined with the risk that a direct-to consumer test result may be used by a patient to self-manage, serious concerns are raised if test results are not adequately understood by patients or if incorrect test results are reported."[7] This restriction is still in place in January 2014. Note, though, this is not a general restriction to selling private genetic tests but specific to a piece of equipment and health advertising. The FDA's intervention for the public good encountered hostile public response, especially on community forums and internet news sites. Consumers mostly defended 23andMe, criticizing the FDA as over-regulating and recently experts have expressed a similar view (Green and Farahany, 2014).

Citizens ask why they should be prevented from buying genetics tests if they want them, and why they need to entrust the management of their genetic data should rest in the hands of experts and large organisations. Given that the consumption of many harmful products burdens health care systems, yet this situation is largely unregulated with regards to adult buyers, it seems that the argument for the exceptional harm

allegedly deriving from DTCGT needs to be actively made rather than simply assumed on the basis of previous and now largely discarded beliefs in the determining power of DNA. Life-style is increasingly seen as a major causal factor for common diseases and medical public health experts and government institutions increasingly demand that individuals self-govern with a view to maintaining their health. Experts and institutions offer life-style guidance, issue food labels, devise smoking bans, set age restrictions on sales of alcohol, and promote sports in schools, in order to influence citizens' behaviours. The DTCGT market could be seen as an instrument to increase health awareness and autonomy in life style choices, if the tests possess decent validity, and ideally are clinically useful. Of course, this ability to encourage healthy life styles depends on the common public understanding of genetics to enable the sensible use of DTCGT results. Initial studies on the uses of DTCGT and its effects on the clinic indicate that this might be assumed (Giovanni et al., 2010). DTCGT buyers are on the whole aware of the complexity of genetic knowledge and that results are indicative not predictive for each individual testee (Hall et al., 2010b). Larger studies about consumer behaviour and professional experience with genetic information are underway.

The DTCGT debates in North-America, Australia and European countries are similar in their arguments concerning risks for public health, the deficit of scientific understanding among consumers and the lack of scientific quality of the tests on offer. This uniformity is remarkable given the different societal effects DTCGT has in the diverse provisions of health care and the cultural differences in the public and political attitudes towards genetics in these countries. Yet regulators and academics predominantly agree that public access to genetic tests ought to be tightly supervised. I am concerned that this grand agreement arises from a potential in DTCGT rarely mentioned in the discourses above, namely that it threatens the authority of science, the medical professions, and bioethicists' special expertise. Some critics of bioethics as a profession (De Vries et al., 2009; Evans, 2012) have pointed out the dilemma inherent in the professionalization and status of ethicists as specialists, that the decrease in demand for their services puts at risk individual careers and expert disciplines. The same can be assumed for genetic counsellors and medical expert professions in the field. The enabling potential of quality-assured DTCGT as a self-determined health strategy may not be borne out because of diverse sets of conflicts challenging the multi-disciplinary panels that advise regulatory organisations, as Nordmann points out with respect to the NIBC convergence (Nordmann, 2007).

The central first level problem is that given the GIG convergence prohibitive regulation may save time but is not a long term method of containment. National laws, moratoria or weak instruments such as the 'Principles', suggesting standards for testing, cannot suppress the use of a product marketed worldwide via the internet if consumers are motivated to have it (Hogarth et al., 2008). Neither the legislation nor the policing institution are in place to prevent online marketing, sale and trade. I suggest elsewhere that international product standards and certification procedures are the only reliable means of securing test quality (Hauskeller, 2011). International quality certificates would not control all products available but would offer consumers the choice of investing in a high quality product, a choice currently unavailable.

Standards can only address test quality and validity, not problems that arise from the diversity between cultural scenarios and value systems within which the same genetic test can take on very different roles and meanings. This problem is best illustrated with the case of non-invasive prenatal genetic testing and especially its use for sex-

determination. This example will also highlight how the authorities' neglect of moving towards a system of global technocratic quality assurance is in the way of a sensible global debate about the culturally dependent and diverse effects of DTCGT.

Non-invasive prenatal Diagnosis (NIPD)

NIPD is a special case of DTCGT because its utility and uses depend on cultural contexts and values. In that it is a challenge for the foresight expectations of CT programmes and agendas which assume that technology benefits can be nationally defined and at the same time subjected to universal ethical stewardship.

DNA from the embryo/foetus circulates freely in the pregnant woman's blood during pregnancy. Technologies to identify the embryo's or foetal DNA in a maternal blood sample, and to ascertain the genetic condition of the embryo or foetus on that basis, have been under development since 1997. The medical and ethical advantage is that the method is non-invasive and can be used early (from week 6) in pregnancy. Many Western medical and public health communities see NIPD as highly desirable because it avoids the medical risks and ethical problems of late abortions carried by the current invasive techniques to extract foetal DNA. In several countries advanced stages of clinical trials with NIPD are under way and the technology is envisaged as a future routine element in antenatal care and national screening programmes.[8] There is a fast growing literature on the topic from which I will cite a selection to set the scene for the reflection on the cross-cultural effects of converging technologies and the resulting problems for science and technology policy-making.

The push to introduce NIPD into clinical routines (Chitty et al., 2008; de Jong et al., 2009) has been criticized by medical ethicists (Newson, 2008) who emphasize problems with informed consent (Wright and Chitty, 2009; Hall et al., 2010a) and the threat it poses to the principle of reproductive autonomy. In an exchange in *Nature Reviews Genetics* Schmitz, Netzer, and Henn defend parental autonomy, emphasizing that routine NIPFD would undermine the right not to know (Schmitz et al., 2009). Against this view Ravitsky argues prospective parents ought to be encouraged to have NIPD as early as possible (Ravitsky, 2009). Others have argued that NIPD is yet another step toward the commodification of pregnancy and the genetic normalisation of children (Skotko, 2009). NIPD offers, like other prenatal genetic testing, no therapeutic choices except continuation or termination of the pregnancy. It provides information on the genetics of the embryo/foetus only, other anomalies remain undetected. Kelly and Farrimond present findings from a small-scale study on public perceptions of NIPD in the UK, with participants generally responding positively but expressing worries about the potential for eugenic discrimination of disability. The participants favoured limiting NIPD to severe disorders (Farrimond and Kelly, 2011) and ask that sustainable regimes of counselling and care are put in place (Kelly and Farrimond, 2011).

The discussion I sketched above about the advantages and problems of NIPD reflects the concerns raised in countries where the sex of a child as such is generally not seen as an important aspect of its desirability. The problems and the general ethical and political picture changes dramatically when NIPD is discussed in cultural contexts in which raising a male child is deemed much more preferable than raising a female child. The existing literature on NIPD mentions sex-determination of the embryo and sex-selection (Wright and Chitty, 2009; King, 2011; Daar, 2011) and suggests restricting sex-selection to medical conditions such as sex-linked diseases. Yet it is recognized that there is no clear boundary which can be drawn in clinical practice

between sex-selection for foetal medical health and family acceptance. The wish for a 'balanced family', denoting a family consisting of mother, father, a boy and a girl, had alarmed ethicists when reproductive technologies became applied in the U.S. for sex-selection of pre-implantation embryos and in selective abortions. If this choice for a balanced family is socio-politically acceptable and part of clinical regimes, how can doctors single out the wish to have a son first? Cultural and political biases that disadvantage those who raise girls have motivated the use of pre-pregnancy sperm selection, sex-selective abortion and have lead to child murder or abandonment in many countries as has been documented since the 1980s (George, 2006). Global cross-cultural migration disperses the different cultural ideals of a desirable child across regulatory realms and challenges the cultural homogeneity implicitly assumed in the values that recommend NIPD in the UK or U.S. as ethically and medically beneficial. In 2012 and 2013 the UK revisited the rules under which sex-selection and abortion are practiced following reports that some doctors abort female foetuses on request. Grounds to prosecute these doctors could not be established. Yet, during the debate the issue was raised as to whether the detrimental effects of the birth of a female child to the mother's wellbeing and health ought to be considered in clinical decision–making about an abortion request in the UK. There are no firm boundaries for medical indications, and under conditions of multi-cultural societies, ethical advice and ideals that built on relative value homogeneity within particular countries are simply inadequate.

The availability of NIPD not only through medical services but also on DTCGT markets means that its effects on practices of sex-selection cannot be tightly controlled. This worries authorities in India and China, for example, where the sex ratio of births is becoming skewed towards male birth, increasingly causing negative effects on social life. It is not possible to prevent the use of technologies that are commonly used in some countries in other countries, or to treat pregnant women differently within one country based on the presumed cultural values of their country of origin or ancestry. The convergence of technologies, information exchanges and multicultural society and life-styles mean that laws and best medical practice guides cannot stop the uptake of NIPD at home. There are also no defensible grounds from which a subsequent demand for an abortion, which we may assume to be in the rational best interest of the pregnant woman, cannot be denied or simply disregarded. Cultural contexts in which it is rational to assume that sex-selection is a long-term social problem can only counter sex-selection through cultural re-evaluations and political interventions that change the status of girls and women. The arguments Susan Sherwin provides for considering the cultural aspects of abortion and female genital mutilation can readily be applied to prenatal sex-selection.

Converging Technologies, Normativity and Socio-Cultural Differences

The convergences that transformed genetics from an expert-only high-risk science to a wide-ranging set of open access technologies can inform science and technology policies in at least two ways. First, the perceived nature of a science or technology can alter quickly and is difficult to predict. Secondly, in liberal-democratic societies the scope for effective national or local government control over knowledge and technologies is decreasing – its time may be over for all knowledge and technologies that can be distributed globally using the new media.

The stark tension between government support for new science and business ventures on the one hand and protective sentiments toward the social status quo in which

authorities govern technologies on the other hand is borne out in the DTCGT debates. Policy makers adopt a paternalist attitude towards the public and portray an attitude of 'humility' concerning current socio-cultural values when demanding control over DTCGT for the good of humanity. The major problem for regulators and authorities is the lack of control over the quality of the tests and over the uses people make of them. Both render unpredictable the wider social effects, not least for the authority of medicine and science itself.

The meaning of DTCGT and NIPD depends on individual, social and political contexts. Some of the tensions over NIPD do not arise from the genetic eugenic technology as such but is grounded in misogynist socio-political conditions. Asking along with Sherwin who establishes these cultural rules and who benefits from them, as feminists in India and China have done, leads to insight into oppressive gender orders that are unjustified and directly harmful to women and subsequently the whole of society.Yet for each woman considered individually, having a female child may involve long-term damage to her, her family, her marriage, and her physical and mental health. Policies that try to manuevre through a morass of radically opposed public and individual interests are unsustainable. Sex-discriminatory practices can only be addressed by changes to the socio-cultural fabric of values and the interests that sustain them.

Drawing on recent social science studies, I have tried to disentangle the web of values, concepts and presuppositions in the DTCGT debate. Nordmann calls the mutual admiration of the scientific and STS communities a potentially 'deadly embrace'(Nordmann, 2007: 226). I want to apply this metaphor for bioethics and STS on convergence more generally. Geneticists, counsellors and many bioethicists owe their livelihood to their contribution to the governance of genetics, so that collusion might seem a life-saver – at least for the time being. Yet, in this 'deadly embrace' they are credited with responsibility for the effects of the resulting practices of governance, and negative social outcomes may undermine the critical function of academia in the medium term. Sherwin proposes that policies need to be assessed critically concerning the power structures that inform and perpetuate themselves within them. Social practices that in effect disregard or oppress parts of a society, be that women or migrants from diverse cultural backgrounds, are morally and ethically unjustifiable. The GIG convergence needs to be reflected upon regarding globalisation in terms of both markets and cultural heterogeneity.

Globally responsible means of ethical and social governance may be needed. The development of international product standards can be an important step towards responsible online markets for genetic tests. Yet another step has to be taken alongside it. We need to develop new representational formats in which cultural diversity can be represented in the interests of the communities affected by the way in which any new technology may be introduced or governed. Currently governments and experts configure their relationship toward the public as if that public was homogenous and needed showing the way. Instead of enhancing the critical ability to manage scientific knowledge and technologies autonomously, restriction policies undermine the potential for individuals to engage with them intelligently. The perpetuation of the discrimination of girls and women through short-term solutions to pre- or post-natal sex-selection, such as restricting access or criminalisation, oppresses pregnant women and should alert democratic governments and ethicists to the urgency with which they need to realize the true challenges posed by scientific and technological convergence. It may be possible to slow down such developments

but black markets cannot be halted as long as individual consumers have strong motives to use the tests.

Diagonal convergence stands for the ways in which there is no homogenous referent for moral values, ethical practice and social and economic interests in ongoing convergence phenomena that can be defined meaningfully. Responsible governance and regulation need transnational integration in order to address the issues of product safety, forms of use, and short- and long-term societal effects locally and globally.

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[8] The UK National Health Service has set up a website on its 5-year NIPD research programme at http://www.rapid.nhs.uk/. This site is kept up to date with links to the most recent scientific articles on NIPD. An expert working group in the UK analyzed the medical, social and ethical aspects of NIPD and its implementation into screening programmes. Its report is published through the Foundation for Genomics and Population Health at http://www.phgfoundation.org/download/ffdna/ffDNA_report.pdf.